Autism and ADHD in York

A Health Needs Assessment



Produced by City of York Council Public Health Team, Summer 2025

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Executive Summary

This is a Health Needs Assessment (HNA) for people of all ages who live in York who have a diagnosis of Autism or ADHD, who believe they are Autistic or have ADHD, or who would like to receive a diagnostic assessment for these conditions.

Some key findings are summarised below

Prevalence and Demographics	In total there are 2,786 people who are registered with a York GP and who have a diagnosis of autism on their health record. National prevalence estimates suggest between 1% and 4% of the population are autistic	Autism is underdiagnosed in York, particularly in older people. There is a 3:1 male to female ratio in diagnoses of both Autism and ADHD in York	
Prevalence and Demographics	In the UK, the prevalence of ADHD in adults is estimated at 3% to 4% With 2,311 people in York having a diagnosis of ADHD, this suggests only around 1 in 3 adults in York are diagnosed.	18.4% of people with an ADHD diagnosis in York also have an Autism diagnosis, and 15.3% of people with an Autism diagnosis also have an ADHD diagnosis.	
Assessment and waiting lists In January 2023 there were 1,560 adults awaiting autism and ADHD assessment and a further 2,000 referrals that had not yet been triaged. It was estimated that the waiting list is currently five years.		Compared to 2021, the children and young people's autism service has seen a 50% rise in monthly referrals, and just over a quarter of children and young people have been on the waiting list for more than a year.	
Health issues York GP data shows that 1096 people with an ADHD diagnosis also have a mental health condition, which is 44%.		12% of people with ADHD will develop an alcohol addiction and 28% develop a drug addiction at some point in their lives. 14% of people with ADHD in York are current smokers, higher than general smoking rates	
Health issues	Autistic people, as a group, face health and wellbeing challenges such as higher levels of homelessness, 5 years lower life expectancy, higher rates of additions, and 40% of this group in fork have a mental health condition		

Project Scope and Approach

This HNA considers the health and wellbeing needs of people of all ages who live in York who are Autistic or have ADHD. This includes people with a diagnosis, people waiting for a diagnosis, and people who recognise traits of Autism and/or ADHD in themselves. The purpose of this needs assessment is to consider the current and emerging Autism and ADHD needs of residents who live in York. Health Needs Assessments are a systematic method of identifying the unmet health and healthcare needs of a population, and this HNA has been written in advance of a new Autism and ADHD Strategy for York, in order to form and shape this strategy.

There are two main aims of this project:

- To build collective understanding of the Autism and ADHD population in York. This includes information about the population size and demographics, current use of health, care, and other key service areas.
- 2) To make recommendations and support preparation for a city-wide Autism and ADHD strategy that is intended for 2025.

This needs assessment does not make specific recommendations. It identifies topics and needs that should be considered in the development of the York Autism and ADHD strategy. This HNA looks at many local data sources:

- Local authority services: SEND team, adult social care
- Health services: Neurodiversity diagnostic and support services,
 GP data, hospital data, addiction recovery services, mental health services, children's social care data
- Other sources: Employment data, criminal justice and police data, large scale research studies

This HNA also looks at national and international research for a wider understanding of the health and wellbeing needs of Autistic people and people with ADHD. This can be particularly helpful when local data is incomplete, out of date, hard to access, or does not clearly contain information about Autism/ADHD.

The document was written by the public health team but with input from the Autism and ADHD strategy working group, from academic partners, and through discussion at a council Scrutiny Committee.

This health needs assessment also includes a 'What Works Guide'. This is a selection of guidance or best practice documents which describe ways of working that can be helpful and inclusive to Autistic people and people with ADHD. In various ways and to various levels, these guidance documents have been developed with input from neurodiverse people.

Definitions and terms used

Neurodiversity means that all people's brains process information differently. To be a neurodivergent person is someone whose brain processes information in a distinctly different way to neurotypical people.

Because neurotypical people make up the largest group of people in our world, the way they process information is thought to be 'typical' or 'normal'. As a result, a lot of our environments are set up to accommodate these typical ways of processing information, which can make some things difficult for neurodivergent people to access.

There are lots of different ways a person can be neurodivergent. It is a collective term to describe people who have conditions such as Autism, ADHD, dyslexia, dyscalculia, dyspraxia, stammering, Foetal Alcohol Spectrum Disorder, or Tourette's syndrome. In most cases, a person is neurodivergent for their whole life. Some forms of brain injury can create this, but this is quite rare. Some people may know they are neurodivergent from a very young age, others may realise this in adulthood.

Specific learning disabilities such as dyslexia are a form of neurodiversity. However, general learning disabilities are not a form of neurodiversity. Some neurodivergent people also have a learning disability, and some do not.

Although there is a wide range of neurodivergent individuals in our society, this needs assessment is only looking at two neurodivergent groups – Autistic people and people with ADHD. This is because York is planning an Autism and ADHD strategy in 2025, and we want this needs assessment to support the strategy planning process.

Autism and ADHD are distinct conditions and experiences; however, we are considering them together in this needs assessment for two reasons.

- Firstly, Autistic people and people with ADHD face somewhat similar challenges, for example, the diagnosis pathway and the societal barriers placed on Autistic people and people with ADHD that impact mental and physical health.
- Secondly, a proportion of people are both Autistic and have ADHD

(around 30%). This is sometimes referred to as 'AuDHD'. We recognise the unique experiences of people with both ADHD and Autism, but also recognise that a proportion of the community may have AuDHD, meaning they have their own unique challenges. For example, individuals with AuDHD may feel a need for routine *and* a need for impulsivity, which may mean they experience internal struggle between these contrasting traits.

The City of York Council has previously committed to supporting the social model of disability when designing places and policies. The social model of disability states that people are disabled by barriers placed on them by society rather than by an impairment or condition.

We recognise that many within the neurodiversity community value this approach. It highlights there is nothing intrinsic to either Autism or ADHD that should mean a person is more likely to become physically or mentally unwell, become homeless, or long-term unemployed; and that these experiences often arise from marginalisation and discrimination.

We also recognise that some within the neurodiversity community do not like the language of 'disability' and do not recognise themselves as disabled. To make things more complicated, some parents reject the social model of disability, especially if their children have additional physical or cognitive needs. Therefore not all members of the neurodiversity community and those that support them agree with the social model of disability, aligning more with traditional medical models.

In this strategy and needs assessment we are using the principles of the social model of disability and neurodiversity, however, the differing opinions of the community are acknowledged despite the use of neurodiversity-affirming language throughout. In relation to Autism, medicalised or potentially stigmatising terminology (e.g., disorder, high/low functioning) have been avoided throughout and identity-first language (e.g., Autistic individual) has been used, following the majority preference of the Autism community.

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¹ Matson, J. L., & Goldin, R. L. (2013). Comorbidity and autism: Trends, topics and future directions. Research in autism spectrum disorders, 7(10), 1228-1233.

Chapter 1: Diagnosing Autism and ADHD in York

In this section we will talk about how Autism and ADHD are diagnosed in children and adults in York. This includes:

- the process of making a diagnosis
- information on which organisations fund and provide diagnosis services
- information on recent waiting times
- information on recent changes to diagnosis services for adults

Children and young people

Autism is diagnosed through a detailed assessment by a team of health professionals with expertise in developmental disorders. Diagnosis of Autism is possible from early childhood, with the average age of diagnosis, globally, being 43 months.²

The National Institute for Health and Care Excellence (NICE) recommends that individuals referred for an Autism assessment should be seen within three months. However, the actual waiting time across the UK ranged from 218 to 306 days (approximately seven to ten months) between April and December 2023.

ADHD can be diagnosed as early as 4 years old, but this is often delayed until the age of 6 or 7 years when children begin formal education, as characteristics are often noticed more commonly in a school environment.

In York, children under 5 years are assessed at the child development centre at York hospital. The assessment process can take around a year, as paediatricians need to rule out other health or developmental issues before conducting a full Autism assessment.

