

Northumberland

All Age Autism Strategy



2023 – 2026

What is Autism?

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. Autism is not a mental health condition or a learning disability, although it is estimated that around 40% of autistic people also have a learning disability and 71% of autistic people may experience a mental health problem. Autism is recognised as a protected characteristic in the Equality Act 2010.

In this strategy, we use the term 'Autistic', and recognise that autism is one of a wide range of neurodivergent conditions, which may overlap.

Signs of autism can include repetitive and restrictive patterns of behaviour or interests and difficulties around:

- **Social communication** - differences with using and understanding verbal and non-verbal language, such as gestures, facial expressions, and tone of voice
- **Social interaction** - problems in recognising and understanding other people's feelings and managing their own
- **Social imagination** - problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine

Many autistic people prefer routine and structure and may find change difficult to deal with. It is also possible for autistic people to experience sensitivity to sounds, touch, taste, smells, light or colours.

The way that autistic people experience their environment can lead to different areas of strength or difficulty, for example:

- Strong attention to detail
- Above average technical or creative skills
- Character strengths, such as honesty and loyalty

Differences in processing of sensory information, including over and under sensitivity

- Difficulty predicting what is going to happen next
- Difficulty knowing or understanding what other people think or feel

It is important for autism to be identified as early as possible. For children, early identification helps them and their family and carers to thrive and to have the best start in life. We know that not everyone who is autistic has or would like a formal diagnosis. Our aim is that changes promoted by this strategy will benefit autistic and other neurodivergent children, young people, and adults regardless of diagnosis.

Autism alongside other conditions

The National Institute for Health and Care Excellence (NICE) states that around 70% of autistic people have another condition, which is “often unrecognised”. The main conditions that co-occur more frequently in autistic people compared with others include:

Mental health conditions

- Research suggests that 70% of autistic people have a mental health condition, and that 40% have two or more. Autistic people are up to four times more likely to have anxiety disorder, and twice as likely to have depression. Autistic people can also have ADHD and or obsessive-compulsive disorder
- Research has shown that autistic people are more vulnerable to negative life experiences, such as challenges navigating friendship groups causing social isolation, which may also impact their mental health
- Compared to the general population, autistic people report having a lower quality of life. Research indicates that suicide is a major cause of early mortality in autistic people

Neurodevelopmental conditions

- Learning disability
- Specific learning difficulties e.g. dyslexia
- Other physical health conditions such as epilepsy
- Thirty percent of autistic people are non-verbal (completely, temporarily, or in certain contexts)
- Autism affects people of all ages, ethnicities, and genders. Inequalities are experienced because of disability and may include discrimination and barriers based on ethnicity, beliefs, sex, gender, sexual orientation, age, pregnancy and maternity, marital status, and socio-economic disadvantage.
- It is estimated that 1% of the population has autism with the rate higher in men than in women (1.8% versus 0.2%). Northumberland has an estimated population of 323,820 (mid-year population estimates 2020). According to the Office for National Statistics, people living in Northumberland will increase by about 4.7% to around 339,415 between 2021 and 2043. This translates to approximately 3,394 autistic people living in Northumberland.
- These numbers reflect only the people we are aware of; there will be many more people without a diagnosis living in Northumberland.
- Some people will be waiting for education health and care plans to support education, and or will be waiting for social care, the exact numbers are not known.

Why do we need a strategy?

Autistic children, young people, adults and their families and carers have told us that there are barriers and gaps which must be addressed to enable them to live their best and most fulfilled lives.

To further understand the points raised by autistic people and their carers, we have:

- Undertaken a series of engagement workshops across Northumberland throughout summer 2022, facilitated by Inclusion North
- Organised a workshop session with the Autism Partnership Board in Summer 2022 which included professionals, autistic people, parents, and carers
- Considered information within the co-produced SEND strategy 2021-2024
- Listened to feedback from the Healthwatch Children and Young People's Autism and Mental Health Survey summer 2022
- Considered feedback from Cumbria Northumberland Tyne and Wear NHS Trust's Autism Consultation 2021-2022

All those involved in developing and implementing this strategy are accountable for delivering its success. The development of the strategy has started with co-production work and feedback undertaken with our autistic residents and their families, as well as those that provide health and social care support for them. This strategy captures their priorities and barriers/gaps and identifies actions to address them.

