

AUTISM INTERIM STRATEGY 2021-2022

March 2021

Department of Health

Autism.Strategy@health-ni.gov.uk

CONTENT

Ministerial Foreword

Section	Content	Page
1	Introduction	2
2	COVID-19	6
3	Stakeholder engagement	7
4	Purpose of interim strategy	10
5	Who is the audience for this document	10
6	Strategic outcomes	11
7	Strategic outcome 1	13
8	Strategic outcome 2	14
9	Strategic outcome 3	16
10	Making a difference	18
Annexes		
Annex A	Lessons learned – Autism Strategy 2013-2020	
Annex B	Autism Strategy Future Priorities: Questionnaire and summary responses	/ of
Annex C	Strategic linkages	
Annex D	Monitoring template	

MINISTERIAL FOREWORD

The publication of the Autism Strategy, 2013-2020, forged new ground as the first cross-departmental strategy of its kind. I believe that we, as a society, have made significant strides in developing improved support and gaining greater awareness and a better understanding of the needs of autistic people, their families and carers throughout this time.

However, I am also acutely aware that we have witnessed increasing rates of referrals and a rising demand for our autism services which have resulted in extensive waiting times for individuals and families who are seeking support. It is clear that we must improve and enhance accessibility to services and ensure that interventions can be provided at an early stage if we are to see sustainable progress in the future.

The publication of this interim Autism Strategy 2021-2022 will set future direction, in the short term, towards key improvements in our services and support – and towards building communities where autistic people, their families and carers, those who may be seeking assessment, and indeed those who choose not to, can feel safe and included, valued and understood.

My Department has gained much from the ongoing stakeholder engagement which has informed the priorities for this interim strategy and I want to thank you for bringing your voice and experience to its development. Whilst it was my wish that a revised autism strategy would be developed through co-production and partnership working, the emergence of the COVID-19 pandemic and associated pressures throughout 2020 constrained the ability to do so. I am very aware of the challenging circumstances that this period has presented for many of you also.

I want to assure you of my commitment to build on the work thus far with the development of a fully co-produced autism strategy later this year. It is my hope that this will commence a period of renewed partnership working across our communities and collaboration across government to shape and influence actions that can truly make a difference and improve quality of life for all.

ROBIN SWANN MLA Minister of Health

1. INTRODUCTION

What is Autism?

Autism is a lifelong developmental condition which affects the way that people experience, communicate and interact with their environment. Many individuals with autism have difficulty processing everyday sensory information like sight, smells, touch, tastes and sounds and some may have repetitive patterns of behaviour, activity or routine.

Autism is a spectrum condition which affects people differently; some individuals can live independently and may never come into contact with services and others will have more complex needs which require specialist support.

Autism Strategy 2013-2020

The first Northern Ireland Autism Strategy 2013-2020 was published in 2014 following the introduction of the Autism Act (NI) 2011, which places a statutory responsibility on the Department of Health to prepare an autism strategy in collaboration with all Northern Ireland Government Departments setting out how the needs of autistic people should be addressed throughout their lives.

The strategy was based upon 11 key themes that aimed to support people with autism to better exercise their rights, choices and life opportunities, have continuing development of an inclusive range of high quality services and to develop clear, achievable actions which were capable of being monitored and evaluated.

Progress

As a result of the strategy there have been a number of achievements which include:

• Increased societal awareness which has led to many public facilities, such as shops, cinemas, museums, government services, airports and public transport

providers making specific adjustments, for example specific hours of opening which are autism friendly, provision of quiet areas in public buildings and also the ability to view transport, for example aeroplanes, online to enable autistic people and their families feel supported within their environment.

- The establishment of regional multi-agency fora in Health and Social Care
 Trusts, comprised of autistic people, carers, clinicians, government
 departments and the community and voluntary sector, has fostered an ethos
 of partnership working and co-production to inform and develop services and
 support.
- The Additional Support Fund, administered by the Department for the Economy, has enabled further education colleges to provide additional support and advice for students who have autism.

Further achievements, as a result of the strategy, are evidenced in Progress Reports published in 2015 and 2019.

https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf

https://www.health-ni.gov.uk/publications/autism-strategy-2013-2020-second-progress-report-2018

Whilst this progress has demonstrated a positive change with greater awareness and understanding in broader society of the specific needs of people with autism, alongside this, a greater prevalence of autism within our communities, the growing waiting lists of autism referrals for assessment and the rising demand for services show that there is still considerable progress to be made.

Autism Trends

Since the implementation of the previous strategy, a range of data has been collated to provide a comprehensive picture of the position on referral for autism assessment and diagnosis. This has been instrumental in enabling policy makers, practitioners, the wider health and social care and education sector to shape future policy and services in response to growing demand.

Statistical data published in June 2020¹ highlights the ongoing rise in the number of autism diagnosis given to under 18's since 2014/15. School census analysis published in 2020 estimates the percentage of school aged children with an autism diagnosis to be 4.2%.

Figure 1

Year ending 31 March	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20
Autism Diagnoses in NI	1,136	1,472	1,942	2,321	2,809	2,562

Number of children diagnosed as having Autism per year

Source: Quarterly Autism Statistics, DoH

Note: Figures relate to young people under 18 years old.

(2014/15 - 2019/20)3,000 2,809 2,500 2,562 2,321 2.000 1,942 1,500 1,472 1,000 1.136 500 2014/15 2015/16 2016/17 2017/18 2018/19 2019/20

The number of children diagnosed as having Autism in 2019/20 was more than double the number in 2014/15 (increase of 126%). There was a peak of 2,809 diagnoses seen in 2018/19.

¹ https://www.health-ni.gov.uk/sites/default/files/publications/health/asd-children-ni-2020.pdf

Whilst these trends relate to children and young people, given the lifelong nature of autism, it is essential that future services are sustainable to provide ongoing provision of care throughout adulthood. Therefore, an action of this strategy will be focussed on longer term transitions planning and a review of adult autism care.

