# **Autism and ADHD in York**

# A Health Needs Assessment 2024

**Francesca Speck**- Public Health Improvement Officer **Jen Irving**- Public Health Specialist Practitioner (Advanced)



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# **Executive Summary**

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

This HNA looks at many local data sources to understand the local autism and ADHD population.

- 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 people with autism and 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 This can be particularly helpful when local data is incomplete, out of date, hard to access, or does not clearly contain information about Autism/ADHD.

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

# **Findings Summary**

To be written

# **Project Scope**

The purpose of this needs assessment is to consider the current and emerging Autism and ADHD needs of residents who live in York.

This Health Needs Assessment is led by the City of York Council Public Health Team. It considers the health and wellbeing needs of people of all ages who live in York who have autism and or ADHD. This includes people with a diagnosis, people waiting for a diagnosis, and people who recognise traits of Autism and or ADHD in themselves.

There are two main aims of this project:

- To build collective understanding of the Autism and ADHD population of 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 is not making specific recommendations. It identifies topics and needs that should be considered for inclusion in the development of the York Autism and ADHD strategy.

# What does neurodivergent mean?

A neurodivergent person is someone who's brain processes information in a different way. The opposite of this is a neurotypical person - a person who's brain processes information in a typical way.

There are lots of different ways a person can be neurodivergent. Neurodiversity is a collective term to describe people who have conditions such as autism, ADHD, dyslexia, dyscalculia, dyspraxia, stammering, or Tourette's syndrome.

In most cases a person is neurodivergent for their whole life. Some forms of brain injury can create a neurodivergence, but this is quite rare.

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.

Some neurodivergent people also have other conditions such as a mental illness. This a separate condition that can come and go over a person's life.

This needs assessment is only looking at two neurodivergent groups – people with autism and people with ADHD. This is because York in planning an autism and ADHD strategy in 2025 and we want this needs assessment to support the strategy planning process.

# Diagnosing neurodiversity in York and England

#### Overview

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

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

Diagnosing autism in children and young people

Autism is diagnosed through a detailed assessment by a team of health professionals with expertise in developmental disorders.

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.<sup>1</sup>

In York, children under 5 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. Due to a significant increase in referral numbers, there is currently a long wait for these assessments within CAMHS.<sup>2</sup> 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.

Diagnosing autism and ADHD in adults

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<sup>3.</sup> The typical waiting time for a completed assessment is close to two years in England. For ADHD there is no central waiting list record, ADHD UK have made freedom of information requests to each ICB individually<sup>4</sup>. 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.

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. In January 2023 there were 1,560 people 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

<sup>&</sup>lt;sup>1</sup> Abreu, L., Parkin, E., Foster, D et al. Autism: Overview of policy and services.

<sup>&</sup>lt;sup>2</sup> <u>York SEND</u>

<sup>&</sup>lt;sup>3</sup> The rapidly growing waiting lists for autism and ADHD assessments | Nuffield Trust

<sup>&</sup>lt;sup>4</sup> https://adhduk.co.uk/nhs-adhd-assessments-waiting-lists-report/

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 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 everyone else 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 Forum<sup>5</sup> begun a legal challenge against the ICB, and HealthWatch published a report collating and describing the public concern<sup>6</sup>. 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 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. The time for assessments in September 2024 was: ADHD - 3.7 years (average); autism – 3.4 years (average)<sup>7</sup>. Currently both autism and ADHD services are assessing referrals from mid 2021 to the end of November 2021.

Going forward, 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 them<sup>8</sup>. The packs are a directory of recommended books, websites, videos, and local support groups.

# The Process of Making a Diagnosis

<sup>&</sup>lt;sup>5</sup> Autism and ADHD Assessment Access - York Disability Rights Forum (ydrf.org.uk)

<sup>&</sup>lt;sup>6</sup> Guidance (healthwatchyork.co.uk)

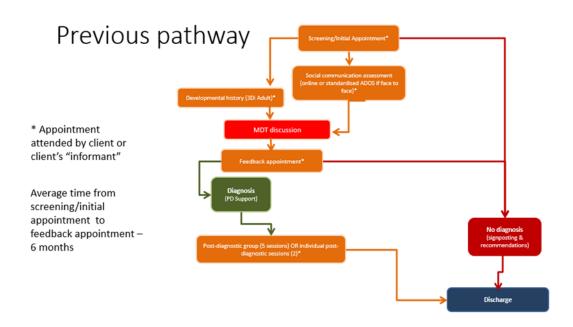
<sup>&</sup>lt;sup>7</sup> <u>https://theretreatclinics.org.uk/waiting-times/</u> (correct September 2024)

<sup>&</sup>lt;sup>8</sup> Autism Post-Diagnostic Pack (theretreatclinics.org.uk)

#### Autism

Autism diagnostic assessments at The Retreat are completed in line with the National Institute for Health and Clinical Excellence (NICE) guidelines (Autism spectrum disorder in adults: diagnosis and management – CG142 – June 2012). 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 Dimensional Interview (3Di) and Autism Diagnostic Interview – Revised (ADI-R).

