

# **AUTISM STRATEGY 2023–2028**

**To Respect, To Listen, To Involve**



Department of  
**Health**  
[www.health-ni.gov.uk](http://www.health-ni.gov.uk)



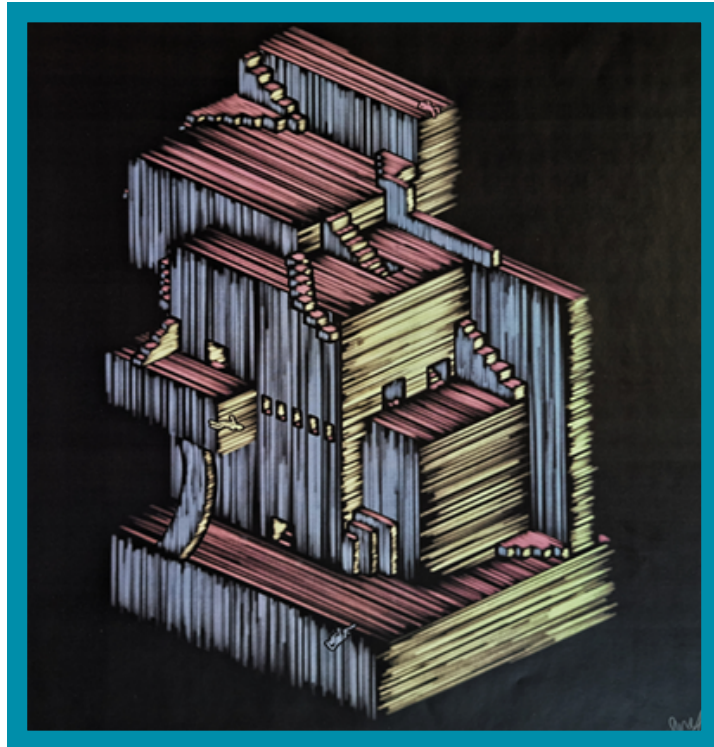
## **CREATIVE VOICES**

The illustrations in this strategy have been created by children and young people who contributed their work to an art exhibition called:

*'What autism means to me: Creative voices.'*

The artwork is their interpretation of what autism means to them.

We would like to thank them for their consent to include their artwork with the Autism Strategy 2023-2028.



### ***Sam's Voice***

I think autism can be described as a different perspective. The way you see things is different, how you respond to things is different, your thought process, your actions, and reactions. They're all different, but as the piece I have made shows, there's no inherently right way to look at things. Each different view on the world will do things differently, and so some will do things better than others. It may be difficult to see other people's perspective, to understand what they are thinking, but that does not mean that their perspective is wrong.

This is how I view autism. A change in perspective, one that drastically changes how you react to stuff, but one that is not incorrect or wrong. This is represented in my piece, as there is no wrong way to look at it, just different angles, different perspectives.

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## Foreword

Autism is becoming ever more prevalent in our society and we as citizens, employers, public services and organisations must recognise and acknowledge that we all have a responsibility and a role to play in ensuring that autistic people and their families can feel understood, accepted and supported within our communities and in the delivery of our services.

Whilst government departments and public bodies have in recent years worked in collaboration to actively raise the profile of autism in the work that we do and promote the need for greater understanding of autism and the challenges that people and their families experience; as a spectrum condition, each person will experience autism in an individual way. There is no 'one size fits all' approach to the support that is required.

In recent years, the Department of Health has engaged and consulted extensively with people who have lived experience of autism and also with the organisations who both represent and support them. The Department has placed continued emphasis on keeping their views central and in providing them with opportunity to inform the actions and work being undertaken across government departments.

In taking this approach, collaborative work across government departments, health and social care and the community and voluntary sector has been strengthened and there is a strong emphasis placed on recognising that improvement can only come if we listen to autistic people and their families to understand their experiences and needs and work together to achieve outcomes which will demonstrate improvement.

Additionally, we welcomed the introduction of the Autism (Amendment) Act (NI) 2022 to guide the direction of further advocacy, support and services which this strategy will progress.

I welcome the publication of this strategy and the opportunity for us all to work towards a more inclusive society, one in which everyone has an opportunity to participate and feel valued.



Peter May  
Permanent Secretary  
Department of Health

## 1. INTRODUCTION

### 1.1. What is Autism.

Autism is a lifelong neurodevelopmental condition which affects the way that people experience, communicate, and interact with their environment.

Many individuals who are autistic will have difficulty processing everyday sensory information such as sight, smells, touch, taste and sounds and some may have repetitive or rigid behaviours, activity or routine.

Autism is a spectrum condition which will affect each individual differently; many individuals will live independently or have interventions which will enable them to manage their condition and never come into contact with services, others may have more complex needs and/or co-existing conditions which will require specialist support.<sup>1</sup>

### 1.2. Terminology

Through consultation and engagement with autistic people we understand there are variations in the terminology relating to autism; individuals, families and practitioners may have preference for specific terms. For example, whilst the term Autism Spectrum Disorder (ASD) is widely used and recognised as a medical condition, many people are less accepting of the use of the term 'Disorder', therefore within this strategy the terminology used will be 'autism'.

Likewise, there may be preference in the terminology used to identify as an autistic person. Some people will prefer to be referred to as an 'autistic person or child' whilst others may use the term 'person with autism'.<sup>2</sup> Following consultation and agreement with stakeholders, the term which is used throughout this strategy and in Department of Health publications is 'autistic person' or 'person who is autistic'. This also aligns with National Institute for Health and Care Excellence (NICE) guidelines<sup>3</sup> which were revised in 2021 to use the term 'autistic child or young person'.

