



Autism and ADHD: The stories that followed

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healthwatch
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Background

Healthwatch Stoke-on-Trent is the independent voice of the public in health and social care services for the people of Stoke-on-Trent. We gather feedback from the public about their experiences and use that information to hold service providers and commissioners to account and work with them to improve their services.

In 2025/2026, following significant feedback about Child and Adolescent Mental Health Services (CAMHS) Autism and ADHD assessments, our Independent Strategic Advisory Board approved the topic as our priority project for the year, aiming to further explore the issues raised. After the conclusion and publication of our project report ["If you start with kind, you've won"](#), more members of the public came forward with their experiences, including that of adults. We worked with these individuals to help share their story, some provided more detailed stories whilst others provided more general feedback.

What is ADHD?

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental condition, which means the brain works differently from most people. People with ADHD may have trouble with things like concentrating and sitting still.

What is autism?

Autism, also called autism spectrum disorder (ASD), is a difference in how the brain develops that affects how they see and experience the world. It can affect communication, how you think and learn, and sensory responses.

**Definitions according to the NHS website.*

Introduction

This report presents a thematic analysis of the lived experiences of ADHD and autism, including the individuals and their families. The intelligence that has informed this report reveal a systematic pattern of diagnostic overshadowing, delayed recognition, poor communication between services, and the emotional

and physical burden placed on families and friends who must navigate the complex systems alone to advocate for their loved ones.

The themes highlight how neurodivergent people often face barriers not because of their conditions, but because the system fails to listen, adapt, or work together. The consequences include avoidable harm, loss of trust, educational disruption, financial strain and long-term emotional distress.

Understanding these experiences will benefit those going through the system and contribute to supporting improvements to services for children and adults with ADHD and autism, both in school and in the NHS.

Purpose of this report

Readers can use this report as a guide to understanding the reality that people with ADHD and autism face when they seek diagnosis or access support. The findings show what happened to individuals and families, while the themes explain the common problems that appear across the stories.

This report can support families who are currently navigating the system, help professionals reflect on their practice and inform leaders who make decisions about healthcare. It is meant to encourage learning and improve understanding.

Our Findings

The following summaries are from more detailed stories that focus on the challenges that neurodiverse children and adults experience when trying to obtain diagnosis and support.

“We spent years searching for answers”

Three family members received neurodevelopmental diagnosis or entered diagnostic pathways following years of delays, rejections, inconsistency, a lack of communication, and administrative errors. This delayed recognition burdened the family with a significant hardship, resulting in one member having to become an advocate for their family. They shouldered multiple responsibilities such as being an interpreter, carer, researcher, support worker and part lawyer simply because no one else was there to support them through their diagnosis journey. Even though the family finally understood why their life seemed more difficult than others and were able to start putting measures in place, it will not reverse their previous struggles and loss of trust in the services that were meant to help them. Neurodivergence can go undetected and unsupported, leaving families to navigate complex systems alone. Emotional and practical burdens are placed on relatives who often go unrecognised, the erosion of trust in services due to delays and poor communication, and the potential for better outcomes when services work together coherently.

A single incident had a lasting impact

During an already difficult transition period of leaving primary school and starting High School, a child was denied access to the toilets. They later wet themselves at school and suffered in silence sitting in their wet clothes as there were too embarrassed to tell anyone. This one incident sparked severe anxiety for the child when it came to access to relieving themselves. Car journeys and the bus to school were consumed with panic of whether they would need the toilet. This anxiety affected their behaviour at school, where they experienced periods of school refusal and suspensions making engaging with learning difficult. The family sought an assessment after the child left school, and they were diagnosed with ADHD. Even though the child faced struggle at High School, their college experience was far more positive – the child thrived in a hands-on physical subject and now has a job they enjoy. Certain policies can negatively affect a child who previously faced no issues, leading to years of mental health and wellbeing challenges and toxic environments can shadow underlying neurodivergence which prevents the relevant support from being provided.

A case on diagnostic overshadowing

This parent revealed their experience of diagnostic overshadowing, where their neurodivergent child's physical symptoms were repeatedly dismissed as behavioural or developmental. Despite years of concern about weight loss, GPs constantly brushed it off as growth spurts. Their child was only diagnosed with Type 1 Diabetes when they collapsed into a coma with kidney failure – earlier testing could have prevented life-long complications including, liver failure and

an enlarged heart. They believe that earlier testing and diagnosis beyond their neurodivergence could have prevented health complications and emotional and financial distress.

Read more

For the purpose of this report, the individual stories that you have just read were summarised. You can read the full case studies in more detail online via our website:

- ["We spent years searching for answers"](#)
- [A single incident had a lasting impact](#)
- [A case of diagnostic overshadowing](#)

If you have had an experience you would like to share with us to be considered for a future case study, please contact us on 03303 130247 or email info@healthwatchstoke.co.uk

Key Themes

From the detailed stories shared with us, alongside further supporting intelligence received in this time, we identified four key themes present in the lived experiences of ADHD and autism that were impacting their pathways to diagnosis and access to support. The themes are:

- Dismissive practices from professionals
- Diagnostic overshadowing
- Disconnected services impacting communication and support
- Individuals and family members taking on advocacy roles

The following section expands on these findings.

