



North Tyneside
Autism Strategy
2021- 2026

Far too long have autistic families struggled with little or no support

Great to see drugs and alcohol services included
(big skills gap knowledge of Autism)

Fantastic, ambitious and exciting

Really what people need and deserve

Massive move forward
Well done to all concerned

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GLOSSARY OF TERMS

<i>Term</i>	<i>Description</i>
NHSE	National Health Service (England)
ODN	Operational Delivery Board
ADASS	Adult Directors of Adult Social Services
LGA	Local Government Association
CAMHS	Child and Adolescent Mental Health Service
SEND	Special Education Need and Disability
CYP	Children and Young People

1. Introduction

This strategy was written by a focus group of people who are committed and dedicated to building an inclusive community for autistic people.

This included:

- People with autism
- Family carers
- Organisations that support people with autism and their families
- Health and social care professionals
- Education professionals

2. What is Autism?

Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.

Autistic people see, hear, and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity.

Autism is a spectrum condition. All autistic people share certain difficulties but being autistic will affect them in different ways. Some autistic people also have learning disability, mental health issues or other conditions, meaning people need different levels of support. All people on the autism spectrum learn and develop. With the right sort of support, all can be helped to live a more fulfilling life of their own choosing.

Throughout the course of this strategy, we use the term 'autism' as an umbrella to cover the range of diagnostic terms that exist to describe autism profiles, such as 'Autism Spectrum Disorder (ASD)', 'Autism Spectrum Condition (ASC)', 'Asperger Syndrome' and 'classic autism'.

3. National and Local Information

National

Autism is much more common than most people think. There are around 700,000 autistic people in the UK - that's more than 1 in 100. People from all nationalities and cultural, religious, and social backgrounds can be autistic, although it appears to affect more men than women.

- Autism does not just affect children. Autistic children grow up to be autistic adults.
- Autism is a hidden disability – you cannot always tell if someone is autistic.
- While autism is incurable, the right support at the right time can make an enormous difference to people's lives.
- 34% of children on the autism spectrum say that the worst thing about being at school is being picked on.
- 17% of autistic children have been suspended from school; 48% of these had been suspended three or more times; 4% had been expelled from one or more schools.
- At least one in three autistic adults are experiencing severe mental health difficulties due to a lack of support.
- Only 16% of autistic adults in the UK are in full-time paid employment and only 32% are in some kind of paid work.

In 2021 the National Autistic Society stated

- More than two in three autistic adults don't get the support they need
- Only 14% said they had enough mental health services in their area
- 50% of parents said they had to wait more than a year for support at school

Local Picture

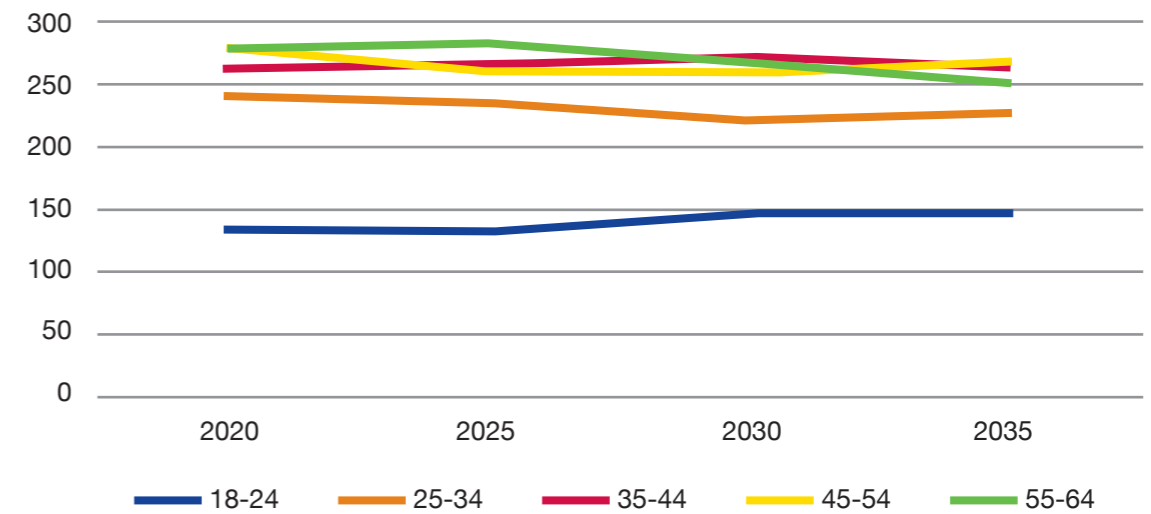
The population of North Tyneside is 205,985 (2011 Census).