Children aged 5-18 are assessed by Child and Adolescent Mental Health Services (CAMHS). Referrals can be made by the GP or School Special Educational Needs Coordinator through to the 'single point of access' SPA. The SPA collect information through some screening

² Van'T Hof, M., Tisseur, C., van Berckelear-Onnes, I., Van Nieuwenhuyzen, A., Daniels, A. M., Deen, M., ... & Ester, W. A. (2021). Age at autism spectrum disorder diagnosis: A systematic review and meta-analysis from 2012 to 2019. Autism, 25(4), 862-873.

forms and a 30 minute phone call, this is to help the 'Neurodiversity screening panel' decide if a full assessment is needed.

Due to a significant increase in referral numbers, there is currently a long wait for Autism and ADHD assessments within CAMHS. As of March 2024 there were 450 children and young people aged 5-18 waiting for an assessment for Autism diagnosis. In March 2024, just over a quarter of children and young people had been on the waiting list for more than a year. Compared to 2021, the service has seen a 50% rise in the number of referral requests each month. ³

A full assessment of Autism in children and young people will involve meeting with the young person, and a separate conversation with parents and the school. For ADHD the team encourage the young person to come into the appointment on their own, with family supporting from the waiting room. Afterwards, the family receive a brief summary of the assessment and confirmation of the outcome. CAMHS is not commissioned to offer ongoing intervention or support for Autism and so the young person is then discharged.

In 2024, Public Health published a full SEND Health Needs Assessment for York which goes into further detail on topics relating to Autism /ADHD in the context of the SEND system.⁴

Adults

The NHS adult Autism and ADHD diagnosis service is delivered by The Retreat in York. The service completes diagnostic assessments for both Autism and ADHD but currently there are separate diagnostic pathways for each.

Autism diagnostic assessments at The Retreat are completed in line with the National Institute for Health and Clinical Excellence (NICE) guidelines.⁵ Assessments are completed by a specialist multidisciplinary team that includes psychologists, nurses and occupational therapists. All members of the multidisciplinary team are trained in the use of standardised Autism diagnostic tools, including the Autism Diagnostic Observation Schedule (ADOS-2), The Developmental Diagnostic

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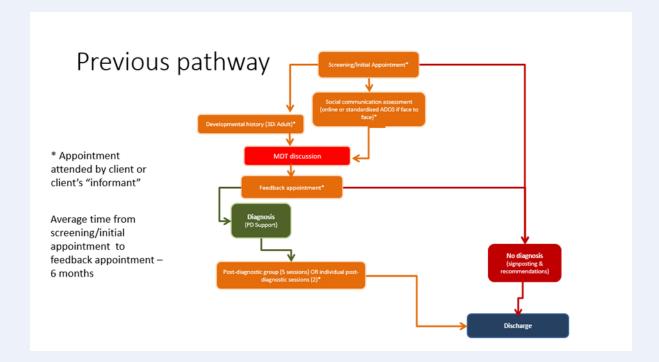
³ York SEND

⁴ Children & Young People with Special Educational Needs & Disabilities

⁵ Overview | Autism spectrum disorder in adults: diagnosis and management | Guidance | NICE

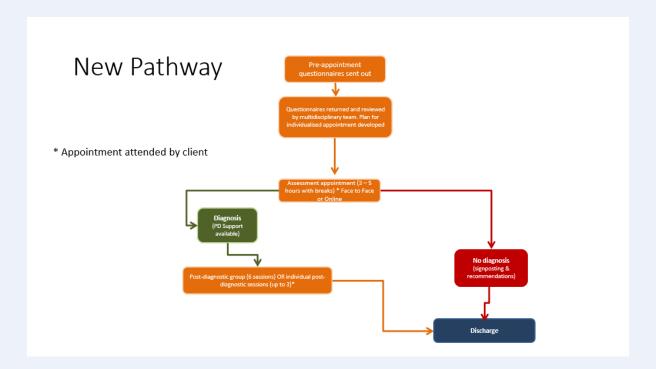
Dimensional Interview (3Di) and Autism Diagnostic Interview – Revised (ADI-R).

In February 2024, The Retreat updated its diagnostic assessment pathway. Previously the assessment had included three diagnostic assessment appointments, a multi-disciplinary discussion and feedback appointment. The time taken to complete this whole process, could vary but the average time between attending the screening/initial appointment to receiving feedback on the outcome of assessment was 6 months.



Between May and December 2023, a project was trialled by The Retreat using an alternative method of completing Autism diagnostic assessments. This process utilised "front loading", the gathering of extensive information in advance of an individual attending to complete an appointment. This process aims for individuals to then be able to attend for one extended individualised appointment, where the aim would be to provide an outcome for their diagnostic assessment within this one appointment. The questionnaires completed prior to appointment included: Information Questionnaire, Sensory Questionnaire, Repetitive Behaviour Questionnaire, Informant Information, and Well-Being Update Questionnaire. The appointment includes interview, observations, multi-disciplinary discussion, and feedback.

A service evaluation followed this trial and detailed feedback was gathered on this assessment process from those who participated in the trial. The overwhelming positive feedback from this trial led to the implementation for this to be the standard pathway for Autism diagnostic assessments at The Retreat from February 2024.



The outcome for approximately 80% of assessments completed is a diagnosis of Autism (sometimes referred to as conversation rate). This has remained consistent for the service for a number of years and continues to be the case within the new diagnostic assessment pathway.

ADHD diagnostic assessments at The Retreat are completed are in line with the National Institute for Health and Clinical Excellence (NICE) guidelines.⁶ Assessments are currently completed by specialist psychiatrists.

Similar to the Autism diagnostic pathway, the ADHD assessment process includes the completion of forms in advance of the individual attending for their assessment appointment. The forms completed include information from an informant, someone who knows the individual well and ideally knew them during childhood. Most ADHD assessments are

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⁶ Overview | Attention deficit hyperactivity disorder: diagnosis and management | Guidance | NICE

completed in an individual appointment which will include a detailed review of current and historic mental health and exploration of examples of the ADHD diagnostic criteria, both during childhood and currently. Assessments are individualised and if required will include the completion of standardised ADHD diagnostic assessment tools, including the Diagnostic Interview for ADHD in adults (DIVA), Conners' Adult ADHD Rating Scales (CAARS) and Neurocognitive screening tests.

In most cases an assessment outcome can be confirmed within a single appointment, but in case where there are additional complexities further appointments can be arranged in order to ensure an accurate outcome to the assessment. The outcome from approximately 79% of ADHD assessments is a diagnosis.

Requests for Autism assessments in adults are growing rapidly across England. In England, 80% of adults now wait more than 3 months for an initial assessment, with half waiting more than 9 months^{7.} The typical waiting time for a completed assessment is close to two years in England. For ADHD there is no central waiting list record, but ADHD UK have made freedom of information requests to each Integrated Care Board (ICB) individually⁸. Only 15% of ICB boards were able to report their ADHD waiting times, so its not possible to describe the average national wait time for assessment.

In January 2023 there were 1,560 adults awaiting Autism and ADHD assessment and a further 2,000 referrals that had not yet been triaged. These figures are for York and North Yorkshire: between April 2018 and July 2023 54% of these referrals came from the Vale of York area. It was estimated that the waiting list would be five years.

In response, the ICB developed a two-tier pathway in order to prioritise resources to those most at risk of harm; the proposal was that this would be used as an acceptance criteria for the current waiting list and not as an expedite criteria. People would be referred for assessment only if they were at immediate risk of harm to themselves or others, at risk of being unable to have planned life-saving hospital treatment or care, or

8 https://adhduk.co.uk/nhs-adhd-assessments-waiting-lists-report/

⁷ The rapidly growing waiting lists for autism and ADHD assessments | Nuffield Trust

were at imminent risk of a family court decision determined on diagnosis; dependent on the outcome of the referral being triaged.

A three month pilot (later extended to a year and is now still ongoing) was implemented by the ICB. This pilot directed individuals who did not meet the acceptance criteria to an online tool known as the 'Do-It profiler'. The profiler was intended as a self-help resource and not a diagnosis tool. In response to these changes and the lack of consultation, the York Disability Rights Forum⁹ begun a legal challenge against the ICB, and HealthWatch published a report collating and describing the public concern¹⁰. There were also two presentations to the Health and Wellbeing Board.

In June, an amendment to the referral and acceptance criteria was launched. Referrals can now be made by GPs and by community mental health teams. The backlog of 2000 referrals from January 2023 have now been triaged, but only a limited number of referrals since March 2023 have been triaged. This is partly due to lack of information to enable triage from the Do It Profiler platform.