In 2021 the Northern Ireland Census will, for the first time, include autism as a separate condition within the data collected. This will provide a full regional baseline of autism in the Northern Ireland population that, when combined with the socioeconomic indicators also collected, will give further insight into how both children and adults with autism form part of our society.

Investment in Services

In recognition of the increasing growth in autism referrals and rising demand for services, and for the need for individuals and families to have access to timely service provision and support, since 2016 significant investment has been made in autism services, with an additional £2 million being allocated to children's autism services on a recurrent basis. Alongside this investment has been the allocation of transformation funding to facilitate the development of a new regional framework, informed by a review of children's autism services, which will underpin greater provision of early intervention for families and will provide the framework for standardisation in autism services.

2. COVID-19

Whilst the Department is committed to the development of a fully co-produced autism strategy to refresh future strategic direction and actions and to build upon the progress already achieved, development of the strategy had commenced as the COVID-19 pandemic emerged. The diversion of key staff in all Departments and in the health and social care sector, and protective measures introduced throughout the pandemic led to work on the strategy being significantly constrained.

We are acutely aware of the challenging circumstances that COVID-19 presented to individuals and to families who require structured routines to manage their day or receive support through schools, day centres and short breaks for respite care. The stark reality of these challenges in terms of mental health, loneliness and caring responsibility has been highlighted in the National Autistic Society report 'Left Stranded', published in September 2020.²

Mindful of the challenges experienced throughout the pandemic and conscious that there should be no delay in implementing actions at a time when need has never been greater, the publication of this interim autism strategy for the period 2021-2022 has been approved by the Minister for Health, Robin Swann MLA, with a commitment to commence development of a fully co-produced strategy later in 2021. There is no doubt that the experiences of COVID-19 and lessons learned throughout this period will influence and shape the delivery of autism services for some time to come.

_

² https://www.autism.org.uk/what-we-do/news/coronavirus-report

3. STAKEHOLDER ENGAGEMENT

Since the publication of the first Strategy and Action Plan in 2014, much has changed both in terms of the strategic direction of health and social care services and wider Government policies and plans.

The ethos of the Department is underpinned by *Health and Wellbeing 2026* – *Delivering Together*, published in October 2016,³ which sets out a ten year road map for the delivery of health and social care reform. The overarching aim of this plan is to place people at the forefront by enabling them to be supported to take control of their health and wellbeing, provided with the education and support to make informed choices and have services that are efficient and sustainable for the future. Central to this is placing emphasis on the user's voice being heard – this will embody future direction of service provision and support for autism.

Broken Promises Report

The publication of the *Broken Promises* report,⁴ jointly published in 2016 by Autism NI and the National Autistic Society, drew on results of a survey designed to find out more about the experiences and opinions of autistic people and their families about support and services in Northern Ireland. Feedback in the report highlighted a range of concerns around involvement of autistic people in developing services, waiting times for assessment, support for carers, access to education and employment and the provision of training and awareness in wider society. Therefore, to identify the key priorities that could make a tangible difference to the lives of autistic people and their families in a revised strategy, and to determine lessons learned, the Department embarked on a period of extensive stakeholder engagement throughout 2019.

³ https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf

https://static1.squarespace.com/static/5cf788f054106a000185c13a/t/5dcc23e5c27c4f1cd261089c/15736596 30308/Autism+NI+Broken+Promises+Report+%283%29.pdf

Stakeholder Response

Based upon the findings of this engagement, further plans had been made to launch a public questionnaire and host a stakeholder workshop in April 2020. Due to the emergence of the COVID-19 pandemic these plans had to be deferred but alternative methods of engagement were deployed to provide opportunity for the views of autistic people, their families and carers to be expressed within the limitations that social distancing restrictions permitted. This included a public questionnaire issued to service users to provide them with opportunity to express their views on key actions to be incorporated within a revised autism strategy. A copy of the questionnaire and a summary of responses can be found at **Annex B**. Key priorities highlighted as a result of the stakeholder engagement are provided in **Figure 2**.

Figure 2

KEY PRIORITIES

- 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.
- Wider provision of supported living.

4. PURPOSE OF THE INTERIM STRATEGY

The interim strategy sets out priorities for action throughout 2021-2022 with the focussed aim of improving the lives of autistic people, their families and carers by enhancing access to service provision and support, increasing understanding of their specific needs and enhancing partnership working within our communities.

We have listened to the feedback received throughout our stakeholder engagement on the impact of managing complex needs, both on the individual and on the wider family, and calls for greater support to address emotional health and wellbeing have been publicly documented in recent years through the recommendations of the NICCY *Still Waiting* report⁵ in 2018 and in the recently published *Mental Health of Children and Parents in Northern Ireland Prevalence Study*.⁶

Therefore, this strategy will also seek to harness actions which can support emotional health and wellbeing outcomes, through formal and informal community and society support.

5. WHO IS THE AUDIENCE FOR THIS INTERIM STRATEGY?

Whilst this document is primarily aimed at autistic people, their families and carers to demonstrate a societal commitment to supporting and understanding their needs, the document will also be used to inform and influence comprehensive planning of service provision across the wider public sector, independent providers and partnerships beyond and for anyone with a role to play in leading and implementing change with the aim of improving outcomes for autistic people and their families.

10

⁵ https://www.niccy.org/media/3114/niccy-still-waiting-report-sept-18-web.pdf

 $[\]frac{\text{http://www.hscboard.hscni.net/download/PUBLICATIONS/MENTAL\%20HEALTH\%20AND\%20LEARNING\%20DIS}{\text{ABILITY/youth-wellbeing/Youth-Wellbeing.pdf}}$

6. STRATEGIC OUTCOMES

You have told us that a future strategy should focus on 'actions and not words' and we have listened. In doing so, we have worked in partnership with all Departments and the wider health and social care sector to identify a framework of outcome based actions that will remain 'live' and dynamic in nature throughout the lifespan of the strategy to enable us to respond to issues that may emerge.