Based on the indication that 1.1% of the UK population is autistic, it is estimated that there are over 2,265 autistic people in North Tyneside (applying this prevalence rate to the Office for National Statistics population estimates in 2016).

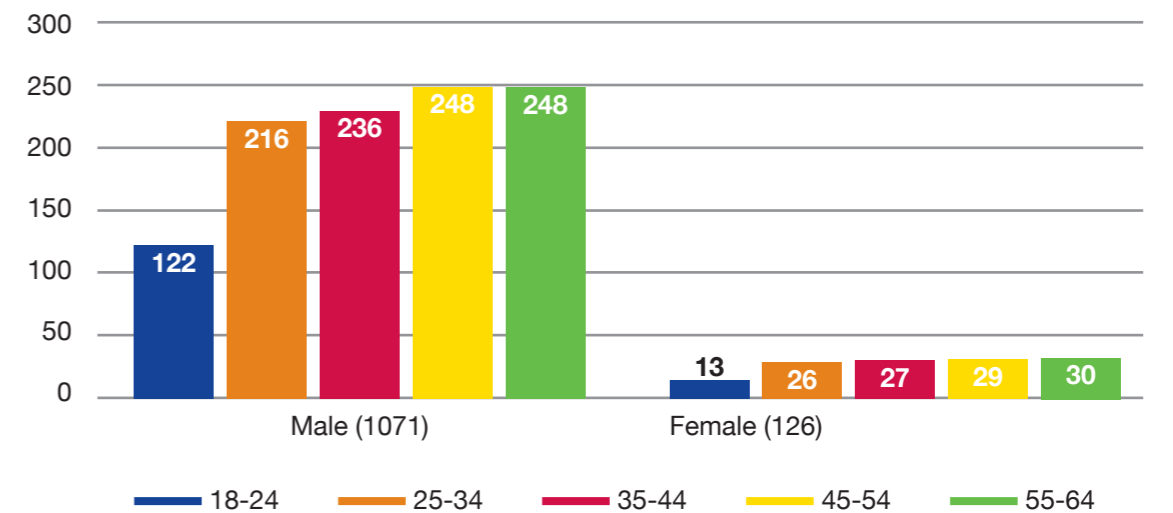
There are 186 people (both children and adults) known to social care with an autism diagnosis at June 2021.

Overall numbers for people with autism spectrum disorder are expected to increase over the next 5 to 15 years.

People aged 18-64 predicted to have autistic spectrum disorders



People aged 18-64 predicted to have autistic spectrum disorders, by age and gender



The North Tyneside school census in January 2021 found we had 481 young people with an autism spectrum disorder assessed need identified with special education need or disability support or an education health and care plan (EHCP) in Table 1.

From our education recording system in May 2021 there are 308 young people with autism spectrum disorder as their primary needs.

Academic year range	No's with ASD primary need
Under 5 years	2
5 to 11 years	130
12 to 16 years	108
17 to 25 years	67

Table 1: ASD – Primary Need/ Census Year*

	Jan-16	Jan-17	Jan-18	Jan-19	Jan-20	Jan-21
EHCP	149	232	230	268	294	347
Sen Support	64	79	118	114	141	134
Total	213	311	348	382	435	481

*The source is the January 2021 school census based on the information about the pupils in our schools. It does not contain those educated out of borough, or post 16 but may include some who have an EHCP maintained by another local authority.

Table 2 is taken from the latest SEND sufficiency plan and needs assessment and gives the local versus national position but includes published data which includes non-maintained special schools located in the borough.