The priority areas identified during this work are:

1. Improve people's understanding of autism
2. Make it easier to get an education and support people as they become adults.
3. Support more autistic people into work
4. Tackle health and care inequality for autistic people
5. Build the right support in the community
6. Improve support within the criminal and youth justice system

Removing barriers will require a better understanding of autism and a change of culture across Northumberland's services and communities. The priorities identified are not quick fixes, but we know that with focused leadership throughout the system over time, autistic children, young people, and adults in Northumberland, can be supported to achieve better outcomes.

The Strategy aims to promote a cultural shift so that all community settings and services understand the needs of autistic people and so can provide an equitable offer for autistic children, young people, and adults to support them in reaching their full potential, living healthy, productive, and happy lives.

This strategy is a living document that will evolve to reflect progress and the changing needs of the communities across Northumberland. The strategy will be underpinned by a multi-agency Action Plan which will describe the actions needed, by whom and when. The Action Plan will be monitored and challenged through the Northumberland Autism Partnership Board.

The delivery of the strategy will continue to champion co-production and engagement with Northumberland's community of autistic people, families, and carers.

A Vision for Northumberland

We asked members of our Autism Partnership Board (made up of autistic people and their parents, families and carers, representatives from across health, justice, social care, education, voluntary sector) to agree a vision and a set of principles for Northumberland that will help us to achieve our goal.

Our vision:

“We want Northumberland to be an autism aware county, one that offers opportunities and is inclusive for everyone, enabling individuals to live healthy and fulfilling lives, regardless of where they live, or what their needs are, including autistic children, young people, and adults. We want to enable and empower all individuals within Northumberland to contribute to their local communities and feel welcomed, supported, and valued in the area they choose to live, ensuring they reach their full potential meaning that no-one is left behind or disadvantaged because of their needs, diversity, or environment.”

Our principles

Our principles were developed through feedback from the Autism Partnership Board and engagement and consultation with autistic people and their parents and carers across Northumberland.

We will:

- keep autistic people and families at the centre of every decision
- build on the strengths of each person and community
- make it easier to get information and support
- increase autism awareness
- reduce inequality and offer services fairly
- empower autistic people to manage their own needs, where possible
- bring the right people together
- support autistic people and their families to have good and healthy lives
- make sure people get the right support at the right time
- support people based on their needs. We will not wait until people have a diagnosis.
- make it easier for autistic people to get support in
 - health
 - justice
 - education
 - housing
 - employment
 - social care

Our approach in Northumberland has included all relevant National Policy, guidance and legislation including:

- Autism Act 2009, the first disability specific law to have been passed in England and Wales
- NICE Guidance (National Institute for Health and Care Excellence)
- The National Autism Strategy
- NHS Long Term Plan
- Care Act 2014
- Children and Families Act 2014

About this strategy

Our identified priorities in Northumberland align with the National strategy, helping to raise awareness of the needs of autistic children, young people and adults and supporting the aims of our strategy. Many of the priorities are associated with other key areas of work such as Northumberland's Emotional Health and Wellbeing Strategy for children and young people and the accommodation strategy for Northumberland County Council.

Our strategy and our priorities should be read in conjunction with other local Northumberland strategies (see Appendix 3).

Governance

Areas highlighted for development through listening to the voice of autistic children, young people, adults, and their families mirror the six national strategic priorities. These are:

Priority Area 1	Improving the understanding and acceptance of autism within society
Priority Area 2	Improving autistic children and young people's access to education and supporting positive transitions into adulthood
Priority Area 3	Supporting more autistic people into work
Priority Area 4	Tackling health and care inequalities for autistic people
Priority Area 5	Building The right support in the community
Priority Area 6	Improving support within the criminal and youth justice system

These six areas will be progressed through dedicated action plans (see Appendix 2 for further detail).

Actions Plans will be supported and monitored from either an autistic person or family member and system partners, shaping the proposed actions and recommendations for the four year delivery of the strategy.

The Action Plan leads will be accountable for each action area and will feedback progress in the Northumberland Autism Partnership Board. The Board will provide support and challenge on progress to ensure the actions are being driven forward within the agreed timescales and where there are any issues arising will provide support and guidance.

