



Impact report:

Progress and Gaps – What Families Say About Autism and ADHD Services

June 2025



Summary

The experiences that families shared with Healthwatch Birmingham have led to positive changes within the ASD and ADHD assessment and diagnostic pathway in Birmingham with a strong emphasis on co-production, early help, and communication. As a result of actions taken by Birmingham and Solihull NHS Integrated Care Board (BSOL ICB) and Birmingham Community Healthcare Trust (BCHC):

- There is less confusion and anxiety for children, young people, and their families due to improved communication from services and information provided.
- Families are getting more support while waiting for assessments and diagnoses.
- Feedback and experience from children, young people, parents, and carers is being used to improve services, develop resources, surveys, and to shape plans.
- Staff are better trained to support children and young people with ASD and ADHD.
- Services are less fragmented and responsive to the needs of children, young people, and their families.
- Transitions for children and young people to adult services are smoother and more joined up.
- Children and young people experience a more compassionate and inclusive service.



Our initial report and key areas of improvement identified

In 2024, children, young people and their families told Healthwatch Birmingham about the barriers and challenges they face when going through the Autistic Spectrum Disorder (ASD) and ADHD assessment and diagnostic pathways in Birmingham. In our report, families told us that it is hard to wait a long time for an assessment, diagnosis and support. Families did not always know what help was available. They noted that professionals – especially those within schools – were not always confident in supporting children, and that communication between services is poor including communication and partnership working between services and families. Families asked for support during waiting periods, more training for professionals, and improvement across the assessment and diagnostic pathway.

What families told us needs to improve:

Support families, children and young people to ‘wait well’

- Better access to information for parents/carers.
- Clear signposting to available support.
- Ensure continuous contact with a key named professional.
- More communication and increased involvement with families.
- Make support available without requiring a diagnosis.

Increase training and support for professionals referring children and young people for assessment

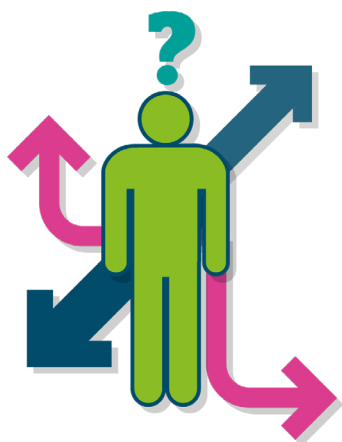
- Improved quality of referrals.
- Reduce the number of referrals delayed due to missing or inadequate information.
- Training and guidance for professionals to understand neurodiverse conditions and the referral pathway.
- Clearer information about assessment criteria and support is available while people wait.

Improve the assessment and diagnosis process

- Use of parent/carer insight in assessments.
- Better communication and co-ordination between agencies and professionals involved in assessment and diagnosis.
- A one stop shop with an interagency and multi-disciplinary approach to assessment and diagnosis.

Progress and impact

We shared what we heard from families with BSOL ICB and BCHC. They listened and have made some important changes as a result. Below we highlight some of these changes (see appendix for the range of changes being made).



Enhanced support for families while they wait

A 12-month pilot programme is being launched this summer (2025) to deliver targeted support before diagnosis, addressing a key area of concern raised by families. This means that families no longer have to face the long gaps without support or contact with services.

- The Autism Hub provides a single point of contact for families, schools, GPs and other professionals. The Hub will give advice, support and updates to families.
- The new Autism Support Team delivers direct school support (e.g. training), advice and faster assessments for urgent needs.
- A co-production team is working with families to help design and test new ideas, shape the support on offer, and resources available to families.



Increase training and support for professionals referring children and young people for assessment

The Partnership for Inclusion of Neurodiversity in Schools (PINS) project launched in September 2024 to help staff in the education sector who support children and young people. Ensuring that staff feel confident and equipped to support every child with neurodiverse needs.

- 40 schools received training on a range of topics including *Sensory Processing in the Classroom and Neurodiversity and School Readiness*.
- 20 schools are participating in PINS in 2025
- The Autism support team is providing schools with ongoing training, and rapid assessments for children/young people identified as high priority.



Improvements to the assessment and diagnosis pathway

An alternative offer pilot for the ASD/ADHD pathway began in 2025 (summer) to build a neurodevelopmental care system that works to meet current needs but also addresses future needs. A dedicated Neurodevelopmental Future Model Group is leading work to improve how children and young people are assessed, diagnosed, and supported. The work carried out ensures:

- Earlier support, integrated services, better transitions to adult services.
- Focus on outcomes rather than just diagnoses.
- Joint commissioning between the NHS and local authorities to make sure support is joined up, efficient, and focused on what really works for families.
- Use of data to shape the new model of care and ensure it meets local needs.
- A respect for the right to choose so that those choosing to access assessments through the independent sector are not disadvantaged or left without support.