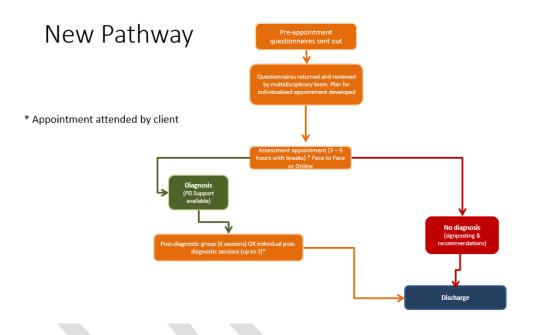
In February 2024, The Retreat updated its diagnostic assessment pathway. Previously the assessment had included three diagnostic assessment appointments, a multi-disciplinary discussion and feedback appointment. The time taken to complete this whole process, could vary but the average time between attending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



Between May and December 2023, a project was trialed 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 you completed prior your appointment included: Information Questionnaire, Sensory Questionnaire, Repetitive Behaviour Questionnaire, Informant Information, and Well-Being Update Questionnaire. The appointment includes interview, observations, multidisciplinary 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.



For those cases where there are additional complexities and it is not possible to complete the assessment within the individual appointment, further appointments can be arranged in order to ensure an accurate outcome to the assessment.

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

ADHD diagnostic assessments at The Retreat are completed are in line with the National Institute for Health and Clinical Excellence (NICE) guidelines (Attention deficit hyperactivity disorder: diagnosis and

management – NG87 – March 2018). 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 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 Nuerocogntive 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.

#### What is autism?

Overview

In this section we will talk about

- How common autism is
- The signs of autism
- Research on the causes of autism
- GP data on autism in York
- Education data on autism in York
- Autism and gender/sex
- Make sure these bullet points are in the right order

#### How common is autism?

Autism is a lifelong condition which affects how people communicate and interact with the world. It is thought that just over 1% of the

population are autistic. This means there are around 700,000 autistic people in the UK.<sup>9</sup>

Autism is a complex neurodevelopmental condition that affects social interaction, communication, interests, and behaviour<sup>10</sup>.

Autism and ADHD

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

Signs of Autism

The signs of autism in younger children include:

- 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

The signs of autism in older children 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

<sup>&</sup>lt;sup>9</sup> National Autistic society

<sup>&</sup>lt;sup>10</sup> NHS Autism guide

The signs of autism in adults include:

- 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
- 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 signs 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

This report will mainly use 'autism', but may also use 'autism spectrum disorder' and 'ASD' where this terminology is used in other sources.

What causes autism?

The cause of autism is unknown, and it is unlikely that there is a single cause for autism. Most likely there are a mix of genetic factors and environmental factors that work together to produce autism. This is known as epigenetics.

We know that siblings of individuals with autism had a significantly higher chance of also having autism themselves, compared to the general population. One study revealed that if an older sibling had autism, the younger siblings had a 30% chance of also having autism.<sup>11</sup>

<sup>&</sup>lt;sup>11</sup> Miller, M., Musser, E. D., Young, G. S., Olson, B., Steiner, R. D., & Nigg, J. T. (n.d.). Sibling recurrence risk and cross-aggregation of attention-deficit/hyperactivity disorder and autism spectrum disorder.

This can rise to 60% for twins<sup>12</sup>. There are similar links between a parent having autism and their child having autism. Because of this, people say that autism can 'run in families'.

A review of all published literature also found that some pregnancy and birth factors are also linked to autism, for example, a child with a low birth weight or who needed support to breath after birth (perinatal hypoxia)<sup>13</sup>. Additionally, a range of environmental influences during pregnancy, including exposure to air pollution and pesticides, have been associated with an increased risk of autism.