It is also understood that many people who are autistic may have a co-existing condition or a learning disability and cognisant of this in recent years there has been a notable trend towards 'neurodiversity'.<sup>4</sup> This refers to the different ways that an individual's brain will process information and highlights how each person thinks, communicates and senses the world around them in a different way.

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<sup>1</sup> [CG142 Autism in adults full guideline \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG142).

<sup>2</sup> [Autism spectrum disorder in under 19s: support and management \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG142).

<sup>3</sup> [Autism spectrum disorder in under 19s: support and management \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG142).

<sup>4</sup> [Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science - PMC \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/35811111/).

Neurodiversity also encompasses a broader range of conditions, which often co-exist with an autism diagnosis, for example ADHD, Dyslexia and Dyscalculia.<sup>5</sup> This terminology will also be reflected within the strategy and in some of the actions, particularly in relation to care pathways, associated in the implementation, delivery and future strategic direction of the strategy.

### **1.3 Why we need an Autism Strategy?**

In Northern Ireland there are currently 35,367 people who identify as autistic.<sup>6</sup> This figure was recorded for the first time in 2021 and published in the Northern Ireland Census in 2022.

Within our school population, figures extracted from the 2022/23 Northern Ireland School Census show that 15,212 school aged children had received an autism diagnosis; this represents an estimated autism prevalence rate of 5% within the school population.<sup>7</sup> Due to differing methods of recording data, there is no statistical data collated across the United Kingdom which can provide an accurate comparative figure, however available statistical evidence would suggest that Northern Ireland has one of the highest prevalence rates of autism within the school population across the United Kingdom.

Additionally, within the United Kingdom differing approaches have been taken in developing strategies to support autistic people, for example, in England a National Strategy for Autistic Children, Young People and Adults: 2021–2026 was published with an implementation plan for 2021 to 2022. This is the first time a ‘whole life’ approach had been taken to development of an autism strategy in England, previously this had been an adult autism strategy. In Scotland, following the conclusion of a ten year autism strategy in 2021; the Scottish Government has committed to introducing a Learning Disability, Autism and Neurodiversity Bill to ensure that the rights of autistic people, people with a learning disability and neurodivergent people are respected and protected. These differing approaches make it challenging to provide an accurate, illustrative and comparative presentation of autism across the United Kingdom.

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<sup>5</sup> [\*Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science - PMC \(nih.gov\)\*](#)

<sup>6</sup> [\*Census 2021 Main statistics for Northern Ireland - Statistical bulletin - Health \(nisra.gov.uk\)\*](#)

<sup>7</sup> [\*The Prevalence of Autism \(including Asperger Syndrome\) in School Age Children in Northern Ireland Annual Report 2023 \(health-ni.gov.uk\)\*](#)

However, a clear picture which has emerged is that whilst the factors affecting the increasing prevalence of autism remain unclear, an impact of escalating figures is the increased demand on services, for example, health and social care provision, housing, education and also community and voluntary sector support. Increasing demand continues to outstrip the capacity of many services to deliver timely support.

This is particularly evident in the increasing numbers of referrals received for autism assessment within the health and social care sector which have led to extensive waiting lists for autism assessment.<sup>8</sup>

Not only does this bring considerable challenges to the wider health and social care sector, but also to individuals and families who are waiting for an assessment, as the need for intervention and support whilst waiting for an assessment can often prove overwhelming and inhibiting to life experience and management. This can often lead to the need for emotional health and wellbeing or mental health support.<sup>9</sup>

This demonstrates that the growing prevalence of autism places a responsibility on us, as a society, to be more equipped and informed in our understanding of autism and in the delivery of our services and to strive to ensure engagement and support in the development of our policies and guidance to enable autistic people, their families and carers to feel supported and live fulfilling lives.

Where difference in thinking is understood and more widely accepted, this can support autistic people in experiencing less anxiety, in seeking opportunity and feeling included, comfortable and confident in their daily life.

#### **1.4. Our Vision**

In implementing this strategy the ethos and vision of the previous Autism – Interim Strategy 2021-2022 will continue; that is that people with lived experience of autism will remain central to informing and co-producing the actions which should be delivered.

In recognition of this it is our commitment that the vision, *'To respect, to listen, to involve'* will remain, to place emphasis on the importance of the inclusion of autistic people and their families in the development of actions, policy and services to ensure they are inclusive in how they are informed, developed and delivered.

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<sup>8</sup> [Quarterly autism statistics for NI \(April – June 2023\) | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/publications/quarterly-autism-statistics-for-ni-april-june-2023)

<sup>9</sup> [CHS Healthcare Autism and ADHD Report FINAL.pdf \(chshc.co.uk\)](https://www.chshc.co.uk/Healthcare/Autism%20and%20ADHD/Reports/CHS%20Healthcare%20Autism%20and%20ADHD%20Report%20FINAL.pdf)



## **1.5. Legislative Context**

The requirement for an autism strategy is supported through the legislative context of the [Autism Act \(Northern Ireland\) 2011](#) and the [Autism \(Amendment\) Act \(NI\) 2022](#).

This legislation places a responsibility on the Department of Health to prepare a cross-departmental autism strategy in collaboration with all government departments which sets out key priorities and actions to enable autistic people and their families to be supported throughout their lives.

