

North Tyneside Joint Strategic Needs Assessment:

Date: September 2024 **Author:** Chris Woodcock

1. Introduction

Autism is a lifelong condition 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.

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.

Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people.

It's something you're born with. Signs of autism might be noticed when you're very young, or not until you're older.

If you're autistic, you're autistic your whole life.

Autism is not a medical condition with treatments or a "cure". But some people need support to help them with certain things.

Autistic people may:

- find it hard to communicate and interact with other people
- find it hard to understand how other people think or feel
- find things like bright lights or loud noises overwhelming, stressful or uncomfortable
- get anxious or upset about unfamiliar situations and social events
- take longer to understand information
- do or think the same things over and over

Most autistic people are adults, but most autistic adults are not diagnosed, or some can be diagnosed later in life. Receiving a diagnosis of autism can provide long-awaited answers and insight into a person's strengths and difficulties, enabling them and others to make reasonable adjustments to improve their well-being.

Between two thirds and three quarters of adults wait longer than the recommended 13 weeks in NICE guidelines for an assessment and diagnosis, with one third waiting longer than 18 months.

2. Key Issues

- Potentially large numbers of undiagnosed residents in North Tyneside and waiting lists exceeding the NICE targets.
- The Autism Spectrum Disorder (ASD) population is likely to continue to grow in North Tyneside in the future.
- The health of the ASD population can be poor with persistent health inequalities across a range of health outcomes.
- There is a significant male/female split in ASD which could be considered in service provision.
- The number of Autistic adults who die are not being considered through the LEDAR reviews. These reviews look at deaths of Autistic and Learning-Disabled people and whether there could have been improvements in their care, reduce health inequalities and prevent premature deaths.

3. High Level Priorities

- Understand the local implications of the National strategy for autistic children, young people and adults: 2021 to 2026 and continue to deliver against the North Tyneside Autism Strategy 2021-2026
- Employment rates for those with ASD are significantly below the general population. Efforts to improve levels of employment and subsequent established health benefits for work, could be considered.

- Support our residents who may be waiting for ASD diagnosis whilst supporting NHS partners in efforts to improve diagnostic rates.
- Improving the referral to complete LEDAR reviews for Autistic Adults and Children with a clinical diagnosis who die and particularly those from ethnic groups or BME communities, so that thematic learning can be shared across health and care services.
- Work with colleagues across the health and wellbeing board to improve a range of health inequalities experienced by those with ASD.

4. Those at Risk

The precise cause of autism is not known, however, a number of different genetic, neurobiological, and environmental factors are thought to play a role in its development.

Factors associated with an increased prevalence of autism in children and young people include

- Some chromosomal and genetic anomalies – such as Down's syndrome, muscular dystrophy, neurofibromatosis type 1, and tuberous sclerosis.
- Preterm birth – gestational age less than 35 weeks
- Parental schizophrenia-like psychosis or affective disorder. Prenatal exposure – maternal use of sodium valproate during pregnancy. Birth complications resulting in central nervous system (CNS) malformation or dysfunction, such as cerebral palsy.
- Neonatal or epileptic encephalopathy, including infantile spasms.
- A learning disability.
- Neurodevelopmental disorders such as attention deficit hyperactivity disorder.
- Family history – the rate of autism in siblings and in parents and grandparents is much higher than the rate in the general population.

Autism diagnosis

Receiving a timely autism diagnosis is vital in getting the right support and helping autistic people and those supporting them to better understand their needs. Many people are still waiting longer than the National Institute for Health and Care Excellence (NICE) recommended 13 weeks between referral and first assessment.

As a result, estimates suggest approximately 750,000 undiagnosed autistic people aged 20 and above in England. If this is the case, the total autistic population in England would exceed 1.2 million people.

Autism and gender

The proportion of males to females diagnosed with ASD varies across studies but always shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1

It is believed that females may “mask” which can delay identification and assessment.

Autism and health outcomes

Nationally Autistic people die on average 16 years earlier than the general population. Locally LEDAR reviews are currently considering Autism but the numbers referred are very low.

Autistic people face substantial health inequalities, are more likely to have poorer general health than non-autistic people and are at increased risk of virtually every cause of death that has so far been studied. Around 70% of autistic people have at least one physical or mental health issue, including anxiety disorders, epilepsy and attention deficit hyperactivity disorder (ADHD), but these are often unrecognised.

They are more likely to develop a wide range of conditions including heart disease, diabetes, stroke, Parkinson’s disease, allergies, gastro-intestinal disorders and autoimmune conditions.