Table 2: Types of Special Educational Need (SEN) in North Tyneside schools (including independent schools)

	SEN Support		EHCP	
	England	North Tyneside	England	North Tyneside
Autistic Spectrum Disorder	6.8%	3.7%	30.1%	24.0%
Hearing Impairment	1.7%	1.4%	2.2%	1.1%
Moderate Learning Difficulty	21.2%	8.1%	10.7%	13.0%
Multi-Sensory Impairment	0.3%	0.2%	0.4%	0.1%
Other Difficulty/Disability	4.6%	8.3%	2.6%	2.9%
Physical Disability	2.3%	2.1%	4.9%	7.2%
Profound and Multiple Learning Difficulty	0.1%	0.1%	3.6%	3.9%
Severe Learning Difficulty	0.3%	0.2%	11.1%	5.1%
Social, Emotional and Mental Health	19.4%	24.4%	14.2%	18.4%
Spcific Learning Difficulty	14.6%	17.4%	3.6%	2.0%
Speech, Language and Communications needs	23.7%	32.8%	15.5%	21.3%
Visual Impairment	1.0%	0.7%	1.2%	0.9%
SEN support but no specialist assessment of type of need	4.0%	0.6%		

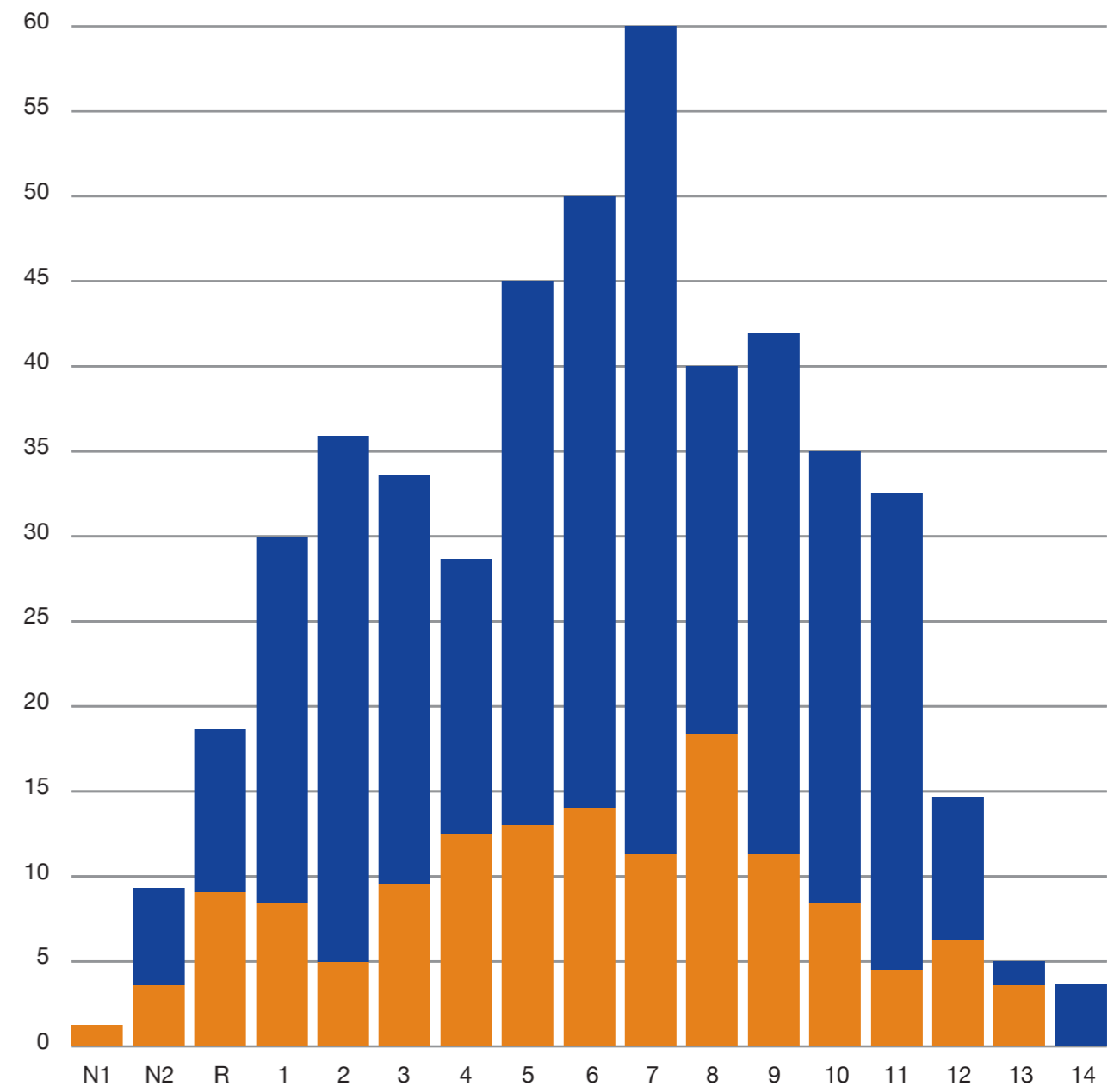
Note: SEND use of moderate etc learning difficulty is NOT referring to people with learning disability.