## **1.6. Wider Strategic Context**

This strategy and associated actions for implementation are informed not only through extensive consultation and engagement, but through evidence and best practice conveyed through international, national and local research and policy. In addition to this, the strategy is supported through increased collaborative working across government departments, the health and social care sector, public bodies and engagement and partnership working with the community and voluntary sector.

This strategy is also aligned to the following documents:

- HSC Children and Young People’s Emotional Health and Wellbeing Framework (currently being developed).
- Children’s Co-operation Act, NI (2015).
- Special Educational Needs and Disability Act (2016).
- Health and Wellbeing 2026 – Delivering Together (2016).
- New Decade, New Approach (2020).
- Children’s and Young People’s Strategy (2019).
- Department of Health Learning Disability Strategic Action Plan (currently being developed).
- ‘We Matter’ – Learning Disability Service Model.
- Mental Health Strategy 2021–2031.
- Children and Young People’s Emotional Health and Wellbeing in Education Framework.
- Northern Ireland Review of Children’s Social Care Report (2023).
- Northern Ireland Act 1998 (Section 75).
- UN Conventions on the Rights of a Child (UNCRC).
- Disability Discrimination Act (1995).

## **1.7. Who is the strategy for?**

### **Autistic people, their families and carers**

The strategy sets out key commitments and actions which have been identified in response to extensive consultation and stakeholder engagement and have been developed to respond to the challenges that we have been told need to be addressed, enhanced or improved to provide support. Reporting on these actions, against associated measures, will be carried out on an annual basis.

### **Government Departments and Public Bodies**

In recent years, recognising the extensive benefits and importance of a 'joined up' approach, there is greater collaborative working across government departments most notably in Education, Communities and Employment. The Department of Health is working with government departments and public bodies to ensure that legislative responsibilities are acknowledged, and actions are considered and developed to support autistic people and their families. This strategy and the associated Delivery Plan set out how each contribute to the key commitments of this strategy and demonstrate where there is greatest need for support and potential for work to be undertaken within their business objectives.

### **Health and Social Care Sector**

This strategy sets out key commitments and actions which autistic people and their families have identified as presenting challenges and greatest need. The Health and Social Care sector work proactively to provide supports and intervention to autistic people. This strategy will enhance the opportunity for collaborative working and sharing of ideas in delivering services to autistic people.

### **Community and Voluntary Sector Groups**

Community and voluntary sector organisations provide a range of advocacy, support and services to autistic people and their families. In addition, many of these will also provide specialised areas of support particularly in relation to housing, employment and training. This strategy presents opportunity for greater partnership working and increased stakeholder engagement to enable actions to support autistic people to be informed and co-produced by people who have lived experience of autism.

## **2. ADVOCACY**

### **2.1. Autism Reviewer**

As a requirement of the Autism (Amendment) Act (NI) 2022, the Department of Health will appoint an Independent Autism Reviewer for Northern Ireland (hereafter referred to as ‘the Reviewer’).

Whilst the Reviewer will be appointed by the Department of Health, the role will be independent of Northern Ireland government departments and will act as an Advocate for autistic people, their families and carers across government departments, public bodies and the health and social care sector.

The Reviewer will provide an independent monitoring role in relation to the implementation of the Autism (Amendment) Act (NI) 2022 and the implementation of the autism strategy.

In carrying out their role the Reviewer will:

- Provide strong public advocacy for autistic people, their families and carers by monitoring and reporting on the implementation and effectiveness of the autism strategy on an annual basis. This will include allocation and expenditure of funding across departments and the health and social care sector.
- Collaborate with stakeholders and people with lived experience of autism.
- Report on the effectiveness of services provided for autistic people, their families and carers.
- Monitor adherence to legislation and practice in relation to autism.
- Commission independent research on support and best practice in relation to autism, as appropriate.
- Carry out any other functions which the Department of Health may confer.

Whilst the Reviewer will have a pivotal role in reviewing and informing the key priorities of the strategy, through stakeholder engagement and research, due to their independent monitoring role they will not have a role in development of the strategy.

### **2.2. Autism Forum**

In commitment to the vision of the previous interim strategy (2021-2022), to enable people with lived experience to have a central role in informing the development of the strategy and inform cross-departmental actions to provide support, an Autism Forum was established by the Department of Health in 2021.

The Forum, which is comprised of people with lived experience and the community and voluntary sector organisations who represent them, is Co-Chaired by the Department of Health and two Adult Advocates who are autistic.

Current representation includes:

- Autism NI
- National Autistic Society
- ARC (Association for Real Change)
- Specialisterne
- Autism Initiatives
- NOW Group
- Barnardo's
- Cedar Foundation
- Orchardville
- Mencap

The Forum meets on a quarterly basis to:

- Provide a platform for discussion and innovation and to connect local and regional work on autism across organisations, departments and sectors.
- Promote opportunity to bring evidence and the experience of autistic people, their families and carers, and the organisations who represent them, and enable voices to be heard.
- Provide a strategic input to the co-production of a longer term autism strategy and inform the development of government policy, data and services, as appropriate.
- Monitor and measure progress in the implementation and delivery of the autism strategy in a meaningful way.
- Encourage participation through members to consult with our stakeholders and the users of our organisations to enable their views to be included in the Forum.