GP data on autism in York

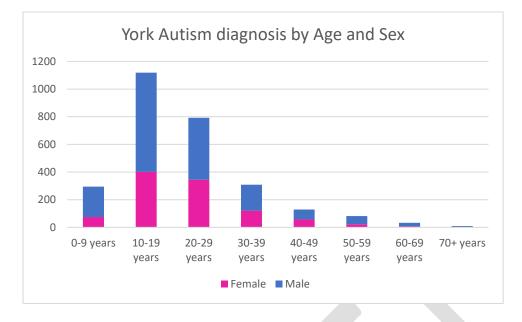
Primary care data can tell us about the number of people who are registered with a GP in York and who have a diagnosis for autism. It is well recognised that not everyone with autism will have a diagnosis recorded.

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 with autism diagnosis. This follows the expected national pattern.

<sup>&</sup>lt;sup>12</sup> Genetics and epigenetics of autism: A Review - Waye - 2018 - Psychiatry and Clinical Neurosciences - Wiley Online Library

<sup>&</sup>lt;sup>13</sup> Early environmental risk factors for neurodevelopmental disorders – a systematic review of twin and sibling studies - PMC (nih.gov)



The data is also separated by age band. It shows that very few older adults have an autism diagnosis (0.2% of the population). This also follows the national pattern. It is because in previous decades autism was less recognised and less diagnosed.

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).

Education data on autism in York

There is also data on the numbers of people with autism 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).

In total, just over 700 children and young people have SEND with autism as their primary need. This is a fifth of all pupils with SEND.

Children and young people living in deprivation in York were no more or less likely to have a SEND record for Autism or ADHD as children living in other areas of York. Autism and gender/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 males has autism<sup>14</sup>.

It is also though that autism in females is sometimes missed or misunderstood. This happens because the signs of autism in females can be different and may look like other conditions. For example, girls with autism 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 females with autism<sup>15</sup>.

The estimates of how many women and girls with autism 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 girls<sup>16</sup>.

# Autism and gender diversity

There is a correlation between autism and trans people, gender diverse people, or people experiencing gender dysphoria. 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<sup>17</sup>.

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 nonbinary'. This is 1.6% of everyone with a diagnosis of Autism on their GP record, about 3 times the prevalence in the general population<sup>18</sup>. This data would not include people who do not currently have an autism diagnosis.

<sup>15</sup> The National Autistic Society

<sup>&</sup>lt;sup>14</sup> https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls

<sup>&</sup>lt;sup>16</sup> <u>https://autisticgirlsnetwork.org/keeping-it-all-inside.pdf</u>

<sup>&</sup>lt;sup>17</sup> <u>Transgender and gender-diverse individuals are more likely to be autistic and report higher autistic traits | University of Cambridge</u>

<sup>&</sup>lt;sup>18</sup> Gender identity, England and Wales - Office for National Statistics (ons.gov.uk)

#### Autism and health and wellbeing

Overview

This section looks at health and wellbeing topics and how they relate to autism. We summarise national research and include local information where it is available.

Topics are discussed alphabetically:

- Adult social care
- Criminal justice
- Downs syndrome
- Ehlers-Danlos Syndrome
- Epilepsy
- Employment
- Gastrointestinal issues
- Homelessness
- Learning disabilities
- Life expectancy
- Mental health (including anxiety, depression, OCD, and bipolar disorder)
- Obesity
- Sensory sensitivity
- Sleep
- Smoking
- Substance misuse (drugs and alcohol)
- Topics may be added to or deleted as we engage with the community through out the strategy development process

Learning disability and adult social care

Lots of people will need help with personal care and day-to-day tasks in older age. Some people also need help as a younger adult, usually this would be because of a learning disability, a physical disability, or a serious mental health condition.

There is a known link between autism and learning disability. The NHS estimate that 60-70% of adults with autism also have a learning disability<sup>19</sup>. As a result, people with autism are more likely to receive help with daily activities as younger adults.

In York, CYC holds a record of 3,900 adults who receive care to help with daily activities. In theory it is possible to know how many people receiving care have autism. In practice the local authority care records list just over 100 adults with autism that are known to it, nearly all of whom also have a learning disability. It is widely acknowledged that the true number of people with autism 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 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, and are also eligible for free flu vaccinations.

Criminal Justice system

<sup>&</sup>lt;sup>19</sup> Estimating the prevalence of autism spectrum conditions in adults - GOV.UK (www.gov.uk)

There are no clear records of the number of Autistic or neurodivergent people in 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. In a publication for The Children's Commissioner the prevalence of Autism among young offenders is estimated to be 15%.<sup>20</sup>

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.<sup>21</sup>

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 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.