At the time of writing the waiting time for assessments in September 2024 was, for ADHD, an average of 3.7 years and, for Autism, an average of 3.4 years.¹¹ Both Autism and ADHD services are assessing referrals from mid 2021 to the end of November 2021.

People who do not meet the updated acceptance criteria will be added to a holding list. They may use the Do-It profiler, but this is not a requirement. The Retreat have also published their post diagnostic support packs for both Autism and ADHD, meaning that anyone who self-identifies as Autistic able to make use of them¹². The packs are a directory of recommended books, websites, videos, and local groups.

Nationally, there has been an increase in the number of private diagnoses of Autism and ADHD, and, through the NHS 'right to choose' care in another area with shorter waits, complex issues have emerged around shared care and ongoing support.

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Autism and ADHD Assessment Access - York Disability Rights Forum (ydrf.org.uk)

¹⁰ Guidance (healthwatchyork.co.uk)

¹¹ https://theretreatclinics.org.uk/waiting-times/ (correct September 2024)

¹² Autism Post-Diagnostic Pack (theretreatclinics.org.uk)

In conclusion, whilst the diagnosis and assessment process within healthcare is usually intended to have a positive and supportive impact on an individual's health and wellbeing, it is clear that in Autism and ADHD assessment, confusion and lack of clarity around pathways, long waiting lists, delayed access to medications and other support is likely to be negatively affecting the health of Autistic people and people with ADHD in York.

Chapter 2: Patterns and trends in Autism

In this section we will talk about

- How common Autism is in York
- What it means to be Autistic
- What GP data tells us about Autism in York
- What education data tells us about Autism in York
- Autism and gender/sex

How common is Autism?

Autism is a lifelong condition which affects how people communicate and interact with the world. Understanding the prevalence of Autism is hard, as medical or educational records will only tell us how many people have received a formal diagnosis, and therefore are an underdiagnosis which does not truly represent the actual prevalence of Autism in any given area. In addition, prevalence across all ages is affected by historical trends in (under) diagnosis which will bring down the average.

One population cohort study suggests that 59–72% of Autistic people may be Autistic and undiagnosed.¹³

Typical estimates are that just over 1% of the global population are Autistic – this is the figure quoted by the WHO¹⁴ and the Lancet¹⁵. This would mean there are around 700,000 Autistic people in the UK.¹⁶ This rate will vary across age bands, as older people are less likely to have received a diagnosis, and some other estimates suggest a much higher number, between 3 and 4%.¹⁷

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¹³ <u>Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data - The Lancet Regional Health – Europe</u>

¹⁴ Autism

¹⁵ The global epidemiology and health burden of the autism spectrum: findings from the Global Burden of Disease Study 2021 - The Lancet Psychiatry

¹⁶ National Autistic society

¹⁷ Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data - ScienceDirect

It is quite common for a person to have both Autism and ADHD, although estimates vary. Roughly 50-70% of Autistic people also have ADHD. Equally, roughly 30-60% of people with ADHD will also be Autistic. These studies are usually based on observed characteristics of Autism and ADHD in people, not on diagnosed rates.

What does it mean to be Autistic?

The NHS website lists a number of traits which Autistic younger children may have, including¹⁸:

- not responding to their name
- avoiding eye contact
- not smiling when you smile at them
- getting very upset if they do not like a certain taste, smell or sound.
- repetitive movements, such as flapping their hands, flicking their fingers, or rocking their body
- not talking as much as other children
- not doing as much pretend play
- repeating the same phrases

Traits which Autistic older children may have include:

- not seeming to understand what others are thinking or feeling
- unusual speech, such as repeating phrases and talking 'at' others
- liking a strict daily routine and getting very upset if it changes
- having a very keen interest in certain subjects or activities
- getting very upset if you ask them to do something
- finding it hard to make friends or preferring to be on their own
- taking things very literally for example, they may not understand phrases like "break a leg"
- finding it hard to say how they feel

Traits which Autistic adults may have include 19:

- finding it hard to understand what others are thinking or feeling
- getting very anxious about social situations
- finding it hard to make friends or preferring to be on your own
- seeming blunt, rude, or not interested in others without meaning to

¹⁸ Signs of autism in children - NHS

¹⁹ Signs of autism in adults - NHS

- finding it hard to say how you feel
- taking things very literally for example, you may not understand sarcasm or phrases like "break a leg"
- having the same routine every day and getting very anxious if it changes

Other traits of Autism include:

- not understanding social "rules", such as not talking over people
- avoiding eye contact
- getting too close to other people, or getting very upset if someone touches or gets too close
- noticing small details, patterns, smells or sounds that others do not
- having a very keen interest in certain subjects or activities
- liking to plan things carefully before doing them

A joint project between Autisticia²⁰, Curtin University in Australia and Karolinska Institute in Sweden concluded that many Autistic people have strengths, abilities and interests that non-Autistic people don't have. Everyone is different, but some common Autistic strengths are:

- attention to detail, ability to hyperfocus, and excellent recall memory
- visual perception
- creative and artistic talents
- mathematical and technical abilities.
- interests or expertise in 'niche' areas
- character strengths such as honesty and loyalty
- a strong sense of justice
- creative problem solving
- less influenced by social biases and norms

Why are some people Autistic and others not?

It is unlikely that there is a single cause for Autism, and genetic factors and environmental factors both may play a part.

We know that siblings of Autistic people individuals had a significantly higher chance of also being Autistic, compared to the general

²⁰ Focus on strengths as well as challenges | Autistica

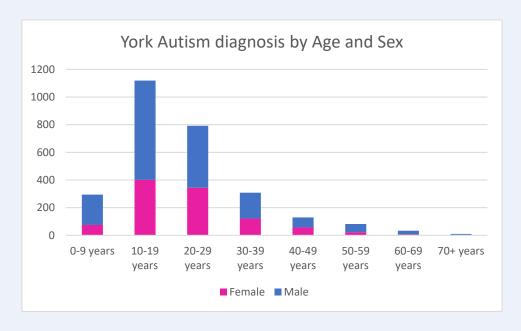
population. One study revealed that if an older sibling is Autistic, the younger siblings had a 30% chance of also being Autistic. This can rise to 60% for twins. There are similar links between Autistic parents and children. Because of this, people say that Autism can 'run in families'. This is important for how organisations and teams design services to consider, because for many people families represent an important source of practical advice and support.

GP data on Autism in York

Primary care data can tell us about the number of people who are registered with a GP in York and who have a diagnosis for Autism. It is well recognised that not every Autistic person will have a diagnosis recorded.

In total there are 2,786 people who are registered with a York GP and who have a diagnosis of Autism on their health record. This information was collected in summer 2024.

The data is separated by sex and shows that there is roughly a 3:1 ratio of men to women diagnosed Autism. This follows the expected national pattern.



The data is also separated by age band. It shows that very few older adults have an Autism diagnosis (0.2% of the population). The majority of Autism diagnosis are in people aged 0-9 (approximately 300 people), 10-19 (approximately 1100 people), and 20-29 (approximately 800

people). This also follows the national pattern. It is because in previous decades Autism was less recognised and less diagnosed.

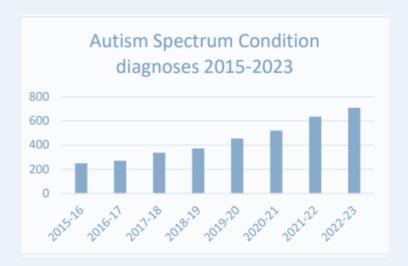
GP data shows that 426 people had a record of both an Autism and an ADHD diagnosis. 18.4% of people with an ADHD diagnosis also had an Autism diagnosis, and 15.3% of people with an Autism diagnosis also had an ADHD diagnosis.

Education data on Autism in York

There is also data on the numbers of Autistic people in the education records. This is held by the special educational needs team.

A child has special educational needs if they need additional or augmented support to access the school or the curriculum. This can come in the form of a SEN-support plan (additional support coordinated by the school) or an Education, Health, and Care Plan (a plan made jointly by these three teams of professionals).