### **2.3. Health and Social Care Trust Autism Fora**

As a result of the first autism strategy (2013–2020), Health and Social Care Trusts ('the Trusts') formed multi-agency stakeholder forums to provide a platform for discussion and exchange of ideas, to inform services and to provide opportunity for co-production from people with lived experience of autism.

The Forums meet on a quarterly basis and are instrumental in providing opportunity for advocacy and raising awareness within their Trust area.

### **3. DEVELOPMENT OF THE AUTISM STRATEGY**

#### **3.1. Approach**

The previous strategy, the Autism – Interim Strategy 2021-2022 (‘the interim strategy’) was developed and published at the height of the Covid-19 pandemic. Whilst short in lifespan, the interim strategy set the direction for the commitment and ethos that a longer term strategy would embed; that is, it would be informed by autistic people and would be developed in response to their needs. The Monitoring and Evaluation Report 2023, published in June 2023, demonstrated what had been accomplished during this period and also emphasised the value and inclusion of autistic people in the co-production of the progress which had been undertaken.

Through increased recognition of the need for greater understanding of autism and the need for a range of support to be provided, there is now enhanced collaboration and partnership, which is inclusive of people with lived experience of autism, across government departments and public bodies. This has been valuable to inform development of strategy and guidance and ensure that this is also cognisant of the needs of autistic people being met.

In acknowledging that many autistic people may have co-existing conditions, for example an intellectual or learning disability or neurodiverse needs, many of the actions presented within the strategy, will be led through intervention and support which is based upon presenting need and focused on getting ‘the right support at the right time’, rather than placing emphasis on an assessment and diagnosis driven approach.

#### **3.2. Engagement and Consultation**

The strategy has been developed in response to continued consultation with autistic people and their families. The Delivery Plan will remain a ‘live’ document and will be further informed through a monitoring report drafted and published on an annual basis to demonstrate how implementation of this strategy has progressed. Actions will continue to be reviewed to respond to emerging need.

The strategy has been developed in response to ‘what we have been told’ with actions, informed through research and evidence based practice, to respond. Through our engagement we have been told that individuals want to see a strategy which is based on ‘actions and not words’ that is:

- People focused, whole life and based upon need;
- Practical and supportive in language and approach; and
- Focused on improving and enhancing supports which are outcome based and measurable, either in a qualitative or quantitative way.

### **3.3. Strategy Development**

#### **3.3.1. Pre-Consultation Questionnaire**

In preparation for development of this strategy a pre-consultation was undertaken to identify the key priorities for inclusion. The pre-consultation launched as a consultative questionnaire, online and in written format, between 23 August – 8 October 2021; 349 responses were received.

From this a [Summary of Responses](#) was published which identified the key priorities to be included in the Autism Strategy 2023–2028.

#### **3.2.2. Autism Forum**

To ensure that the key priorities identified through the pre-consultation, and which are being developed across departments, are informed by people with lived experience of autism, a theme was identified for each Autism Forum meeting. Appropriate representatives from relevant government departments and public bodies were invited to attend to provide opportunity for discussion and stakeholder engagement. This included education, housing, employment and the health and social care sector.

#### **3.3.3. Cross-Departmental Autism Working Group**

In commitment to cross-departmental working and to ensure that government departments are aware of their responsibilities in relation to the autism strategy, a Cross-Departmental Autism Working Group comprised of senior officials across departments was established. Representatives are responsible for identifying key contacts in each department and providing a mechanism for collaborative working and engagement in fulfilling their legislative responsibilities in relation to the autism strategy.

### **3.3.4. Stakeholder Engagement**

Stakeholder engagement is central to the work of this strategy. This provides opportunity for people with lived experience of autism, community and voluntary sector organisations, government departments and the health and social care sector, to have an opportunity to discuss the challenges that autistic people experience.

From this engagement the actions that need to be achieved can be identified and the outcomes can be agreed which would best demonstrate improvement.

In bringing all stakeholders together to exchange ideas and consider outcomes to be achieved, two facilitated [Strategic Outcome Workshops](#) were held on 20th and 29th September 2022.

These workshops also provided opportunity for stakeholders to contribute to how the role of the Independent Autism Reviewer would be developed.

### **3.3.5. Public Consultation**

The information which was gathered from the pre-consultative stage and stakeholder engagement workshops informed the key priorities upon which a public consultation was carried out to determine what autistic people and their families and carers consider need to be enhanced or improved.

The public consultation was carried out over a twelve week period between 14 December 2022 – 8 March 2023, responses were gathered from written consultation documents and an electronic version provided through Citizen Space; over 200 responses were received.

Ten public consultation sessions were held during this period; sessions were carried out on digital platforms, or 'in person' and facilitated by organisations representing autistic people with Department of Health representatives in attendance. A [Consultation Summary Report](#) of responses is published on the Department of Health website.

### **3.3.6. Equality Considerations**

In adherence and commitment to the requirements of Section 75 of the Northern Ireland Act 1998, due consideration was given to Equality Screening, Disability Duties and Human Rights Assessment; Rural Needs Impact Assessment requirements were also considered. These can be viewed on the Department of Health website.



## **4. IMPLEMENTATION AND DELIVERY**

### **4.1. Key Commitments**

We have listened to what we have been told throughout consultation and engagement; from this we have set out the key priorities and actions of the strategy in **Annex A** which will be fulfilled through the following commitments.

#### **Commitment 1**

Through improved regional pathways of care, individuals and families will have access to early intervention and support which can meet emotional health and wellbeing needs.

