

# “If you start with kind, you’ve won”

**Children and Young People: Autism and ADHD**

June 2026



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# 1. Background

Healthwatch Stoke-on-Trent is the city's independent health and social care champion. We are here to listen to the experiences of local people using local health and care services, and about the issues that matter to the people of Stoke-on-Trent.

During the financial year April 2024 – March 2025, we received significant feedback about Child and Adolescent Mental Health Services (CAMHS) and delays in, and rejection of, referrals for Autism and ADHD referrals.

In April 2025, our Independent Strategic Advisory Board approved an engagement project to explore these issues, along with Special Educational Needs and Disability (SEND) services for children and young people, to better understand the difficulties faced.

This report feeds back on the themes identified through a period of engagement. Some of the themes are illustrated by personal stories, and we have used data to test out what we heard.

This topic contains much jargon and we have explained some of the key concepts using coloured boxes.

## Jargon and key concepts

Jargon and key concepts are explained in boxes like this.

## A personal story – Michelle

*So, what are our good qualities?*

People with ADHD are doers. We are the people on the ground floor usually getting things done. We can usually see problems before they happen and solve them quickly.

We are great company and loyal; we would do anything for you. Building relationships with people is what we like to do. We don't always get it right but if you can see past our ADHD, we are amazing friends.

We are creative and spontaneous, but this has to be in our control. We say the things that you think but dare not say.

We have endless amounts of energy and are very persistent, this could be counted as a barrier too but for me it's definitely a positive.

We are so resilient. We must be because we face so many barriers and many people see our disability as fake.

We have a strong sense of fairness, after living with accommodations – or perhaps struggling without them – people with ADHD know that 'fair' doesn't always mean 'equal'. They understand that different people need different things to succeed, and they're committed to helping others.

As an adult living with ADHD, I have learnt so many skills that I didn't have as a child, however, I still need those reasonable adjustments making. I need them making because life is still complicated. It's still hard and as an adult with ADHD I often think about my childhood and how hard it was. I'm not sure things have changed so much.

ADHD can be semi good on some days and knock me off my feet other days. It's not a superpower like other people describe; it's so misunderstood by so many. It's a condition that can be so disabling and really hard to live with. However, with the right support and understanding, on those days I get knocked over, I stand back up quicker and that's because I am lucky, I have a network of people that understand and support me, some aren't that lucky.



To contribute to an improved understanding of Autism and Attention Deficit Hyperactivity Disorder (ADHD), we have summarised the definitions according to the National Institute for Health and Care Excellence.

## A definition of Autism

According to the National Institute for Health and Care Excellence, the term Autism describes:

**“qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact”<sup>1</sup>**

A clinical diagnosis may be made if a child or young person meets the criteria defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-11) or the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

The National Institute for Health and Care Excellence offers the following advice to primary care professionals (GPs) about managing a child or young person with a diagnosis of Autism:

“Following specialist assessment, the child or young person may be allocated a key worker from the local autism team to manage and co-ordinate ongoing care and support in the following areas if needed:

- Behavioural assessment and treatment.
- Care management and community nursing.
- Epilepsy care.
- Educational needs.
- Independent supported living.
- Mental health, psychiatry, and psychology.
- Specialist occupational therapy and creative therapies.
- Speech and language therapy.
- Support for children with complex health needs.
- Support for parents, families, and carers.”<sup>2</sup>

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<sup>1</sup> National Institute for Health and Care Excellence (NICE). *Autism in children: What is it?* Accessed: 11/05/2026. <https://cks.nice.org.uk/topics/autism-in-children/background-information/definition/>

<sup>2</sup> National Institute for Health and Care Excellence (NICE). *Autism in children: Scenario: How should I manage a child or young person with confirmed autism?* Accessed: 11/05/2026. <https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prevalence/>

# A definition of Attention Deficit Hyperactivity Disorder (ADHD)

According to the National Institute for Health and Care Excellence, Attention Deficit Hyperactivity Disorder (ADHD) is:

“a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development”.<sup>3</sup>

This is explained as follows:

- Inattention includes difficulty with persistence, keeping focused and with organisation
- Hyperactivity in a child includes running around, excessive fidgeting, tapping or talkativeness. An adult may experience extreme restlessness or wearing others out with their activity
- Impulsivity refers to hasty actions that occur in the moment without forethought and that have high potential for harm to the individual. An example of impulsive behaviour is interrupting people excessively and/or making important decisions without considering the long-term consequences.

The treatment options depend on the person's age and their degree of functional impairment. They can include group parent-training programmes, environmental modifications, and drug treatments. A course of cognitive behavioural therapy (CBT) may be offered to young people with ADHD who have benefited from medication, but whose symptoms are still causing significant impairment, addressing areas such as social skills with peers, problem-solving, self-control, active listening skills, and dealing with and expressing feelings.

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<sup>3</sup> National Institute for Health and Care Excellence (NICE). *Attention deficit hyperactivity disorder. How common is it?* Accessed: 07/05/2026.

<https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prevalence/>

## 'Building the Right Support' guiding principles

The Integrated Care System produced a Joint Strategic Needs Assessment for Learning Disabilities and Autism in October 2022.

A Joint Strategic Needs Assessment sets out current and future health and care needs to inform decision making. It provides an assessment of people's needs using evidence, data, analysis, and insights.