The number of pupils who are SEND and with Autism as their primary need has been rising rapidly over the last decade, and this trend is likely to continue given the backlog of children waiting for diagnostic assessment:



In total, just over 700 children and young people have their primary need listed as Autism. This is a fifth of all pupils with SEND. Children and young people living in deprivation in York (based on postcode and the Index of Multiple Deprivation) are equally likely to have a SEND record for Autism or ADHD as children living in other areas of York.

Autism, gender and sex

It is thought that Autism is more common in males than females. There are different estimates, but most likely the prevalence is one female to every 3 or 4 males²¹.

It is also thought that Autism in females is sometimes missed or misunderstood. This may happen because the traits of Autism in females can be different and may look like other conditions, and professionals may be less equipped and / or aware when supporting people who think they may have autism. For example, Autistic girls may be able to 'mask', meaning they can copy others behaviour and behave like a neurotypical person in some social settings. This can be very stressful and is known to increase feelings of anxiety in Autistic females²².

The estimates of how many Autistic women and girls may be undiagnosed vary considerably, and there is no consensus at this time. The Autistic Girls Network have summarised the current understanding and impact of Autism on women and girls²³.

A UK project looking at 600,000 adults found that transgender and gender-diverse adult individuals were between three and six times more likely to say that they were diagnosed Autistic compared to the general adult population of the UK.

Data from GP practices in York says that there are 48 people with a medical diagnosis of Autism and a record that they are 'trans or non-binary'. This is 1.6% of everyone with a diagnosis of Autism on their GP record, about 3 times the prevalence in the general population. This data would not include people who do not currently have an Autism diagnosis.

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²¹ https://www.autism.org.uk/advice-and-guidance/what-is-autism/Autistic-women-and-girls

²² The National Autistic Society

²³ https://Autisticgirlsnetwork.org/keeping-it-all-inside.pdf

Chapter 3: Autism and health and wellbeing

This section looks at health and wellbeing topics and how they relate to Autism. There is nothing intrinsic or inbuilt into Autism or ADHD that makes a person more likely to have most physical ill health conditions, or to become homeless, or addicted to substances or experience many of the other conditions and circumstances that we talk about in this health needs assessment. However, the attitudes of society and the level of access to support make it more challenging to thrive as an Autistic person or a person with ADHD. By talking addressing these topics we hope to move closer to York being a health generating city for all.

We summarise national research and include local information where it is available.

Topics are discussed alphabetically:

- Criminal justice
- Employment
- Homelessness
- Learning disabilities
- Life expectancy
- Mental health
- Other health issues
- Sleep
- Substance misuse (drugs and alcohol)

Criminal Justice

Data is limited on the number of Autistic or neurodivergent people in the criminal justice system. Some characteristics of Autism might make young people more at risk of offending. This might include a having smaller social support network and social naivety, meaning others can 'take advantage' of Autistic people in some circumstances. There are also studies which show that juries are more likely to convict autistic/young people with SEND. In a publication for The Children's Commissioner the prevalence of Autism among young offenders was estimated to be 15%.²⁴

²⁴ https://www.childrenscommissioner.gov.uk/resource/nobody-made-the-connection/

In July 2021, a national review on Neurodiversity within the criminal justice system highlighted insufficient efforts to address the needs of neurodivergent individuals. Responding to this, the Ministry of Justice released a Neurodiversity action plan in June 2022, with updates in January 2023. The revised plan outlines the introduction of Neurodiversity support managers in prisons, with a goal to have one in each facility across England and Wales by 2024.²⁵

In York the youth outcome panel, which aims to divert people from criminal justice, knows if young people on their caseload have diagnosed neurodivergence or are awaiting assessment. This means that the actions of the rehabilitation orders can be tailored to suit the young people. The youth justice service also follow up young people with SEND to understand their longer term outcomes.

North Yorkshire police have annual training that includes responding to Neurodiversity and have 'trigger plans' in place for meeting alternative communication or sensory needs for individuals who they routinely support through mental health crisis.

North Yorkshire police have also scoped their custody suits for reasonable adjustments that could be made to support sensory sensitivity. This includes sensory toys, adjustable lighting, ear defenders, and backboard paint walls. The age and layout of some of the buildings create limitations but refresh of the lighting was completed in 2024.

Employment

Employment is associated with better mental and physical health for individuals and is important for the wider economy.

Autistic people are over twice as likely to experience unemployment, despite most people wanting to work. The national Buckland Review²⁶ of Autism employment found that only 30% of working age Autistic adults are in employment, rising only to 36% for Autistic people with a degree.

²⁵ Abreu. L et al., (2024) Autism: Overview of Policy and Services, Research Briefing, UK Parliament

²⁶ Landmark review calls on employers to boost support for Autistic people - GOV.UK

Employed Autistic people are most likely to be on zero-hour contracts, and have temporary contracts.

The Buckland review also found that application and interview processes are rarely adapted to suit the needs of Autistic people. Autistic jobseekers face barriers from vague job descriptions, ambiguous interview questions and sensory environments. Too often the emphasis is placed on social skills rather than job skills.

Access to reasonable adjustments is inconsistent. In most cases the onus is on the Autistic employee to identify and advocate for adjustments. Around one third of Autistic employees felt unable to discuss their adjustment needs at all, and those who did request adjustments, over a quarter were refused and more than 1 in 10 found the adjustment was poorly implemented.

The Retreat post-diagnosis resources do include some information on employment, but people are not directed towards any schemes operating locally. We are not aware of any York specific data that could indicate the employment rates for neurodivergent people living in York.

Homelessness

The current research suggests that Autistic people are more likely to experience homelessness. In 2017 in the UK a sample homelessness key workers were asked to consider their clients against the diagnostic criteria for Autism²⁷. The researchers found that 12% of the group were described as showing 'strong traits' of Autism, and another 10% showing some Autistic traits. Although this was not a diagnosis, this research suggests that Autistic traits are much more common in homeless people than in the general adult population.

Homeless Link say that "Personal social challenges, a lack of community understanding and support, and employment disadvantage and discrimination are likely to be key reasons why Autistic adults may be more at risk of homelessness." In addition, Autistic people who are homeless are more vulnerable to further harms from violence or abuse.

https://homelesslink-1b54.kxcdn.com/media/documents/Autism_and_Homelessness_Toolkit_ Edition_2.pdf

Homeless Link have produced a toolkit²⁸ which provides resources to help key workers to identify people with traits of Autism in their clients and to consider suggests in reasonable adjustments to working practices which can make services more accessible to Autistic people. Homeless Link recognise that in many cases neurodiverse people experiencing homelessness have not received a diagnosis, and levels of self-identification vary.

Currently, the homelessness support services in York don't specifically ask whether a person is Autistic as a standard question, but do seek to understand the health and wellbeing needs of their clients, and recognise Autistic characteristics in many of their client group.

GP data is not a particularly good source of information on homelessness. GP data shows there are currently 19 people with a diagnosis of Autism who also have current homelessness recorded on the GP record.

Learning disabilities

Many Autistic people also have a learning disability – up to 60-70% of Autistic adults according to NHS estimates.²⁹ As a result, Autistic people are more likely to receive help with daily activities than non-Autistic people.

In York, CYC holds a record of 3,900 adults who receive care to help with daily activities. It is not possible to put a precise figure on how many people receiving care are Autistic, as not all people will be diagnosed and of those that have, some will not have let the council know about their diagnosis. The local authority care records list just over 100 Autistic adults, nearly all of whom also have a learning disability.

It is widely acknowledged that the true number of Autistic people known to the local authority is higher, but that due to nationally defined criteria we recognise that many people with a primary need of learning disability

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²⁸ https://homelesslink-

¹b54.kxcdn.com/media/documents/Autism and Homelessness Toolkit Edition 2.pdf

²⁹ Estimating the prevalence of autism spectrum conditions in adults - GOV.UK (www.gov.uk)

have not yet had their Autism diagnosis included on their individual care record.

Record keeping is slowly improving as the team are now taking greater steps to record known Autism diagnosis for new and existing customers.

The York GP data can also help us to understand about Autism, learning disability, and care need. Compared to other local authorities nationally, York has a statistically significantly lower prevalence of people diagnosed with a learning disability. This might suggest that there is an element of under-diagnosis amongst the population.

