



# Experiences of the neurodevelopmental assessment and diagnostic pathway for children and young people in Birmingham

July 2024



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## Executive Summary

### Background

There has been a rapid increase in waiting times for assessment and diagnosis for children and young people with neurodevelopmental conditions in the last five years. The Nuffield Trust estimates that 1.2 million people with autism and 2.2 million people with Attention Deficit Hyperactivity Disorder (ADHD) are waiting for a diagnosis and support. There is an even longer wait for a first appointment after being referred, due to factors such as long waits for initial referral and people requiring multiple appointments before further investigations. For autism, NICE recommends that an assessment should start within three months of referral, so that people receive appropriate support. Referral or waiting times for ADHD assessments are less certain as no framework or standard exists. However, a report in 2023 showed large variation in ADHD waiting times between areas with some people waiting months and others years.<sup>1</sup>

Delayed or missed assessment and diagnosis delays access to support, and has a negative impact on wellbeing, participation, and quality of life (Rutherford et al, 2021). For some children, failure to provide timely support has led to an increased prevalence of mental ill health and greater risk of school exclusions.<sup>2</sup> The Birmingham strategy for autistic children, young people and adults (2021–2026) also recognises that more work is needed to address long waits for diagnosis and support following diagnosis. In February 2023, a debate in Parliament recognised the problem of waiting lists for autism and ADHD assessments for children and announced increased funding to reduce waiting times.

Increased demand for autism and ADHD assessment, diagnosis and support can lead to some children and young people waiting years for health and education support. To address the problem, suggestions have been made to move to a system where faster support is offered without relying on a diagnosis. This will entail changing the perception that a diagnosis is needed before support can be given. Early identification and support mean that children and young people with autism and ADHD are more likely to thrive in mainstream schools and their needs are supported in a timely way.<sup>3</sup>

### Objectives

This study focused on understanding the experiences of the Autistic Spectrum Disorder (ASD) and ADHD assessment and diagnostic pathways for children and young people in Birmingham, the barriers and challenges they face, the support they receive whilst waiting and what can be improved. The report provides service leads with findings to take forward to improve the diagnostic and support pathway as well as the support provided while people wait.

<sup>1</sup> <https://www.nuffieldtrust.org.uk/news-item/the-rapidly-growing-waiting-lists-for-autism-and-adhd-assessments>

<sup>2</sup> <https://www.nuffieldtrust.org.uk/news-item/the-rapidly-growing-waiting-lists-for-autism-and-adhd-assessments>

<sup>3</sup> <https://www.centreforyounglives.org.uk/news-centre/new-analysis-reveals-autism-assessment-and-support-crisis-with-tens-of-thousands-of-children-waiting-months-and-years-for-help-after-demand-rockets-by-over-300-since-covid>



## Methodology

A questionnaire was co-produced with parents of children going through the ASD and ADHD assessment and diagnostic pathway. The questionnaire was shared through social media, and various stakeholders including Birmingham Community Healthcare NHS Foundation Trust (BCHC), community groups and the Birmingham Parent Carer Forum. One hundred and fifty-two people responded to our questionnaire. We excluded the experiences of those aged 20 – 25 years old as they fall between children and adult services<sup>1</sup>, therefore responses from 137 people were used to write this report. We further explored issues with three of the people through semi-structured interviews.

## Key findings

Since the Ofsted and CQC SEND inspections of 2018 and 2021<sup>2</sup>, including a report on progress in 2023, work has/is being carried out by providers and commissioners of the neurodevelopment pathway to make improvements. Especially, around inter-agency working, coordination of assessments, waiting times, co-production, parental engagement among others. We therefore acknowledge the amount of work taking place in the system to improve the neurodevelopmental assessment and diagnostic pathway. Indeed, for people who told us they had a positive experience, the things that worked well was the quick diagnosis they received from a specialist, clear communication and follow through with actions agreed. Most people (71%) whose children had a diagnosis expressed satisfaction with the professional that disclosed their child's diagnosis.