Both nationally and within North Tyneside schools the highest prevalence of need amongst those with SEN Support is for speech, language and communication needs. The second highest prevalence nationally is for those with moderate learning difficulties, whereas in North Tyneside it is for social, emotional and mental health needs.

Within the EHCP cohort, the most common need both nationally and in North Tyneside schools is autism, followed by speech, language and communication needs.

In the January 21 school census (in North Tyneside maintained schools and academies) there were 347 children with an EHCP and primary need recorded as ASD. 16 in foundation stage, 54 in KS1, 108 in KS2, 102 in KS3, 54 in KS4 and 13 in KS5. There were a further 134 SEN support pupils, in the January 20 school census, have ASD recorded as their primary need. 12 in foundation stage, 12 in KS1, 48 in KS2, 40 in KS3, 13 in KS4 and 9 in KS5.

SEN by year group (All/Jan-21)





4. Our Vision

Our vision is to work with people with autism and their families to make North Tyneside an inclusive place, where autistic people of all ages have the same opportunities as everyone else, and where they and their families feel supported. We want people to feel optimistic about their future and able to contribute to their communities.

5. Our Aim

The aim of this strategy is to ensure autistic children, young people, and adults and their families can have the same life chances as others in North Tyneside. This strategy provides focus and clarity on the local priorities for improving services and support for these people over the next five years. We are committed to continuing to listen to people and that autistic people and their families will be at the heart of everything we do.

6. Why do we need a strategy?

The Autism Act 2009 says we need to make services better. It tells us that not all autistic people get the support they need, we have also heard this from local organisations and from the conversations we have had with local autistic people and their families.

The policies we have detailed below, help to give us direction but more importantly we have listened to local people, so we know what is important to them and what needs to change for North Tyneside residents.

This strategy has been informed by:

Health and Social Care Integration and Innovation – working together (2021) – services working together to support autistic people.

The Autism Act 2009 places a duty on the Secretary of State for Health and Social Care to publish a strategy for meeting the needs of autistic adults in England, and to review it from time to time.

The National Autism Strategy 2021 to 2026

On the 21st July 2021 the new National Autism Strategy for young people and adults and the linked action plan for 2021 to 2026 has been published. Our local strategy takes account of those key priorities to support clients in North Tyneside.

The new national strategy has an “implementation plan” and there are links to both documents and the easy read version below. It also takes account of the impact of the COVID19 Pandemic and learning on how best to support Autistic people to live their best lives.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1005277/autism-strategy-implementation-plan-2021-to-2022-annex-a.pdf

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/995880/national-strategy-for-autistic-children-young-people-and-adults-easy-read.pdf

Its key themes are

- Helping people understand autism
- Helping autistic children and young people at school
- Helping autistic people find jobs and get the skills and training they need
- Making health and care services equal for autistic people
- Making sure autistic people get help in their communities
- Help autistic people in the justice system

The Care Act 2014

The Care Act 2014 covers the needs of people eligible for social care and the duties of preventative approaches such as early support; advance planning; helping people to maintain independence and wellbeing and avoid a crisis. The provision of advice and information which needs to be timely and in an appropriate format was given a greater focus.

The Care Act also requires statutory agencies to work together in partnership with individuals and families within assessment and care planning processes, including help with accommodation and employment/meaningful activity, supporting families, and accessing necessary health and social care services.

Additionally, the Act placed additional duties and responsibilities on local authorities with regards to supporting carers and to assess a carers own needs for support; explore the outcomes that a carer wants to achieve in their daily life; and the impact of caring responsibilities on their desire and ability to work and to partake in education, training or recreational activities.

