WHY DIAGNOSIS MATTERS

healthwatch Rotherham

About us

Healthwatch Rotherham is the independent champion for people who use health and social care services in Rotherham. We are here to make sure that those running services put people at the heart of care.

Our sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. We focus on ensuring that peoples' worries and concerns about current services are addressed and work to get services right for the future.

Contents

Introduction:

For many people, receiving a diagnosis of ADHD or autism can be life-changing. It can provide answers to questions that may have existed for years, help people better understand themselves, and open the door to support, adjustments, and services that can improve their quality of life.

This report explores the experiences of Rotherham residents who have sought, received, or are currently waiting for an ADHD and/or autism diagnosis. Through surveys and personal accounts, people shared their experiences of referral pathways, waiting times, support services, and the impact that diagnosis—or the lack of one—has had on their daily lives.

The findings highlight significant challenges, including long waiting times, limited support while awaiting assessment, difficulties accessing information, and concerns about not feeling listened to by professionals. Many respondents described spending years trying to understand their experiences before receiving a diagnosis, while others continue to wait for answers.

At the same time, the report demonstrates why diagnosis matters. For many people, receiving a diagnosis brings clarity, validation, and a better understanding of their strengths and challenges. It can improve access to support, help individuals advocate for their needs, and positively affect their wellbeing, relationships, education, and employment.

By sharing the voices and lived experiences of local residents, this report aims to raise awareness of the barriers people face when seeking an ADHD or autism diagnosis and to identify opportunities to improve services, support, and outcomes for people across Rotherham.

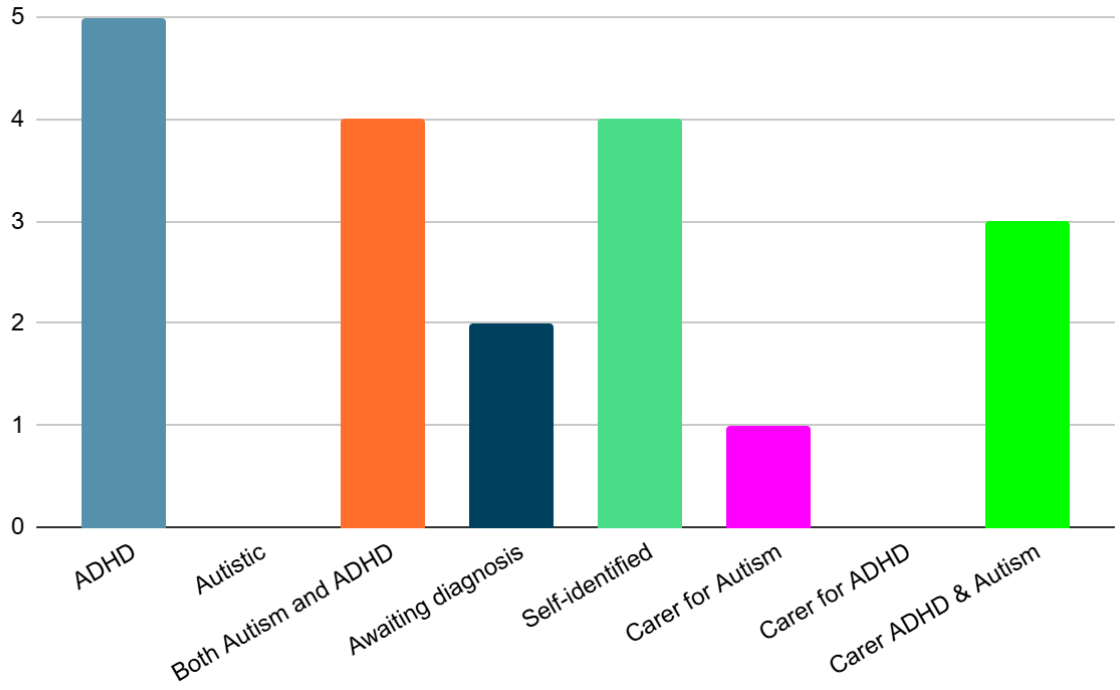
Findings:

During April, Healthwatch Rotherham conducted a survey to gather deeper insights from individuals who have been diagnosed with ADHD or autism, as well as those currently seeking a diagnosis. The surveys were published online, shared via social media, along with written surveys distributed at engagement groups.

The respondents covered a wide age range, from 18 to 79 years old. The largest group was those aged 25 to 49, making up 50% of the total. All respondents identified as White (British, English, Northern Irish, Scottish, or Welsh).

Of those surveyed, 25% were male, 66.67% were female, and 8.33% identified as transgender.

The first question we asked was, **'What best describes you?'**



From this response you can see that the majority of respondents were ADHD diagnosed (41.67%), closely followed by people with Autism and ADHD (AuDHD)(33.33%) and self-identified (33.33%). The category "self-identified" was included to reflect respondents who believe they have Autism or ADHD but do not

have a formal diagnosis. This may be because they are able to manage their symptoms, or because their condition does not significantly affect their daily life. Half of the respondents reported having a formal diagnosis, while 25% said they were still awaiting a diagnosis.

We wanted to understand how long Rotherham residents are waiting to be assessed for Autism and ADHD through Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH). According to RDaSH's published data (as of May 2026), the average waiting time for an adult referral for both ADHD and Autism is over 104 weeks.

Adult attention deficit hyperactivity disorder (ADHD)	Over 104 weeks	↑
Adult autism spectrum disorder (ASD)	Over 104 weeks	↓

However, this figure does not appear to reflect the full length of the wait. Evidence from a message sent by RDaSH to a patient on 10/12/2025 states: *"You have been placed onto a waiting list for an ADHD diagnostic assessment. Due to long waiting times, we are currently seeing patients referred in Dec 2022. You will be connected in due course. Regards, ADHD Service"*This suggests that the actual waiting time is closer to 156 weeks, indicating that the published estimate may understate the true length of time patients are waiting for assessment.