Co-production and parent-carer involvement

The involvement of children, young people, parents/carers is ensuring that their lived experience inform service planning, design, and implementation.

- The Birmingham Parent Carer Forum (BPCF) is helping develop resources, shape plans, and improve letters to families (e.g. myth-busting information and letters that are sent to parents) through regular meetings.
- Parents and carers have co-produced new information materials and 'myth-buster' guides.
- The SEND Parent Carer Forum have co-produced two surveys to hear from families and young people regularly.
- Families are helping redesign the way services assess and diagnose ASD/ADHD in children and young people.
- A commissioning engagement session with young adults was held in February 2025 to help identify commissioning priorities in 2025/26.
- NHS Commissioners have received co-production training to ensure all are equipped to make our collaboration with parent carers as meaningful as possible.



Improved communication and transparency with families

New resources to help families find support have reduced confusion and anxiety, and helped set clearer expectations for those waiting for assessments. Families are better informed and this has improved satisfaction.

A new support letter for families on the waiting list includes:

- An acknowledgement that a referral has been received and explains the assessment process
- A link to the latest waiting times to help set expectations www.bhamcommunity.nhs.uk/ndp-waiting-times
- A link to a support pack for families while waiting: www.bhamcommunity.nhs.uk/ndp-asd-support-for-children-and-families

The support pack includes:

- The process from referral to discharge
- Support available while you wait
- Where to find more help for children and young people with SEND
www.localofferbirmingham.co.uk
www.localofferbirmingham.co.uk/specialist-send-support-services
- Who to contact in a crisis or if child's mental health worsens

Support Letters have been sent to over 200 families (with 500 sent out each week) acknowledging referrals, signposting support, and setting expectations.

Myth-buster resources co-produced with Birmingham Parent Carer Voice to improve understanding of the autism and ADHD pathway.

New videos and online information

- An information film has been produced to provide a visual explanation of autism and ADHD services <https://vimeo.com/1074316625>

Conclusion and next steps

We're pleased that work by partners across the NHS, education and social care is starting to make a difference to the experience of children, young people and families who are referred for an autism or ADHD assessment. But we know things are still not the same for everyone, and there's more to do to make sure everyone has a good experience and gets the support they need.

Many children, young people and families still face challenges, such as:

- Finding it hard to get the support they need
- Not being sure why or when a diagnosis is needed – in most cases, support can start before a diagnosis is given
- Delays when young people move from children to adult services
- Some new services not yet being available in every part of the city
- Long waits for an assessment

We're committed to working together to improve these things, and to making sure that being neurodiverse doesn't stop any child or young person from learning, developing or moving into adulthood with the right support.

The feedback that children, young people, and parents and carers shared with Healthwatch Birmingham has already helped to bring about real changes. Families now have:

- Better access to information
- More support while they wait for assessments
- More chances to help shape services
- Schools that feel more confident to support children and young people with different needs

Birmingham and Solihull NHS (BSOL ICB) and Birmingham Community Healthcare Trust (BCHC) know there's still more to do to make long-term improvements to support autistic and ADHD children and young people.

Healthwatch Birmingham will keep listening to families and making sure their voices are heard, shared and used to make services better.

As part of our wider work around SEND, Birmingham Children's Trust asked how we could better hear from parents and carers. We're now creating a new feedback form to help families tell us more clearly about their experiences. What we learn will be shared with the right people to help improve support for families using SEND services.

You can share your experiences by:

- Visiting our online Feedback Centre here: [Find a service Healthwatch Birmingham](#)
 - Calling Healthwatch Birmingham on 0800 652 5278
 - Emailing: info@healthwatchbirmingham.co.uk
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Who is Healthwatch Birmingham?

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and consider, the public voice. Healthwatch Birmingham listens to and gathers public and patient experiences of using local health and social care services such as general practices, pharmacists, hospitals, dentists, opticians, care homes and community-based care. We hear these experiences via our Information and Signposting Line, our online Feedback Centre, and through our community engagement activity led by staff and volunteers. You can read more about the work of Healthwatch Birmingham here: <https://healthwatchbirmingham.co.uk/about-us/>

Appendix: BSOL NHS ICB and BCHC Response

What resources will you produce to inform and signpost children, parents and carers?