In total there are 222 people in York who have both Autism and a learning disability coded on their GP health record. This equates to around 7% of all people with an Autism diagnosis. Evidence suggests that around 1 in 3 (33%) of Autistic people also have a learning disability, although this varies by age group. The ICB has piloted various initiatives to improve learning disability recording in GP practices. This is important because people with learning disabilities are eligible for routine Annual health checks throughout their adult lives, will receive a different offer of support through education, and are also eligible for free flu vaccinations.

Life expectancy

The average life expectancy in the UK is 80 years for men, and 83 for women.

The life expectancy for Autistic people is about 5 years shorter, and about 10 years for Autistic people with a learning disability.

	Men	Women
General population	80	83
Autism	75 (-5 years)	77 (-6 years)
Autism and Learning	72 (- 8 years)	70 (-13 years)
Disability		30

The reasons for this are likely to be complex. This health needs assessment identifies many factors which can impact life expectancy, and we do know that the main causes of early death include for this are early heart disease and suicide (this could however be said for the

³⁰ Premature death of Autistic people in the UK investigated for the first time | UCL News - UCL – University College London

general population) and that 69% of autistic adults have untreated health problems.³¹ Additionally, the report into life expectancy describes that Autistic people may find it more difficult to explain their health symptoms to others and this can complicate access to healthcare services. It is not possible to report York specific data on life expectancy and Autism.

Mental health

There is no central data set looking at Autism and mental health in England so the best information comes from big research studies that collect information from medical records. This type of research shows that Autistic people are about twice as likely to experience anxiety and also depression as people who are not Autistic³²³³³⁴. The research showed that anxiety symptoms rise in teenage and 20s. This is also true of the general population, but the rates of anxiety are higher. The research also shows that Autistic people are particularly likely to have social anxiety or OCD symptoms.

York GP data shows that in total 40% of people with diagnosed Autism also have a mental health condition in York:

33% have an anxiety condition,

21% have depression

3% have a serious mental illness.

In line with national data, this is considerably higher than the expected values for non-Autistic adults.

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³¹ Doherty M, Nielson SD, O'Sullivan JD, Carravallah L, Johnson M, Cullen W, Gallagher L. Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. medRxiv 2020.04.01.

³² Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis | Psychological Medicine | Cambridge Core

³³ Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study - PMC (nih.gov)

³⁴ Association of Comorbid Mood and Anxiety Disorders With Autism Spectrum Disorder | Anxiety Disorders | JAMA Pediatrics | JAMA Network

Other health issues

A cross-sectional study on an American insured population found that Autistic adults had significantly increased rates of all major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive—compulsive disorder, schizophrenia, and suicide attempts. Nearly all medical conditions were significantly more common in adults with autism, including immune conditions, gastrointestinal and sleep disorders, seizure, obesity, dyslipidemia, hypertension, and diabetes. Rarer conditions, such as stroke and Parkinson's disease, were also significantly more common among adults with autism.³⁵

Sleep

According to the National Autistic Society, 'Sleep problems are the most common co-occurring conditions experienced by autistic individuals', with over 70% of autistic adults said they experienced difficulty falling asleep or staying asleep.³⁶

There may be several explanations for this, but the best evidence is the cause being a combination of sensory issues and higher levels of anxiety interfering with circadian rhythm, patterns of rest and sleep hygiene.

Lower quality sleep has been shown to be associated with poorer mental health, relationship issues, and poorer physical health including immune system strength and blood pressure.³⁷

Sleep issues for young people and children also negatively affects the health and wellbeing of parents and carers of young people with Autism and ADHD.

Substance misuse

Autistic individuals are less likely to report regularly consuming alcohol or binge-drinking compared to non-Autistic individuals. However, survey

³⁵ https://journals.sagepub.com/doi/10.1177/1362361315577517

³⁶ Autistic adults and sleep problems

³⁷ Sleep problems - Every Mind Matters - NHS

data^{38, 39} shows they are almost nine times more likely to use alcohol or drugs to 'self-medicate' i.e. to use substances to help manage stress and anxiety. In one study, 20% of treatment-seeking substance misuse disorder outpatients had clinically elevated autistic traits but were undiagnosed.⁴⁰ Autistic adults were also more likely to report using drugs at a young age or being coerced into using drugs by others. This is important for people working to support people with addiction and/or mental illness and safeguarding.

The GP data for York records 40 Autistic people who also have 'drug or alcohol abuse' on their health record. This is 1.3% of everyone with diagnosed Autism.

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³⁸ Weir, E., Allison, C., & Baron-Cohen, S. (n.d.). Understanding the substance use of Autistic adolescents and adults: A mixed-methods approach

³⁹ Understanding the substance use of Autistic adolescents and adults: a mixed-methods approach Elizabeth Weir, BA Carrie Allison, PhD, Prof Simon Baron-Cohen, PhD

⁴⁰ https://onlinelibrary.wiley.com/doi/10.1111/ajad.13247

Chapter 4: Patterns and Trends in ADHD

This section looks at:

- How common ADHD is
- What it means to have ADHD
- Why some people have ADHD and others don't
- GP data about ADHD in York
- ADHD and gender/sex

How common is ADHD?

The NHS estimates are that that the prevalence of ADHD is 4%; this figure includes both people with and without a diagnosis. Some estimates suggest that it is closer to 6%, or even higher.

NICE CKS evidence summary states that there are three subtypes of ADHD:

- The inattentive subtype accounts for 20% to 30% of cases.
- The hyperactive-impulsive subtype accounts for around 15% of cases.
- The combined subtype accounts for 50% to 75% of cases. 41

It also notes that 'ADHD is more commonly diagnosed in boys than girls. Prevalence ratios are generally estimated at 2–5:1, while clinic populations show a ratio as high as 10:1. This sex difference may be due to the fact that boys present more often with disruptive behaviour that prompts referral, whereas girls more commonly have the inattentive subtype and have lower comorbidity with oppositional defiant disorder (ODD) and conduct disorder.'

In the UK, the prevalence of ADHD in adults is estimated at 3% to 4%, with a male-to-female ratio of approximately 3:1.

⁴¹ Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

What does it mean to have ADHD?

According to the NHS, the characterises of Attention Deficit Hyperactivity Disorder (ADHD) can be described by two broad categories: "inattentiveness" and "hyperactivity and impulsiveness".

The main signs of inattentiveness are:

- having a short attention span and being easily distracted
- making careless mistakes for example, in schoolwork
- appearing forgetful or losing things
- being unable to stick to tasks that are tedious or time-consuming
- appearing to be unable to listen to or carry out instructions
- constantly changing activity or task
- having difficulty organising tasks

The main signs of hyperactivity and impulsiveness are:

- being unable to sit still, especially in calm or quiet surroundings
- constantly fidgeting or excessive physical movement
- being unable to concentrate on tasks
- excessive talking
- being unable to wait their turn or interrupting conversations
- acting without thinking
- little or no sense of danger

It is thought that 50%-75% of people with ADHD have both inattentive and hyperactive-impulsive symptoms with the remainder mainly have one type of symptoms⁴².

The way in which ADHD affect adults can be different from the way it affects children. Typically, adults have fewer symptoms of hyperactivity, but retain the symptoms of inattentiveness. This means that adults with ADHD may continue to find things like organising, prioritising, finishing tasks, or dealing with stress challenging.

The ADHD Foundation emphasize the strengths of many adults with ADHD, including:

• An ability to 'hyperfocus' on things they are interested in

⁴² Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

- Willingness to take risks
- Spontaneous and flexible
- Good in a crisis
- Creative ideas thinking outside the box
- Relentless energy
- Often optimistic
- Being motivated by short term deadlines working in sprints rather than marathons
- An eye for detail." ⁴³

Why do some people have ADHD and others not?

The cause of ADHD is unknown and it is likely to have a combination of factors. There is a strong between-sibling link for ADHD, and also a strong parent-child link. The link is especially strong for twins, if one twin has ADHD there is a 74% chance that the other twin will also have ADHD⁴⁴.