Our plan is to publish our waiting times figures monthly. We will use the key icons below to show any change in timescales:

Waiting times key

Metric	Icon
Meeting 4 week target or better	★
Improved based on last month	↓
Same not meeting 4 week target	← →
Waiting time increased from last month	↑

Based on our survey, respondents reported waiting between two and six years for an assessment. Several comments also suggested that waiting times for an ADHD diagnosis are often longer than for an Autism diagnosis.

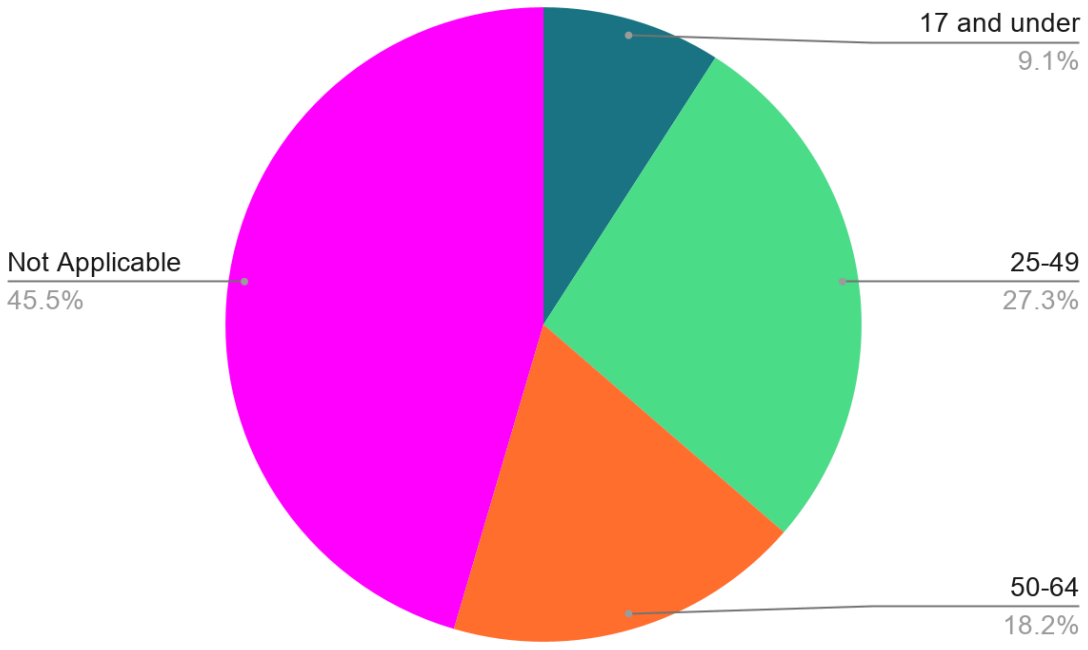
"I have been waiting for a diagnosis since 2020"

''Currently have waited 3 years"

"ASD dx 12 months in 2019 ADHD not yet diagnosed - told wait is currently 3 years"

"Approx 4 years from referral to diagnosis for autism. Still waiting for ADHD assessment."

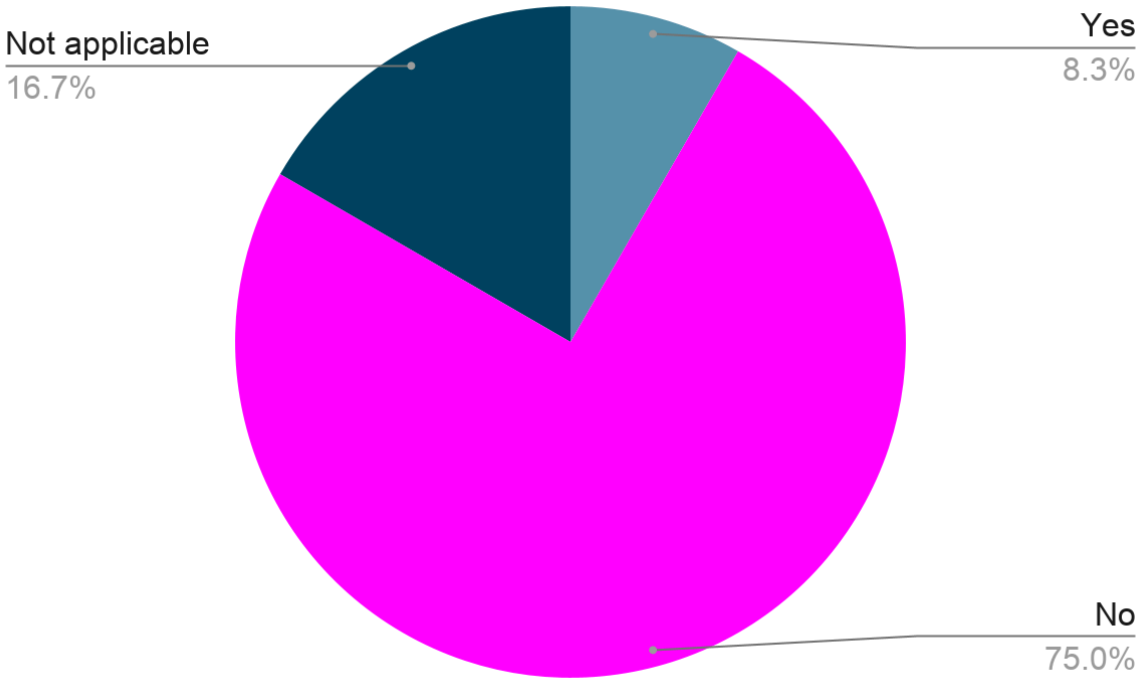
Among those who reported a diagnosis, only 9.1% were diagnosed before the age of 17, while 27.3% received a diagnosis between the ages of 25–49 and a further 18.2% between the ages of 50–64. This pattern suggests that a substantial proportion of diagnoses occur in adulthood or later life, which may reflect delayed recognition of neurodevelopmental conditions such as ADHD and autism.