Ehlers Danlos syndromes and hypermobility syndromes

<sup>&</sup>lt;sup>20</sup> <u>https://www.childrenscommissioner.gov.uk/resource/nobody-made-the-connection/</u>

<sup>&</sup>lt;sup>21</sup> Abreu. L et al., (2024) Autism: Overview of Policy and Services, Research Briefing, UK Parliament

Ehlers-Danlos Syndromes are a group off rare inherited conditions that affect connective tissue<sup>22</sup>. This can lead to hypermobility and stretchy skin. People with these syndromes can be at more risk of physical injury from things like heavy lifting or contact sports. It is thought these conditions run in families and overlap with autism. Around 8% of autistic people also have an Ehlers-danlos syndrome themselves<sup>23</sup>.

#### Gastrointestinal issues

People with autism are more likely to have Gastro-intestinal health issues. This causes constipation, diarrhoea, acid reflux, difficulty absorbing nutrition from food leading to vitamin deficiency, stomach pain, and intolerance to lactose or gluten. Estimates vary considerably, and there are only a few big studies, but it is thought that at least a third of people with Autism are impacted by GI issues<sup>24</sup>.

In some cases, gastro-intestinal health issues can be made worse by restrictive eating (when a person eats only a small number of foods), however this is not usually the primary cause.

#### Employment

People with autism are over twice as likely to experience unemployment. The national Labour Force Survey tells us that 30% of working-age autistic adults are employed, compared with 50% of disabled adults, and 80% of non-disabled adults<sup>25</sup>. Data from the Association of Graduate Careers Advisory Services indicates that autistic graduates also face challenges with only 36% working full-time employment a year after graduating.

Employment is associated with better mental and physical health and is important for the wider economy. The Retreat post-diagnosis resources do include some information on employment, but people are not directed towards any schemes operating locally.

<sup>&</sup>lt;sup>22</sup> Ehlers-Danlos syndromes - NHS (www.nhs.uk)

<sup>&</sup>lt;sup>23</sup> <u>Ehlers-Danlos Syndrome and Its Comorbidities as a Co-Occurring Health Issue in Autistic People -</u> <u>Autism Spectrum News</u>

<sup>&</sup>lt;sup>24</sup> Prevalence of gastrointestinal symptoms in autism spectrum disorder: A meta-analysis -ScienceDirect

<sup>&</sup>lt;sup>25</sup> Abreu. L et al., (2024) Autism: Overview of Policy and Services, Research Briefing, UK Parliament

We are not aware of any York specific data that could indicate the employment rates for neurodiverse people living in York.

#### Homelessness

The current research suggests that people with autism 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 autism<sup>26</sup>. The researchers found that 12% of the group were described as showing 'strong signs' 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.

Homeless Link have produced a toolkit<sup>27</sup> 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 help people with autism to fully access the support on offer. 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 has Autism 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.

<sup>&</sup>lt;sup>26</sup> https://homelesslink-1b54.kxcdn.com/media/documents/Autism and Homelessness Toolkit Edition 2.pdf

<sup>&</sup>lt;sup>27</sup> https://homelesslink-1b54.kxcdn.com/media/documents/Autism and Homelessness Toolkit Edition 2.pdf

Life expectancy

The average life expectancy in the UK is 80 years for men, and 83 for women. The life expectancy for people with autism is about 5 years shorter, and about 10 years for people with autism and a learning disability<sup>28</sup>.

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

The reasons for this are likely to be complex. This health needs assessment identifies may factors which can impact life expectancy. Additionally, the report into life expectancy describes that autistic people may find it more difficult to explain their symptoms to others and this can complicate access to healthcare services.

#### Substance misuse

Autistic individuals are less likely to report regularly consuming alcohol or binge-drinking compared to non-autistic individuals. However, survey data<sup>29</sup>, <sup>30</sup> shows they are almost nine times more likely to use alcohol or drugs to 'self-medicate' i.e. to use substances to help manage the symptoms of stress and anxiety. 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 people with autism who also have 'drug or alcohol abuse' on their health record. This is 1.3% of everyone with autism.

<sup>&</sup>lt;sup>28</sup> <u>Premature death of autistic people in the UK investigated for the first time | UCL News - UCL - University College London</u>

<sup>&</sup>lt;sup>29</sup> Weir, E., Allison, C., & Baron-Cohen, S. (n.d.). Understanding the substance use of autistic adolescents and adults: A mixed-methods approach

<sup>&</sup>lt;sup>30</sup> Understanding the substance use of autistic adolescents and adults: a mixed-methods approach Elizabeth Weir, BA Carrie Allison, PhD, Prof Simon Baron-Cohen, PhD

# 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 do not have Autism<sup>313233</sup>. 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 adults without Autism.

# Epilepsy

Epilepsy is more common in people with autism, especially if the autistic person also has a learning disability.