The Children and Families Act 2014

The Children and Families Act 2014 addresses the needs of children and young people up to the age of 25, including those with Special Educational Needs or Disabilities (SEND). Reforms include a single coordinated birth to 25 Educational, Health and Care (EHC) Plan for these children and young people whilst in education; improving cooperation and collaboration between all the services that support individual and families, particularly local authorities, education providers and health services; and the introduction of the ‘Local Offer’ including centralised information, advice and guidance.



NHS Long Term Plan

The NHS Long Term Plan was released at the beginning of 2019. This has highlighted learning disabilities and autism among the key priorities for NHS services over the next 5-10 years and sets out a series of commitments to improve the services and support currently being provided.

The Long Term Plan also makes it clear that carers should not have to deal with emergencies on their own. It also makes specific reference to the need to prevent young carers struggling on their own with difficult and multiple challenges.

In November 2019, the Government announced the introduction of the Oliver McGowan Mandatory Training in Learning Disability and Autism for all health and social care staff, relevant to their role, this is still being considered but has been delayed due to the national pandemic.

The Local NHS 3 Year plan, makes a commitment to

Year 1 (2021/22)

- Agree the North Tyneside community offer for people with autism or suspected to have autism pre diagnosis and explore how we jointly work across health and social care within a multidisciplinary model of service delivery.
- Enhance information and advice offer for people with autism
- Improve pathways of care for hospital discharge and placement planning for people with an autism only diagnosis
- Develop the autism workforce plan to inform the Integrated Care System in addition to placed based workforce planning, including working with providers.
- Develop a training plan with a particular emphasis on changes to the Mental Health Act and Liberty Protection Safeguards

Year 2 (2022/23)

- Implement the Community Model for Autism
- Crisis response with early intervention
- Post diagnostic support for young people

Year 3 (2023/24)

- All autistic residents in North Tyneside have an allocated key worker

Outcomes focus rather than diagnostically lead

North Tyneside partners acknowledge there are some perceived concerns from individuals and their families in accessing an Autism Diagnosis. This strategy supports people both pre and post diagnosis and whilst a diagnosis is important for individuals and families, a diagnosis may not necessarily change the outcomes for an individual.

The model being developed is not driven by a diagnosis. It is a person-centred outcomes model, with early help and early intervention being critical to understanding the outcomes for an individual and their family.

We have begun to pilot this approach by having early help workers placed in Children and Adolescent Mental Health Service, who offer individual support packages to families where the threshold for Children and Adolescent Mental Health Service was not met; therefore, working with the family to support managing the presenting behaviours within the family, not focussing on if there is a diagnosis or not.

We aim to further shape this approach through consultation with families

The NHS Operational Delivery Network which is a strategic group of Clinicians and Social care professionals and Commissioners have developed an Autism Pathway, this is a group that covers the North East and North Cumbria ODN, their role is to enhance quality of care, improve access, reduce inequality. The ODN has created an overarching toolkit which has 16 measures and standards and 11 recommendations to streamline the Autism pathway. <https://www.england.nhs.uk/ourwork/part-rel/odn>

ADASS/ LGA Outcomes and Improvement framework

This supports adults with learning disabilities and autism to have better lives and makes the following recommendations:

Challenging inequalities

1. ADASS should engage with DHSC and NHSE to ensure that the needs of people with LD are met fully by the next phase of the COVID vaccination programme, building on their experience to date.

Co-producing better support

2. Councils and their sector partners should ensure that their planning out of lockdown, and subsequent decision making reflects the voices of this community and works with it to co-produce better and more resilient support arrangements.
3. The pandemic fuelled innovation. Councils and their partners should learn the lessons from this and review commissioning and service provision in the light of what worked.
4. There is a need for greater awareness of learning disability and autism in the wider workforce e.g. housing that needs to be developed and strategic re-alignment – from buildings and services to opportunity and community.
5. Councils and their sector partners should consider moving away from a heavy reliance on building-based services, investing instead in a more diverse set of opportunities for enablement and independence in communities. This shift will include appropriate use of new technologies and support for micro-providers.