Late diagnosis can mean that many individuals spend significant portions of their lives without appropriate support, accommodations, or understanding of their difficulties. This can impact education, employment, mental health, and self-esteem, as people may be mislabelled or struggle without knowing the underlying reason for their challenges until much later in life.

Support

Did you receive any support whilst awaiting your diagnosis?



Most respondents answered “no” to this question, indicating that many people were waiting years for a diagnosis without receiving support, resources for managing their condition, or reasonable adjustments during that time. One respondent reported self-medicating with other substances in an attempt to “quiet their brain.”

"Could have done with help. Self medicated with cocaine and cannabis to help quiet my brain."

"No help as I have not had a diagnosis yet"

No, I have been trying to seek help from my GP and are unable to offer or prescribe medication until I have been assessed by RDasH - Very frustrating as I have been diagnosed as a child, but over the last 5 years my ADHD has been causing me a lot of issues

" My Teaching assistant"

"None available in Rotherham"

What help/support would you have liked whilst waiting for your diagnosis/self diagnosis?

I think I would have liked to be at least acknowledged, I wasn't even given a leaflet with support or resources. It was a really lonely time and I feel support that you felt like you wasn't on your own or made to treat like you were just jumping on the 'bandwagon' would have gone a long way. Off of the top of my head I think a list of national and local support services for neurodivergence would have been ideal, and also support on how to communicate with my employers about what I was going through would have also helped.

"Advice on how to manage things and self regulate"

"I'd have liked Rdash CMH teams to make adjustments! Not to get my CPA withdrawn when Rdash's published polices weren't followed. "

"Information, emails about the wait time for assessment, confirmation that i was on a waiting list."

"Schooling, help me understand why im different and help me with my masking issues"

"Guidance on areas of struggle and some strategies/tools to try"

"Suggested ways to cope with difficulties associated with ADHD."

"General coping mechanisms, more framework and conversations around self regulating and planning your day"

"Easier process the forms were really long and repetitive"

Overall, the feedback shows that people felt quite unsupported during this period and were looking for clearer communication, practical guidance, and emotional reassurance.

A major theme is a lack of communication and acknowledgement. Several responses mention not even being told they were on a waiting list, or receiving no updates about timelines. This left people feeling uncertain and isolated. Simply being recognised, kept informed, and given confirmation of their status would have made a meaningful difference.

Another key point is the need for accessible information and guidance. People wanted advice on managing their difficulties, understanding their experiences (such as masking or differences in learning), and learning coping strategies. There's also a strong desire for practical tools, things like self-regulation techniques, planning support, and ways to handle ADHD-related challenges.

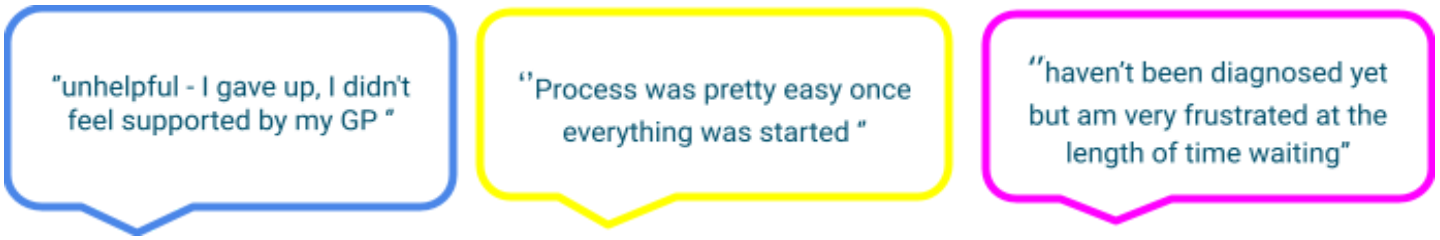
Support at a systems level also came through. Respondents highlighted the need for services to make adjustments earlier, rather than waiting for a formal diagnosis, and for clearer, less repetitive processes. Some also wanted help communicating their needs to employers or schools, as well as signposting to local and national support services.

The following question asked people to **describe their experience of getting diagnosed**, and the responses show a very mixed picture, ranging from smooth and supportive to frustrating and distressing.

"The diagnosis process I found really difficult. My GP didn't even know the process of RIght to CHoose, which as someone who also is extremely anxious was very concerning. Throughout the process and even with my provider i choose through RIght to CHoose I was continually having to advocate for self (or my support network did on my behalf) as I felt that a lot of my symptoms weren't acknowledge. Once I was diagnosed, I also found the lack of support extremely isolating and overwhelming. I was refered to one website and the referral pathways 'app' but I felt the resources and support were not helpful and was overall very generic such as 'use a timer', 'eat well' and 'sleep better' and whilst I know they help it is very difficult when the meds they put me on stripped all this away. My diagnosis actually made me feel much worse than when I was undiagnosed. "

"Process was pretty easy once everything was started"

"It happened very quickly after 8 years of trying to remember to book an appointment with my GP to start the process. I used Right to Choose, which made the process much quicker. Spoke to a supportive GP regarding the referral."