Progress on the Autism Action Plan will be reported to all key relevant Strategic Boards for Northumberland.

Our plan also includes five underpinning enablers:

1. Quality Assurance and Measurement of Success – all workstreams will monitor and review their work
2. Digital and Data – improved data about autistic people in Northumberland to inform service planning
3. Pathways and linking of services – autistic people have told us that they experience “falling through the gaps” between services. All workstreams will seek to address this
4. Transitions – transitions across an autistic person's lifespan need to be better identified and supported. Autistic people have talked about the big change in moving from child to adult services, however there are also many other transitions which can affect an individual and their needs

5. Finance and Funding Implications – improving access for autistic people is the right thing to do and is also likely to be more cost effective for services and the support system. This strategy does not bring additional funding but is ambitious in making change across the system through collaborative working, making the best use of existing resource.

Actions

These are relevant to all of the priority group areas. They will be delivered by six groups of professionals and people with lived experience, overseen by the Autism Partnership Board.

Each group will have an action plan over three years (see more detail in Appendix 2).

- Look at pathways of care from the perspective of all services and people with a lived experience to check for gaps and opportunities for improvements in care
- Develop workplace education for all service providers
- Develop existing services for identification of autism
- Develop school provision to support autistic people
- Develop benchmarking processes for all services
- Develop neurodivergence pathways for all services
- Develop services for transition from child to adult services
- Exploring carer needs and making sure support options are advertised
- Exploring suitable housing support and pathways
- Use trauma informed care in all settings
- Making sure the communications plan for the strategy is appropriate for the health literacy of the population and autistic people, to ensure all people who need it can find the information about services for autistic people

Appendix 1 – Priority Areas

Priority Area 1 - Improve people's understanding of autism

What we want to achieve

For autistic people across Northumberland to feel included in the communities they live in, to have the same opportunities as everyone else with equal access to services, enabling them to feel valued, supported to reach their full potential, and lead fulfilled and healthy lives.

People have told us:

1. We would like the communities and services across Northumberland to become fully autism aware and inclusive
2. It is sometimes hard to get mental health support once diagnosed with autism; health workers say that mental health is just part of our autism
3. We do not all want a diagnosis; we need to get better at treating and seeing people as individuals with their own needs
4. We need to get better at identifying the signs of autism earlier in children and young people, especially girls who often 'mask' these signs by copying the behaviours of others

Priority Area 2 - Make it easier to get an education and support people as they become adults.

What we want to achieve

Autistic children and young people in Northumberland will be able to access the right support, at the right time and the right place to help enable them to reach their full potential.

People have told us:

1. Some autistic children and young people experience long travel times to attend a school able to meet their needs. We need to work towards providing education provision for autistic children across the whole of the county, so autistic children can go to school nearer to their homes and communities
2. Some autistic children and young people are supported well in mainstream schools, although this experience is not consistent, particularly at secondary school. We need to support educational settings to be able to identify and support all autistic children and young people consistently in inclusive environments
3. We need to improve communication and partnership working between schools and parents and carers to ensure genuine co-production and that their voice, and that of their autistic child is at the heart of all support, Education Health Care Plans (EHCPs) and referrals for additional support
4. It is important for educational settings to understand that autistic children may have other conditions e.g., dyslexia, mental health, learning difficulties, learning

disabilities and that these needs should be identified and supported separately from their autism

5. There is no provision for parents and carers and children under the age of five who have received their diagnosis through Paediatric Consultants, to provide support before they attend school with understanding and managing the diagnosis

Priority Area 3 - Supporting more autistic people into work

What we want to achieve

We want to close the employment gap for autistic people across Northumberland, ensuring that those who are able and want to work are supported to do so, and to support those already in work to remain in employment.