Supporting independence

6. Established opportunities for supported employment may reduce following the pandemic. Councils and their partners need to ensure these are sustained. This will require a stronger focus on transition planning into adulthood.

Sector-led improvement – promoting new ways of working

7. National and regional professional and improvement organisations should move quickly to facilitate sector-led improvement processes, including benchmarking and guidance for place and asset based commissioning.



7. Covid-19

The Covid-19 pandemic has been particularly challenging for autistic people and their families. Some families have told us that they felt that they were left to struggle without support for months, and that professionals do not understand how this impacts on the whole family. Closure of services and schools has been particularly challenging and has increased waiting times for appointments for services that are already overstretched.

Parents have told us that they did not understand their Education Health Care Plans (EHCP's) or that they weren't able to access suitable material to aid their understanding.

Disruption to routine has caused major emotional and behavioral upheaval, several national and local lockdowns has further limited access to services.

Case study Living and working with Autism during Covid-19

We caught up with Vickie to find out how she has found working at St. Oswald's Hospice throughout Covid-19 and how changes to everyday life have affected her.

"The pandemic has obviously been very stressful for everyone but coping with such massive changes to everyday life and having Autism has been tough.

I've continued to work on the Outpatient Unit at the Hospice throughout Covid-19 but there have been lots of changes to deal with.

"St Oswald's has been incredible ensuring that guidelines are followed and measures are put in place to keep staff, volunteers, patients and families safe but I've found certain aspects of my role more stressful. Before I knew I was autistic I struggled with daily anxiety, panic attacks and depression both at work and in everyday life.

"Since being diagnosed, I understand myself better and now realise that my panic attacks were actually due to sensory overload, which led to meltdowns. All of my senses were in overdrive from the amount of people, movement, noise, bright lights and smells. Covid-19 has resulted in lots of changes including more signage everywhere you go, everyone having to socially distance, facemasks being worn, which makes it harder to understand what people are saying and all of this has been very overwhelming for me and caused sensory overload.

"I'm also really missing having contact with others, before Covid-19 I would often hug other members of staff, but we obviously can't do this anymore.

"St Oswald's have been so supportive since I was diagnosed and during the last 12 months this has continued. My line manager and the Staff and Volunteer Support Team have provided lots of emotional support to help me cope with Covid-19. They are always there if I need them.

"I'm not ashamed of being Autistic and openly talk about it to my colleagues. Some of the other staff and my line manager have even read books about the condition to learn more about it and how it affects me and others."

Vickie said "I'm extremely grateful to St Oswald's for all of the support and adjustments they have made to enable me to continue to work and the support I've received during the pandemic. Only 16% of autistic people are in employment, being able to work means a lot to me and I see working throughout the pandemic as a huge achievement."

Family Carers experience through COVID

"Have found that the lockdown has been very isolating"

"Without the internet, difficult to get support, not sure of where to turn"





8. Developing our Plan

We have worked hard for over a year to bring together people, families, professionals, and services to help us to understand what we are getting right and what needs to change.

We have brought people together to map out what we have, how it works, what people value and what gets in the way of providing great support to people and families when they need it.