#### **Commitment 2**

We will work in partnership to enable autistic people to feel understood and supported throughout their education, to experience educational environments which are inclusive to their needs and to have a workforce who are equipped with understanding to recognise and respond to the specific needs of autistic pupils and students.

#### **Commitment 3**

We will seek opportunity for increased understanding of autism in the workplace to enable individuals to feel supported within employment and enhance career opportunity.

#### **Commitment 4**

Through increased understanding of autism, our housing providers will be more equipped to provide supportive engagement and adequately support the needs of autistic people.

#### **Commitment 5**

We will work within our community to increase understanding and acceptance of autism and create inclusive environments to support the needs of autistic people and their families and carers.

## **4.2. Delivery Plan**

The Delivery Plan will remain a 'live' document to enable response to emerging issues and specific need.

At the time of development, Northern Ireland government departments are experiencing unprecedented budgetary challenges that have placed some constraints upon initial implementation of this strategy, for example, the appointment of an Independent Autism Reviewer. A number of strategies and supports which were underway, and inclusive of autistic people, particularly in relation to provision of children's services in education and in employment and disability support, have been paused.

In consideration of these constraints, and to ensure that provision of support and services is not delayed and can continue to be delivered within the current financial constraints, an initial two year Delivery Plan 2023–2025 has commenced implementation of this strategy.

The Delivery Plan will set out the actions to be achieved against commitments, associated outcomes and the delivery partners involved.

## **4.3. Data**

Whilst the Northern Ireland Census, for the first time, provided us with more accuracy in relation to the prevalence of autism within our population, there is still limited data available in relation to autism to further inform strategic planning and service delivery. This particularly relates to the adult demographic, as many will not seek support through services, disclose their diagnosis or have a co-existing condition or a learning disability which can be captured through a different lens of data.

This strategy will seek to identify gaps in statistical data and investigate how this could, or should, be captured where possible.

## **4.4. Research**

It should be noted that this strategy has been informed through local, national and international research and evidence. Whilst research has been undertaken in relation to individual actions being taken forward by respective owners, the implementation and subsequent Delivery Plans will continue to be further developed by research and data collection being taken forward as part of this strategy.

#### **4.5. Monitoring and Reporting**

The Delivery Plan for 2023–2025 will be reviewed on an annual basis and a monitoring and funding report will be produced and published on the Department of Health website. This report will set out the progress on implementation of this strategy, the outcomes that have or will be achieved and how this will be measured. The report will also capture the funding, where possible, which has been allocated to support and deliver the commitments of this strategy. A sample Monitoring and Reporting template is provided at **Appendix 1** of the Delivery Plan.

Whilst this role will be fulfilled by the Independent Autism Reviewer, in adherence to legislative requirement, until this appointment is made this duty will be fulfilled by the Department of Health.



### **Asher's Voice**

Sometimes autism feels like being a static TV. It is hard to communicate when my senses are overwhelmed.

*Too loud...*

*Too heavy...*

*Too tired...*

*Too overwhelmed...*

*Too much!*

## **AUTISM STRATEGY 2023-2028**

### **Strategic Actions**

Actions within this strategy have been informed through extensive stakeholder engagement and consultation with autistic people and their families and with the community and voluntary organisations who represent them.

Further detail on how development of this strategy was taken forward is set out in Section 3 of this document.

We have listened to what we have been told and in response we have collaborated across government departments, public bodies and the health and social care sector to develop actions which can respond to the needs of autistic people.

Actions are set out in five commitments which will be delivered throughout the lifespan of this strategy.

## **Commitment 1**

Through improved regional pathways of care, individuals and families will have access to early intervention and support which can meet emotional health and wellbeing needs.

## **This is what we were told:**

- The provision of support and intervention, based upon presenting need, at an early stage is crucial for individuals both pre and post autism assessment to support them as they try to process how they feel, their behaviours and how these can be managed.
- Improved and timely communication is required, particularly for those who may be waiting on lengthy waiting lists for an autism assessment, which clearly sets out the process to enable individuals and families to understand, and to feel informed and prepared for each stage of the assessment process.
- Identifying appropriate services can be difficult and challenging; greater and more accessible signposting is required to direct individuals and families to services and supports in relation to autism, for example, health, education and housing.
- Health and social care professionals should have an increased understanding of autism, to understand the individualised communication needs of autistic people and be aware of how the sensory and environmental surroundings can impact on their wellbeing and ability to manage medical appointments and care.
- There is inconsistency in the provision and use of Direct Payments and recipients are finding the process labour intensive and difficult to manage, particularly in the supporting the specific needs of autistic people who require a constant and consistent approach both in the support being provided and the people who are involved in providing the support. Irregularity and change can increase anxiety. More guidance is required and flexibility in use to enable the provision and use of payments to be more supportive to an individual's or family's needs.
- Siblings of an autistic family member can often need support, particularly those who fulfil a role as a young carer. It must be recognised that other members of a family can be impacted by the emphasis which must be placed on caring responsibilities and managing routines and interventions for an autistic person.
- Short breaks and respite services need to be planned and regular to provide consistency and routine to support an autistic person's needs; irregularity and change can present challenges and increase anxiety.

- Transitions are wide ranging and include children to adult services, education, employment and life changes, such as moving house, bereavement, changing relationships. This can present challenging times for individuals and families. Support and communication throughout transitions processes must be strengthened, improved and planning must commence at an early stage.
- Increased numbers of individuals presenting with gender dysphoria may have an autism diagnosis or present with characteristics of autism. Additionally, we have been told that transitions in support of LGBTQ+ can be particularly challenging and there must be more acknowledgement of the need for recognition and support.