Since the development of the previous strategy the strategic focus of government has changed with the commitment of the Northern Ireland Executive, reaffirmed in the *New Decade*, *New Approach*⁷ document, to the development of an outcomesfocussed Programme for Government (PfG) and the Executive have agreed to have a strategic, multi-year Programme in place by April 2021. The framework for this interim strategy is based upon three strategic outcomes which will align to the PfG, thereby keeping actions within the core of Executive priorities, and also reflecting the vision for person centred health and wellbeing outlined in *Health and Wellbeing 2026 – Delivering Together*.

The actions which will be delivered through this interim strategy are based upon the key priorities that you have told us can make a difference. However, we recognise that the success of implementing these actions can only be determined through the influence of those people to which they apply, therefore it is essential that the development of actions will provide opportunity for collaborative working and co-production. Underpinning this will be our vision for the interim autism strategy:

To respect, to listen, to involve.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/856998/2020-01-08 a new decade a new approach.pdf

⁷

STRATEGIC OUTCOMES 2021-2022

To respect, to listen, to involve.

Strategic Outcome 1

A healthy life with access to services on an equal and timely basis.

We 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.

Strategic Outcome 2

A life with opportunities to live as an active citizen.

We will 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 throughout life stages.

Strategic Outcome 3

An independent life supported by greater societal understanding and choices.

We will provide opportunity for autistic people to live safe and independent lives within our communities and have equal access to services where they are met with respect and understanding.

8. STRATEGIC OUTCOME 1

A HEALTHY LIFE WITH ACCESS TO SERVICES ON AN EQUAL AND TIMELY BASIS

We 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.

What you told us:

- That there should be standardised regional services with equity of access across the Health and Social Care sector.
 - Early intervention and personalised support for families is a key support and should not be based upon diagnosis.
 - There should be equity in provision of Adult Autism Services across the region.
 - Good mental health is critical to autistic people and their families and services must be more accessible.

This is what we will do:

- We will implement a new framework of care to deliver a proactive, integrated
 and streamlined pathway for children and young people across the region and
 provide a range of early intervention approaches and support to meet their
 needs and that of their families and carers.
- A review of Adult Autism Services will be undertaken to determine how future, sustainable provision of care and support can be enhanced and standardised across the region.
- Mental Health service pathways and structures will be improved following the implementation of a new ten year mental health strategy. This will provide better access to support for autistic people, their families and carers throughout their lives.

9. STRATEGIC OUTCOME 2

A LIFE WITH OPPORTUNITIES TO LIVE AS AN ACTIVE CITIZEN

We will 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.

What you told us:

- Greater integration between education and health is needed.
- Our education sector must be equipped with a greater understanding of the needs of autistic people and how they react to the environment around them.
- A wider range of choices for education and employment post 16 should be provided.
- That employers must have an understanding of the needs of autistic people and how they should be supported in their working life.
- There should be a streamlined whole life approach to transitions planning to ensure that autistic people are supported throughout their lives.
- There should be greater focus on assisting autistic people to develop life skills to support them at all stages of life.
- Autistic people and their families should have greater involvement in the development of policy and services.

This is what we will do:

- We will support our children and young people by promoting emotional wellbeing, strengthening self-esteem and resilience with a strong focus on promotion, prevention and early intervention.
- Through the phased implementation of a new Special Education Needs (SEN)
 Framework we will improve participation and empowerment for all children
 going through the SEN assessment process. We will ensure that autistic
 people are supported throughout their education.
- We will deliver focussed training that will enable our workforce to respond to the specific needs of people with autism and how they view their environment.
- We will actively and meaningfully engage autistic people and their families in the co-design of new employment and skills supports.
- We will have well planned, whole life transitions to ensure that autistic people are supported throughout their lives.
- We will provide more responsive support and development of skills to enhance employment opportunity.
- We will develop and co-produce policy and services, as appropriate, in collaboration with autistic people, their families and carers to enable lived experience to shape future services.

10. STRATEGIC OUTCOME 3

AN INDEPENDENT LIFE SUPPORTED BY GREATER SOCIETAL UNDERSTANDING AND CHOICES

We will provide opportunity for autistic people to live safe and independent lives within our communities and have equal access to services where they are met with respect and understanding.

What you told us:

- Greater awareness and understanding of the needs of people with autism is required within our communities and across all sectors.
- Emphasis should be placed on signposting to services and assistance to financial support.
- More provision of supported living is required to enable autistic people to live independent lives.
- There should be more focus on social inclusion and providing opportunity for autistic people and their families to socialise and integrate within our communities.

This is what we will do:

- We will provide training to equip the workforce, particularly those in our frontline services, with the skills to understand the needs of autistic people and how this impacts on a person's life and to provide surroundings where they can feel safe and supported within the environment.
- We will work in partnership to develop a new Supporting People Strategy to facilitate and deliver high quality housing support and promote independent living to those most in need.

We will provide opportunity within our communities to support autistic people
and their families and enable them to experience greater social interaction
and activity in an accessible way and feel connected to their environment.

11. MAKING A DIFFERENCE

How will we know the interim autism strategy is making a difference?