People have told us:

1. We need to work with employers more to enable them to gain a better understanding of reasonable adjustments for autistic people
2. Provide support for autistic people to explore opportunities for self-employment and enterprise options
3. Workplaces to have a more flexible, supportive and autism inclusive environment
4. Support families to navigate the welfare system, to access appropriate benefits and financial entitlements, to maximise opportunities for parents/carers to undertake employment which enables safe continuation of a caring role (where this is sought) and to acknowledge that parents/carers are sometimes unable to work, work fewer hours, or take early retirement due to caring and support responsibilities
5. Provide better more tailored support for young autistic people to make the transition from secondary school into college, apprenticeships, or employment

Priority Area 4 - Tackle health and care inequality for autistic people

What we want to achieve

Remove the health and care inequalities that autistic people face to enable autistic people in Northumberland to live healthier, happier, and longer lives.

People have told us:

1. We need to join up physical health, diagnostic and mental health pathways, instead of being told that these issues are the result of being autistic
2. Mental health issues in autistic children and young people can be ignored as being 'part of autism', leading to lack of support
3. Waiting times can still be too long on the neurodevelopmental pathways, especially for those waiting on the adult pathways
4. Focus on early identification to enable the right support to be in place at the earliest possible point, gives children and young people the best opportunities and start in life

5. Ensure all autistic people are aware of additional support that is available to them in and out of the workplace
6. Continue to promote and find different ways to engage and encourage autistic people to undertake physical health checks
7. Aim to deliver a consistent experience for autistic people accessing services within education, health (primary and secondary care) social care, ensuring that environments are autism friendly, reducing stigma and ensuring appropriate access and ongoing engagement
8. Suicide rates amongst autistic people and/or those with a learning disability are higher than the national average
9. There is a strong link between Anorexia and Eating Disorders and those with autism
10. We need to provide more focus on autistic women as this is often not recognised until later in life due to their ability to 'mask' their autistic traits by mirroring others including maternity support and support at transitions

Priority Area 5 - Build the right support in the community

What we want to achieve

1. We want to reduce the numbers of autistic people in Northumberland admitted into inpatient mental health services
2. We would like support for autistic people who do need an inpatient mental health setting, to be of a consistent quality, and tailored to an individual's needs within an inclusive environment
3. When in hospital, we want people to receive the support they need to be ready to leave to ensure a successful transfer out of hospital. We want to see individuals discharged in a timely way as soon as they are well enough to leave hospital and into the most suitable accommodation
4. We want to ensure that autistic people have the same opportunities to access support around their interests and activities within their communities, as other residents, enabling them to live happy, healthy, and fulfilled lives, building their own resilience through community support and feeling included within their communities
5. Improve the suitability and availability of housing support across the county to provide the right type and quality of support, enabling individuals to live as independently as possible in their own homes.

People have told us:

1. We would like to see a better understanding of autism across all social care teams with experienced staff, who can identify and provide or suggest the right support to meet an individual's needs
2. Ensure that Information about where to find advice, signposting and support across education, health, social care, and the community is in place and is in a consistent format that is easily accessible to all
3. We need ongoing support after diagnosis, which provides help throughout a person's life span to deal with difficult life situations and periods of change and transition as they arise

4. We would like better support whilst we are on a waiting list for an assessment
5. We would like to see improved signposting after diagnosis to services for ongoing support with emotional wellbeing and physical health
6. We want mainstream health services such as GPs, dentistry, optometry, audiology, chiropody etc. to make reasonable adjustments to ensure autistic people get access to the health care they need
7. We want, where appropriate, support for individuals to develop independent living life skills such as daily tasks, banking and budgeting, shopping, medical appointments, mail/information, benefit claims, travel passes, activities etc
8. Support Primary Care in recognising and joining up the family dots; people within the family unit may have different conditions but are all inter-related, providing easy signposting for family members who feel they need assessment
9. We would like to see the same member of staff on a regular basis. They would act like a key worker to be able to spend time understanding an individual's ongoing needs and provide families and individuals with better support to identify and navigate the services and support available
10. We would like the further development of short breaks and respite care for families and carers
11. We would like earlier intervention with the whole family to identify and potentially avoid a crisis
12. Improve links across pathways such as Community Learning Disability Team (CLDT) and Speech and Language Therapy (SLT), specialist autism and Learning Disability services and acute hospital admissions should a person be physically unwell

Priority Area 6 - Improving support within the criminal and youth justice system

What we want to achieve

We want to build on the current criminal justice models and pathways already in Northumberland, ensuring that neurodivergent diagnosis is considered in the Criminal and Youth Justice System, that staff are trained, environments are autism inclusive, and intervention plans are tailored to an individual's needs.