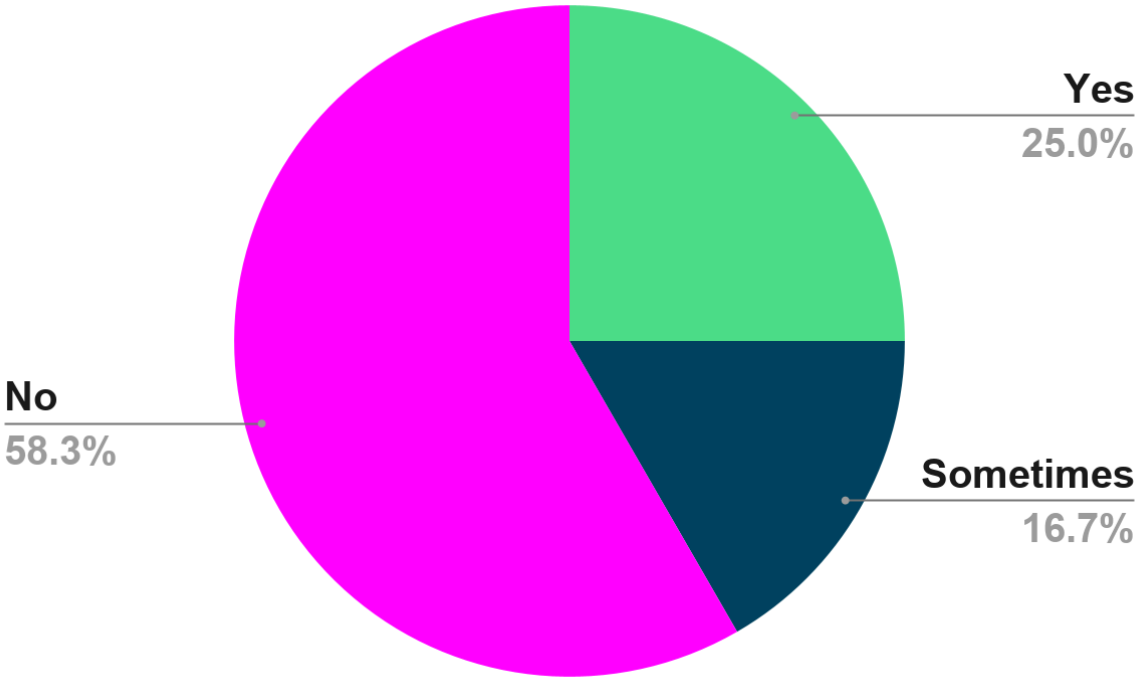
A clear theme is inconsistency in experience. Some people described the process as straightforward or relatively easy once it began, especially when they had access to supportive professionals or alternative routes like Right to Choose. Positive experiences highlighted respectful, accommodating environments where individual needs were considered, such as adjusting lighting or creating a calm, safe space. In these cases, people felt listened to and supported.

However, many responses point to significant challenges. Long waiting times were a common frustration, with some people still waiting for diagnosis and feeling stuck or overlooked. Others described the process as complicated, difficult, or unhelpful, particularly when GPs lacked knowledge about referral pathways. This lack of clarity made it harder for individuals, especially those already dealing with anxiety, to navigate the system.

Self-advocacy also emerged as a major issue. Several people felt they had to push for recognition of their symptoms or rely on others to advocate on their behalf. In some cases, even after receiving a diagnosis, individuals felt unsupported and isolated, with generic advice that didn't reflect the reality of their challenges. For one respondent, the experience of diagnosis actually worsened their wellbeing due to the lack of meaningful follow-up support.

Overall, the feedback suggests that while some diagnostic pathways work well, many people experience barriers such as long waits, unclear processes, and limited post-diagnosis support.

Do you feel listened to by professionals regarding concerns to do with your ADHD or Autism?

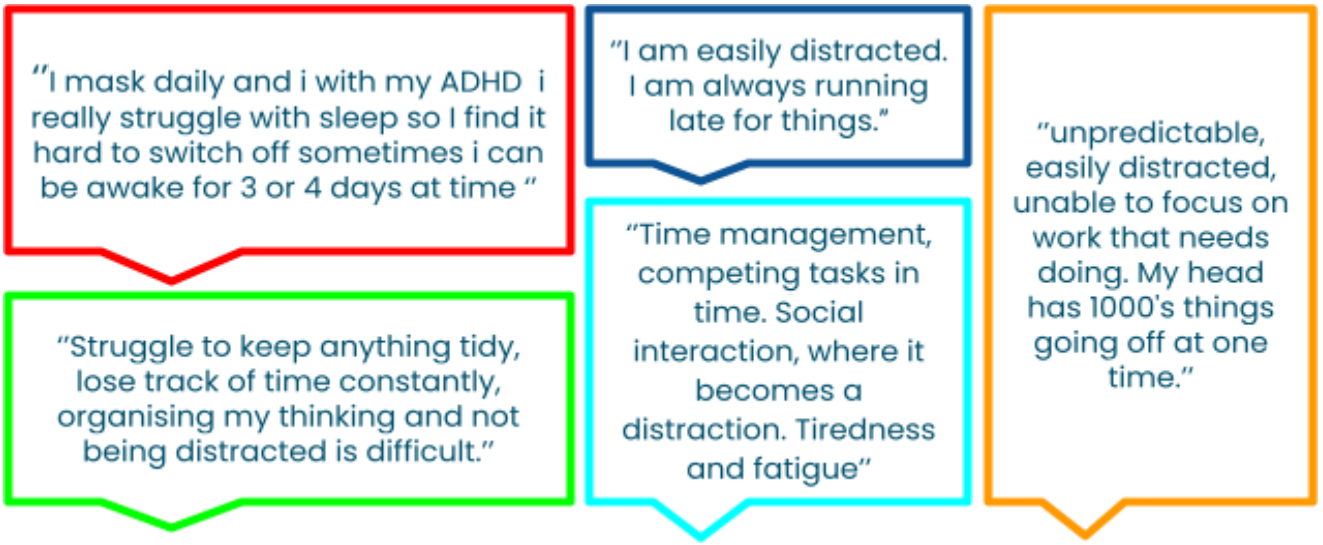


Respondents felt 'Fobbed off,' others said that their ages/life stages allowed medical professionals to blame it on hormonal changes. One person stated that 'they were not interested as it was a paper exercise". All of these issues contribute to delays in referrals and people not being diagnosed and symptoms being overlooked.