## **This is what we will do:**

- We will implement a new framework of care to improve support and provide interventions to children and young people with emotional health and wellbeing needs, including autism. The framework will support health and social care services to collaborate broadly to develop and integrate high quality, evidence-based support, intervention and diagnostic pathways that will best meet the presenting needs of our children and young people both pre and post diagnosis. Acknowledging the considerable good practice across the statutory, voluntary and community sector and family support programmes, the framework will be informed through stakeholder engagement and provide the basis for better co-operation and collaborative working between all services.
- Recognising that many people who are autistic may also have a learning disability or complex needs, the Department of Health along with partners across the Health and Social Care sector will develop and implement a Learning Disability Strategic Plan which will be underpinned by a renewed focus on effective governance, evidence and data to shape future services for people with a learning disability and/or autism in Northern Ireland. It will also address the need for better transitions planning between children's and adult Learning Disability Services, this includes people who have a co-existing diagnosis of autism.
- Through provision of accessible step-by-step guidelines, Health and Social Care (HSC) Trusts will improve the provision of relevant information and communication to those referred for assessment for autism to ensure that individuals and families feel prepared and supported throughout the referral and assessment process.
- We will develop a Regional Autism Information Service to provide methods of signposting to sources of support and information to ensure that services are accessible and easily navigated by people who may require advice and support from public services, for example, health, education, housing and benefits or financial advice.
- Through the development of regional training videos, GPs and the HSC workforce will have access to training which will further inform and increase their understanding of autism as a condition and provide opportunity for greater understanding of the challenges that autistic people experience. This will assist in managing practical approaches to healthcare and support, particularly in relation to communication and sensory needs in respect of medical appointments, and how autistic people can feel supported and confident within the HSC services and environment.

- In response to a Review of Adult Autism Services which was commissioned by the Department of Health and undertaken across Northern Ireland in 2022, we will:
  - Ensure that effective commissioning processes are in place and that accurate data for adult autism is collated to inform and plan for future development.
  - Identify the investment required to provide intervention and address waiting lists and ensure client needs are supported and met.
  - Review the current service model to provide consistent service models across Northern Ireland with clear pathways and age appropriate assessment and intervention processes and establish waiting time targets for assessment.
- We understand that provision of short breaks and respite care is vital for individuals and families and the need for planned and regular services to provide consistency of routine and care for autistic people. We will work towards re-implementation of services which are planned and consistent in a way that is necessary for individuals and carers.
- We understand that many siblings who have an autistic family member may feel anxious because of the challenges and restrictions that characteristics and responsibilities of managing the condition present in family life and it is recognised that many will fulfil a role of carer within the home. We will work with HSC Trusts and community and voluntary sector groups to identify or enhance sources of support and recreation to enable families to have opportunity to feel supported.
- We understand that transitions in health, education and in employment and also those which can be influenced by life changes, for example, bereavement, moving house, relationships, can create anxiety and present challenges. We have established a Joint Education/Health Working Group which also includes representatives from our Careers Service and wider education sector. This Group will survey experiences and review processes to create more streamlined, supportive and timely transitions processes.

- Following a review of Gender Identity Services for adults, children and young people in Northern Ireland, proposals and options for a service model will be brought forward to an incoming Health Minister. Research suggests that people with gender dysphoria were more likely to be autistic.<sup>10</sup> Prevalence of autism and the challenges being experienced have been acknowledged within this review and will identify appropriate support once a service can be considered and commissioned.

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<sup>10</sup> *Adolescent with autism and gender dysphoria. Case Report. Child and Adolescent Psychiatry, Vol. 12, 2021.*

## **Commitment 2**

We will work in partnership to enable autistic people to feel understood and supported throughout their education, to experience educational environments which are inclusive to their needs and to have a workforce who are equipped with understanding to recognise and respond to the specific needs of autistic pupils and students.

## **This is what we were told:**

- School environments can be challenging for children and young people resulting in overstimulation and anxiety as they try to manage the expectations of the school day and adapt to different surroundings and routines. Some children need to make adjustments to their learning environment to facilitate sensory need and concentration and adapt their learning styles to assist and support them in regulating their emotional responses and behaviours and ability to manage change. This can be particularly challenging in post primary and further education where there may be changing timetables to adapt to, different peers in each class and movement to a range of differing environments dependent on curriculum choices. Strategies should be provided to enable pupils and students to have the best possible educational experience through identifying their own individualised learning styles and support mechanisms, rather than increasing anxiety through the need to conform.
- Teaching and academic staff would benefit from autism specific training so that characteristics of autism and appropriate interventions could be provided to effectively support pupils and students within the educational environment, particularly those who may be waiting for assessment and/or have not yet a diagnosis. This can be particularly evident in further and higher education as many students, and research highlights females<sup>11</sup> as an example, may not receive an autism diagnosis until adulthood as the characteristics of autism have been masked or not recognised throughout primary and post primary education. Many respondents considered this training should be mandatory.
- Within further and higher education it was stated that an autism advocate or nominated 'link person' would be beneficial to enable students to have a 'first point of contact' to navigate and adapt through college and university life, particularly in the early stages of their academic experience. Children and young people who may have had a statement of educational need throughout their school life will not have this transferred to further and higher education. Some may choose not to disclose their autism diagnosis. Often people who have had a challenging experience within the academic sector may not complete their education or pursue employment.