It quotes the guiding principles of 'Building the Right Support'. Under the heading of 'A good start in life', it states:

**"As a child or young person, I want good opportunities and experiences as I grow up. For me, this means I have a timely autism diagnosis that enables me to access the support I need to live an ordinary life."**

Readers of this report are invited to consider to what extent the children and young people of Stoke-on-Trent are experiencing this principle.

### Building the right support

'Building the Right Support' is a national plan published in 2015 by NHS England, the Local Government Association and Association of Directors of Adult Social Services (ADASS). It sets out how commissioners develop support for Autistic people. Its action plan was published in July 2022.

### Integrated Care System

The Integrated Care System is a partnership of the NHS and local councils that plans, buys, and provides health and care services.

## 2. What we did

To capture people's experiences, we offered a number of engagement opportunities; online surveys, in-person and online focus groups, drop-in sessions, 1:1 conversations, and an invitation to provide written testimonies.

The in-person sessions were spread throughout the city, and sessions were offered during the hours of 9am-5pm as well as evenings, to accommodate work and caring responsibilities.

The most successful sessions were those where we worked in partnership with trusted organisations. For example, we worked with Parent Engagement Group in Stoke (PEGiS) to co-design engaging and interactive in-person and online sessions, exploring three questions about the NHS assessment process:

- How easy was it to getting a referral into the service – if you didn't get one, why not?
- If you have accessed the service, how did you find the assessment process?
- If you have reached the end of the assessment process, how was your report?

We attended several Community Lounges located across the city, including PEGiS' own SEND Community Lounge. It was at one of these lounges that a parent spoke the words that have formed the title of this report, "If you start with kind, you've won."

We gained much insight from conversations with local Voluntary, Community and Social Enterprise (VCSE) organisations and healthcare providers including:

- Access4All
- Lifeworks
- Our Space
- The Peter Pan Centre
- Project Indi
- North Staffordshire Combined Healthcare NHS Trust

In addition to our engagement, we also sourced data using Freedom of Information requests, which were made to both North Staffordshire Combined Healthcare NHS Trust and Stoke-on-Trent City Council.

# 3. Key Findings

This chapter, detailing our key findings, consists of several sections:

- A. Increasing, not reducing, health inequalities
- B. Opportunities to improve relationships
  - i. Parental blame
  - ii. Lack of understanding of pathways/poor communication
  - iii. Lack of transparency
- C. Getting on to the waiting list for an assessment
- D. Alternative providers
  - i. Risk to Right to Choose
- E. Falling between services and teams
- F. Experience of assessment
- G. Post-diagnosis support
- H. The role of school
  - i. Education completing the referrals without the knowledge or culture to do so
  - ii. Not understanding the different presentations
  - iii. Getting an Education, Health and Care Plan (EHCP)
  - iv. Impact on families
- I. Looked After Children

## **A. Increasing, not reducing, health inequalities**

North Staffordshire Combined Healthcare NHS Trust provides an all-age Autism service to the children and young people of Stoke-on-Trent City and North Staffordshire. It is funded to do this by the Integrated Care Board mentioned on page 7. There is no additional funding for the ADHD services for children & young people or adults. These are funded from the core budget for Children and Adolescent Mental Health Services (CAMHS) and the services have been developed in response to the needs of those referred to the Trust. The project team came across three examples of services not available to residents of Stoke-on-Trent City that are available to residents in other areas covered by the Integrated Care Board.

### **Enhanced Autism Support and Empowerment (EASE) service**

Children and young people in South Staffordshire who:

- are open to Midland Partnership University NHS Foundation Trust's Crisis and Intensive Support Team
- have a diagnosis of Autism
- show significant features of Autism
- are awaiting an Autism diagnosis

have access to:

- Family peer support and enhanced support
- Dedicated care teams
- Coordinated support across Autism Care Teams, Key Worker Service and Intensive Support Team.

### **New CAMHS service for Shropshire and Telford & Wrekin**

Children and young people in Shropshire, Telford and Wrekin have a new service that covers mental health, emotional wellbeing, and neurodevelopmental needs.

The new Child and Adolescent Mental Health Service Shropshire, Telford and Wrekin (CAMHS STW) is provided by Midlands Partnership University NHS Foundation Trust (MPFT) and replaces and expands on the previous BeeU service.

It provides:

- Emotional wellbeing, and mental health support for children and young people aged 0-25 years and their families with ongoing support where needed for young people up until 25 years of age

- Neurodevelopmental assessments for children and young people (Autism for children and young people aged 5–18, and Attention Deficit Hyperactivity Disorder (ADHD) for children and young people aged 6–18)
- Community Eating Disorder Services for children and young people aged up to 18 years.

## Transitional Care Team

Young people under South Staffordshire’s Child and Adolescent Mental Health Services (CAMHS) who are transitioning to adult mental health services get support from the Transitional Care Team. The team provides a consistent point of support during the transition and has the flexibility to meet the young person in a location that suits them.

### Recommendations

**Recommendation 1:** The Integrated Care Board conducts a full strategic commissioning review of Autism/ADHD services to assure Board members, it is not widening health inequalities in the city, when compared to other areas within the Integrated Care System.