- The Cross-Departmental Autism Stakeholder Forum, chaired by the Department of Health, will provide strategic oversight of the implementation of the strategy and co-ordinate a monitoring and evaluation role to ensure that actions are included in commissioning plans for the health and social care sector and in the Programme for Government Delivery Plans and that they have been implemented. Evidence of the impact they are making will be sought on an annual basis. A monitoring form is attached at Annex E.
- Through partnership working with Health and Social Care Trust regional multiagency autism fora, comprised of multi-disciplinary clinicians, government departments, and autistic people and carers, the Department will attend forums on a quarterly basis as a reporting mechanism to seek views from stakeholders on the implementation and delivery of actions and the impact this is making on the lives of autistic people, their families and carers.
- The Special Educational Needs (SEN) Steering Group, jointly chaired by the
 Department of Education and the Department of Health will provide an
 oversight role and governance arrangements in monitoring implementation of
 the new SEN Framework and associated strategies and linkages to the
 development and implementation of the autism strategy throughout the period
 2021-2028.
- The Department will provide an update report highlighting progress to the Committee for Health and to the All Party Group on Autism on an annual basis.
- An evaluation of the implementation of the actions in the interim strategy will be undertaken, in consultation with autistic people, their families and carers, after a period of two years. This will ultimately inform a Progress Report to be presented to the Minister for Health to lay before the Northern Ireland Assembly in 2023 and will be shared on the Department of Health website.

ANNEXES

Annex A

AUTISM STRATEGY 2013-2020

LESSONS LEARNED

November 2020

1. Background

Following the introduction of the Autism Act (NI) 2011 ("the Act"), the first cross-departmental autism strategy 2013-2020 was published in 2014 with the aim of setting out how the needs of people with autism could be supported throughout their lives.

The strategy contained 11 key themes which provided the framework for an action plan for the 2013-1016 period; this was subsequently extended to 2017 by the then Minister, Simon Hamilton. Due to the cross-departmental nature of the strategy no further actions were developed in the absence of the Executive throughout the period 2017-2020.

2. Implementation and Governance

Reporting structures for the implementation of the strategy were carried out through a number of specifically established roles/groups:

- An HSC Regional Autism Co-ordinator was recruited by the Health and Social Care
 Board to encompass a cross-departmental remit in terms of managing and coordinating reporting.
- The Autism Strategy Regional Multi-agency Implementation Team (ASRMAIT)
 led by the Regional Autism Co-ordinator and comprised of a range of agencies
 representing health, social care, education, justice and employment along with
 community and voluntary sector and service user representatives, was responsible
 for directing, co-ordinating and managing the implementation of the strategy on a
 cross-departmental basis.
- An Autism Strategy Inter-Departmental Senior Official Group (ASISOG) provided a governance and oversight role on behalf of each government department.
- Regional Autism Fora, comprised of clinicians, service users, community and
 voluntary sector and inter-departmental representatives, were established in each
 Trust area to provide opportunity for service user involvement and inter-agency
 partnership working in the development of services and support.

- Northern Ireland Autism Strategy Research Advisory Committee (NIASRAC)
 was established to ensure that the most recent research findings were available to
 ASISOG and other key structures to inform implementation of the strategy and action
 plans; and to government departments and their agencies to inform the design,
 planning and delivery of services.
- A Regional Multi-Agency Implementation Team was established to monitor the implementation of the Strategy and commission input from relevant Departments regarding the development of three yearly progress reports to lay before the Northern Ireland Assembly.

Since the autism strategy was introduced, the NICS has experienced considerable restructuring and whilst governance structures under the current strategy have not been formally stood down, there have been no further meetings since the ending of the action plan in 2017. The activities of NIASRAC were also paused in 2018.

A review of the post of the Regional Autism Co-ordinator identified the need for greater focus on ensuring co-ordination and collaboration across Departments to fulfil the requirements of the Act. As a result, funding for this post was subsumed into the Department to create a new post to enhance this work, strengthen cross-departmental connections and to identify strategic outcomes based upon future autism priorities post 2020. This position was filled in November 2018.

Regional fora within the Health and Social Care Trust continue to meet on a quarterly basis and have provided improved opportunity for inter-agency working, participation from service users and strengthening partnerships with the community and voluntary sector within their regional area.

In reflecting changes in Departmental structure since the publication of the autism strategy and in preparation for the development of a revised cross-departmental strategy a refreshed NICS Autism Stakeholder Group was formed by the Department in 2019. The purpose of this group was to assist with the preparation of revised autism priorities, based upon stakeholder feedback, for consideration by an incoming Minister, recognising the significant developments that have taken place since publication of the first strategy in 2014 which now include New Decade, New Approach 2020 as well as the Outcomes Delivery Plan for the

Programme for Government and Health and Wellbeing 2026: Delivering Together. Membership of this group will be further expanded as preparations for the development of a fully co-produced autism strategy advance.

3. Progress on Implementation

As a requirement of the Act, Progress Reports were published in 2015 and 2019 and laid before the Assembly. The reports demonstrate the progress achieved as a result of the strategy and can be viewed at the links below.

https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf

https://www.health-ni.gov.uk/sites/default/files/publications/health/autism-strategy-second-progress-report-2018.pdf

The Progress Reports clearly indicate that whilst much has been achieved throughout the lifespan of the strategy, considerable progress is still required, particularly in relation to rapidly increasing waiting lists for assessment and equity of access to early intervention and support and standardisation across the regions.

4. Stakeholder engagement

To assess lessons learned from the first autism strategy and to identify future priorities for a revised autism strategy, stakeholder engagement commenced in 2019 to determine the impact that the implementation of the strategy has had on the lives of autistic people, their families and carers. Regular meetings were held with representatives from the health and social care sector, community and voluntary sector and service users to obtain their views on the aspects of the strategy which had worked well and areas which should be strengthened.

Reponses emerging from this feedback were as follows:

 The lack of an overarching action plan post 2017 had reduced the drive and focus for actions and progress to be achieved.