<sup>11</sup> *Living in a world that's not about us: The impact of everyday life on the health and wellbeing of autistic women and gender diverse people.* Women's Health. London. January 2023. Available at:

[10.1177\\_17455057231189542.pdf \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/37455057231189542/)

## **This is what we will do:**

- Children and young people must be supported within their educational environment based on their presenting need for support, this should be regardless of a referral for autism assessment having been made or a diagnosis having been received. Through a review of Education Authority Pupil Support Services, including the Autism Advisory and Intervention Service, an enhanced model of support will provide the appropriate level of support to meet a pupil's needs.
- We will develop guidance within our School Building Handbook to incorporate design of inclusive learning environments to accommodate children with wide ranging needs, including autism, in the delivery of the curriculum. This will contribute to improved and accessible learning environments which will be supportive of children and young people's needs.
- We will commence a review of Special Educational Needs, which includes examining initial teacher education and continual professional development to have an appropriately equipped educational workforce who can deploy reasonable adjustments within the learning environment to enable children and young people to feel understood and supported and provide an enhanced model of pupil support which is based on presenting need ensuring that the right support is provided at the right time and that there is improved access to resources and training for parents and educational staff.
- As part of a Special Educational Needs and Disabilities (SEND) Transformation Programme a review of the Educational Psychology Service is being undertaken and new models of delivery are being explored to provide improved access to educational psychologists for both pupils and schools.
- We understand that working in partnership across the health and education sectors is essential in ensuring children and young people's needs are supported. This requires careful planning and active engagement across both sectors to provide an integrated approach to the child and young person's needs. To support proactive and integrated planning the Department of Health has provided funding to each Health and Social Care Trust to progress the appointment of a Special Educational Project Lead Officer who will scope the healthcare needs of Children and Young People and work with colleagues across both the health and education sector to develop integrated models of support.

These roles will support enhanced partnership working and will assist in the planning and a better understanding of services for children including when transitioning to adult services.

- Whilst significant progress has been made within higher and further education to support autistic people, we recognise that there is still more to be addressed to ensure this practice is consistent across all regions. We will continue to work in partnership with colleges and universities to provide key mechanisms for support, for example, training to increase understanding of autism across the academic workforce, key points of contact, quiet spaces and support throughout the transition process from post-primary education to further and higher education.

### **Commitment 3**

We will increase understanding of autism in the workplace to enable individuals to feel supported within the work environment enhancing career confidence and opportunity.



## **This is what we were told:**

- Careers advice needs to be adapted to support the individualised needs of autistic people and provided by staff who have been trained to have an understanding of the communicative and sensory needs of autistic people and to support them in recognising skills and making career and employment choices.
- Autistic people can feel anxious and misunderstood within the work environment. They may find it difficult to integrate and manage the communication and social interactions which are often expected and are a requirement of the workplace and relationships with colleagues.
- Employers need to have more understanding of autism and to promote and encourage this within the workplace. There needs to be greater awareness of the 'reasonable adjustments' that could be considered and implemented, for example, a quiet space to manage overstimulation within a sensory environment, adjusted working patterns or hybrid working.
- There should be more focus and support available to underpin and enhance life skills to support individuals as they manage transition and adapt into careers and employment, for example, completing application forms, preparing for interview, managing social interactions and dealing with change.
- Interview processes are stressful for many people. For an autistic person, the sensory and communicative expectations and challenges which can be experienced throughout this process can often mean that they are not successful in gaining employment or may prevent them from seeking employment due to the anxiety that this will present.
- The cessation of the European Social Fund (ESF) created considerable uncertainty and removed employment opportunity for many individuals and organisations.

## **This is what we will do:**

- We will promote training and the need for understanding of the individualised needs of autistic people and consideration of communicative approaches to staff who are working in a careers advisory setting. This will enable them to increase their understanding and approach in how they engage with and advise autistic people and work with them to identify strengths, skills and challenges and how these can be managed in pursuing career opportunity and employment.
- We will work in partnership with people who have a lived experience of autism, and with the Equality Commission NI, to provide guidance which will be accessible to employers and will set out steps which can be taken to provide reasonable adjustment, in relation to communication, workstyle and sensory challenges, within the recruitment and work environment to support the needs of autistic people.
- In Northern Ireland we must work to increase the rate of employment for those with disabilities, including autism, by creating the right environment and circumstances to allow them to participate in the labour market, supporting all stages of the employment journey from pre-employment, right through to progressing their careers. Much work has been undertaken by the Department for Communities and partners, including those people with lived experience, to develop a strategy that will set this ambition, focussing on key areas of support; enhancing access to training, skills and careers advice; supporting employers so that they can be more confident in employing people who have a disability, including autism and related conditions.
- Labour Market Partnerships (LMP) are a multi-agency collaborative approach designed to improve labour market conditions and employability outcomes at a regional and local level. One of the six main themes within LMP delivery is disability with a focus on addressing the disability employment gap. LMPs will continue to work with both participants and employers to make a real difference for individuals, including those with autism.
- The Department of Health will continue to monitor the conclusion of the European Social Fund (ESF) and the introduction of the UK Shared Prosperity Fund (UKSPF) and will engage with Health and Social Care Trusts and independent sector providers to assess the potential impact on people who are autistic and/or have a Learning Disability.