There is a link between a child having ADHD and the family experiencing poverty, but it is not straightforward to explain why. Data from the Millennium Cohort Study links ADHD to living in social housing, to having a younger mother, and to living in a single parent household, and to having a parent with few qualifications⁴⁵. However, many of these factors, together or separately, can link to low income. These studies simply describe a connection, but do not equate to a cause.

GP data in York about ADHD

Not everyone with ADHD has a diagnosis, but GP data is still a valuable source of information about ADHD in York.

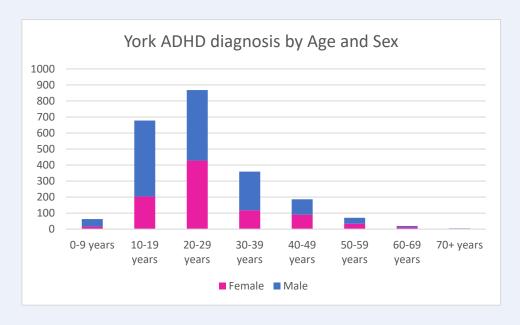
⁴³ An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)

https://idp.nature.com/transit?redirect_uri=https%3A%2F%2Fwww.nature.com%2Farticles%2Fs41380%E2%80%90018%E2%80%900070%E2%80%900&code=233eb717-46d0-4955-9812-62cbc1965bd9

⁴⁵ <u>Featured news - ADHD linked to social and economic disadvantage -</u> University of Exeter

GP records show that 2,311 people in York have a diagnosis of ADHD. This is 1.1% of the York population. For the whole of England the diagnosed prevalence of ADHD is 0.8%, suggesting that it is more typical to get a diagnosis of ADHD in York than average.⁴⁶

The chart below shows the spread of ADHD diagnosis by age. It shows that most people with an ADHD diagnosis are in their teens and 20s. It is expected that only a small number of young children have an ADHD diagnosis as it is rarely confirmed in early childhood. Additionally, few older adults have a diagnosis of ADHD. This is also expected as the modern understanding of ADHD is relatively new⁴⁷, and ADHD was less identified in previous decades. AutismUK estimates there are 2.6 million people in the UK with ADHD (708,000 children, 1,9m adults) based on The Lancet and NICE which give a childhood ADHD incidence rate of 5% and a consistent adult ADHD incidence rate of 3.5% across all adult age bands.



ADHD and Gender or Sex

The prevalence of diagnosed ADHD in the UK is approximately three boys to every one girl. It is generally accepted that ADHD is more common in boys. It is also thought that boys are more thoroughly diagnosed as they have more 'classic' characteristics

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⁴⁶ Attention deficit hyperactivity disorder (ADHD) and epilepsy - NHS England Digital

⁴⁷ The history of attention deficit hyperactivity disorder - PMC (nih.gov)

ADHD is usually first suspected because of behaviours that are visible to other people (i.e. difficulty sitting still or impulsivity). Often these visible behaviours are more common in boys than girls. By contrast, females with ADHD are more likely to have difficulty organising their thoughts or anxiety-like symptoms. This has led some people to think that female ADHD is sometimes missed or diagnosed late⁴⁸. This remains an under researched area, although there is a recent commentary on the impact of heritability, diagnostic criteria, societal expectation and more factors which outlines the subject of gender and ADHD in greater detail⁴⁹.

There is little academic research on the topic of ADHD and gender diversity or trans. Two systematic reviews, one from 2019⁵⁰ and another from 2022⁵¹ both looked at all the available studies on the topic. Both found a lack of research, and in particular a lack of good quality research, and both were unable to draw any firm conclusions.

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⁴⁸ <u>Gender differences in adult ADHD: Cognitive function assessed by the test of attentional performance - PMC (nih.gov)</u>

⁴⁹ Why are females less likely to be diagnosed with ADHD in childhood than males? - The Lancet Psychiatry

Prevalence of Autism Spectrum Disorder and Attention-Deficit
Hyperactivity Disorder Amongst Individuals with Gender Dysphoria: A
Systematic Review | Journal of Autism and Developmental Disorders
(springer.com)

⁵¹ <u>A PRISMA systematic review of adolescent gender dysphoria</u> <u>literature: 2) mental health | PLOS Glob</u>al Public Health

Chapter 5: ADHD and Health and Wellbeing

This section looks at what we know about the health and wellbeing of people with ADHD. We combine information from national surveys or research, and local data where it is available.

In this section we look at alphabetically.

- Criminal justice
- Employment
- Life expectancy
- Mental health
- Other health issues
- Smoking
- Substance misuse (drug and alcohol addiction)

Criminal justice

The Children's Commissioner estimates the prevalence of ADHD among young offenders is 12%⁵². The ADHD foundation suggest that 25% of adults in prison have ADHD, and that 96% have a further need such as addiction or personality disorder⁵³.

ADHD is significantly associated with conviction and incarceration, with substance misuse and lower socioeconomic status increasing this risk. ADHD medication is a protective factor in reducing the risk of offending.⁵⁴

In York the youth outcome panel, which aims to divert people form criminal justice is able to know about any young person with diagnosed Neurodiversity or who is awaiting assessment. This means that the

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⁵² Nobody Made the Connection | Children's Commissioner for England (childrenscommissioner.gov.uk)

⁵³ Takeda ADHD-in-the-CJS-Roundtable-Report Final.pdf (adhdfoundation.org.uk)

⁵⁴ Christina Mohr-Jensen, Charlotte Müller Bisgaard, Søren Kjærsgaard Boldsen, Hans-Christoph Steinhausen, Attention-Deficit/Hyperactivity Disorder in Childhood and Adolescence and the Risk of Crime in Young Adulthood in a Danish Nationwide Study, Journal of the American Academy of Child & Adolescent Psychiatry, Volume 58, Issue 4, 2019, Pages 443-452, https://doi.org/10.1016/j.jaac.2018.11.016

actions of the rehabilitation orders can be tailored to suit the young people. Since 2023 the youth justice service also follow up young people with SEND to understand their longer term outcomes such as education, employment or training. This is early data and it describes very small numbers of young people, but it is positive at this stage.

North Yorkshire police have annual training that includes responding to Neurodiversity and have 'trigger plans' in place for meeting alternative communication or sensory needs for individuals who they routinely support through mental health crisis.

North Yorkshire police have also scoped their custody suits for reasonable adjustments that could be made to support sensory sensitivity. This includes sensory toys, adjustable lighting, ear defenders, and backboard paint walls. The age and layout of some of the buildings create limitations, but refresh of the lighting was completed in 2024.

Employment

It is not easy to get UK data on employment and ADHD, but data from other countries suggests people are less likely to be in work and are more likely to lose their jobs. People with undiagnosed ADHD may struggle to obtain reasonable adjustments in the workplace which may make it harder to gain or retain employment.

The Scottish ADHD coalition highlights that many people with ADHD have particular strengths which can be very useful in the workplace⁵⁵, for example creative thinking, an eye for detail, and being good with short deadlines.

Life Expectancy

There is no national review of early deaths of people with ADHD. Death certificates would not ordinarily include reference to ADHD. As discussed through this health needs assessment, people with ADHD are more likely to experience obesity, smoking, mental ill health, unemployment, and a range of other chronic physical health conditions. One small study,

⁵⁵ An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)

not from the UK, tried to model the impact on projected life expectancy and found a reduced life expectancy⁵⁶.

Additionally, several systematic reviews have found convincing evidence that people with ADHD are at greater risk of early death from 'unnatural causes' such as accidents⁵⁷. However, the way that the studies were presented means the researchers could not look at other important factors, for example other health conditions or social deprivation. People with ADHD have a reduced life expectancy of 8-13 years, but the mortality risk is greatly reduced with earlier treatment. ⁵⁸

Mental health

People with ADHD are more likely to develop depression as teenagers and adults, compared with people who do not have ADHD. One large study of nearly a million people estimates people with ADHD are six times more likely to develop depression⁵⁹. One explanation is that people with ADHD are more likely to experience chronic stress linked to social relationships, school, or work, and this can increase the risk of depression. Related to this, a large Swedish study shows people taking ADHD medication are at 20% lower risk of depression than those not taking medication⁶⁰.

The York GP data shows that 1096 people with ADHD diagnosis also have a mental health condition, this is 44%.