A review suggests that 12% of people with autism also have epilepsy<sup>34</sup>, possibly rising to has high as 26% in autistic teenagers<sup>35</sup>. Epilepsy is also most common in autistic people who also have a learning disability, 22% compared to 8% without a learning disability<sup>36</sup>.

The NHS page on 'living with epilepsy' says that people who have epilepsy should avoid excess stress or becoming too tired, as these

<sup>&</sup>lt;sup>31</sup> Anxiety and depression in adults with autism spectrum disorder: a systematic review and metaanalysis | Psychological Medicine | Cambridge Core

<sup>&</sup>lt;sup>32</sup> Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study - PMC (nih.gov)

<sup>&</sup>lt;sup>33</sup> Association of Comorbid Mood and Anxiety Disorders With Autism Spectrum Disorder | Anxiety Disorders | JAMA Pediatrics | JAMA Network

<sup>&</sup>lt;sup>34</sup> NHS England » National bundle of care for children and young people with epilepsy: annex 2

<sup>&</sup>lt;sup>35</sup> <u>Clinical characteristics of children with autism spectrum disorder and co-occurring epilepsy -</u> <u>PubMed (nih.gov)</u>

<sup>&</sup>lt;sup>36</sup> Epilepsy in autism is associated with intellectual disability and gender: evidence from a metaanalysis - PubMed (nih.gov)

things can trigger epilepsy episodes. People are also advised to cut down on alcohol. There are also considerations for reasonable adjustments at work, driving a car, doing sports, pregnancy and looking after young children.

The York GP data does not agree with these national findings. In York only 1% of the people with a diagnosis of autism also had epilepsy on their health record. This may need further exploration.

# What is ADHD

Overview This section looks at:

- The symptoms of ADHD in children
- The estimated prevalence of ADHD in England
- Data on the diagnosed prevalence of ADHD in York
- Data on diagnosed ADHD in York by age
- National and international trends on age of diagnosis
- The symptoms of ADHD in adults
- Research on ADHD and sex or gender
- Research on Gender dysphoria and ADHD
- Review bullet points when sections are finalised
- Possibly add something about sleep?

How common is ADHD?

The true prevalence of ADHD is thought to be 3%-4%<sup>37</sup>, this figure includes both people with and without a diagnosis.

The signs of ADHD

The symptoms 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

<sup>&</sup>lt;sup>37</sup> Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

- 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 symptoms<sup>38</sup>.

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 Scottish charity 'ADHD Foundation' are keen to emphasize the strengths of many adults with ADHD in a publication for employers.<sup>39</sup>

"Many adults with ADHD are noted for strengths such as:

- Ability to 'hyperfocus' on things they are interested in
- Willingness to take risks
- Spontaneous and flexible
- Good in a crisis
- Creative ideas thinking outside the box
- Relentless energy
- Often optimistic

<sup>&</sup>lt;sup>38</sup> Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

<sup>&</sup>lt;sup>39</sup> An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)

- Being motivated by short term deadlines working in sprints rather than marathons
- Often an eye for detail."

What causes ADHD?

The cause of ADHD is unknown and it is unlikely to be caused by one single thing.

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 autism there is a 74% chance that the other twin will also have ADHD<sup>40</sup>.

There are also factors in pregnancy and early childhood linked to ADHD. There is convincing evidence of the link to, maternal obesity before pregnancy, childhood eczema, maternal high blood pressure during pregnancy, and maternal pre-eclampsia<sup>41</sup>.

None of this evidence can say what causes ADHD, just that these things are likely to be present where ADHD is present. This may have an impact on the care plans for a pregnant lady with ADHD.

Some researchers have looked at pollutants and ADHD, in particular lead and heavy metals exposure in childhood<sup>42</sup>. However, in the UK exposure to high levels of lead is very rare (7 cases in 1 million children)<sup>43</sup>, and so this cannot be a major cause of ADHD.

There are various news stories about a link between ADHD and air pollution. One review of all available studies found credible evidence that various air-borne pollutants are linked to higher rates of symptoms ADHD, the authors were cautious in their findings, as there was not agreement between the studies on the amount of air pollution that was

40

<sup>43</sup> <u>Lead Exposure in Children Surveillance System (LEICSS) annual report, 2021</u> (publishing.service.gov.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

<sup>&</sup>lt;sup>41</sup> <u>Vitamin D Status and Attention Deficit Hyperactivity Disorder: A Systematic Review and Meta-</u> <u>Analysis of Observational Studies - PubMed (nih.gov)</u>

<sup>&</sup>lt;sup>42</sup> Environmental pollution and attention deficit hyperactivity disorder: A meta-analysis of cohort studies - ScienceDirect

harmful, and also that most individual studies looked at parent identified symptoms rather than a clinician led diagnosis<sup>44</sup>.