Almost 8 in 10 autistic adults experience a mental health problem. Autism is not a mental health condition itself, but mental health problems are one of the most common and serious challenges experienced by people across the spectrum. Up to 10% of adults in inpatient mental health settings are autistic, even though only 1% of the population is on the spectrum.

Autistic people are often unable to access community mental health support. Reports suggest difficulties for mental health services in integrating autism.

Autistic people are less likely to be satisfied with the healthcare they receive, and to understand and be understood by health professionals. Differences in experience, expression and interpretation can mean that issues like pain are dismissed (known as clinical overshadowing).

International evidence suggests that autistic people are more likely to end up in hospital care or using emergency services. Problems that could be identified and managed early are often left to escalate, unnoticed by health professionals or even by autistic people themselves, until a crisis is reached.

Autism and employment

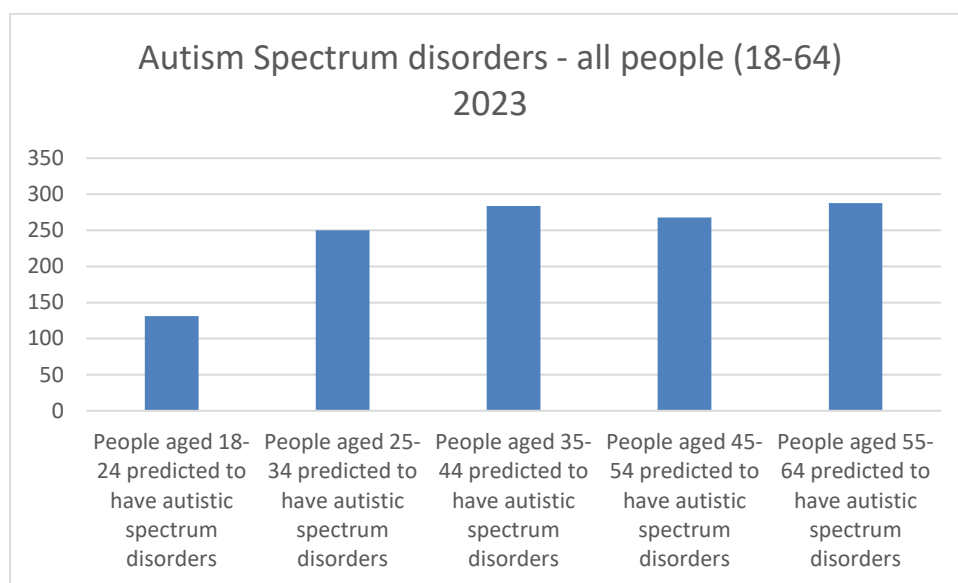
Evidence shows that there is currently a significant employment gap for autistic people. Data published by the Office of National Statistics for the first time in February 2021 shows that as of December 2020, 22% of autistic people aged 16 to 64 are in employment, in contrast to 52% of disabled people, and 81% of non-disabled people.

5. Level of Need

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).

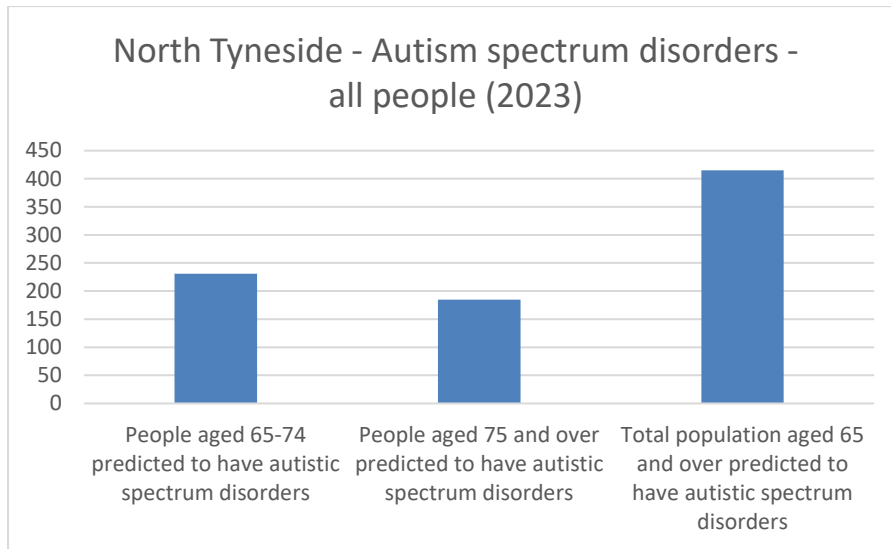
There are 186 people (both children and adults) known to North Tyneside Council social care with an autism diagnosis at June 2021.