Dismissive practices from professionals

Across the feedback shared, individuals and families constantly describe feeling dismissed, judged, or ignored when raising concerns. This lack of listening directly affects diagnosis, access to support and trust in services. One person raised how “repeated delays, misunderstandings, conflicting advice and feeling unheard” created exhaustion and reluctance to engage with services. Another participant described being blamed for their child’s behaviour, one person said:



“The first thing with neurodivergence is parental blame.”



Professionals here assumed the parents were to blame for their child’s difficulty, leading to their actions being misinterpreted. This practice places fear on parents being judged and could lead to a wariness of families seeking help. One individual’s feedback revealed sexist dismissal, as they told “my mood and my problems were blamed on my menstrual cycle and that made me feel like we’re in the 1700s.” Outdated practices hinder those who are just wanting an explanation for the challenges they face.

It’s not just the diagnosis journey that is harmed when professionals are dismissive towards patients. Methods of supporting those with ADHD or autism can be challenged or criticised. In other experiences, someone added that their service dog was viewed negatively. At a GP appointment, the doctor asked them, “she’s not going to attack me, is she?” The lack of respect towards a support aid signals judgment and suggests ignorance towards individual needs.

Feeling unheard is not an isolated instance. Many patients report a general issue of needing to constantly voice their concerns and defend their support. Dealing with this treatment can cause emotional burdens.

Diagnostic overshadowing

Diagnostic overshadowing happens when symptoms are incorrectly blamed on a pre-diagnosed condition. This theme appears in multiple of the stories shared causing other medical conditions to be missed. This story demonstrates this when the young person's diabetic symptoms were dismissed until they fell into a coma. The parent explained, "as soon as there's a note saying a child might be neurodivergent, they don't look at the physical health again." Type 1 Diabetes causes the body to stop producing insulin – a hormone that controls the body's blood sugar. If untreated, it can cause death. Professionals failed to investigate the child's diabetic symptoms, assuming their neurodivergence was the cause. This shows that professionals treated neurodivergence as the answer to everything, when it was just a part of the child that needed understanding.

In another story shared, the opposite occurred. The signs of ADHD were overlooked, and symptoms were blamed on anxiety. It was not until after leaving school that the child sought an ADHD assessment. However, if the symptoms of ADHD were recognised sooner, support could have been provided at an earlier stage in the child's life.

When existing diagnoses are treated as the cause of all symptoms a person presents, it leads to delays in additional treatment and support. Assumption risks burdening children and adults with unnecessary difficulties and, in some cases, leaves them facing life-threatening conditions alone. Professionals must approach symptoms with curiosity.

Disconnected services impacting communication and support

Families described systems that feel disjointed, inconsistent and difficult to navigate. Services often fail to communicate across their channels, leaving families having to coordinate communication themselves. One person said the experience of using different services was "like criss-cross... nothing lines up or matches up," showing that there are gaps in the patient's care when accessing systems. Another person referred to the "conflicting advice" they faced when services failed to work together. One individual shared how they ended up receiving a diagnosis via Right to Choose with a private provider. However, her diagnosis was not accepted by the NHS despite it being an approved provider. This has left the individual in a difficult place because they are relying on the private provider to continue their prescription.

Seamless services are essential for neurodivergent people to receive diagnosis and access support. Consistent and coordinated communication reduces delays and unnecessary emotional and physical harm.

Individuals and family members taking on advocacy roles

Many families told us of their experiences of having to be the ones to speak up and make services listen to them. We were told:



“Over time, I found myself acting as:
an interpreter, a carer, an advocate, a
researcher, an administrator, a complaint
writer, a support worker, a benefits adviser,
and a case manager.”



None of these roles were formally assigned to them, and they received no professional training in how to perform these roles. It reveals the hidden labours families must go through to access services suggesting they are not designed with patients in mind. Another family said:



“It is hard to navigate when you’re disabled
yourself and trying to support the person
you’re caring for.”



This shows the additional challenges placed on people who are managing their own health needs.

Complex services affect not only the individual seeking diagnosis or support, but also the family members who have stepped up to support them. Emotional and physical burdens are placed on people that are rarely recognised. It also reveals the unequal access individuals experience when using services. Some may have to face this alone, acting as their own advocate, where they do not have a support system surrounding them.

Our Conclusion

The feedback presented in this report reveal a consistent pattern of dismissive practices, diagnostic overshadowing, disjointed services and the burden of advocacy. These issues create barriers that prevent neurodivergent individuals from receiving timely, appropriate and compassionate support. The emotional and physical consequences are significant, affecting not only individuals but entire families.

Improving outcomes requires services to listen more carefully, work collectively, recognise neurodivergent needs without making assumptions, and provide clear, accessible pathways to diagnosis and support. When services are seamless, respectful and curious, the impact will be transformative. These lived experiences offer vital insights that should inform future improvements across healthcare, education and social care.

Thank You

We are grateful to everyone who helped shape this document by sharing their stories, thoughts, and reflections.

The contract to provide the Healthwatch Stoke-on-Trent service is held by
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We are committed to the quality of our information. Every three years we perform an in-depth audit so that we can be certain of this.

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