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 also 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 qualifications<sup>45</sup>. Many of these factors, together or separately, can link to low income. As with the previous section on pregnancy factors, these studies simply describe a connection, but do not explain if one thing is causing another.

There is a lot of discussion in the news about the influence of social media on childhood development, and specifically in ADHD. A publication in 2022 looked at all available research on the connection between 'digital media use' and ADHD symptoms in children and teenagers. They found that there was a two-way relationship between social media use and severity of ADHD symptoms. They say that 'Children with ADHD symptoms appear more vulnerable to developing high or problematic use of digital media and that digital media also have effects on later ADHD symptom levels, either because of specific characteristics of digital media or because of indirect effects on for example sleep and social relationships."

A related publication in 2022 promotes the idea that support for young people with ADHD should specifically include support and guidance on social media use<sup>46</sup>.

# 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.

<sup>&</sup>lt;sup>44</sup> Exposure to environmental pollutants and attention-deficit/hyperactivity disorder: an overview of systematic reviews and meta-analyses | Environmental Science and Pollution Research (springer.com)

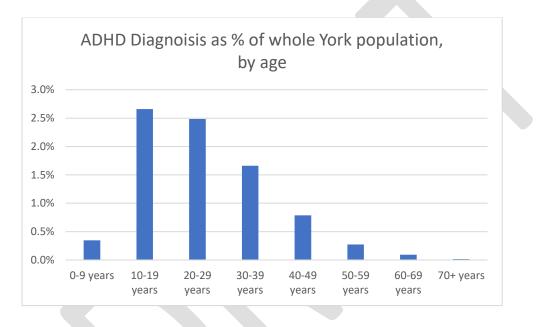
<sup>&</sup>lt;sup>45</sup> Featured news - ADHD linked to social and economic disadvantage - University of Exeter

<sup>&</sup>lt;sup>46</sup> <u>Understanding Problematic Social Media Use in Adolescents with Attention-Deficit/Hyperactivity</u> <u>Disorder (ADHD): A Narrative Review and Clinical Recommendations - PMC (nih.gov)</u>

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%<sup>47</sup>.

The table 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 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 new<sup>48</sup>, and ADHD was less identified in previous decades.



# 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' symptoms.

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

<sup>&</sup>lt;sup>47</sup> Attention deficit hyperactivity disorder (ADHD) and epilepsy - NHS England Digital

<sup>&</sup>lt;sup>48</sup> The history of attention deficit hyperactivity disorder - PMC (nih.gov)

ADHD is sometimes missed or diagnosed late<sup>49</sup>. 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 detail<sup>50</sup>.

#### Gender diversity and ADHD

There is little academic research on the topic of ADHD and gender diversity or trans. Two systematic reviews, one from 2019<sup>51</sup> and another from 2022<sup>52</sup> 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.

#### ADHD and Health and Wellbeing

#### Overview

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.

- Diabetes
- Sleep
- Smoking
- Criminal justice
- Life expectancy
- Mental health (including depression and anxiety)
- Obesity
- Epilepsy
- Substance misuse (drug and alcohol addiction)
- Employment

<sup>&</sup>lt;sup>49</sup> <u>Gender differences in adult ADHD: Cognitive function assessed by the test of attentional performance - PMC (nih.gov)</u>

<sup>&</sup>lt;sup>50</sup> Why are females less likely to be diagnosed with ADHD in childhood than males? - The Lancet Psychiatry

<sup>&</sup>lt;sup>51</sup> 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)

<sup>&</sup>lt;sup>52</sup> <u>A PRISMA systematic review of adolescent gender dysphoria literature: 2) mental health | PLOS Global Public Health</u>

 These may change, as the strategy develops. Additionally, need ordering

Diabetes

A review of all available evidence found that children with ADHD were twice as likely to also have type 2 diabetes than children without ADHD<sup>53</sup>. Additionally children with ADHD and diabetes were more likely to have high blood sugar and high ketone, both suggesting that the diabetes is not well controlled. It is thought that children with ADHD may need additional support to keep on top of the daily monitoring and management of diabetes.

Need to look at local data - pending

Smoking:

People with ADHD are more likely to smoke and start smoking at a young age<sup>54</sup>. There was no difference in eventual successful quit rates, but people with ADHD were more likely to make a quit 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.

The York stop smoking service does not currently collect information neurodiversity when people are referred to stop smoking.