## B. Opportunities to improve relationships

Although some people reported improvements in parental engagement by North Staffordshire Combined Healthcare NHS Trust, many parents referred to having to ‘fight’ for their child’s needs to be recognised, and were concerned about those families who lacked the ability to fight.



“These days, we have to fight and prove so much.”

“How many have been discharged and didn’t fight because they’re fighting so many other things?”

“I’m running on empty, I’m not fighting, just putting up with it.”

“Luckily we have a lot of fight in us but a lot don’t, they just give up.”



There were three themes that ran through the feedback that could be opportunities to improve relationships further:

- Parental blame
- Lack of understanding of pathway/poor communication
- Lack of transparency.

## Parental blame

Parents and carers spoke of how, when their child had been referred for assessment, the first response was often to require them to attend a parenting course. Whilst most parents and carers had attended the courses asked of them, none of them felt they had helped with the issues they were experiencing and that requiring them to attend was indicative of parental blame.

One parent spoke of how their family were now on the child protection register because they have continued to pursue a diagnosis. Another expressed concern that by asking for help they would be at risk of losing their children.

Others spoke of how they felt they had been labelled as aggressive parents for pursuing a diagnosis.



“A lot of parental blame- you are sent on a course.”

“I said I would go on it but I needed to know what I was going to learn from it, and they said I had a negative attitude and wouldn't let me on it.”

“They don't like it when you challenge and say it's not my parenting.”

“They get sent on parenting courses because, you know, we've got to fix the parents.”

“While I find Riding the Rapids beneficial, I feel it is inappropriate to suggest I need help managing my child's Autism rather than addressing [their] individual needs.”



## Lack of understanding of pathways/poor communication

Parents and carers said they did not understand the pathways or what to expect from the process. They suggested that being given a simple diagram of the pathway would aid understanding. One spoke about their child having been assessed but they had not heard anything else, they did not know if the assessment was complete nor what to expect next. People spoke about how they had not had reports about the assessment outcomes or the reasons for their children being discharged from the service.

Some spoke about not understanding the system and being unaware of where they could find information. For one, their first language was not English which added a further barrier when they were trying to understand and when they were speaking with professionals.



“If they gave us a diagram of what the pathway should look like we wouldn't have to keep going back to them.”

“How many parents say they've been referred for an ADHD assessment, but their child is 5 or 6 and they think they're on the pathway, but they aren't on the pathway because they're not old enough?”

“Now we've had the assessment done, we've had no paperwork saying that the assessment is done, what is going to happen next...”

“You know, they don't know what services are available to them or if there's any services available to them.”

“It's difficult to explain things because it's not your first language. I feel like I don't know anything yet, I don't know where to learn.”



## Recommendations

**Recommendation 2:** Undertake an evaluation of the parenting courses on offer by engaging with those who have taken the courses and those who have delivered them. Engage the City Council's adult education team in the evaluation.

**Recommendation 3:** Work with parents and carers to produce an accessible guide to the pathway, including a simple diagram.

### Lack of transparency – Subject Access Requests

Parents and carers told us how they had resorted to Subject Access Requests (SARs) to gain access to the notes on their children, as there was not open and transparent communication with them.

Once they had access to the notes there was information in them that they were not aware of and judgements about the family or parents. Parents told us how in some cases the notes were inaccurate, or that there was no context to the information which could lead to misunderstandings.

Parents also resorted to SARs as they sometimes lacked information about who had been involved in the assessment of their child and why particular decisions had been reached. One parent told us how they had made a request and it told them a lot they did not know about the people involved in discussions about their child.



"Reliant on parents doing SARs to get the information on the referrals."

"Surely there must be a report somewhere, how can it go to MDT [Multi-Disciplinary Team] or panel without one?"

"Sometimes I regret asking for SARs as it's not nice to read as it's just not accurate."

"[There's] no context to notes."

"No explanation... they basically discharged with no reason."

"Even if you don't get a diagnosis, you should get a report of what is going on and how they have reached that decision."



## C. Getting on to the waiting list for an assessment

In this section, we share the experience of the referral process which leads to getting on the waiting list for an assessment.

One theme was the number of rejected referrals, sometimes multiple rejected referrals, and it was not always clear why the referrals had been rejected. It means getting onto the waiting list for an assessment was a drawn-out experience.

Parents and carers felt in many cases the referrals were rejected because the person completing the referral either lacked the knowledge of how to complete the forms or that the person designated to complete referrals did not necessarily know the child well enough. This theme is reflected in the role of school in completing referrals, see the section entitled 'Education completing the referrals without the knowledge or culture to do so' on page 31.

Parents and carers told us how referrals were rejected due to lack of evidence, but rather than ask for further evidence the referral was rejected, meaning the process had to start again from the beginning.



"Rejected three times through CAMHS."

"Referred six times."

"Had 12 referrals."

"Referrals are done by professionals who don't know the child."

"If a referral gets rejected you can't get another referral without a significant change. Nothing will change significantly because the paperwork wasn't filled in properly."

"They don't have all the evidence and then it gets rejected."

"It was mainly put down to evidence; they needed more evidence."

"We experienced multiple rejections which were often generic in nature and lacked clear guidance on what evidence was required."



## A personal story – Jack\*

In line with guidance from the National Institute for Health and Care Excellence, Jack has met the criteria for Autism as defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-11) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).