Autism spectrum disorders – all people predicted (18–64) 2023



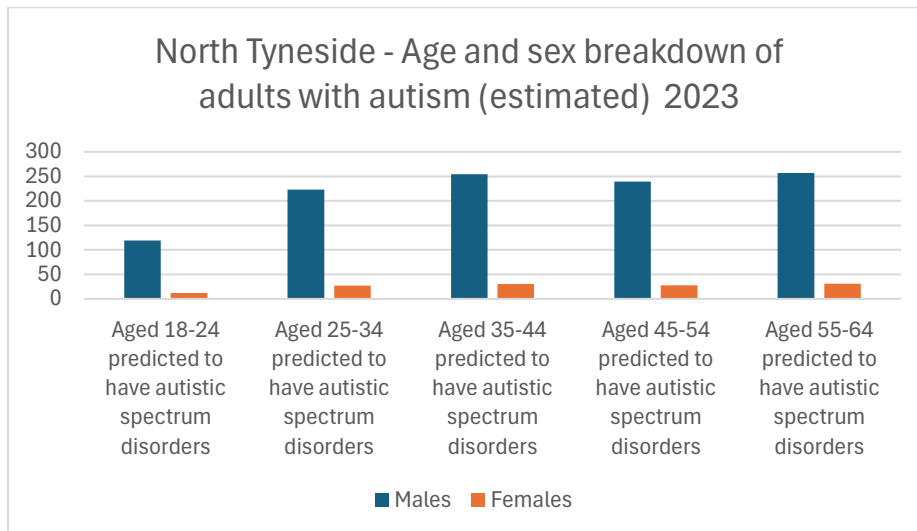
The population sizes may reflect the poor health outcomes for those with autism with a smaller population in the older cohorts.

North Tyneside Autism spectrum disorders - predicted (over 64) 2023



Total population aged 18-64 predicted to have autistic spectrum disorders is 1,221 adults

Autism and gender



As highlighted earlier, there is a significant gender bias for Autism which can be seen in North Tyneside.

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

6. Unmet Needs

The National Institute for Health and Care Excellence (NICE) guideline notes that autism may be under-recognized and under-diagnosed in girls and children and young people with a learning disability.

Studies of autism in adults have shown that up to 80% of people have experienced a difficulty in obtaining a diagnosis, and many adults will not have received a formal diagnosis.

In North Tyneside, there were 760 patients aged 18 and over with an open suspected autism referral in the month (September 2023) that has been open for at least 13 weeks.

As of July 2024, Child and Mental Health Services (CAMHS) have 597 waiting, and the longest wait is 72 weeks.

As of April 2024, for adults, there was an open caseload of 2,508 and 91% of these (1,809) were waiting more than 18 weeks.

In 2021 the National Autistic Society state that more than two in three autistic adults do not get the support they need and only 14% said they had enough mental health services in their area.

The North Tyneside Autism strategy acknowledged there are some perceived concerns from individuals and their families in accessing an Autism Diagnosis.