Obesity

People with ADHD are more likely to be overweight or obese. Research looking at lots of individual studies found that as many as 70% of adults with ADHD also experience overweight obesity<sup>55</sup>. There are many reasons for this. For example, the ADHD medications are known to

<sup>&</sup>lt;sup>53</sup> Association of ADHD symptoms with type 2 diabetes and cardiovascular comorbidities in adults receiving outpatient diabetes care - PMC (nih.gov)

<sup>&</sup>lt;sup>54</sup> <u>Cigarette Smoking Progression Among Young Adults Diagnosed With ADHD in Childhood: A 16-year</u> Longitudinal Study of Children With and Without ADHD - PMC (nih.gov)

<sup>&</sup>lt;sup>55</sup> <u>The Association between ADHD and Obesity: Intriguing, Progressively More Investigated, but Still</u> <u>Puzzling - PMC (nih.gov)</u>

cause weight gain as a side effect, and people with ADHD can be drawn to high carbohydrate and high sugar foods which can cause weight gain.

In York, the data does not agree with the national studies; 37% of people with an ADHD diagnosis are overweight or obese according to their GP record, this is less than the rates of overweight and obesity in the general adult population.

It is possible, though not explored, that this finding is because the overwhelming majority of people with diagnosed ADHD in York are young people and young adults and that people with a younger age also typically have a lower BMI.

Criminal justice

ADHD includes symptoms such as 'acting without thinking' and 'little or no sense of danger', in some circumstances this can lead to offending behaviour. The Children's Commissioner estimates the prevalence of ADHD among young offenders is 12%<sup>56</sup>. The ADHD foundation suggest that 25% of adults in prison have ADHD, and that 96% have a further need such as addiction or personality disorder<sup>57</sup>.

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 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

<sup>&</sup>lt;sup>56</sup> <u>Nobody Made the Connection | Children's Commissioner for England</u> (childrenscommissioner.gov.uk)

<sup>&</sup>lt;sup>57</sup> Takeda\_ADHD-in-the-CJS-Roundtable-Report\_Final.pdf (adhdfoundation.org.uk)

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.

#### 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 depression<sup>58</sup>. 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 medication<sup>59</sup>.

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
- 3% have a serious mental illness

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

Drugs and alcohol

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 lives<sup>60</sup>. 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

<sup>&</sup>lt;sup>58</sup> Longitudinal association between mental disorders in childhood and subsequent depression – A nationwide prospective cohort study - ScienceDirect

<sup>&</sup>lt;sup>59</sup> <u>Medication for Attention-Deficit/Hyperactivity Disorder and Risk for Depression: A Nationwide</u> <u>Longitudinal Cohort Study - ScienceDirect</u>

<sup>&</sup>lt;sup>60</sup> 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.

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 with ADHD also have drug and alcohol abuse or dependency included on their health record. This is 58 individuals.

Early death and causes of deaths:

Unlike with autism, 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, not from the UK, tried to model the impact on projected life expectancy and found a reduced life expectancy<sup>61</sup>.

Additionally, several systematic reviews have found convincing evidence that people with ADHD are at greater risk of early death from 'unnatural causes' such as accidents<sup>62</sup>. 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.

There is no local data on this topic.

<sup>&</sup>lt;sup>61</sup> <u>Hyperactive Child Syndrome and Estimated Life Expectancy at Young Adult Follow-Up: The Role of</u> <u>ADHD Persistence and Other Potential Predictors - Russell A. Barkley, Mariellen Fischer, 2019</u> (sagepub.com)

<sup>&</sup>lt;sup>62</sup> 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

Employment:

It's 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 be fired from a job.

The Scottish ADHD coalition highlights that many people with ADHD have particular strengths which can be very useful in the workplace<sup>63</sup>. For example, creative thinking, an eye for detail, and being good with short deadlines.

Heart health:

Some people with ADHD take an amphetamine medication to help manage symptoms. In the long term, this medication is linked to weight gain and some chronic heart conditions.

A Swedish study<sup>64</sup> followed over 5,390,000 adults without cardiovascular disease and found that 38% of ADHD individuals went on to develop CVD, compared with 24% of non-ADHD individuals. People with ADHD were also becoming ill at a young age. The risk was higher again if the person also had a mental illness.