We also asked how ADHD and Autism effects their daily lives:

"Hyper-focus on interests forgetting/neglecting self care and loved ones, easily distracted, time management issues. sensitive to smell, noise, textures, unfamiliar surroundings. My need to do things 'the correct' way, causing frustration and misunderstanding of others. High levels of anxiety which i take sertraline to manage"

"Difficulties starting tasks, getting dressed. Noise & being startled are the worst sensory factors.
Emotional overload often leads to seizures & consequently disruption to routines. Many problems with online information & processes. What used to be simple now causes uncertainty."



There are clear patterns where respondents have difficulties with focusing, time management, becoming overstimulated with noises and the thought of a growing task list. One respondent said that they mask their symptoms, 'masking. ADHD consciously to fit in is a deeply exhausting coping mechanism. While it can help you avoid social stigma or meet neurotypical expectations in the short term, the long-term effects are incredibly draining and can deeply impact your mental health.

Case Study: What we heard

As a 50-year-old woman, I now look back on my life through a completely different lens following my diagnoses of ADHD and autism. So many experiences that once felt confusing, painful, or somehow my fault now make sense in a way they never did before.

For most of my life, I believed my struggles were the result of childhood trauma. My mother died suddenly when I was just nine years old, without warning. Within a year, I gained an unkind step-mother, while my father was often absent due to serving in the armed forces and, when he was home, struggling with alcoholism. These experiences shaped me deeply. They forced me to grow up quickly, to become self-reliant and resilient in order to survive. I was fortunate to have some positive influences, including my aunt and uncle, and a cousin close in age to me who shared my interests and understood me in a way others didn't. That connection mattered more than I realised at the time.

At school, I never quite fitted into the order of things. Outside of lessons, where there were rules and structure, I felt like a rebel without really knowing why. There was no clear sense of where I belonged. I drifted from friend to friend, forming deep, intense connections for short periods of time before moving on to someone else. At the time, I didn't understand why this kept happening, I just knew that friendships seemed to burn brightly and then fade, leaving me once again on the edges.

As a teenager, I always felt a little different. I thought of myself as "quirky" and often preferred my own company. I had friends, but I rarely felt deeply connected in a lasting way. I didn't have what people call a "ride-or-die" friendship, but I told myself I didn't need one. My bedroom became my sanctuary — a space I meticulously organised, where everything had its place and felt safe. I developed intense interests and would immerse myself completely in them, researching and learning everything I could. At the time, I believed this was just who I was.
To fit in, I learned to watch other people closely and mimic them. I copied how they dressed, how they spoke, even how they behaved, depending on who I was with. I believed I was shy, that my preference for solitude and discomfort in groups

was simply part of my personality, not realising how much effort it took to present myself as acceptable to the world around me.

In my late teens and early twenties, I experienced domestic violence. It took years to escape, years of fear, confusion, and survival. During this time, I had two children. One of my sons had severe learning disabilities and life-limiting conditions. I became his advocate, learning medical language and systems so that I could fight for his needs and ensure his voice was heard. I had to be strong because there was no other choice.

In my mid-twenties, I married a partner who truly understood me and my children. He supported me when I felt broken and overwhelmed, and for the first time, I felt someone had my back. As my children grew, I worked full-time, but the workplace was often another space where I felt misunderstood. I was seen as aggressive when I believed I was being clear and assertive. I followed instructions exactly as they were given and felt deep distress when expectations were vague or changed. Each misunderstanding chipped away at my already fragile self-esteem.

Throughout my life, I carried a constant feeling of being "less than" — as a worker, a mother, a carer, and a friend. I would become intensely focused on interests or goals, investing everything I had into them, only to feel frustrated and disappointed when I didn't meet my own impossibly high expectations.
At 46, I left my job without knowing what came next. Eventually, I found work in community development, where for the first time I felt valued, supported, and recognised for who I was. That sense of safety became even more important when my world fell apart again with the death of my son. The compassion and understanding shown by my employer allowed me to return to work when I was ready, giving me a sense of purpose at a time when everything else felt unbearable.

When my son was diagnosed with ADHD at university, I learned that neurodivergence can be inherited. At 50, I decided to seek screening myself. I expected to be told I had mild ADHD. Instead, I was shocked to discover I met the

criteria for autism. Through the NHS Right to Choose pathway, I received a formal diagnosis within four months.

That diagnosis changed everything. It helped me understand decades of exhaustion, anxiety, social withdrawal, and declining health. I finally realised how much I had masked throughout my life — often without knowing I was doing it — and why everyday functioning had become harder as I got older.
Now, at 51, I am relearning who I am. I am beginning to understand my sensory needs, to communicate them openly with my partner, and to exist without constant self-criticism. There is sadness in recognising what I missed out on because my diagnosis came so late, but there is also relief. For the first time, I am learning to be kinder to myself and to live with greater self-acceptance and confidence.

Why an autism diagnosis matters

For many women, getting an autism diagnosis can be life-changing.

It can help explain why everyday things have always felt harder than they seem to be for other people – like social situations, noisy or busy places, changes to routine, or managing emotions and energy. A diagnosis can also help women understand themselves better and be kinder to themselves.

Importantly, a diagnosis can help women get the right support. This might include reasonable adjustments at work, better understanding from healthcare professionals, and access to specialist services. Without a diagnosis, women are often treated for anxiety or depression without anyone looking at the underlying cause.