- A significant increase in referral lists for assessment and services was continuing to place pressure both on families who were waiting for assessment and/or support and on service delivery in regional Health and Social Care Trusts. As a result, the community and voluntary sector also reported a notable rise in requests from families seeking advice, intervention and support whilst families were waiting for referral. A need for greater emphasis to be placed on early intervention, with or without diagnosis, has been clearly expressed.
- Concern was raised regarding the variance in regional referral and access to services and a primary need for standardisation across the regions to be addressed.
- It was felt there had been no formal accountability, departmental monitoring or evaluation embedded in the implementation of the strategy and this should be included in a revised strategy to ensure that actions are making a difference and, if not, how they can be redressed.
- The awareness campaign which was included as a requirement of the Act and in the autism strategy had not come to fruition.
- Autism is a lifelong condition and the inconsistency in provision of adult autism services needs urgent attention, particularly given the growing prevalence rates of autism which have become evident in recent years.
- There is no 'one size fits all' for people with autism and therefore support and intervention must be personalised and specific to the needs of the individual.
- Joint working between education and health must be significantly improved.
- The need for autistic people, their families and carers to be involved in the development of relevant policy and service provision should not be underestimated.
- A future autism strategy should be co-produced and developed with focused outcome based actions which can be monitored and evaluated and have a streamlined reporting structure with clear terms of reference.

5. Next Steps

The Department has taken cognisance of the issues raised throughout stakeholder engagement and the positive partnerships that have been fostered throughout this process have informed preparatory work and key priorities for a revised strategy which will include:

- The need for early intervention and support for families, particularly given the growing prevalence rates for autism and increasing numbers of referrals for both children and adults.
- Closer working between and greater integration of health and education;
- Robust monitoring processes are in place to determine that actions within the strategy are progressed and the impact of these actions on autistic people, their families and carers are evaluated.
- More focus on provision and equitable access to services for adults with autism.
- Stronger partnership working with the community and voluntary sector.

Whilst work to develop a fully co-produced autism strategy for implementation in 2021 has been severely impacted by the COVID-19 pandemic, the Minister for Health, Robin Swann MLA, has approved the publication of an **interim autism strategy** early in 2021; this will encompass actions for the period 2021-2022 with development of a fully co-produced autism strategy commencing later in the year.

6. Covid-19

Lessons learned and the development of a revised autism strategy, whilst constrained in progress, has continued to be conducted throughout the COVID-19 pandemic. It is recognised that this period has presented significant challenges for autistic people, their families and carers. The reduction of service provision and the closure of many schools, day centres and short breaks for respite care has adversely impacted on the familiar routines and supports which are a vital coping mechanism for families who are managing complex needs.

Collaboration continues both on a cross-departmental basis and across the wider health and social care sector to ensure that appropriate actions in response to the challenges presented as a result of COVID-19 and the learning from delivery of services and support during this period will shape future actions in the years to come.

Annex B

AUTISM STRATEGY 2021-2028 FUTURE PRIORITIES QUESTIONAIRE

Summary of Responses

October 2020

1. Introduction

The Autism Act (NI) 2011 places a statutory responsibility on the Department of Health to prepare an autism strategy every seven years. The current autism strategy (2013-2020) will conclude in December 2020 and in preparation for this, the Department has been engaging with stakeholders throughout 2019 and early 2020 to determine lessons learned from the current strategy and to identify emerging priorities for future actions in a revised strategy.

Preparations had been at an advanced stage to commence further stakeholder engagement in early March 2020. This included the launch of a public questionnaire during World Autism Week to inform the development of the revised strategy due for implementation in 2021. However, these plans were significantly impacted as a result of the COVID-19 pandemic.

Whilst much of the preparatory work undertaken has involved engagement with other Departments, health sector colleagues and regional fora, the community and voluntary sector and service users to obtain views on progress delivered by the current strategy (**Table 3 attached**), the Department was mindful of the extent to which autism impacts on families, and our communities, and the importance of enabling their views to be expressed to influence how we shape future autism priorities in Northern Ireland.

In adherence to the restrictions which continued to be in place in relation to social distancing, the Department drafted a questionnaire (**attached**) to issue to autistic people, their families and carers via the mailing lists of the following organisations:

- Health and Social Care Trust Service Users contact lists, Autism Fora and Support Groups;
- Patient and Client Council:
- Community and Voluntary Sector organisations; and
- Statutory Organisations e.g. Equality Commission Northern Ireland, the Children's Law Centre Northern Ireland.

The Department also offered to participate in any support groups who may wish to host sessions using digital platforms.

The questionnaire enabled completion in both electronic or hard copy format, and an easy read version was also provided. Responses could be emailed or posted to the Department with a response date of 1 September 2020. Respondents were assured that the questionnaires would be anonymous.

2. Questionnaire

The questionnaire was based around 5 key themes:

- Access to Services
- Supporting Education.
- Life Changes.
- Independent Living.
- Support for Carers.

Respondents were requested to list their three 'top asks' in response to each theme. The provision of an 'Additional Comments' box was included for those who wished to add comments outside of the themes, or for those who preferred to complete a single section rather than those relating to specific themes.

A summary of the responses received by the Department is provided at **Table 2**.

3. Key Priorities

From an analysis of the responses received, the following key areas have been raised as priorities to be addressed through the development of a revised autism strategy:

- 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 and carers in the development of policy and services.
- Equity in provision and access to Adult Autism 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 respite services.
- Wider provision of supported living.
- Improved signposting to services and assistance with financial support.

4. COVID-19

It is recognised that the pandemic has presented significant challenges for autistic people, their families and carers. The reduction of service provision and the closure of many schools adversely impacted on the familiar routines and supports which are a vital coping mechanism for families who are managing complex needs.

In addition to the key priorities identified as a result of stakeholder engagement, collaboration continues both on a cross-departmental basis and across the wider health and social care sector to ensure that appropriate actions in response to the challenges presented as a result of COVID-19 are included in a revised autism strategy.