34% have an anxiety disorder

29% have depression

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Hyperactive Child Syndrome and Estimated Life Expectancy at Young
 Adult Follow-Up: The Role of ADHD Persistence and Other Potential
 Predictors - Russell A. Barkley, Mariellen Fischer, 2019 (sagepub.com)

Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis | Attention Deficit/Hyperactivity Disorders | JAMA Pediatrics | JAMA Network

⁵⁸ https://journals.sagepub.com/doi/full/10.1177/10870547231158572

⁵⁹ Longitudinal association between mental disorders in childhood and subsequent depression – A nationwide prospective cohort study - ScienceDirect

⁶⁰ Medication for Attention-Deficit/Hyperactivity Disorder and Risk for Depression: A Nationwide Longitudinal Cohort Study - ScienceDirect

3% have a serious mental illness

These figures are far higher than prevalence in the neurotypical population of York.

Other health issues

There is a significant link between ADHD and obesity, and some studies have shown that treatment for ADHD can improve engagement and success in services aimed at tackling obesity.⁶¹

In a study in 2023 revealed that a diagnosis of adult ADHD was associated with a nearly three times greater risk of developing dementia, including Alzheimer's disease. There was, however, no clear increase in the risk of dementia associated with adult ADHD among those who received psychostimulant medication.⁶²

Smoking

People with ADHD are more likely to smoke and start smoking at a young age⁶³. There was no difference in eventual successful guit rates, but people with ADHD were more likely to make a guit attempt.

GP data records 351 people with ADHD who are current smokers, this is 14% of everyone with ADHD, and is higher than you would expect to find in the general adult population of York (around 9%)

The York Stop Smoking Service does not currently collect information Neurodiversity when people are referred to stop smoking.

Substance misuse

The UK Addiction Treatment Centre says that of all people with ADHD. 12% will develop an alcohol addiction and 28% develop a drug addiction at some point in their lives⁶⁴. In the general adult population, around 1% of people will develop these conditions. It is suggested that ADHD can lead to greater difficulty maintain relationships, achieving academic or

⁶¹ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6826981/

⁶² https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2810766

⁶³ Cigarette Smoking Progression Among Young Adults Diagnosed With ADHD in Childhood: A 16-year Longitudinal Study of Children With and Without ADHD - PMC (nih.gov)

⁶⁴ https://www.ukat.co.uk/mental-health/adhd-and-addiction/

career goals, and increase chronic stress and impulsivity, all of which are factors that increase the vulnerability to addiction. Impulsive decisions and a maladaptive reward system make individuals with ADHD vulnerable for alcohol use and up to 43% develop an Alcohol Use Disorder (AUD); in adults with AUD, ADHD occurs in about 20% but is vastly under-recognized and under-treated.⁶⁵

The addiction recovery service askes all clients a set of standard questions about disability or health conditions. In response, 0.8% of clients said they had 'Autism or an other health condition'.

However, the addiction recovery service estimate that more than half of people in addiction recovery show characteristics of Neurodiversity, mainly these are ADHD type characteristics, and predominantly individuals do not have a diagnosis.

GP data shows that 2% of all people in York with ADHD also have drug and alcohol abuse or dependency included on their health record. This is 58 individuals.

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https://www.sciencedirect.com/science/article/abs/pii/S0149763421003092

Chapter 6: The experiences of neurodivergent people in York

This report has not utilised any qualitative methods in assessing the health needs and experiences of Autistic people and those with ADHD in York, as extensive work will be done on this through the coproduction of the strategy.

Work has however been caried out by York Healthwatch in this area. In their January 2025 report 'Listening to Neurodivergent Families in York', they found that:

- Societal awareness and understanding of ND is still low, and parents experience stigma from friends, family and services.
- Parent blame is still often the first thing parents seeking help experience.
- Parent experiences are also worsened by poor administration and poor communication from services.
- Support is still focused in silos, with thresholds for support, making finding the right help for a range of lower-level issues challenging.
 Capacity in the system is overstretched, leaving many services looking for how to say "no" to providing a service.
- Some schools are still not considering the needs of neurodivergent children at times of transition. Others support transition well but do not maintain support beyond transition and fail to see the traits when a child begins to struggle.
- School behaviour charters often ask for behaviour that is impossible for neurodivergent children. This reinforces negative views many neurodivergent people already hold about themselves that there is something wrong with them and they are not good enough. There is a significant challenge in setting behaviour codes that maintain a good environment for all pupils without punishing ND pupils. However, meeting this challenge is vital. Low self-esteem increases the problems many neurodivergent children grapple with, but there are many strengths associated with neurodivergence which need to be recognised, valued and celebrated.

 There is significant overlap between children who are neurodivergent and children who are gender questioning. Our systems are not geared up to support these young people. Many are asked to choose which they want support with, and may also be advised to 'hide' part of themselves to receive support with the other element of their identity

In their 2023 independent evaluation of the new pilot pathway for assessment of Autism and ADHD, they found that:

- The pathway did not meet hoped for outcomes
- The DHT (Do-It Profiler) was inaccessible for some.
- Output from the DHT was informative and useful, but it told people what they already knew. Some found it condescending.
- Many are reluctant to apply or share the output from the DHT as they don't feel it would be of benefit.
- The pathway lacked clarity for both patients and professionals.
- Professionals welcomed an efficient and direct pathway to diagnosis and support for neurodivergent individuals.
- People have concerns around whether equality legislation was followed. There is concern regarding:
 - What engagement took place prior to the pilot being implemented.
 - The narrow referral criteria which only consider elements of mental health crisis.
 - o Whether HNYHCP considered the patient's right to choose.
 - Whether the DHT used within the pathway meets the scientific rigour required for its use within a diagnostic pathway.
 - Whether the DHT used within the pathway meets the requirements for clinical risk management.
 - Consideration for wider NICE guidelines for the use of DHT to assist and inform patients.
 - Consideration of NICE guidelines on the use of DHT to direct treatment and collect data to make service delivery decisions.
 - Consideration made to the Public Sector Equality Duty.
 - o Consideration of data protection principles and legislation.
 - Consideration made to legal requirements of the 2016 Accessible Information Standard

Chapter 7: Conclusions and next steps

This report has described the population in York who are Autistic and/have ADHD, set out the diagnostic / assessment pathways in this area, as well as the challenges around underdiagnosis, waiting lists, pathways and patient experience, and explored the available data and research on the health needs of Autistic people and people who have ADHD

These findings demonstrate that:

- our neurodivergent community in York is growing in size, is comprised of those with a formal diagnosis and a large number who aren't diagnosed, and has specific gender, age and geographical patterns
- Autistic people and people with ADHD face a number of challenges around societal structures, culture and practice which don't always enable them to live the lives they would want to live
- there are additional health and social needs faced by Autistic people and those with ADHD above and beyond those related to their neurodivergence, which should be taken into consideration when planning services
- healthcare services to assess and support neurodivergent people are seeing severe capacity issues which, at population level increases the risk of additional health harm for Autistic people and people with ADHD, potential underdiagnosis and lack of adjustments in key settings which would lead in improvements in quality of life
- Autistic people and people with ADHD bring personal and unique strengths to our schools, workplaces and to the city in general without which York would be a poorer place

The next step following this HNA is to work with partners and organisations in the city, alongside Autistic people and those with ADHD, to coproduce a five-year Autism and ADHD Strategy.

Appendix: Examples of good practice in Autism and ADHD

This chapter of the health needs assessment gives some examples of 'what works' or 'good practice' for neurodiverse people. This includes making adaptations or designing services or places for neurodiverse people. They are examples, not all evidence and research are included.