***Had to wait for consultant appointment to come through but diagnosis was given after 1 appointment, did not have to go back and forth with school as they had given letters.***

This report aims to focus activity in areas where parents and carers feel would have the most impact increasing support for them and their child. Overall, more people are dissatisfied with the ASD and ADHD assessment and diagnostic pathway in Birmingham with 71% describing it as poor or very poor. People see the ASD and ADHD assessment and diagnostic pathway in Birmingham as stressful, a battle and a burden on parents. It is long, made up of lengthy and multiple assessments and lacking in support for children and young people as well as parents. The referral was the first battle in the process that people faced leading to a diagnostic delay. Barriers to a referral include:

- Length of wait for the referral and professional support.
- Professionals not submitting documents on time and referrals being missed, further delaying the assessment and diagnostic process.
- Restrictive criteria and thresholds.
- Professionals knowledge of the referral pathway – how, when and who to refer to.
- Focusing on parenting style and child's behaviour rather than the child's symptoms.
- Poor communication and partnership working with families.

The second battle for people in the pathway was the diagnostic assessment with 64% of the people rating their wait for an assessment as poor or very poor. People described the assessment process as nerve-racking, lengthy, confusing process, lacking in communication and engagement, and with changing thresholds leading to increased waiting times, lack of support and feeling alone.

<sup>1</sup> These experiences have been entered onto our feedback system and will be shared with commissioners and providers including the CQC.

<sup>2</sup> <https://www.localofferbirmingham.co.uk/ofsted2021/accelerated-progress-plan/>



Delayed diagnoses have had a negative impact, as without a diagnosis children and young people are living without the support they need. Long waiting times delay intervention which not only prevent people from getting vital care and medication but also affects the management of ASD and ADHD. This leads to academic and social struggles, emotional distress and prolonged periods of unmanaged symptoms.

*I feel the long delay in getting referred and assessed for almost 8 years has robbed my child and me of enjoying her Secondary School years. Mainly due to having no support and no diagnosis until aged 16yrs.*

*There's many places and even education wise where my child is missing out on appropriate support for her needs, as she has not received diagnosis and without the diagnosis. There are not many places that will support. So basically, my child is stuck in limbo waiting until we can receive an official diagnosis to help.*

Living with undiagnosed or unmanaged ADHD and autism has an impact on people's mental health, resulting in anxiety, depression and self-esteem. It also leaves a strain on families left to manage the day-to-day challenges posed by ADHD and autism symptoms.<sup>1</sup>



Support received throughout the assessment and diagnostic pathway was rated poor or very poor by most people. Many told us that they did not receive any support with only 29% telling us they received information about post-diagnosis support.



*Waiting lists are generally years long. Clinicians are not properly trained. Services are gate kept by discriminatory criteria that disadvantages certain autistic presentations and is dependent on the knowledge and good will of schools having knowledge and putting effective SEN support in place. There is no support pre diagnostically and little to no support post diagnostically. Access to mental health and educational support is poor and again professionals are not always neuro informed.*

Exploring referrals and waiting times for autism and ADHD assessments and treatment is crucial to understanding the problem. However, many children and young people are blocked from getting care and support until they get a diagnosis. A report by the Child of the North initiative (2024) set out several recommendations. Key was a move away from a diagnosis led to a needs led approach where care and support are offered in a timely way without waiting for a diagnosis. Given the long waiting lists, many children and young people with ASD and ADHD are not receiving the support that they need.

<sup>1</sup> <https://thinkadhd.co.uk/for-patients/adhd-diagnosis-and-nhs-waiting-times/> <https://www.nuffieldtrust.org.uk/news-item/the-rapidly-growing-waiting-lists-for-autism-and-adhd-assessments>

## Key areas for improvement

### Support families, children and young people to 'wait well'

Families in Birmingham told us the following steps would help them while they wait for assessment and diagnosis:

- Improved access to information to help parents and carers support their children.
- All individuals are signposted to available support.
- Ensure continuous contact with a key named professional.
- Work in partnership with parents and carers, with increased involvement and communication.
- Reduce the reliance on diagnosis and develop support making it available to families without a diagnosis.

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

Families identified that more needs to be done to improve the quality of referrals made for assessment and reduce the number of referrals delayed due to missing or inadequate information. Parents and carers feel increased training and guidance is needed for professionals across all disciplines to understand neurodiverse conditions. Also ensuring that they have clear knowledge about the neurodiversity referral and assessment pathway alongside clear guidance on the criteria for referral and what support is available while people wait.