A referral was made for an ADHD assessment when Jack was in year one of primary school. Having heard nothing a year later, mum chased the referral and was told by CAMHS they had no record of it.

The initial assessment eventually took place two years later and Jack was placed on a waiting list for a care co-ordinator.

One year after that, CAMHS wrote to mum to say they would not proceed with the ADHD assessment because he is “meeting expectations academically”.

Later that same year, the ADHD assessment was re-started. We spoke to mum almost one year on from the observation and she was still waiting for someone to review the results.

*“The waiting list may not seem too bad, but it doesn't count the years waiting to be put on a waiting list.”*

\* Jack is not their real name.

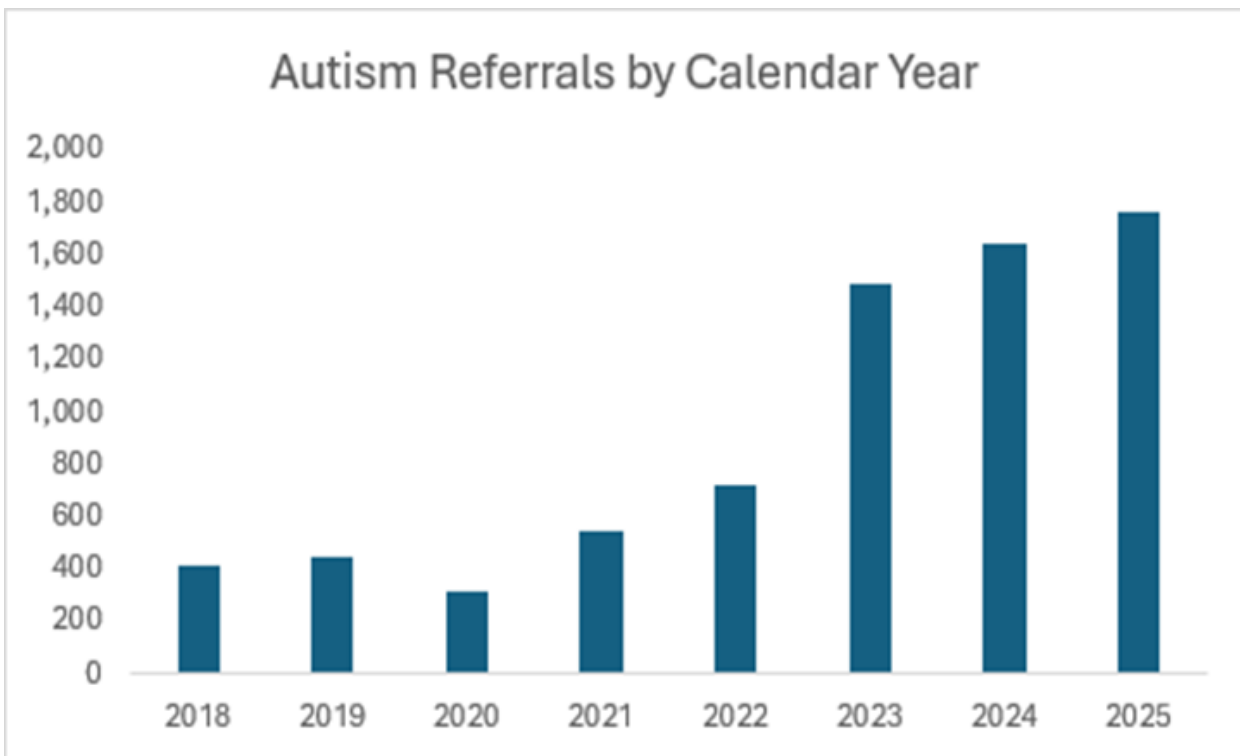
## Increasing demand for Autism assessments

There has been much media coverage of the increasing demand for Autism assessments and so we approached North Staffordshire Combined Healthcare NHS Trust for data relating to the local position. The data shows that the increase in referrals for assessment is experienced locally.

In 2018, there were 416 referrals for an Autism assessment and by 2025 this had increased by 423%, with 1760 children and young people referred for an Autism assessment. This is shown in the table and graph on the next page.

## Number of Unique Children Referred in Calendar Year

Autism	2018	2019	2020	2021	2022	2023	2024	2025	Total by Age Bracket
Up to 2 yrs	12	11	14	35	40	48	67	54	281
3 - 4 yrs	80	92	70	137	152	292	297	282	1402
5 - 7 yrs	116	104	73	120	145	340	375	392	1665
8 - 9 yrs	56	68	49	61	104	194	235	237	1004
10 - 14 yrs	115	142	80	140	199	451	502	593	2222
15 yrs	19	16	11	22	33	76	59	93	329
16 - 17 yrs	18	15	17	30	52	88	104	109	433
Annual Total	416	448	314	545	725	1489	1639	1760	



The data relating to repeat referrals for an Autism assessment also shows an increasing trend, as demonstrated by the table below.