People have told us:

1. We would like to see better awareness of autism across the criminal and youth justice system with a greater understanding of early identification of needs and support in responding to this.
2. Introduction of a flexible approach across the criminal justice system and the need to make reasonable adjustments to environments and processes
3. Ensuring that all those working across the whole of the criminal justice system are trained to recognize the signs of potential autism and understand the support required, signpost and adjust environments accordingly to ensure they are autism inclusive
4. CNTW and other key autism and mental health services to collaborate more closely with the police and wider criminal justice system, sharing relevant

information and supporting these services to recognize when and where to make appropriate referrals for support

5. Ongoing development of the early warning suicide alert system and communication to health care professionals to ensure that early intervention and support can be offered
6. Appropriate interventions and group work strategies whilst in custody ensuring they are accessible and inclusive for all to access
7. Appropriate post discharge planning and assessment for autism/learning disability from custody ensuring the right holistic support is in place to give individuals the best opportunities of moving forward and not repeating the offending cycle

Appendix 2 – Actions to be carried out across each of the workstreams

These will be delivered by six groups of professionals and people with lived experience, overseen by the autism partnership board. Each group will have an action plan over three years.

- Looking at where existing work/services are operating in health, education, justice, and social care to look for gaps and inform all services of provision across Northumberland, aiming to make easier access to services. Look at the pathways together with people with lived experience to see what a patient/family may experience
- Develop workplace education for education, justice, health, and social care. Mandatory [everyone has to do it] training in autism and learning disability is being rolled out nationally [The Oliver McGowan Mandatory Training on Learning Disability and Autism | Health Education England \(hee.nhs.uk\)](https://www.hee.nhs.uk/learning-disability/oliver-mcgowan-mandatory-training) over the next three years
 - this awareness and acceptance training will inform and support our pathways of recognition, identification of all needs and reasonable adjustments [Reasonable Adjustment Campaign « Learning Disability Network \(necldnetwork.co.uk\)](https://www.necldnetwork.co.uk/) and can be explored in short and long term conditions in mental health and physical health care
 - should include training on the mental capacity act.
 - consideration of the needs for training for the voluntary sector partners and local communities.
 - this also links to the [Reasonable Adjustment Flag - NHS Digital](https://www.nhs.uk/healthcare-digital/reasonable-adjustment-flag/) for health and care to make sure people are aware of and provide reasonable adjustments
- Building on existing work to support the identification of autism and needs in hidden populations e.g. girls/boys who mask
- Building on the updates to the Ordinary available provision of support in schools
- Explore benchmarking and quality checking [e.g. kitemark] for education facilities, employers, workplaces, and custody buildings to make sure they can demonstrate they are autism accepting
- Explore a review of existing lifespan neurodiversity pathways
 - considering pre-diagnostic support options, strengthening post-diagnostic offers
- Explore preparation for adulthood and transitions
 - within services, and after age 25 services
 - including care/justice system leavers
 - to include life skills training, employment opportunity improvement and to promote a more diverse workplace
- Exploring carer needs and making sure support options are advertised
- Exploring suitable housing support and pathways

- Introducing support for trauma informed care and continuity of care using health and care passports [Resource List - Trauma Informed Approaches and Autism Spectrum and Other Developmental Disabilities | PACEs in Education | PACEsConnection My health passport \(autism.org.uk\)](#)
- Making sure the communications plan for the strategy is appropriate for the health literacy of the population and autistic people, to ensure all people who need it can find the information about services for autistic people

Appendix 3 – Strategy Documents

Northumberland Strategies

- [Children and Young People's Emotional Health and Wellbeing Strategy 0-25 2022-2025](#)
- [Northumberland SEND Strategy 2021-2024](#)
- Accommodation Strategy
- Adult Social Care Plan
- Adult Social Care Engagement Strategy
- Northumberland County Council's Corporate Plan 2021-2024.
- [Northumberland Children and Young Peoples Plan 2019 – 2022](#)
- Northumberland Multi Year Accessibility Plan 2022-2025
- [Local JSNAA \(Joint Strategic Needs and Asset Assessment\)](#)

[The National Autism Strategy](#)