

**Responses to the report entitled
“If you start with kind, you’ve
won”**

June 2026

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Introduction

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 assessments.

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.

A report feeding back the themes identified was published on 18th June 2026. Organisations named in the report were given the opportunity to check the accuracy of the report prior to publication and to provide a comment. This document contains the comments received.

Caudwell Children was invited to comment as it was named in the draft report. It was incorrectly referred to as a provider on the Right to Choose framework. This was amended in the final report, but for completeness, Caudwell Children's response is included in this document.

Integrated Care Board

We acknowledge the findings and recommendations of the report and respect the opinions and experiences of families reflected within it.

Children and young people, along with mental health, are two of the key priority areas for the ICB's new approach to Neighbourhood Health and we recognise the importance of getting these services right.

There are recognised gaps in meeting the demand for ADHD and Autism support, as there are across the country. We are taking learning from Shropshire, Telford and Wrekin and Staffordshire to address any inequity in access to services now we are established as a cluster.

Some of the services referenced, such as EASE in South Staffordshire, are specific transformation pieces led by the providers themselves and funded via the Children's Provider Collaborative Toucan. These funding streams are open to all providers to bid for to pilot new initiatives based on the needs of the children and young people in their geography, however can lead to variation across the cluster as these ideas are means tested, evaluated and then potentially expanded upon.

In response to the recommendations related to the ICB:

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

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.

We are currently undertaking a system-wide piece of work to review referral pathways, criteria, and service gaps. The aim is to ensure that children and young people are seen by the most appropriate service(s) first time, reducing the risk of children and young people being bounced between services or requiring multiple referrals before accessing the support they need.

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.

There is a plan for the Learning Disability and Autism Joint Strategic Assessment to be refreshed in 26/27. The ICB will consider alongside other partners, including people with lived experience, the validity of refreshing yearly thereafter.

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.

The ICB will work with North Staffordshire Combined Healthcare NHS Trust to validate the repeat referral data and to understand the issues behind repeat referrals for the same child.

North Staffordshire Combined Healthcare NHS Trust

We welcome the Healthwatch Stoke-on-Trent report and the opportunity to reflect on the experiences shared by children, young people and their families. We are committed to continuous improvement and recognise the importance of co-production and meaningful engagement.

Our Response re the key themes;

Parenting Support and Perception of “Parental Blame”

The report highlights concerns that parenting courses are perceived as a form of blame or a requirement to access services.

We would like to clarify:

Parenting programmes are not a requirement for referral acceptance.

We accept referrals regardless of course completion.

The pathway is flexible and not rigid.

Parenting programmes are offered in line with NICE guidance, which identifies parent training/education as a first-line intervention for ADHD and associated behaviours. These programmes are designed to support and empower families, not to attribute blame.

We recognise that the current perception does not reflect service intent, and we are committed to shifting this narrative through clearer communication.

Service Improvements and Developments

1. Co-Produced Referral Process

We have introduced a new joint Neurodevelopmental referral form, this has been co – produced with Parents, Carers and Schools; early feedback is positive with reports that it is helping to improve clarity and quality of the referral process.

2. Strengthened Parent Engagement

We have significantly increased opportunities for direct engagement:

Our ADHD and Autism Team Leads regularly attend SEND Lounge sessions

Our Staff are attending all the PEGiS in the park events to improve engagement and visibility.

Our Service Manager also attends the SEND Lounge, PEGiS events and has a monthly zoom parent drop-in session.

This is reflective of our ongoing intentions to maintain a consistent approach to co-production and listening to families.

3. Pre-Assessment Support

In response to feedback:

We are introducing pre-assessment workshops for families on waiting lists. These will be delivered both Face to face at the Hazel Tree and online for accessibility purposes.

These will provide:

Clear information about the pathway

Practical strategies and early support

4. Improved Communication and Information

To further address concerns regarding lack of clarity of our processes and pathways, we are in the process of developing a dedicated ADHD and Autism (all- age) webpage / portal. The content of this will be co-produced with parents and will include pathway guidance, resources and support advise and options.

We would like to offer assurance that our commitment to ongoing engagement, co-production with families as our key partners is one of our key priorities, we believe this is fundamental to ongoing improvements across the pathway.

Furthermore, we remain committed to working collaboratively with Healthwatch, families and system partners to ensure services are accessible, supportive and responsive to need.

Caudwell Children

We would like to clarify that we are a charity that funds clinical assessments, and in order to maximise the number of families we can help, we ask families to contribute 20% to the total cost of the assessment. We have decided not to be on the NHS Right to Choose framework as this would draw funds from the available amount for NHS providers, and we are seeking to enhance that amount incrementally instead of drawing from it.

Our diagnosis and reports are widely accepted by NHS services, and where there are questions, our clinical team will gladly have a conversation with any service to explain the validity of our assessment process. Once this conversation has happened, the diagnosis is always accepted. We have also carried out assessment on behalf of the NHS, as part of the reduction to waiting list initiatives.

We would also like it to be clear that the "Risk to Right to Choose" section does not apply to us, as firstly, we are not on the Right to Choose framework as mentioned above, and secondly, because our assessment process is fully NICE compliant, and gold standard.

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