5. NEXT STEPS

In acknowledgement of the preparatory work undertaken to develop a revised autism strategy and mindful of the additional challenges which have risen throughout the pandemic for families who are managing complex needs, the Minister for Health, Robin Swann MLA, has taken the decision to publish an interim autism strategy early in 2021, with a fully co-produced autism strategy being developed later in the year, to ensure there is no further delay in the implementation of actions to provide the support that is so evident at this time. The strategy will be based upon a framework of outcome based actions focussed on delivering appropriate support to improve the lives of autistic people, their families and carers in the years to come.



AUTISM: FUTURE PRIORITIES

HAVE YOUR SAY...

AUGUST 2020

INTRODUCTION

The Autism Act (NI) 2011 places responsibility on the Department of Health to prepare a cross-departmental autism strategy which sets out how the needs of people with autism, their families and carers are to be addressed throughout their lives.

The current strategy will come to an end in December 2020 and to help us in our preparations for a revised strategy we want to hear your views on how we can improve support for autistic people, their families and carers so they can get the right support when they need it most.

We would be grateful if you would 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. You may want to ask a representative from a support organisation to help you to complete 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 Tuesday 1 September 2020.

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.

SECTION 1

ACCES	S TO SERVICES	
How ca	an we improve access to all services for people with ample: health, education, community, benefits or train	autism? nsport.
Tallace		
i eli us	your top 3 things that you would ask for:	

2. SUPPORTING EDUCATION				
Tell us how we could improve our education services to support autistic people?				
Tall up your tan 2 things that you would call for				
Tell us your top 3 things that you would ask for:				

3. LIFE CHANGES
How can we support people with autism to develop skills to help them at key times in their lives? For example: moving from education to employment, supporting employment, moving home, death of a family member.
Tell us your top 3 things that you would ask for:

4. INDEPENDENT LIVING
What support can we provide to autistic people to have an independent life and socialise within their community? For example: setting up home, making friends, managing finances.
Tell us your top 3 things that you would ask for:

5. SUPPORT FOR CARERS
3. SUFFORT FOR CARERS
How can we improve support to families and carers? For example: short breaks, training, emotional support or financial support.
Tell us your top 3 things that you would ask for:

6. ADDITIONAL COMMENTS
Do you have any additional comments you would like to make?

SECTION 2

Please tick the boxes that apply.

I am:

A person with autism	A parent/carer of	Other e.g. relative	Organisation		
with autism	a person with autism	Telative	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 Tuesday 1 September 2020.

Thank you for your comments.

TABLE 1
Breakdown analysis of Respondents

Number of Respondents	Total number of Respondents	Age Group		Respondent	
20 Individual	58	18-25	2%	Parent/Carer	17%
3 Groups		25-50	16%	Person with Autism	5%
(facilitated through		51-65	7%	Statutory Organisation	5%
Community/Voluntary		65+	2%	Community/ Voluntary	73%
Organisation)				Organisation	
		Unknown	73%		

1 session was also hosted by the National Autistic Society and attended by the Department – this was attended by 6 carers.

TABLE 2
Summary of Responses

SUN	SUMMARY OF RESPONSES						
1.	Access to Services	Comments					
	How can we improve access to all services for people with autism?	Timely access to services. Greater integration between health and education. Early intervention, particularly when waiting for assessment. Greater signposting to benefits and services with less complicated systems. Involvement of autistic people in development of services and policy. More accessibility to social activity and opportunity, particularly in rural or suburban communities. Access to mental health services. More training and awareness to identify and understand the needs of autism (particularly in schools/teachers). Improved joined up 'whole life' transitions planning. Regional standardisation of autism services/equity of access to services. Access to transportation to support groups and activities.					
2.	Supporting Education	Comments					
	Tell us how we could improve our education services to support autistic people?	Equality of access to education. Commitment from health sector to relevant multi-disciplinary therapies in schools. Amendment to legislation to address deficiencies and improve educational experience.					

		Greater awareness and training for all school staff on the range of the autistic spectrum and the specific needs required. Autism specific schools/more Special schools places/specific provision in schools for those with PDA. Greater support for those awaiting assessment. Review of statementing process. Wider range of opportunity post 16. Break out areas/ appropriate sensory areas in schools. Duplication of training for autism – more intervention approaches required. Joint Health/Education regulatory body for Special schools.
3.	Life Changes	Comments
	Tell us how we support people with autism to develop skills to help them at key times in their lives?	Early introduction to life skills, resilience, social interactions. Advanced planning for transitions. Raise awareness and tackling prejudice. Key workers in workplace, community, schools to remove dependency on one person. Greater awareness for employers of the specific needs of autism. Health professionals or mentors who can offer strategies in dealing with key life changes e.g. death, illness, finance, moving house etc. Specialist hubs within a professional/employment environment.
4.	Independent Living	Comments
		Early introduction to life skills and skills development/Mentoring services. Community supports/peer groups for autistic people to feel part of and contribute to. More provision of supported living.

		Greater input from autistic community to advise the support required and how it could be provided. More investment in Adult autism services. Dedicated specialist advice for access to benefits and other services. Autism champions within banking/financial support services, trained in the needs of people with autism, to advise on financial support.
5.	Support for Carers	Comments
		Current system stressful, understaffed and heavily administrative.
		More support and guidance required for Direct payments – very rigid rules and
		significant administrative burden.
		More provision of respite services.
		Parent groups – more provision to provide opportunity for support.
		Individualised, wraparound support and interventions for families.
		An autism helpline.
		Input from carers/autistic people on development of training and provision.
		Training should be geared towards families with autistic adults (and also autistic carers) and not just children.
		Improved signposting for carers/ a carers open day.
		Investment in specialist foster carers for autistic children.
		Tailored emotional health and wellbeing services.