### Number of Children with Repeat Referrals by Calendar Year (Stoke-on-Trent and North Staffordshire)

Autism	2018	2019	2020	2021	2022	2023	2024	2025	Total by Age Bracket
Up to 2 yrs	0	0	0	1	1	1	2	11	16
3 - 4 yrs	3	1	1	0	5	10	39	60	119
5 - 7 yrs	8	9	5	8	28	30	56	115	259
8 - 9 yrs	6	7	11	12	18	24	38	66	182
10 - 14 yrs	10	14	13	27	37	61	86	216	464
15 yrs	2	1	2	5	7	10	16	30	73
16 - 17 yrs	5	4	7	8	6	17	24	43	114
Annual Total	34	36	39	61	102	153	261	541	

The Trust was not able to supply referral data for ADHD; their response stated “prior to the Trust having a specific CAMHS ADHD service created, CAMHS ADHD referrals were subsumed within the Trust’s Core CAMHS Community Mental Health teams. As we are unable to extract ADHD specific referrals from our Core CAMHS Community Mental Health teams referrals, we are unable to provide an accurate response in relation to ADHD referrals trends.”

### Views on the increased demand

During the engagement, we asked a few people for their views on what was driving the increased demand and there was speculation about the possible reasons:

- In primary school, children have one teacher that knows them well and can put in appropriate support. When young people move up to middle school, they are taught by different teachers which means they don’t consistently get the support they need
- To ensure children transitioning to middle school get support, primary schools are seeking a diagnosis for children in year six (10-11 years of age)

- It is believed that a diagnosis is required for children to get support via an Education, Health and Care Plan
- Young people who didn't go to school during the COVID-19 pandemic didn't get the opportunity to develop masking skills
- Impact of social media "Hordes of people think they have these conditions that don't and this is taking up space for the people that do"
- Awareness has been raised by celebrities which means people are now recognising traits as ADHD/Autism.

## Increasing waits for an Autism assessment

Once a referral has been accepted, the child or young person will be put on a waiting list for an assessment. The waiting times between referral and assessment are long and growing. The Joint Strategic Needs Assessment from October 2022 shows an increase in waiting times for an Autism assessment, from 26 weeks in 2019/2020 to 49 weeks in 2021/22. See the table below.

Updated data from North Staffordshire Combined Healthcare NHS Trust shows waiting times have increased to 98 weeks for children and young people (2025/26 financial year) and 115 weeks for an adult Autism assessment.

	North Staffordshire Combined Healthcare NHS Trust service	Waiting Times (weeks)		
		2019/20	2020/21	2021/22
Children	School Age Autism Spectrum Disorder	26	40	49
Adults	Autism Assessment Service	19	40	46
Children	School Age Autism Spectrum Disorder (yr/yr growth)		53.80%	22.50%
Adults	Autism Assessment Service (yr/yr growth)		110.50%	15.00%

## Recommendations

**Recommendation 4:** The Joint Strategic Needs Assessment for Learning Disabilities and Autism be reviewed annually to ensure it is keeping up with trends in rising demand.

**Recommendation 5:** To reduce the number of repeated referrals for the same child, a deep dive should be conducted to fully understand the reasons and then all system partners should work together to improve the quality of referrals and the communication surrounding rejected referrals. Parents and carers should be equal partners in this process.

### D. Alternative providers

The waiting lists are so long and referrals are being rejected multiple times that parents and carers are pursuing alternative ways of getting an assessment. They are either paying for a private assessment or going via the NHS Right to Choose.<sup>4</sup>

The service offered by providers under the NHS Right to Choose was not always appropriate to the individual or family circumstances.

We heard of instances where, having received a diagnosis through either of these routes, the diagnosis was not accepted by North Staffordshire Combined Healthcare NHS Trust and so the child or young person was still unable to access support and were once again waiting for an assessment from North Staffordshire Combined Healthcare NHS Trust.

#### Right to Choose (England)

If a GP needs to refer you for a physical or mental health condition, in most cases you have the legal right to choose the hospital or service you'd like to go to. This includes private providers and applies to assessments for ADHD & Autism. The assessment is free to the individual. The NHS pays no more than they would pay an NHS provider.



"it isn't free so you have to find the money to pay for it."

"Won't accept a right to choose diagnosis."

"Some right to choose providers not NICE [National Institute for Health and Care Excellence] compliant."



<sup>4</sup> NHS. *Your choices in the NHS*.

<https://www.nhs.uk/using-the-nhs/about-the-nhs/your-choices-in-the-nhs/>

## Funding Right to Choose

The Staffordshire and Stoke-on-Trent's Integrated Care System's original financial savings plan for 2025/26 included a £3m reduction in its expenditure on private ADHD assessments. This led to concerns from the city council that this “may hinder adults and children accessing the wider forms of help they need – such as in their workplace or school – which often require a formal diagnosis before assistance and adjustments are made.”

This concern contributed to the council commissioning the Nuffield Trust to review the financial savings plan to understand how spending reductions would affect local residents and the extent to which the plans might increase cost and care burdens on to the local authorities and/or local residents.

The Nuffield Trust report states “There is evidence that these private assessments do not meet required clinical or quality standards, leading to delays, duplicated spend and patient distress when people receive a private diagnosis yet are unable to access medication or a treatment plan.”

The Integrated Care Board advised Healthwatch Stoke-on-Trent that it met all its obligations for clinically appropriate Right to Choose expenditure during 2025/26 and continues to do so.

### E. Falling between services/teams

Parents spoke of how their child had been passed between teams when they were awaiting an assessment, this was particularly the case when children had co-morbidities or a learning disability.