Why autism is often missed in women

Thttps://www.durham.ac.uk/research/current/thought-leadership/women-with-autism--adhd-arent-diagnosed-until-adulthood/

According to an article from Durham university in 2022;-

Why many women with autism and ADHD aren't diagnosed until adulthood – and what to do if you think you're one of them

Dr Alokananda Rudra, from our Department of Psychology, addresses a number of reasons why autism and ADHD are both often missed or even misdiagnosed in girls and women and that the importance of a greater awareness of the symptoms and behaviour associated with autism and ADHD will be critical in changing how both are diagnosed.

Over the last decade or so, there's been an uptick in the number of adults being diagnosed with autism and ADHD. Any number of factors might explain this rise, including greater public awareness of both conditions, broader diagnostic criteria and changing perceptions in who autism and ADHD affects.

But while autism and ADHD still affect a greater number of men, more women are reporting being diagnosed with these conditions as adults. Again, this increase is probably due to any number of factors. But social media may also be playing a role, with women able to use platforms such as Twitter and TikTok to spark discussions and share their experiences and stories.

One constant in the experiences that many women have shared on social media is how long they waited for a diagnosis. Many have even spoken about how they were even brushed off by healthcare professionals when seeking a diagnosis, told pointblank that they're "not autistic" or that their problem is "anxiety and not ADHD". For many, not knowing why they felt different from others left them feeling confused and even depressed.

This isn't surprising, as autism and ADHD are both often missed or even misdiagnosed in women. Nearly 80% of women with autism are misdiagnosed – often with conditions such as borderline personality disorder, eating disorders, bipolar disorder and anxiety. It's currently unknown how often women with ADHD are misdiagnosed.

But there are a number of reasons that may explain why this happens. The first is that autism and ADHD symptoms are different in women than they are in men. Other conditions common in people with autism and ADHD (such as anxiety and depression) may also make it appear that symptoms are the result of these conditions instead. Women with autism and ADHD may also learn over time how to hide their symptoms from people – which may further lead to misdiagnosis or delayed diagnosis.

Another major problem is that autism and ADHD are still often seen as "male disorders". While it's true that both conditions affect a higher proportion of men than women, it also means that the current tools used to diagnose people with these conditions tend not to recognise female symptoms as readily.

Girls with autism may have less obvious social difficulties and often have better verbal communication than a boy with autism might. For girls with ADHD, they often aren't as hyperactive and may not have the disruptive behaviour some boys may have. This means that many girls with these conditions may be overlooked by their parents, teachers and even clinicians as the diagnostic criteria do not match with their symptoms.

The right diagnosis

When not properly diagnosed and treated in childhood, girls with autism or ADHD may experience poor academic performance, behavioural problems and trouble making friends. As they get older, this could make it more difficult for them to cope with professional demands in the workplace. It may also lead to anxiety and stress because they feel misunderstood or confused about why they find certain experiences so difficult, alongside other mental health problems such as depression and eating disorders.

In one study of women who weren't diagnosed with ADHD or autism until adulthood, many participants reported feeling like they were "wrong" and didn't fit in anywhere. Others even went as far as trying to change their clothes or personality to better fit in. But after diagnosis, participants felt they better understood why they might feel the way they do and felt a greater sense of personal value after receiving their diagnosis.

Diagnosis can sometimes have a negative effect – with some women fearing they may be discriminated against, that others may think badly of them or that people will look down on them. But in general, finally receiving the right diagnosis makes most women feel they are empowered and have a better quality of life.

If you think that you may have autism or ADHD but haven't been diagnosed, there are many things you can do. Online resources, such as AADDUK, ADHD aware and National Autistic Society all provide advice and suggestions on how to approach your GP with questions, and what support or specialist clinics there are in your area.

If you're planning to visit your GP, it might be helpful to take a loved one along with you for support and help in explaining why you think you may have autism or ADHD. This may be as simple as telling them you have read about the conditions and have experienced similar symptoms.

Since all GPs may not have in-depth knowledge of autism or ADHD, it's important to present your experiences as clearly as you can. Use real-life examples if you can and feel comfortable. If you don't get a referral from your GP after your visit, seek a second appointment or even ask to see another GP at the surgery. After a referral, you will be advised to visit a diagnostic service which should help you get the appropriate support you need.

Greater awareness of the symptoms and behaviour associated with autism and ADHD in girls and women will be important in changing how both are diagnosed – and hopefully mean that more girls and young women receive the help they need. And social media may be one important way in helping people learn more about these conditions, and connecting people with similar experiences.

National Autistic society

Autistic women and girls

More women and girls than ever before are discovering that they are autistic. Many had been missed or misdiagnosed due to outdated stereotypes about autism. But that is slowly changing.

In the past, it was assumed that autistic people were overwhelmingly men and boys, and only very rarely women and girls. This is wrong. There are many women, girls and non-binary people on the autism spectrum.

Although we now know much more about the experiences of autistic women and girls, society's understanding of autism has been limited by outdated stereotypes and incorrect assumptions. Although autism research and professional practice are slowly catching up to the realities of life for autistic women and girls, many barriers to diagnosis and support remain.

Does autism present differently in women and girls?

It is important that autistic women and girls receive a diagnosis (or recognise that they are autistic) so they can understand themselves and access support. However, because of stereotyped ideas about what autism looks like and who can be autistic, many autistic women and girls struggle to get a diagnosis, receive a diagnosis late in life or are misdiagnosed with conditions other than autism.