### Improve the assessment and diagnosis process

Parents and carers stated that the following would improve the assessment and diagnosis process, to avoid duplication and delays:

- Use of parent/carer insight as part of assessment.
- 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.

## **NHS Birmingham & Solihull Integrated Care Board (NHS BSOL) response**

NHS BSOL has committed to taking the following actions to address the issues raised in this report. See Appendix 1 for the full response, including specific objectives and timelines.

### **Support families, children and young people to 'wait well'**

We are developing better resources for parents, carers and young people explaining the support available to people while they wait for assessment.

This would include:

- Practical strategies to help support your child.
- Information about support that is available to everyone, regardless of whether a child has a diagnosis.
- Information about the process of assessment and diagnosis and what this means.
- Myth busting information.
- Information about how long you might have to wait for an diagnosis and the choices available to you.

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

We will take steps to ensure that we have a clear understanding of the training needs of professionals and explore how these needs can be met. We are currently working with 40 schools across Birmingham and Solihull as part of the Partnership for Inclusion of Neurodiversity in Schools (PINS) Project. The project is being run in collaboration with the Birmingham Parent Carer Forum with the aim of developing bespoke training plans for individuals' schools based on their own priorities.

### **Improve the assessment and diagnosis process**

We are launching a quality improvement programme focused on improving this process and reducing waiting times. The programme will bring together parent carers and young people, schools, local authorities, and the NHS to develop clear plans for meaningful change.

## **Next steps**

We have shared this report with BCHC, NHS BSOL and Birmingham City Council (BCC). Healthwatch Birmingham will be monitoring progress of the actions NHS BSOL has developed in response, and will publish evidence of related changes in early 2025.

## Introduction

This study was prompted by the feedback we received between November 2022 and November 2023 from people who use SEND services. Concerns ranged from waiting times, communication, transition in care and support during transitional periods, support from healthcare practitioners, support for neurodevelopmental conditions and access to medication and treatment. This report focuses on support for neurodevelopmental conditions. We heard about:

- Inadequate awareness and understanding of autism at various service levels.
- Limited support for individuals with ADHD, ASD, and related conditions.
- Delays in autism assessments.
- Struggles faced by families in navigating the system.

## Background

Autism spectrum disorder (ASD) and attention-deficit hyperactivity disorder (ADHD) are neurodevelopmental conditions. ASD is a communication and interaction difficulty disorder. It is a lifelong neurodevelopmental condition that affects how people perceive, communicate and interact with the world. This means that a child or young person may have difficulties saying what they want, understand what is being said to them or do not understand or use social rules of communication, making it harder to build relationships with others. Autism affects people in different ways, and this is why it is considered a spectrum condition.

Attention Deficit and Hyperactivity Disorder (ADHD) relates to social, emotional and mental health difficulties. It is a range of behaviours associated with difficulties with attention span, including restlessness and hyperactivity. Obtaining a diagnosis in childhood for ASD and ADHD often starts with parents noticing their child's development, which they present to a health professional before being referred to a specialist or a multidisciplinary team for diagnosis.<sup>1</sup> In some cases, school or nursery staff might be the first to notice concerns.

Barriers to getting an ASD and ADHD diagnosis include delays caused by seeing multiple specialists, lengthy wait periods between presenting with a concern and eventual diagnosis and limited access to specialists who can reliably diagnose such as paediatricians, psychiatrists, or clinical psychologists. This leads to delays in assessment and diagnosis and therefore long waiting times, leaving people to struggle with the symptoms of ASD and ADHD<sup>2</sup>.

The huge rise in demand for ASD and ADHD diagnosis has further negatively impacted waiting times and timely diagnosis. According to the Nuffield Trust, there are now 1.2 million autistic people and 2.2 million people with ADHD in England. This makes finding the right support a challenging task. In Birmingham, the number of children and young people on an Education, Health and Care Plan (EHCP) and requiring Special Educational Needs (SEN)<sup>3</sup> support continues to rise.