1. New Support Letter for Families on the Waiting List

Families with a child or young person on the current waiting list for an autism assessment will now receive a **support letter** developed by Birmingham Community Healthcare NHS Foundation Trust (BCHC).

The letter includes:

- Confirmation that your child's referral has been received.
- Acknowledgement that the demand for assessments is very high.
- A link to the latest waiting time updates:
www.bhamcommunity.nhs.uk/ndp-waiting-times
- Information about how children are booked in for assessment – based on both clinical need and the time they've been waiting.
- A link to a **support pack** for families while waiting:
www.bhamcommunity.nhs.uk/ndp-asd-support-for-children-and-families

The support pack explains:

- What happens from referral to discharge from the service.
- What support is available while you wait.
- Where to find more help for children and young people with special educational needs or disabilities (SEND), including the Birmingham Local Offer:
www.localofferbirmingham.co.uk
www.localofferbirmingham.co.uk/specialist-send-support-services
- How to request a printed copy of the pack.
- What to do if your child's mental health worsens, including crisis contact details for Forward Thinking Birmingham.

So far, 200 letters have been sent out, and 500 more are going out each week.

- We have worked closely with Birmingham City Council and Birmingham Parent Carer Voice to develop a range of 'myth-buster' resources. The aim is to provide parents and professionals with clear information about assessments for conditions like autism and ADHD.

2. Information Films

We have produced a short information film, available on the BCHC website which gives information about ADHD and Autism services. You can find it here:

<https://vimeo.com/1074316625>

3. A New Pilot Programme to Support Families While They Wait

In March 2025, BCHC got approval to start a **12-month pilot programme** to better support children, families, and professionals while they wait for autism assessments. This pilot will begin in **Summer 2025** and includes three main parts:

A. The Autism Hub

- A single point of contact for families, schools, GPs and others.
- Helps gather information early and signpost to helpful resources, workshops and support groups.
- Families will receive regular updates and communication.

B. The Autism Support Team

- Provides advice, support and training to schools and families.
- Works directly with schools to support children at risk of exclusion.
- Offers faster assessments for children with more urgent needs.

C. The Co-Production Team

- Makes sure the views of families and professionals shape how services develop.
- Feedback will help improve the support on offer and guide future plans.
- This work is linked to wider improvements being led by the local NHS.
- The team will be dedicated to coproduction but will also support all staff to work more collaboratively with parents, children and young people.

We are currently identifying schools that will be part of the pilot.

Please note:

This new offer is a **pilot** – it's not the final model. We'll keep listening and adapting based on feedback from families, carers, and professionals.

We are also working in partnership with Birmingham City Council who have invested additional resource to support the neurodevelopmental pathway for children, young people and families. Schools are also at the heart of this work.

How will you collaborate with parents and carers and involve them in developing these resources?

Our NHS family in Birmingham is committed to working with children, young people and families to improve experience and achieve better outcomes. We know that we have more work to do to ensure that our approach to co-production is effective and acknowledge that we can do better in this area.

Since the Healthwatch report was produced we have done a number of things:

Producing information resources: Birmingham Parent Carer Forum (BPCF) have been part of the group of people that developed the myth-busting information and helped us to improve the letters that were sent to parents.

Parent Carer Survey: We are working to establish a reliable baseline to assess the performance of Special Educational Needs and Disability (SEND) and Alternative Provision (AP) services.

As part of this effort, the SEND parent carer forum has co-produced two surveys—one for parent carers and another for young people with additional needs who either have an Education Health Care Plan (EHCP) or receive SEND support.

The survey was open during March and the link was sent out to all organisations who are part of the SEND Network in Birmingham. We also held engagement events with Parents and carers to review the survey and to ensure the questions were accessible.

This survey will be sent out at regular intervals in the future and the results will be shared within this report once received. Opportunities to participate in future survey will be published through Birmingham Parent Carer Forum and via posters in clinics and on the Birmingham Community Healthcare Trust Website.

We are now launching a programme of work to **redesign the way in which we assess and diagnose ADHD and autism in children and young people**. We say more about this in section 4, below. This work is being led by a Neurodevelopmental Future Model Group made up of staff from Birmingham City Council, the NHS and members of the Birmingham Parent Carer Forum. We are also seeking representation from schools and early years settings. Our approach to redesign will enable parents, carers, children and young people to suggest changes which we can 'test' using a process called 'system-modelling'.