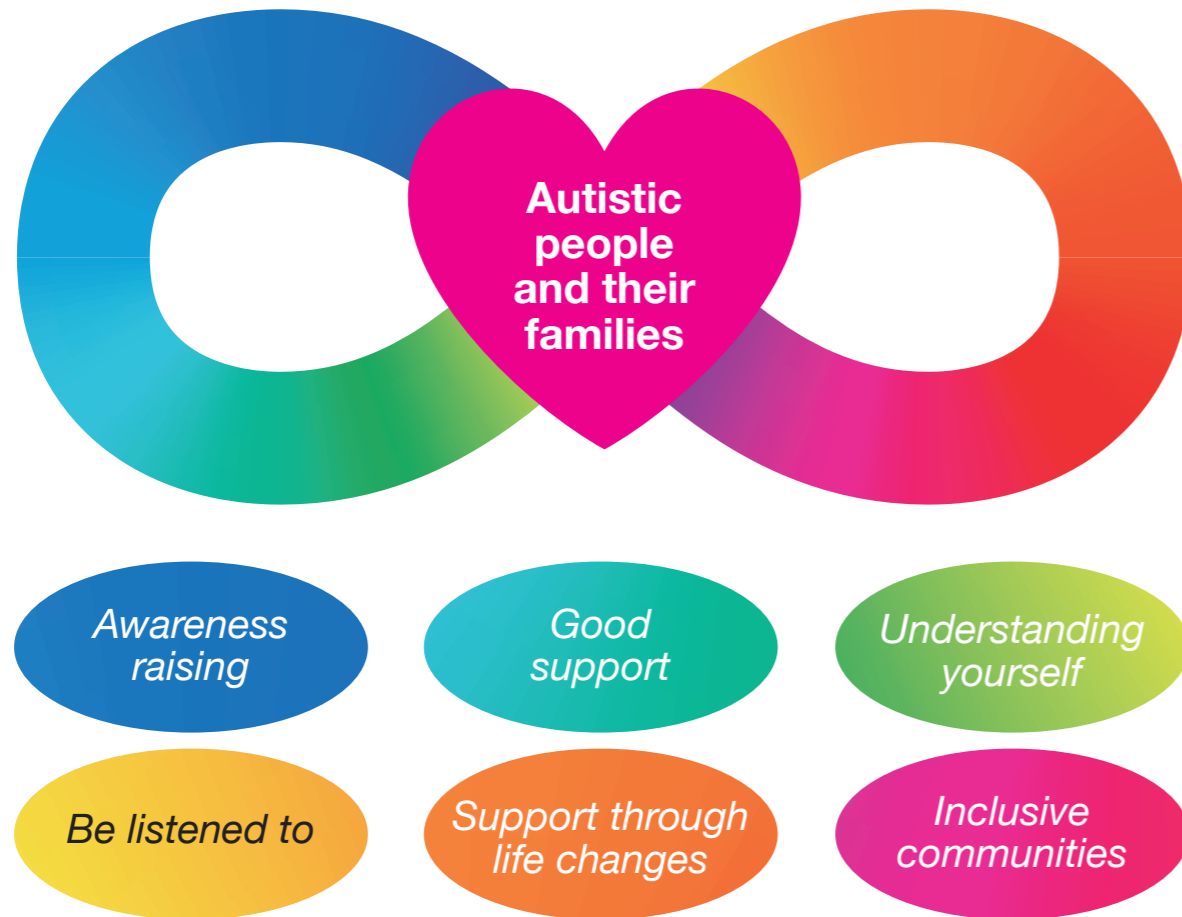
This has given us a great basis to work from and a fundamental understanding of what needs to change. Together we have identified six priorities that are grouped into three areas (see section 9 which describes the six priorities) we need to achieve to make a difference. These priorities will be our focus for the life of this strategy and move us firmly towards a better future for autistic people in North Tyneside.

For example:

- What could we do better – working with schools' inclusion, understanding Education, Health and Care Plans (EHCP's), not needing a diagnosis, more online support, accessing services differently learning from the pandemic.
- What we need – earlier intervention and self help and support pre and post diagnosis
- What we would like – a simpler system, services working together, to “tell our story once”, to have things available when we need them, to develop this together and to be listened to.

9. Our Priorities

We have identified six high-level priorities from the co-production work we have carried out so far. We want autistic people and their families to be at the heart of everything we do.



Awareness raising

Although we heard examples of universal support being exemplary in what they delivered to all members of the community, we need to build on this. People and families had many experiences of both services and communities who did not know about autism and therefore couldn't even attempt to make reasonable adjustments for them to take part in or have access to what should be available to all.

We know many people don't need specialist services, however they require universal services, schools, and communities to think differently and openly about how they support and welcome all citizens.

Good support

Through working together with people and families we have consistently heard that we need to offer clarity of referral routes, dedicate more to early identification and awareness, and ensure we have less waiting time for referrals to clinicians for diagnosis.

All parties involved said we needed to work on the waiting times for assessments as they can be often over a year long – we need to understand the workforce and issues concerned with this and bring together the system work on solutions.

And access good support pre and post diagnosis.

Understanding yourself

We heard from people who said that they completely understand how being autistic affects the needs they have and the types of environments they need to thrive. However, for some people this didn't happen until many years after being diagnosed and them having to struggle with how they felt about the different ways in which they experience life compared to others.