TABLE 3

	AUTISM STRATEGY 2021-28 - Communication and Stakeholder Engagement						
STAKEHOLDER EI	NGAGEMENT	- COMMUNITY AND VOLUM	NTARY SECTOR POINTS ARISEN FROM CURRENT	POINTS TO CONSIDER FOR NEXT			
ORGANISATION	MEETING	ORGANISTION	STRATEGY	STRATEGY			
Autism NI	08.05.19 05.09.19 05.03.20	Family support Training RAFT (Early intervention service) Campaigning NI Helpline GAP	Middletown training provision Exclusion/reduced timetable for school children due to behavioural issues or lack of support. Variance in service provision and funding across Health and Social Care Trusts Need for greater accountability. Actions need to be timebound and monitored. Awareness campaign not carried out. Action plans not developed post 2017	Early intervention is a necessity. Mandatory teacher training is essential to support children in schools. Need for greater provision of adult autism services. Approach to private diagnosis needs addressed across Trusts. April/May 2020 – consulted on revision of guidance COVID 19 travel restrictions. 21 July 2020 advised that questionnaire would issue to stakeholders.			
National Autistic Society NI	13.05.19 30.01.20 02.09.20	Training Education Adult services Social groups Advice line Family support	Adult autism service provision needs addressed. Need for monitoring and evaluation of implementation of actions in autism strategy. Use of IQ in diagnosis.	Specific focus on complex needs. Action plans need developed and delivered. Independent scrutiny is required. Consultation and engagement with sector and families is essential.			

<u> </u>		_
	Integration and availability of multi-	Mandatory teacher and whole school
	disciplinary therapies.	teaching is essential.
	Need for greater signposting to	Adult autism services need to be
	services.	addressed.
		Regional consistency and
		standardisation across Trusts.
		Early intervention – not dependent on
		diagnosis.
		Greater provision of housing and
		supported living.
		Emphasis on cross-departmental
		working and collaboration.
		Regional funding needs addressed.
		30/1/20 Advised of launch of
		questionnaire
		4.00.00.00.00.00
		April/May 2020 – consulted on
		revision of guidance COVID 19 travel
		restrictions.
		21 July 2020 advised that
		questionnaire would issue to
		stakeholders.
		2 September 2020 – discussion with
		parents/carers (via Zoom) regarding
		impact of COVID-19 and priorities for
		a revised autism strategy.

Autism Initiatives NI	20.05.19	Independent living Day care service Outreach services Autism talks Advice Line	Variance in procedures across Trusts. Supported living and transitions requires urgent attention. Funding is unclear and inconsistent.	Enhanced awareness is essential. Emphasis on social inclusion and community integration to reduce isolation. Early intervention is essential. Need for consistency across regions. Lack of Occupational Therapists and Speech and Language Therapists needs addressed. 21 July 2020 advised that questionnaire would issue to stakeholders.
NOW Group	28.05.19 10.05.20 (meeting cancelled by NOW Group due to availability of staff)	Employment with support LOAF coffee shop/Pottery Jam Card Gauge NI Training Social groups Family services Transitions Projects Volunteer services Ambassadors	Variance in approach across Trusts. Funding is unclear and inconsistent. Impact of current autism strategy is not evident.	Joined up approach between health and education. Transition needs greater emphasis. More consultation required to obtain views. 21 July 2020 advised that questionnaire would issue to stakeholders.
Solas Special Needs Charity	10.06.19	Early years intervention Kids/parent/home support Afterschool and youth clubs Transition Respite	Current strategy focussed on gathering data, practical support now required. Direct payment awareness to parents/ carers	Co-production is essential. Funding needs to be clear and transparent. Collaboration across departments. Personalised early intervention is essential. Sibling support required.

		PEC therapy (picture exchange card)	Personalised and specific information around processes and support.	21 July 2020 advised that questionnaire would issue to stakeholders.
PEAT NI	04.07.19	ABA Therapy Family training/visits Staff training Triangle approach: parent/ child/school	Utilise resources available (ABA). Funding is unclear and inconsistent. Awareness has risen, but not understanding.	Early intervention is essential. Multi-disciplinary team approach is required. Focus on greater understanding of autism required. Transition processes need greater attention. 21 July 2020 advised that questionnaire would issue to stakeholders.
Barnardos NI	09.10.19	Forward steps Home links Short breaks Kids clubs including siblings Early intervention - parent and child Home support TEACCH Pilots	Early diagnosis/intervention is essential. Family support hubs are required. Variance in learning techniques cause difficulties.	Transition processes need addressed. Puberty/hormonal training is required. Social skills are essential. Links between autism/CAMHS is essential. Follow up intervention is required to ensure no one falls through cracks. Advocacy workers are beneficial. Staff need appropriate training across all areas. Understanding is now needed. Embed skills learned rather than moving on. Funding to be clear and transparent.

Helping Hands	29.11.19	Parent & Toddler groups CYP activities Training and information sessions Social community events Parent support network Alternative therapy Health & wellbeing Life skills support Family excursions	Variance across diagnosis/assessment. Support for young adults (>18) is priority. Psychiatric support very poor.	Joined up approach – DoH & DE. Waiting lists are postcode lottery. Early intervention follow up required. Clear communication to parents and across professionals. Adult services need attention. Respite needs attention for families. Transition processes need addressed. Puberty/Sexuality awareness needs addressed. Links between autism & CAMHS is essential. Support across all spectrum.
---------------	----------	--	--	---

The Department also participated in a Forum in June 2020, hosted by Specialisterne, and comprised of organisations representing autistic people, to discuss the impact of COVID-19. The issues raised related specifically to lockdown experiences and concerns in relation to employment.