7. Projected Need and Demand

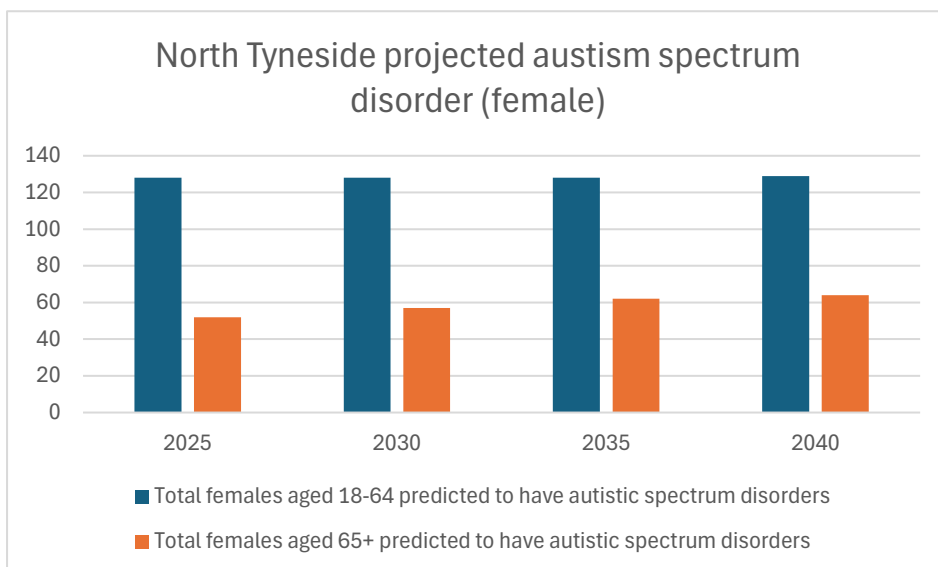
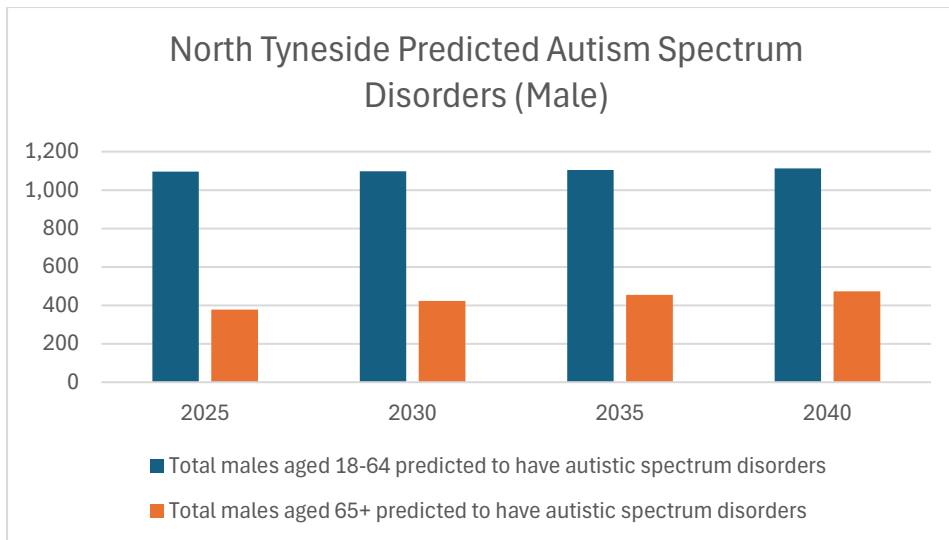
Research suggests that autism spectrum disorders will continue to rise in the coming years with a combination of increased awareness and improved diagnosis.

North Tyneside autism spectrum disorders projections (18-64)

Autistic spectrum disorders - all people	2023	2025	2030	2035	2040
People aged 18-24 predicted to have autistic spectrum disorders	131	135	149	151	143
People aged 25-34 predicted to have autistic spectrum disorders	250	246	232	239	255
People aged 35-44 predicted to have autistic spectrum disorders	284	284	294	291	275
People aged 45-54 predicted to have autistic spectrum disorders	268	269	274	288	301
People aged 55-64 predicted to have autistic spectrum disorders	288	290	274	264	266
Total population aged 18-64 predicted to have autistic spectrum disorders	1,221	1,224	1,226	1,233	1,241

North Tyneside autism spectrum disorders projections (18-64)

Autism spectrum disorders – all people	2023	2025	2030	2035	2040
People aged 65-74 predicted to have autistic spectrum disorders	231	235	260	270	260
People aged 75 and over predicted to have autistic spectrum disorders	185	195	221	246	278
Total population aged 65 and over predicted to have autistic spectrum disorders	415	430	480	515	538



The project rise is more noticeable in the male population which reflects the greater number of diagnosis.

8. Community Assets and Services

Adult Autism Diagnostic Service

This service provides assessment and diagnosis for people who may have Autistic Spectrum Disorder (ASD). The service is available for people over 18

years of age in Newcastle, North Tyneside, Northumberland, Sunderland, South Tyneside and Gateshead.

We are Better Together

Regular drop-in sessions are held for those who are autistic and their families and care givers in North Tyneside.

North East Autism Society

For over 35 years they have provided specialist care, education and services for children, young people and adults with autism, across the North-east of England.

9. Evidence for Interventions

- Autism spectrum disorder in adults: diagnosis and management. Clinical guideline [CG142]
- Autism- Quality standard [QS51]Published: 21 January 2014
- Enabling positive lives for autistic adults. NICE. 2019

10. Views

In developing the Autism strategy, North Tyneside Council 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.

Residents mapped out what is in place, 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 provided 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

Awareness raising – ensuring services and communities are aware, and able to make reasonable adjustments

Good support – clarity of referral routes, dedicate more to early identification and awareness and support NHS colleagues in delivering shorter waiting times for diagnosis

Understanding yourself – helping autistic people and their families have a good life

Be listened to – 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 – 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.

Inclusive communities – helping North Tyneside to be an autism friendly area.

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.

11. Additional Needs Assessments Required

Learning difficulty

12. Key contacts

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