For some people they then had an opportunity through people they met, or when they attended a group, to explore why they felt the way they did. They explained the value in meeting others who shared the same experiences and being given the space and tools to explore how to feel included and supported. This understanding was fundamental to autistic people and their families being able to cope and live a good a life.

Although providing better information that is easily accessible is needed, we heard that for some people they don't really know what might help them or what they need. Talking to others about how they have approached challenges might help in this area.

We want to make sure these things don't happen by chance and that all people have opportunities to explore this in a safe way for them.

Be listened to

We heard from people and families about individual workers, or teams and services that have been the lifeline they needed to get through some of the most challenging times, where people felt respected, supported, and listened to.

However, on too many occasions we heard that people and families do not feel they are listened to and their needs are not taken seriously. They have felt they have had to repeat their story and have not been believed when they have raised concerns, which has delayed the right support being available, they would like to "tell their story once". This also has a very damaging effect of the trust people and families hold towards the system.

We want all people and families to be supported at the earliest opportunity, and we want services to work in partnership with people and families so people can have happy, healthy, fulfilled lives in communities.

Support through life changes

The North Tyneside pathway must take account of all life changes.

Transition from children's to adults services is a common place where we see things starting to unravel for people, we need to make sure this point in time is well thought out and supported.

Autistic adults may need support through different life changing events, such as starting work or college; moving to a new house; new relationships or changes to support.

We know that with good support in these times, crisis can be averted, and people can make changes more smoothly, both big and small.

Inclusive communities

We want North Tyneside to be an autism friendly areas.

We heard of some great examples of spaces that encourage all people to come together to learn, play and explore, without judgement. We need this to be mirrored across the communities that we live in, and within our schools. We want this to be the model for North Tyneside.

We heard examples from people of children and young people not having the support they need and not feeling included or welcome in the spaces they attend, this included schools. The national pandemic has brought attention to how we can deliver things differently and we need to build on this learning going forward.

10. Making our plan happen

An action plan has been developed to support this strategy. The plan outlines the key actions that will be taken to address each of our priority areas. This plan will be reviewed and updated yearly.

We recognise that we have a long way to go and that the priorities or starting points may be different for children and adults.

Leads have been identified for all of the priority areas. These leads will be responsible establishing a working group and for making sure that work progresses, they will provide regular updates to the Learning Disability Care Forum and the Health & Wellbeing Board.

We will publish a 'Plan on a Page' so that people know what we are working on and this will be updated annually.

Safeguarding will be an overarching priority that we will consider throughout this work.



11. Governance

A steering group has been established to oversee this work. This consists of the Learning Disability Integration Board. All organisations involved are fully committed to delivering this plan and will ensure the plan is adopted and the relevant people are held accountable.

Additional task and finish groups will be established to progress each priority and area of work that has been identified in our plan, the lead for each group will be required to report on progress to the steering group.

A reference group of people with autism and carers will be established to support this work.

This plan was ratified by the Health and Wellbeing Board on 16th September 2021 and the Children's Board on the 20th September 2021.

This strategy will be delivered through a delivery plan which will contain detail about what will be done, by whom and by when. It will be refreshed annually.

The strategy and delivery plan will be overseen by the Learning Disability Integration Board. This board will take which will take a leadership role for ensuring the delivery of the key pieces of work which are needed to implement our priorities.

Autism is considered in several areas within North Tyneside, including the Future Care Board, the SEND Strategic Board; Whole Life Disability Board; Working Age Mental Health Board; Carers' Partnership Board; and Living Well Locally.

We need to strengthen links and communication with the following services.

- Drug and alcohol
- Mental health
- Public Health
- Homelessness,
- Suicide prevention
- Criminal justice
- Employment
- Community groups and providers

Collaboration with these boards/groups and services will be required to ensure the needs of people with autism and their families, are being fully considered and addressed. Relevant actions from our delivery plan may also need to be incorporated into the work plans of these other boards.

North Tyneside Autism Strategy Governance Arrangements



Links also into Carers Board, Mental Health Boards (children and young people, working age adults and older persons/late in life)





This plan has been agreed by the following organisations.



North
Tyneside
Council

NHS
Cumbria, Northumberland,
Tyne and Wear
NHS Foundation Trust

NHS
North East and
North Cumbria