HSC Emotional Health and Wellbeing	Department attends on a monthly basis to provide input to a development of a regional framework to
Framework Reference Group	standardise services, including autism, across the region.
	No meeting held since February 2020 due to COVID-19
Southern Region – Multi Agency Forum	Department attends on a quarterly basis to communicate on the development of the autism strategy
	development obtain an overview of regional issues.
	Last meeting 6 January 2021.
Northern Region – Multi Agency Forum	Department attends on a quarterly basis to communicate on the development of the autism strategy
	development obtain an overview of regional issues.
	Last meeting 20 January 2021.
Belfast Region – Multi-Agency Forum	Department attends on a quarterly basis to communicate on the development of the autism strategy
	development obtain an overview of regional issues.
	Last meeting 19 January 2021.
Western Region – Multi Agency Forum	Department attends on a quarterly basis to communicate on the development of the autism strategy
	development obtain an overview of regional issues.
	Last meeting 2 December 2020.
South Eastern Region Parent Group	Newly formed group.
	No meetings as yet attended.
*Regional Multi-Agency Forums – con	larged of multi-disciplinary therapists, community and voluntary sector, service users, NICS

Northern Region Reference Group
(comprised autistic people, families and
carers.)

Meets monthly.

11 September 2019 - Invitation extended to and accepted by Department of Health.

STAKEHOLDER ENGAGEMENT – UK-WIDE

Four jurisdictions (England, NI, Scotland and Wales) held on a quarterly basis to discuss emerging issues in each region and policy action being undertaken.

STAKEHOLDER ENGAGMENT - NICS

NICS Autism Open Day - 5 April 2019

Hosted by NICS Autism Working Group of which the Department of Health is a member. Purpose of the day was to bring a wide range of autism support services and community and voluntary sector representatives together to raise awareness and understanding of autism and advise of support available, to discuss issues arising and obtain views on the support required particularly in relation to frontline services. Over 200 civil servants were in attendance.

NICS CROSS-DEPARTMENTAL STAKEHOLDER FORUM

Comprised of cross-departmental autism representatives. Workshop hosted by Department of Health on 9 April 2019 to advise Departments of their responsibility in relation to the Autism Act (NI) 2011 and discuss preparations for the development of a revised autism strategy. Meetings reconvened (via virtual platform) on an individual departmental basis throughout COVID-19.

NICS AUTISM Working Group

Formed in 2019 and chaired by the NICS Autism Champion, a cross-departmental group comprised of civil servants who are autistic or carers of an autistic family member and Department of Health autism policy representatives. The purpose of the group is to provide support, raise awareness throughout the NICS and influence the shaping of services in the wider civil service.

Strategic linkages

Mental Health Strategy

A 10 year Mental Health Strategy will be developed to take a whole life approach to the mental health needs of the population at all stages in life with prevention and early intervention as a key consideration, bringing together work being taken forward across government.

Interdepartmental Action Plan in response to Still Waiting

An Interdepartmental cross-sectoral action plan has been developed in response to the NICCY 'Still Waiting' report, a rights based review of mental health services and support for children and young people in Northern Ireland. The action plan sets out a range of actions to address the agreed recommendations of the report and improve child and adolescent mental health services (CAMHS) and development of regional guidelines to improve transitions between CAMHS and Adult Mental Health Services and more mental health support in schools.

Health and Social Care Children and Young People's Emotional Health and Wellbeing Framework

Following a review of children's autism services, the Children and Young People's Emotional Health and Wellbeing Framework has been developed to deliver a proactive, integrated and streamlined pathway for children who present to Trust children's services. The implementation of the Framework will enhance standardisation of access to autism services and early intervention approaches across the regions.

Disability Strategy

The development of a new cross-Departmental Disability Strategy will be aimed at addressing inequalities and obstacles that directly affect the everyday lives of all disabled people, including those with autism. The new Strategy will be published by end 2021. A fully co-produced autism strategy will be developed in tandem with the Disability Strategy

to enable robust linkages to be identified, where appropriate, to benefit and support autistic people, families and carers.

Emotional Health and Wellbeing in Education Framework

Developed in partnership with the Department of Education, Department of Health and the Public Health Agency, the implementation of the new Emotional Health and Wellbeing in Education Framework will support those working in educational settings to help them promote emotional wellbeing, strengthen self-esteem and resilience in our children and young people and effectively respond to presenting needs as required.

Supporting Equality through Inclusive Employment: An employment strategy for people with disabilities.

The Employment Strategy for People with Disabilities is focused on supporting those people with the most significant disability related barriers to work and to secure and sustain paid employment opportunities across all employment sectors.

Children's and Young People's Strategy

The Children's and Young People's strategy has been developed to deliver improved wellbeing for children and young people, to give them the best start in life and to enable them to develop their full potential.

Supporting People Strategy

The Housing Executive, through the Supporting People Strategy (2021-2024), aims to work together with partners to facilitate and deliver high quality housing support and to promote independent living to those most in need, whilst making best use of the available funding.

The Supporting People Programme funds a number of services; both accommodation based and floating support, for adults with autism. In year one of the strategy the Housing Executive will work with partners to scope future housing support needs for individuals with

a learning disability, explore the reconfiguration of services and work with partners in reviewing shared accommodation models.

Learning Disability Service Model

A regional service model for learning disability, being developed by the Health and Social Care Board, will aim to secure regional consistency of services and enable individuals with a learning disability to be respected and empowered to lead a full and healthy life within their community.

MONITORING TEMPLATE - STRATEGIC OUTCOMES 2021-2022

Strategic Outcome 1

A healthy life with access to services on an equal and timely basis.

We 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.

What did we do?	When did we do it?	What difference did it make?	Lead responsibility/ Partnership working

Strategic Outcome 2

A life with opportunities to live as an active citizen.

We will 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 throughout life stages.

What did we do?	When did we do it?	What difference did it make?	Lead responsibility/ Partnership working

Strategic Outcome 3

An independent life with greater societal understanding and choices.

We will provide opportunity for autistic people to live safe and independent lives within our communities and have equal access to services where they are met with respect and understanding.

What did we do?	When did we do it?	What difference did it make?	Lead responsibility/ Partnership working