People also spoke about looked after children (children who are cared for by the City Council) having a different service route, but that service did not provide assessment and diagnosis.

We also heard about the lack of communication between services in different organisations – University Hospitals of North Midlands NHS Trust (UHNM), school and North Staffordshire Combined Healthcare NHS Trust.



“There's a gap between Learning Disability service and ADHD/Autism. They will only see LD for severe to moderate. If your child only has a mild learning disability, they should be seen under Core CAMHS, but they can't meet the needs. So, Core and LD argue about who should pick them up and the child is left unsupported.”





“We were put on the CAMHS waiting list. They waited 12 months and then said they couldn't assess because they are non-verbal. So referred to the LD team and they wouldn't do a full assessment.”

“Looked after children, foster children and adopted children, they can't access it, a diagnostic through CAMHS. They have to go through Yellow House, but they can't diagnose.”

“This lack of communication puts the responsibility entirely on the family to keep everyone updated... it is unacceptable that those services are not automatically communicating, particularly when medication is involved.”



Below is the list of teams within North Staffordshire Combined Healthcare NHS Foundation Trust serving children and young people. Some of the parents we spoke to had children under the care of more than one of these teams.

- CAMHS Autism Spectrum Disorder Team
- CAMHS Eating Disorders
- CAMHS North Stoke (includes ADHD)
- CAMHS South Stoke (includes ADHD)
- Children and Young People Intensive Support Hub (CYP ISH)
- Children's and Young People's Community Learning Disability Team
- Looked After Children (Yellow House)
- Crisis Care Centre
- Health-based Place of Safety (MH Act)
- Mental Health Support Teams for Schools
- Paediatric Psychology Service
- Parent and Baby Service (perinatal)
- Specialist Children's Short Breaks Service
- Transforming Care Programme
- Additional Roles Reimbursement Scheme (ARRS) staff in Primary Care
- Darwin Centre

## Recommendations

**Recommendation 6:** Identify opportunities to proactively integrate the offer made to children and young people, creating seamless routes between organisations and teams. The integrated offer should be extended to siblings and parent/carers.

### A personal story – Jenny\*



Jenny was diagnosed with Autism when she was two and is now 16 years of age. Jenny is too complex for core CAMHS but the learning disability team will not assess her.

*“If you can meet the criteria for CBT for core CAMHS, you’re fine, you’re picked up by core CAMHS. If you’re very complex, the LD team will pick you up.... because Jenny doesn’t meet the criteria for the LD team, doesn’t meet the criteria for core CAMHS, so Jenny’s left with nothing.”*

The reasons that have been given for not assessing Jenny for a learning disability include; she can problem-solve so can’t be learning disabled, her behaviour is too challenging, and her presentation leans more towards Autism.

Jenny’s behaviour is escalating and mum believes there is an underlying presentation which hasn’t yet been found.

Jenny has no access to an

- LD assessment
- ADHD assessment
- Autism Team for specialist support.

*“Jenny’s world is so small now... there’s no groups for Jenny to go to... Jenny can’t go to school, Jenny can’t even be with peers. Jenny’s social anxiety is that bad, she’s doing nothing. She goes to respite... she’s not with any other children. They don’t let her in the garden because it’s a flight risk.”*

\*Jenny is not their real name.

## F. Experience of assessment

Some parents and carers felt those undertaking the assessments of their children lacked the knowledge and experience they needed. They also spoke of their belief that there was a lack of training about Autism and ADHD for mental health nurses, and that the Oliver McGowan training they received was inadequate for their specialism.

This feedback warrants a deeper dive into the training of mental health nurses.

Oliver McGowan training

Mandatory training on Learning Disability and Autism designed to improve understanding, awareness and support.



“Most of these psychologists and nurses are textbook trained.”

“Mental health nurses only get half a day’s training on ADHD and Autism.”

“Oliver McGowan training is about making adjustments. It’s not for nurses who work with people or who support people with ASD or ADHD.”

“If a nurse is truly to support a young person they need to know about Autism and ADHD.”



## G. Post-diagnosis support

We received little feedback about the support offered post-diagnosis, largely because a lot of people we spoke to had not yet received a diagnosis.

One parent that had received a diagnosis from University Hospitals of North Midlands NHS Trust was signposted to the website of National Autistic Society. This feedback was shared with North Staffordshire Combined Healthcare NHS Trust as they offer a 12-week follow-up course to everyone who is diagnosed with Autism. Of the 150 people who have been offered the option, only 30 people have taken it up. Following engagement with PEGiS, videos have been created of the course content and the two organisations are working together to show the videos to parents.

## Recommendations

**Recommendation 7:** UHNM is reminded to include the offer of the 12-week programme post-diagnosis

### H. The role of school

The scope of this project included exploring issues within Special Educational Needs and Disability (SEND). As we introduce the role of school, let's return to the guiding principles of 'Building the Right Support'. This is what it states about school:

"As a child or young person, I want good opportunities and experiences as I grow up. For me, this means:

I feel safe and supported in a school that understands and meets my needs, without living in fear of exclusion and restraint.

My school enables me to reach my potential by building on my strengths.

If I need one, I have an Education, Health and Care Plan that me and my family are involved in developing, and my education setting is confident in delivering the support it sets out."