NHS commissioners have received **co-production training** or attended a refresher session since the initial report, to ensure all are equipped to make our collaboration with parent carers as meaningful as possible. They also had a **commissioning engagement session with young adults** in February, where neurodevelopment was discussed as being a priority area for commissioning in 25/26 and they agreed with that.

Senior leaders from NHS organisations meet with the chair of the Birmingham Parent Carer forum on a regular basis to talk informally about how we are doing and how we can improve our approach.

Increase training and support for professionals referring children and young people for assessment

Families and professionals told us that school staff need more training to better support children with autism, ADHD, and other neurodiverse needs. The PINS Project was launched in September 2024 and, after a successful first year will run again this year.

In 2024:

- **40 schools across Birmingham** took part in the project.
- Schools could choose from a **menu of training options**, delivered by specialist teams from different agencies.
- The main training topics included:
 - *Understanding Sensory Processing in the Classroom* (delivered by Occupational Therapists).
 - *Neurodiversity and School Readiness* (delivered by Occupational Therapists and Speech & Language Therapists).
- Training was offered as a **mix of face-to-face and virtual sessions**, depending on what each school preferred.
- Staff gave **positive feedback**, and the training led to helpful follow-up conversations and advice for school teams.

What's Next: More Support for Schools

As part of a wider pilot programme launching in Summer 2025, we are expanding this work:

- A further 20 schools will be supported through PINS in 2025.
- The new **Autism Support Team**, linked to the Autism Hub, will:
 - Continue to offer **advice, training, and workshops** to schools and families.
 - Work directly with schools to support **children at risk of exclusion**.
 - Carry out **rapid assessments** for children who have been identified as a high priority.

This is part of our commitment to helping schools feel confident and equipped to support every child with neurodiverse needs

Improve the assessment and diagnosis process

We know that families want more timely, consistent, and meaningful support – not just a diagnosis, but real help that improves everyday life.

Since November 2024 we have been running a quality improvement programme to identify and make changes. So far we have focused on improving the information available to parents and carers, which is described in above.

There is lots more work to do, however. That's why Birmingham and Solihull NHS Integrated Care Board (ICB) are launching a dedicated **Neurodevelopmental Future Model Group**. This group is leading a wide programme of work to improve how children and young people are assessed, diagnosed, and supported.

What We're Doing

- **Creating a better pathway:** The focus is on making sure that children and young people get the **right help at the right time**, including earlier support and access to assessment where needed.
- **Overseeing wider improvements:** The group is also coordinating work across the **whole life course**, including:
 - Better transitions to adult services.
 - Improving shared care between health services and families.
 - Supporting choice, including for those who use the independent sector for assessments.
- **Linking with other key services:** This work is being joined up with wider improvements in:
 - Mental health support for children and young people.
 - Early Help and **Family Hubs**.
 - **Neighbourhood teams** working with children and families in local communities.
- **Learning from others:** We are looking at how other areas of the country have successfully improved their services, and using that knowledge to shape what we do in Birmingham and Solihull.
- **Working better together:** We're exploring **joint commissioning** between the NHS and local authorities. This means pooling resources to make sure support is joined up, efficient, and focused on what really works for families.

- **Using data to make smarter decisions:** We're working with business intelligence experts to use local data to shape the new model of care and ensure it meets local needs.

Testing and Improving the New Approach

We won't roll out big changes all at once. Instead, we will **co-design a new model** with input from families and professionals, and **implement with a small group of schools and Family Hubs** first. This will help us learn what works best and make improvements before wider rollout. We are aiming to co-design a new approach in the Spring and Summer and begin to implement in the autumn.

We are also working alongside **adult neurodevelopmental services** so that children and young people experience smoother support as they grow up — creating a joined-up, 'life-course' approach to neurodiversity.

Respecting the Right to Choose

We will make sure families who choose to access an assessment through the independent sector under the NHS **Right to Choose** policy are not disadvantaged or left without follow-up support.

Working in Partnership

This programme is being developed **with families, schools, healthcare providers, and local services**. Design groups include Parent Carer Forums, community providers, and education representatives — ensuring the voices of those who use and deliver services are at the heart of change.

A Long-Term Commitment

We understand the scale of the challenge and that there are **no quick fixes**. But this is a long-term plan, with clear milestones for improvement. It's backed by the new **alternative offer pilot** starting in Summer 2025.

Our commitment is to build a neurodevelopmental care system that works better — not just for today, but for the future.





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