- The Northern Ireland Civil Service, as an employer, will explore and deliver interventions to support and promote neurodiversity in its workplace. In addition, we will work in partnership with key stakeholders including people who have a lived experience of autism to review and implement a new reasonable adjustment process and develop a range of supporting resources for managers.



### **Orlaith's Voice**

*My autism changes how I think, as well as how I experience sensory information. I don't feel or see myself as 'different'. I often feel that my way of thinking makes more sense than that of those who aren't autistic. My autism makes some things, that other people find easy, much harder for me. Things that don't bother other people can make me feel scared and confused. I also can do things with ease that others can't and things that bother some of my friends are trivial to me.*

### **Commitment 4**

Through increased understanding of autism our housing providers will be more equipped to provide supportive engagement and support the housing needs of autistic people.

**This is what we were told:**

- The Northern Ireland Housing Executive, as a statutory provider, need a greater understanding of autism to provide appropriate support to those seeking housing advice and in the provision of accommodation to ensure that appropriate methods of communication can be used and that sensory needs can be addressed.
- Consideration should be given to explaining housing options and the methods of communicating the financial support available to autistic people, and associated processes, must be improved.
- A lack of suitable housing in Northern Ireland to accommodate the needs of autistic people can present a barrier to the ability to develop and maintain independence.
- Collaborative working between Housing and Health should be enhanced.

## **This is what we will do:**

- In collaboration with Health and Social Care Trusts, the Northern Ireland Housing Executive will continue to support transitional arrangements for applicants who may be seeking housing.
- As a commitment to providing support for autistic people, in collaboration with people who have lived experience of autism, the Northern Ireland Housing Executive will:
  - Provide training to increase staff understanding of autism and enable them to identify and provide appropriate and preferred communication styles
  - Provide full and proper consideration as we develop our approach to supporting autistic customers. In accordance with the Disability Discrimination Act 1995 (DDA) the Housing Executive has developed a reasonable adjustments policy for staff. We will also explore provision of supportive customer facing environments which will meet the needs of autistic people.
  - Will continue to review our Communication Support Services and will give due consideration to any needs associated with supporting autistic customers, this will include a formal review of communication.
  - Develop and provide a housing advice leaflet which will clearly set out the planning and preparation process for housing application pathways to assist autistic people in feeling informed throughout the application process.
  - The Housing Executive's Housing Options service seeks to provide advice and assistance to everyone. A case management approach enables the Housing Executive to understand the customer's individual needs and explore their housing and support options. This will include understanding a customer's current and future housing aspirations. For more complex cases our Housing Support Officers will provide a specialist service for those customers who require a housing solution outside the general housing solutions remit.
  - Work proactively to connect housing and health staff in seeking appropriate housing solutions which can accommodate needs.
  - Set up Regional Escalation Panels, as appropriate, to manage the needs of individuals who may have complex needs.

- Develop an Inclusive Design Guide to complement the adaptations toolkit which can support cognitive and sensory needs, this will include autism and neurodiverse conditions.
- The Housing Executive will continue to commit to the continued engagement with Disability Forums, including Autism Forums, to provide opportunity for collaboration and feedback to inform policy, guidance and service delivery.



## **Commitment 5**

We will work with our Councils and within our community to increase understanding and acceptance of autism and promote the development of inclusive environments to support the needs of autistic people, their families and carers.

## **This is what we were told:**

- Autistic people often feel anxious and isolated within community life, with increased understanding and acceptance this would provide a more inclusive environment where people would feel supported, involved and accepted. Additionally, whilst some autistic people may prefer not to engage in social activity or interaction, this understanding could also assist them to feel that this choice and preference is also respected and accepted.
- Autistic people would like to see more provision of support in public areas and buildings which would assist them in managing sensory challenges or anxieties which may occur, for example, quiet spaces to calm and regulate their sensory or stimulative responses and behaviours, signage where there may be unexpected or loud noise and ear defenders to provide a more peaceful and managed experience within an environment.
- People with lived experience of autism should be involved and included in planning and influencing service delivery in public services, for example, in activity or services developed by and within local Councils. Councils should be proactive in promoting autism friendly opening times, activities, buildings and events in a prominent and accessible way which attracts and promotes public attention.
- Autistic people and their families can often feel overwhelmed by the need to access information and services and require greater signposting and ease of access to navigating sources of support, points of contact and community life.

**This is what we will do:**

- In partnership with people with lived experience of autism, we will work with Northern Ireland Councils to encourage and promote a proactive response and approach to increasing understanding of autism in our community and in promoting autism friendly facilities and activity where autistic people, and their families, can feel accepted, understood and supported.
- Through partnership working we will develop a Regional Autism Information Service which will provide signposting to support and services to enable autistic people and their families to have readily accessible information, guidance and navigation to points of contact and sources of support.
- To ensure that the needs of autistic people, and those with neurodivergent conditions, feel supported within our communities we will work in partnership with people who have lived experience of autism and the Equality Commission NI to revise and enhance Business Accessibility Checklists to promote and enable the needs of autistic people to be reflected in guidance and accommodated within our community.



***The Way I Grow  
By May***

*I specifically made the butterfly wings different. Each wing represents how no two autistic people are the same. No matter how similar we may seem, we are all differently perfect in own way. I really believe that I see the world in my own beautiful way. Art is my comfort zone. It really helps calm my tics. This piece represents me as I grow and learn more about what autism is to me.*

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