Autistic characteristics in women and girls may differ from those of other autistic people. They might seem to have fewer social difficulties than autistic men and boys, but this could be because they are more likely to 'mask' their autistic traits (though the stress of doing so can result in anxiety and overwhelm). At school, autistic girls may be more likely to be part of a friendship group and this could be a reason that teachers don't notice their differences. They may also be missed if their academic achievement masks difficulties they are facing in other areas.

Some of the core characteristics of autism are having 'repetitive behaviours' and highly-focused interests. Stereotyped examples of these include rocking backwards and forwards, and a fascination with trains. However, in autistic women and girls these behaviours and interests may be similar to those of non-autistic women and girls, such as twirling hair and reading books, and as such may go unnoticed despite the greater intensity or focus typical for autistic people.

Doctors and other healthcare professionals can lack knowledge about how autism may present differently in women and girls. This means women and girls may be misdiagnosed with mental health issues or their autistic traits may be missed amid the symptoms of co-occurring conditions. Some tools used to diagnose autism are designed to identify autistic characteristics that may be more common in autistic men and boys. This means the process may not be as sensitive to characteristics more commonly found in autistic women and girls.

Gender stereotypes play a role

Unconscious bias can also affect diagnosis. Some professionals still assume autism is "mostly a male condition", or that women are just shy, sensitive, or anxious.

This means women are more likely to be told their difficulties are due to personality, stress, or mental health issues – rather than autism. Many women are only considered for an autism assessment after reaching crisis point.

What needs to change

Awareness is improving, but there is still a long way to go.

To make sure autistic women are not missed, we need:

- better understanding of how autism presents in women
- training for healthcare professionals
- diagnostic processes that reflect real experiences, not stereotypes
- Listening to women's experiences is a vital part of this change.

Many women learn to mask or camouflage

One of the biggest reasons autism is missed in women is something called masking.

Masking means hiding autistic traits to fit in. Many autistic women learn from a young age to mirror how others behave, force themselves to make eye contact, rehearse conversations, or push through situations that feel overwhelming.

On the outside, they may appear to be coping well. On the inside, they may be exhausted, anxious, or struggling. Because they look like they are managing, teachers, GPs, and other professionals may not see that anything is wrong.

Over time, masking can seriously affect mental health and lead to burnout.

Why many women in the UK need an autism diagnosis and why it's often missed

For a long time, autism has been seen as something that mainly affects boys and men. Because of this, many women in the UK grow up without anyone realising they are autistic. Some are diagnosed much later in life, and many are never diagnosed at all.

We now know this isn't because autism is rare in women. It's because the way autism shows up in women is often misunderstood or overlooked.

Masking can include:

- Copying how other people talk, act, or dress
- Forcing eye contact even when it feels uncomfortable
- Rehearsing conversations in advance
- Hiding stimming (self-soothing movements) or strong interests
- Autistic traits in women can look different

Autism doesn't look the same in everyone. In women, autistic traits are often more internal and easier to miss.

For example:

Women may have intense interests, but in things that seem socially "normal", like books, animals, or relationships

They may be chatty or empathetic, but still struggle to understand social rules or feel overwhelmed by interaction

They may be good at school or work, but feel constantly anxious or drained

Because these traits don't match outdated ideas of what autism looks like, they are often dismissed or misunderstood.

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What happens when diagnosis is delayed or missed

When autism is missed, women often spend years feeling like they don't quite fit in, without knowing why. They may experience ongoing anxiety, depression, or exhaustion, and may move between services without getting the right help.

Being diagnosed later in life doesn't mean autism appeared later – it means it wasn't recognised earlier. Many women say that finally getting a diagnosis brings relief, clarity, and a sense of being understood.

Many suffer different forms of abuse as they are less likely to spot the signs until it's too late. Taking risky decisions due to not seeing all the warnings of what the consequences could mean to whatever choice is made.

More likely to suffer break down in relationships with family members who can't understand their actions.

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Our Role in Shaping Better Services

The Challenge

In March 2025, a local resident called us here at Healthwatch Rotherham as she had been provided with some conflicting information regarding an autism assessment for her 16 year old daughter. Rotherham Child and Adolescent Mental Health Services (CAMHS) waits were running at 2–3 years, so she hoped to use the NHS Right to Choose pathway for a faster referral to a specialist.

"The school had already told me that the CAMHS waitlist would be 3 years plus. My daughter is in year 11 and a transition year for college and suffering with significant poor mental health so we wanted this done as quickly as possible"

The family first asked their GP for a direct referral, only to be told local rules, policies and procedures wouldn't allow it. After speaking with us and after we provided the necessary information about the early stages of the process, her daughter's school referred her to CAMHS and they quickly confirmed that the request for an autism assessment was appropriate in this case. However, further barriers developed. When they contacted the private provider, they discovered it accepted only GP-issued referrals. For two months, the family bounced between school, GP and provider, growing more frustrated and anxious as exam time approached.

What is CAMHS?

CAMHS stands for Child and Adolescent Mental Health Services, the NHS teams that assess and treat children and young people with emotional, behavioural or mental health difficulties

What Is the NHS Right to Choose?

The NHS Right to Choose (RTC) is a policy that lets you pick any NHS provider in England for certain services without extra cost. Instead of waiting for your local service, you can ask your GP or hospital team for a Right to Choose referral and access care under the same NHS quality and safety standards.

How It Works

- After your GP or specialist confirms you need treatment, you can ask to be referred to any NHS provider in England that offers the same service.
- Your local NHS team, usually the Integrated Care Board (ICB) , arranges the referral and covers the cost—just like they would for your nearest service.
- You don't pay extra and your care remains under the NHS umbrella, with guaranteed quality and safety standards.

Why It Matters

- It helps you avoid long waits by tapping into less busy services elsewhere.
- It gives you choice over the location, appointment times and sometimes the specialist you see.
- It encourages local NHS teams to improve services when patients have options.