During our engagement we heard examples where schools fell far short of these guiding principles. We heard from parents and carers about education completing the referrals without the knowledge or culture to do so. We heard that the process of getting an Education, Health and Care Plan was "10 times worse than diagnosis process", with lots of waiting and deadlines not being met. We heard about non-typical presentations and the lack of understanding amongst school staff. We also heard about the economic and well-being impact on families when school can't manage the child in class.

## A personal story – Mehmet\*



From the age of two, mum has been trying to get a referral to CAMHS for Mehmet and has been unsuccessful. Mehmet is now 10 years old and has not yet made it onto the CAMHS waiting list.

In preparation for Mehmet going to middle school, a diagnosis was secured through a local alternative provider. With the outcome, mum went to her GP who referred to CAMHS, but CAMHS didn't accept the assessment and signposted to charities.

Without a diagnosis, Mehmet has been getting support in school and mum spoke highly of the Autism Inclusion Team (AIT), which has provided training in school, funded by school. AIT provides specialist support, training and interventions for children and young people with Autism up to the age of 25 and is part of Staffordshire County Council's education service.

Mum described ways in which school is not meeting Mehmet's emotional needs:

- Teaching staff can be sarcastic and Mehmet doesn't understand sarcasm
- School doesn't understand self-regulation and Mehmet has been punished for stimming
- Mehmet experiences anxiety-induced nausea in relation to school and when he feels sick in school, he is told "You just want to go home; you were running around at lunchtime and so you must be OK."
- Mehmet is overwhelmed by the noise in the playground and ways in which he managed this were removed. Alternative adjustments were put in place but mum did not feel they were sustainable.

### Stimming

Stimming refers to repetitive behaviours or movements used to self-regulate emotions, reduce anxiety, manage sensory overload and provide comfort

Mum asks:

"What about the quiet children, who are struggling but not expressing this through behaviour?"

\* Mehmet is not their real name. This story was shared by a parent who lives in Staffordshire, it has been included here as the NHS provider is the same as the one city residents access.

## Education completing the referrals without the knowledge or culture to do so

Parents felt there was an overreliance on education to complete referrals for assessment without teachers necessarily having the knowledge or understanding of how to complete the referral.

Some felt there was an onus on teachers to, in effect, diagnose Autism or ADHD before they were able to complete the referral to the standard needed to be accepted for an assessment by health.

Others felt the culture in schools was to accentuate the positive in relation to a child's behaviour and attainment, and this worked against a successful referral.

Likewise, schools were putting in place support for the child which would then mean some of the behaviours were not present at school.



"They're not the trained people who know what they're looking for, so they don't know how to fill in the form."

"Schools don't have the evidence or the qualifications to make referrals."

"Schools don't see symptoms- children have meltdowns at home."

"Why are they putting diagnostic criteria on to the SENCO [Special Education Needs Co-ordinator]? They just know the child needs help."

"Putting too much on schools. Basically, diagnosing at referral to get an assessment."

"Schools are used to [emphasising] the best bit. They won't say the worst bit; they aren't programmed that way."

"What if school isn't an issue?"

"School put in adjustments and that becomes the norm. They don't realise they are providing support."



## **Not understanding the different presentations**

Concern was expressed by parents and carers of children who were considered quiet or compliant in the school setting. They felt they were not being picked up because they did not present in a way that teachers expected for Autism or ADHD.

One spoke of how their child was quiet at school compared to their classmates so was not seen as being in particular need of support.

Some spoke about how their child had not received a diagnosis because they were seen as intelligent, despite there not being a link between Autism & ADHD and intelligence.

More than one parent spoke about their child not needing education support but very much needing emotional support.

One parent was told by the Special Education Needs Coordinator (SENCO) that their child's shoes were too tight because they were walking on tiptoes. This is a known indicator of Autism.

Anxiety presents in many ways, including needing to go to the toilet. We heard about a 14-year-old who was refused a request to go to the toilet and they got into trouble for going anyway. When their parent asked why they left the classroom, they said they didn't want to wet themselves in front of their friends.

We also heard of numerous examples where parents were penalised and threatened for their children not achieving 100% attendance, demonstrating a lack of understanding of what a parent goes through to get their child to school. One parent told us that school avoidance is not recognised. The associated anxiety brings on physical symptoms such as sickness and stomach ache. When school texts mum to say her child is late "You feel as though you are failing".

The parent of a child who was given a detention for not sitting still and for talking, pulled the child out of detention because of the distress their child was experiencing.



“Compared with the rest of the class my child is very compliant.”

“Those that cannot mask and are disruptive, they get a diagnosis... but those who don't present like that get missed.”

“How can children be in crisis if they go to school every day? It doesn't look at what they are then doing in school every day.”

“They're telling people they can't have ADHD because they're clever.”

“Doesn't need academic support, needs emotional support to succeed.”



## Getting an Education, Health and Care Plan (EHCP)

Some organisations felt that schools were not putting in adequate support for children without an Education, Health and Care Plan and so parents were seeking a diagnosis to access support for their children in school.



“Parents often don't want the diagnosis, the piece of paper, for their child but they need it to get the EHCP and the support. They may not need an EHCP, they may not reach the levels.”