Example topics:

- Education
- Mental health
- Criminal justice
- Workplaces
- Communication adaptations
- Buildings and public spaces adaptations

Title	Autism: A guide for GPs
Source	https://Autismwales.org/resource/AutismA-Guide-for-
	GPs-English.pdf
Summary	This short guide provides practical advice for GPs that can
	be impliemnted in their daily practice. It includes:
	- Identifying traits of Autism
	- Appointments
	- Communication style
	- Pain and physical sensory processing
	- Assessment and treatment

Title	Autism and education
Source	Good Autism Practice Guidance Autism Education Trust
Summary	This set of guidelines is written by members of the Autism Centre for Education and Research (ACER) at the University of Birmingham. The guidelines have been generated from a review of the research evidence, current policy documents, expert opinion, statutory guidance and from the accounts of Autistic individuals. They identify eight key principles of good Autism practice in education, from early years through to post-16 education. 1. Understanding the strengths, interests and challenges of the Autistic child and young person. 2. Enabling the voice of the Autistic child and young person to contribute to and influence decisions. 3. Collaboration with parents and carers of Autistic children and young people 4. Workforce development to support children and young people on the Autistic spectrum. 5. Leadership and management that promotes and embed good Autism practice. 6. An ethos and environment that fosters social inclusion for Autistic children and young people. 7. Targeted support and measuring process of children and young people on the Autism spectrum. 8. Adapting the curriculum, teaching, and learning to promote wellbeing and success for Autistic children and young people.

Title	Delivering talking therapies to Autistic children and adults
Source	Good practice guide (Autism.org.uk)
Summary	Our Mental Health Project, in collaboration with Mind, aims to establish how to make mental health talking therapies better for Autistic people. This guide incorporates the views of over 1,500 Autistic people and almost 1,000 family members who responded to our mental health survey in October and November 2020. It is also based on our indepth discussions with 17 Autistic people, eight family members and 15 mental health professionals The key points for service design: 1) Improve Autism understanding for all staff through training 2) Make the physical environment in both waiting rooms and therapy rooms less overwhelming 3) Think about ways you can all change the way therapy is delivered in your service to make it more Autismfriendly 4) provide additional support to Autistic clients 5) ask for and use feedback from your Autistic clients 6) make sure the information about your service is Autism-friendly, clear, concise and specific 7) explain the different therapy delivery types you can offer and give your client a choice about what works best for them. Key points for therapy sessions: 1) make sure the therapy room isn't overwhelming 2) Use simple, plain language 3) Give time for Autistic people to process information and answer questions 4) Ask them if they would like someone close to them to be involved in sessions 5) Support them to be able to label their own feelings and emotions 6) Try to integrate Autistic people's interests if that will help them 7) Note down what you have covered and share this with the Autistic person

Title	Guidance on criminal justice for Autistic people
Source	NAS Police Guide 2020 17092020.pdf (thirdlight.com)
Summary	This guide provides background information about Autism and aims to help all police officers and staff who may come into contact with Autistic people meet their responsibilities under the Equality Act 2010 (Disability Discrimination Act 1995, Northern Ireland), Police and Criminal Evidence Act 1984 (Northern Ireland Order 1989) and the Mental Health Act 1983 (Mental Health Northern Ireland Order 1986) It includes help in identifying someone who may be Autistic or have different communication needs. It also includes dos and don'ts for arrest, custody and interviewing, strip searching, being in a cell, and the use of appropriate adults for vulnerable adults.

Title	Statutory guidance for Local Authorities and NHS organisations
Source	Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (publishing.service.gov.uk)
Summary	Statutory guidance for Local Authorities and NHS organisations to support implementation of the adult Autism strategy. The report covers: 1. Training of staff who provide services to Autistic adults 2. Identification and diagnosis of Autism in adults, leading to assessment of needs for relevant services 3. Planning in relation to the provision of services for Autistic people as they move from being children to adults 4. Local planning and leadership in relation to the provision of services for Autistic adults 5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015 6. Reasonable Adjustments and Equality 7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity 8. Employment for Autistic adults 9. Working with the criminal justice system

Title	The workplace: wellbeing and retention for neurodiverse
	people
Source	Neurodiversity at Work 2023 (berkshirehealthcare.nhs.uk)
Summary	Birbeck University of London in collaboration with major employers including McDonalds, Roles Royce, and Sage developed a questionnaire on the experience of being a neurodivergent in the workplace. The research outcomes focus on strategies to retain employees and strategies to
	improve employee wellbeing.

Title	The workplace: Recruiting Autistic people
Source	Employing Autistic people (Autism.org.uk) and Advertising a role - Employment Autism
Summary	The recruitment process can inadvertently create barriers for Autistic individuals. Organisations can implement minor adjustments to make it easier for Autistic candidates to apply and showcase their skills, ultimately benefiting all candidates and improving recruitment efficiency. The resources above list adjustments to:
	 Job descriptons and adverts Application forms The interview process and alternatives to interviewing

Title	Designing work places for people with ADHD
Source	ADHD Reasonable Adjustments (ADHDuk.co.uk) ADHD in the workplace (berkshirehealthcare.nhs.uk)
Summary	These publications by ADHD UK and Berkshire Healthcare NHS foundation trust describe how some aspects of the work place can be additionally challenging to people with ADHD and potential adjustments that can support. These adjustments include: - Modifications to the working environment: protected quiet spaces, working from home, permanent desk spaces - Flexibility in working practices: flexible working (where possible), protected time for hyperfocus tasks - Working practices: communicating deadline and work task expectations, - Using feedback: agile working practices, utilising ADHD traits to the benefits of the job role - Useful technology: headphones, diary management tools
	 HR policies: training for managers, antidiscrimination policies overtly mention Neurodiversity, coaching for employees

Title	Designing public buildings to accommodate neurodiverse people
Source	Environmental checklist for people (southwestyorkshire.nhs.uk)
	Guide-for-cognitively-inclusive-design-in-primary-care- environments-FINAL.pdf (dimensions-uk.org)
	Building-Better-Together-Dimensions-Assura-report-web-final.pdf (dimensions-uk.org)
Summary	In 2015 Kirlees Council and the South West Yorkshire Partnership NHS Foundation Trust created an Autism-Friendly Environments Checklist. The Checklist was designed for organisations providing NHS and Local Authority services. The checklist is organised by sensory category (i.e. smell, sight), with opportunity to make notes about solutions and discussion. Service providers are suggested to start with the smallest spaces and then expand out to larger areas. The 'Designing for Everyone' guide and toolkit brings together current research, evaluation and best practice in design for cognitive impairment and Neurodiversity together with reports commissioned by Assura from the Patients Association and Dimensions which focus on the patient experience of health centre buildings. The report is structured around four themes; Independence and choice: signage and getting around Dignity: privacy, reception, and toilet facilities Feeling relaxed: sensory environment and decor Customer service and patient care: flexibility and involvement

Title	Designing buildings sympathetic to Neurodiversity
Source	Designing buildings sympathetic to Neurodiversity: a new guide (theconstructionindex.co.uk)
Summary	BSI, the British Standards Institution, has published guidance on designing the built environment to include the needs of people who experience sensory or neurological processing differences. These are detailed in PAS-6463

Title	How to design spaces to better meet the needs of neurodivergent groups
Source	How to design spaces to better meet the needs of neurodivergent groups (hdsunflower.com)
Summary	This publication considers - The acoustic environment - Reducing visual noise - An easy entrance - Creating welcoming sanitary facilities - Recalibration and sating

Title	Meeting the needs of Autistic adults in mental health services
	services
Source	https://www.england.nhs.uk/long-read/meeting-the-needs-
	of-Autistic-adults-in-mental-health-services/
Summary	A guide for ICS and other health organisations that
	recognises that the NHS has seen a 50% rise in in patient
	mental health care over 5 years. The guidance is about
	preventing escellating need, and the importance of
	ensuring services are accessible and acceptable to Autistic
	adults.

Title	Making meetings accessible
Source	https://www.england.nhs.uk/learning- disabilities/about/get-involved/involving-people/making- meetings-accessible/#accessible-meeting This host practice describes making meeting accessible
Summary	This best practice describes making meeting accessible to Autistic people and people with a learning disability. It describes a range of adjustments, for example - Before the meeting tell people who will be in the meeting and what their role is - Choose a meeting room with lots of natural light and let people choose where they sit in the room. - During the meeting, keep to the timings on the agenda and make sure only one person talks at a time There is also advice on giving accessible presentations, this includes information about the layout of slides, using handouts, and using the right language.

Title	Tips for communicating with an Autistic person
Source	https://www.Autism.org.uk/advice-and- guidance/topics/communication/tips
Summary	This guide includes information on topics like: - Getting and keeping attention - Processing information and information overload - Avoiding open questions - Asking for help - Being clear and saying what you really mean - Understanding distressing behaviour - Saying no and keeping a boundary

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