Good practice: A what works guide

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

 <sup>&</sup>lt;sup>63</sup> An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)
 <sup>64</sup> Attention-deficit/hyperactivity disorder as a risk factor for cardiovascular diseases: a nationwide population-based cohort study - Li - 2022 - World Psychiatry - Wiley Online Library

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

Title	Autism and education
Source	Good Autism Practice Guidance   Autism Education Trust
Summary	<ul> <li>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.</li> <li>1. Understanding the strengths, interests and challenges of the autistic child and young person.</li> <li>2. Enabling the voice of the autistic child and young person to contribute to and influence decisions.</li> <li>3. Collaboration with parents and carers of autistic children and young people</li> <li>4. Workforce development to support children and young people on the autistic spectrum.</li> <li>5. Leadership and management that promotes and embed good autism practice.</li> <li>6. An ethos and environment that fosters social inclusion for children and young people in the autism spectrum.</li> <li>7. Targeted support and measuring process of children and young people on the autism spectrum.</li> <li>8. Adapting the curriculum, teaching, and learning to promote wellbeing and success for autistic children and young people.</li> </ul>

<b>T</b> :41 -	Delivering telling the provide to existing elighter and edults
Title	Delivering talking therapies to autistic children and adults
Source	Good practice guide (autism.org.uk)
Summary	<ul> <li>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</li> <li>The key points for service design: <ol> <li>Improve autism understanding for all staff through training</li> <li>Make the physical environment in both waiting rooms and therapy rooms less overwhelming</li> <li>Think about ways you can all change the way therapy is delivered in your service to make it more autism-friendly</li> <li>provide additional support to autistic clients</li> <li>ask for and use feedback from your service is autism-friendly, clear, concise and specific</li> <li>explain the different therapy delivery types you can offer and give your client a choice about what works best for them.</li> </ol> </li> <li>Key points for therapy sessions: <ol> <li>make sure the therapy room isn't overwhelming</li> <li>Use simple, plain language</li> <li>Give time for autistic people to process information and answer questions</li> <li>Ask them if they would like someone close to them to be involved in sessions</li> <li>Support them to be able to label their own feelings and emotions</li> </ol> </li> </ul>

7) Note down what you have covered and share this with the autistic person
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Guidance on criminal justice for Autistic people
NAS_Police_Guide_2020_17092020.pdf (thirdlight.com)
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.

Statutory guidance for Local Authorities and NHS organisations
Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (publishing.service.gov.uk)
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 adults with autism

<ol> <li>Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services</li> <li>Planning in relation to the provision of services for people with autism as they move from being children to adults</li> <li>Local planning and leadership in relation to the provision of services for adults with autism</li> <li>Preventative support and safeguarding in line with the Care Act 2014 from April 2015</li> <li>Reasonable Adjustments and Equality</li> <li>Supporting people with complex needs, whose behaviour may challenge or who may lack capacity</li> <li>Employment for adults with autism</li> <li>Working with the criminal justice system</li> </ol>

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
<ul><li>Application forms</li><li>The interview process and alternatives to interviewing</li></ul>

Title	Designing work places for people with ADHD	
Source	ADHD Reasonable Adjustments (adhduk.co.uk) ADHD in the workplace (berkshirehealthcare.nhs.uk)	
Summary	<ul> <li>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.</li> <li>These adjustments include: <ul> <li>Modifications to the working environment: protected quiet spaces, working from home, permanent desk spaces</li> <li>Flexibility in working practices: flexible working (where possible), protected time for hyperfocus tasks</li> <li>Working practices: communicating deadline and work task expectations,</li> <li>Using feedback: agile working practices, utilising ADHD traits to the benefits of the job role</li> <li>Useful technology: headphones, diary management tools</li> </ul> </li> </ul>	
	<ul> <li>HR policies: training for managers, antidiscrimination policies overtly mention neurodiversity, coaching for employees</li> </ul>	

Title	
Source	
Summary	

Title	Designing public buildings to accommodate neurodiverse people
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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
	<ul> <li>Feeling relaxed: sensory environment and decor</li> <li>Customer service and patient care: flexibility and involvement</li> </ul>

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	<ul> <li>This publication considers</li> <li>The acoustic environment</li> <li>Reducing visual noise</li> <li>An easy entrance</li> <li>Creating welcoming sanitary facilities</li> <li>Recalibration and sating</li> </ul>

Title	Meeting the needs of Autistic adults in mental health 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
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 <ul> <li>Before the meeting tell people who will be in the meeting and what their role is</li> </ul>

and let people choo - During the meeting, agenda and make s time There is also advice on gi	oom with lots of natural light se where they sit in the room. keep to the timings on the ure only one person talks at a ving accessible presentations, about the layout of slides, using ight language.
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Title	Tips for communicating with an autistic person
The	
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
	<ul> <li>Saying no and keeping a boundary</li> </ul>

We will continue to develop and explore this section as we engage, coproduce, and consult on the autism strategy.