Because parents mentioned the long wait for an EHCP, we asked Stoke-on-Trent City Council for the data. The statutory timeframe for an EHCP is 20 weeks. This is met in over 60% of cases in Stoke-on-Trent. We were told that, in 2026, there are 3,727 children in the city with a Special Educational Need and Disability EHCP.

During the engagement, we were told children were being removed from school by their parents because school couldn't meet their needs and so we asked the city council for the data around this. There are 108 children and young people aged 5-25 years with an EHCP who are awaiting educational provision.

We heard the story of one child who got an EHCP last year, which named mainstream provision, but the mainstream schools said they couldn't meet the child's needs. They have been told there are no places at a special school and so the parent has lodged an appeal and has had to provide more evidence. It is

unlikely that the child will have a school place secured by September and so will be out of education.

## Impact on families

Parents spoke about the impact that trying to get a diagnosis for their child had on their own mental health and wellbeing. Others spoke about how it had impacted on the wider family. We also heard from parents who have given up work because school couldn't meet the needs of the child. With a significantly reduced household income, children are at risk of being pushed into poverty, creating an additional disadvantage.



"I got therapy because they made me feel like I was crazy."

"Affects parents' mental health and they then blame the child's behaviour on parental mental health."

"Families are breaking apart."

"Impacting on the other three children."



## I. Looked after children

We heard from parents who had adopted children. They told us that the post adoption support fund has been reduced in value. It used to provide £2k for an assessment and £5k for therapy. This has been cut to £3k in total and assessment costs have increased to £2.5k, leaving only £500 for therapy.

As children age and start to encounter transitions, they start to experience greater anxiety and this can be communicated through aggression. We were told there is no crisis team for children under the age of 13.

When a child younger than 13 was taken to the Emergency Department at Royal Stoke Hospital because they were dis-regulated to the point of being a danger to themselves and others, they were sent to Harplands Hospital. After being locked in a room for some time, the parent was told there was no psychologist who would see them because of their age and complexity. Mum was asked whether she felt safe enough to take them home. As there was no other option, she did. When mum phones the crisis team, she is told to ring the Police if she doesn't feel safe.

# 4. Our conclusions

Healthwatch Stoke-on-Trent set out to explore the issues associated with Child and Adolescent Mental Health Services (CAMHS) and delays/rejection rates of Autism and ADHD assessments, along with Special Educational Needs and Disability (SEND) services for children and young people.

We captured various accounts from parents and carers as well as organisations providing support. Our key findings have been grouped into themes, which have informed our recommendations.

We acknowledge that much work is going on in this area and we hope this report builds on the conversations that we know to be happening and that it will help create sustainable solutions, where all actors are equal.

## Recommendations

**Recommendation 1:** The Integrated Care Board conducts a full commissioning cycle review of Autism/ADHD services to assure Board members it is not widening health inequalities in the city, when compared to other areas within the Integrated Care System.

**Recommendation 2:** Undertake an evaluation of the parenting courses on offer by engaging with those who have taken the courses and those who have delivered them. Engage the City Council's adult education team in the evaluation.

**Recommendation 3:** Work with parents and carers to produce an accessible guide to the pathway, including a simple diagram.

**Recommendation 4:** The Joint Strategic Needs Assessment for Learning Disabilities and Autism be reviewed annually, as is required of the Health and Wellbeing Board's JSNA.

**Recommendation 5:** To reduce the number of repeated referrals for the same child, a deep dive should be conducted to fully understand the reasons and then all system partners should work together to improve the quality of referrals and the communication surrounding rejected referrals. Parents and carers should be equal partners in this process.

**Recommendation 6:** Identify opportunities to proactively integrate the offer made to children and young people, creating seamless routes between organisations and teams. The integrated offer should be extended to siblings and parent/carers.

**Recommendation 7:** UHNM is reminded to include the offer of the 12-week programme post-diagnosis

# 5. Next Steps

## Hearing from adults with Autism and/or ADHD

Over the last few months, we have spoken with a number of adults who were diagnosed with Autism or ADHD later in life and will be publishing a series of in-depth case studies. A common theme was that they had been diagnosed with other mental health conditions earlier and, therefore, received inappropriate interventions, or no support at all.

## Presenting the voice of children and young people

This report reflects what we heard from parents and carers and we would really like to follow up with a piece of work that presents the voices of children and young people, so are looking for organisations that we can work with to achieve this.

## Keeping the conversation going

Healthwatch Stoke-on-Trent will be organising workshops related to Autism and ADHD, follow us on Eventbrite to find out more. In the meantime, we would welcome any contributions to this very important topic. We would be particularly keen to hear from GPs or primary care professionals, schools, employers and universities. Our contact details are at the very end of the report. Please keep the conversation going.

# 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  
**Engaging Communities Solutions C.I.C.**

Blakenall Village Centre, 79 Thames Rd, Walsall, WS3 1LZ.

Tel: 0800 470 1518 | Email: [contactus@weareecs.co.uk](mailto:contactus@weareecs.co.uk)



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**healthwatch**  
Stoke on Trent

[www.healthwatchstokeontrent.co.uk](http://www.healthwatchstokeontrent.co.uk)

t: 03303 130 248

e: [info@healthwatchstoke.co.uk](mailto:info@healthwatchstoke.co.uk)



@HealthwatchSoT



[Facebook.com/HealthwatchStoke](https://www.facebook.com/HealthwatchStoke)