Using Your Right to Choose

1. Talk to your GP or hospital team about your diagnosis or treatment plan.
2. Ask specifically for a "Right to Choose" referral to an alternative NHS provider.
3. Decide together which provider offers the speed, location or specialist expertise you need.
4. Your GP or hospital makes the referral paperwork; you simply attend your chosen clinic.

Things to Remember

- Not every service is covered by Right to Choose—check with your GP if you're unsure.
- Travel costs aren't usually covered, so factor in transport when picking a provider.
- If you change your mind, you can ask to switch back to your local service at any time.
- Keep all letters and appointment details handy to avoid confusion.

The impact of unclear policies and processes

Parenting can feel confusing and overwhelming at the best of times but when your child's needs aren't fully understood or supported this can create further challenges.

Getting a timely diagnosis for some young people and their families can make a huge difference. It can create a greater understanding of some behaviours and help to manage and improve relationships. It can also help with accessing support at school and in the workplace.

"Whilst I'm thankful we are now under way, the whole process really took its toll on both myself and my daughter's mental health, it was so much more time consuming, stressful and more difficult than the process should have been"

How Healthwatch Rotherham helped

We mapped the entire referral process and compared it with other parts of South Yorkshire. We spoke to GPs and RDaSH teams to clarify roles and uncovered a widespread lack of understanding about how under 18 referrals should work. Armed with these findings, we met senior leaders at the Integrated Care Board to explain how the existing rules were failing families and GPs alike—adding unnecessary stress to young people and their families.

Within four weeks, the ICB Transformation team updated its guidance and made contact with Right To Choose providers explaining the process for Rotherham and explaining how it differed from other areas of South Yorkshire.

"It took almost 3 months to get a provider to accept us on the RTC pathway. It seems it's a postcode lottery, had we lived a few miles away in Sheffield our GP could have done the referral and it would have been accepted within weeks"

This meant the family's daughter was booked in with her preferred provider without any further waiting times. Her mother told us she felt a huge weight lift off her shoulders—and since then, we haven't received any new reports of this barrier.

To clarify the process:

- The child's school is the only service that can make a referral for an autism and/or ADHD assessment
- This is sent to RDaSH CAMHS CYP (Children and Young People) Neurodevelopmental pathway team
- CAMHS decide whether an assessment for the young person is appropriate
- If it is, parents and the young person can choose their NHS "Right to choose" provider for the assessment
- The provider will then make contact with CAMHS to arrange a transfer of care.
- The provider completes the young person's assessment

At Healthwatch Rotherham, we're proud to amplify family voices and drive changes that ensure every child can access the assessments they need—when they need them.

At Healthwatch Rotherham, we believe knowing your rights helps you get the best care possible. If you ever hit a snag using the Right to Choose, get in touch and we'll help you navigate the process.

Conclusions

This report shows that getting a diagnosis for ADHD or autism in Rotherham can take a very long time, often several years. During this time, many people feel unsupported, unsure about what is happening, and left without the help they need.

For many people, diagnosis happens later in life. This means they may spend years struggling without understanding why, which can affect their mental health, confidence, work, and relationships.

The feedback also shows that people often feel they are not listened to by professionals and have to push hard to be taken seriously. Communication is often unclear, and people are not always told what is happening with their referral or how long they will wait.

Despite these challenges, getting a diagnosis can be life-changing. It helps people understand themselves better, feel validated, and access the right support.

Overall, the findings highlight a need for shorter waiting times, better communication, earlier support, and improved understanding of ADHD and autism, especially in adults and women.

Recommendations and/or next steps

Recommendations need to be:

- **1. Reduce waiting times for diagnosis:** Services should review current capacity and pathways to reduce long waiting times for ADHD and autism assessments, which are currently reported as lasting several years. This may include increasing staffing, improving triage systems, or expanding access to alternative pathways such as Right to Choose.
- **2. Provide support while people are waiting:** People should not be left without help while awaiting diagnosis. Services should offer interim support such as advice, coping strategies, peer support groups, and access to information to help individuals manage their symptoms.
- **3. Improve communication with patients:** Clear and regular communication should be provided to people on waiting lists. This includes confirming they are on the list, giving realistic waiting time updates, and explaining next steps so people feel informed and reassured.
- **4. Increase awareness and training for professionals:** Healthcare professionals, particularly GPs, should receive improved training on ADHD and autism, including how these conditions present in adults and across different genders. In particular, professionals need greater awareness that autism may present differently in children whose traits do not match the more traditionally recognised or stereotypical presentation, which can lead to it being missed or misunderstood. Better training would help reduce missed or delayed diagnoses and improve referral experiences.

  Healthcare professionals should receive ongoing training and regular updates on ADHD and autism referral pathways to ensure they have an up-to-date understanding of referral processes, waiting list arrangements, and available diagnostic options.

- **5. Improve access to clear information and signposting:** Provide easy-to-understand information about ADHD and autism, the diagnostic process, and available support services locally and nationally, so individuals can better navigate the system.

Responses

Councillor Baker-Rodgers - Chair of the Health and Wellbeing Board Thanked Healthwatch Rotherham and requested to be updated throughout the process.

Healthwatch Rotherham invited Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH) to provide comments on this report. The Trust did not provide a response within the response period. Should a response be received after publication, it will be published on the Healthwatch Rotherham website alongside this report.

Acknowledgments

Thank you to Rotherham people that shared their stories and responded to our public survey to use in this report.

We want to thank the Improving lives select commission, for working with Healthwatch Rotherham ensuring our concerns were listened to and escalated to the right teams.

References

- National Autistic Society;
- RDasH
- Thttps://www.durham.ac.uk/research/current/thought-leadership/women-with-autism--adhd-arent-diagnosed-until-adulthood/ *According to an article from Durham university in 2022;-*