<sup>1</sup> <https://www.tandfonline.com/doi/pdf/10.1080/20473869.2023.2166197>

<sup>2</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8617836/> <https://www.bma.org.uk/media/2056/autism-briefing.pdf>; <https://thinkadhd.co.uk/for-patients/adhd-diagnosis-and-nhs-waiting-times/>

<sup>3</sup> Special educational needs and disability, often referred to as SEN or SEND, is a term for children and young people who need special health and education support. An Education, Health and Care Plan is a document which details the education, health and social care needs of a child or young person. It details what is needed in their early years setting or school, beyond that which the school or setting can provide.



In December 2022, there were 11,123 young people with an EHCP: an 18% rise since January 2019. 30,000 people required SEN support. Between January 2019 and January 2022, there was a 25% increase in young people with autism requiring support.<sup>1</sup> Increased demand for ASD and ADHD assessments has led to the prioritisation of severe cases leaving people who are less severe without a clear diagnosis or treatment plan.

## Demographics and information about participants

We heard the experiences of 137 people. Some people had children diagnosed with either autism (40%), ADHD (5%), and autism and ADHD (18%). Thirty-four percent told us they are waiting for an assessment for autism/ADHD, and 3% have a formal diagnosis for one condition and were waiting for an assessment for the other condition.<sup>2</sup> Most (71%) people told us about the experiences of children and young people aged between 6 and 16 years.

- 20% of the experiences were about children aged 0–5 years.
- 9% were for those aged 17 to 19 years.

Seven percent of the experiences were for young people aged 20 to 25. The experiences of those aged 20–25 have been excluded from this analysis.

Individuals (80%) who directly care for the child or young person were more likely to complete the survey, than family members or friend (19%) or other (1%). Most (55%) participants were from a white (British/English/Northern Irish/Scottish/Welsh) background; 21% were from a minority background (Asian/African/Caribbean); 7% from a mixed heritage or multiple ethnic group background; 7% identified as white other and 1% as Irish.

Based on the 109 people that left us their postcode, a majority (71%) live in a deprived area of Birmingham (Index of Multiple Deprivation [IMD] 1–4)<sup>3</sup> with 38% living in the most deprived area of Birmingham (IMD 1). Twelve percent of the respondents live in the least deprived areas of Birmingham (IMD 6 – 10, ten being the least deprived) (see Appendix 2).



<sup>1</sup> Birmingham SEND Strategy 2023 - 2028 ([localofferbirmingham.co.uk](https://localofferbirmingham.co.uk))

<sup>2</sup> One respondent has a formal autism diagnosis and waiting for an ADHD assessment, and 3 have a formal diagnosis for ADHD and waiting for an ASD assessment.

<sup>3</sup> IMD (Index of Multiple Deprivation) is a measure of relative deprivation in England based on income, employment, education, health, crime, barriers to housing and living environment. This measure is on a scale of 1-10, 1 being most deprived area and 10 least deprived area.

## Findings

### Referral process

In Birmingham<sup>1</sup>, a referral for ASD and/or ADHD has to be done by a professional working in either healthcare, social care or education (including voluntary sector organisations).<sup>2</sup> To encourage early intervention and support prior to referral BCHC recently changed its criteria so that referrers would need to demonstrate that a child has received six months or two terms of support for their needs before referral.<sup>3</sup> A child or young person has to display one symptom suggestive of ADHD (e.g. forgetfulness, disorganisation, hyperactivity, find it difficult to play or work quietly, impulsive, poor concentration, excessive chattiness) for a referral to be made.

People told us they were first to notice atypical patterns of development or behaviour in their child. Only 2% had no worries until a professional raised concern. Most (72%) told us their initial concerns were the child or young person's social development e.g. how they related to people. Behaviour problems, such as hyperactivity or tantrums and sensory sensitivity, were identified by 68%. Rituals/obsessions/dislike of change/object attachments (60%) and sleeping problems (59%) were other concerns. A small number (7%) indicated 'other', and when we asked them to specify, a key concern was anxiety, depression and mental health issues.

These issues led people to contact a professional for help, either in a school, healthcare or social care setting. For more than half of people, the general practitioner (56%) and school (51%) are the main source for help and advice to support the referral process, while 21% rely on health visitors for support. People that indicated other (15%) said that they rely on nursery staff, social workers, health specialist staff (e.g. psychologist, occupational therapist) and other services (e.g. CAMHS, FTB, PAUSE, SPECTRUM Northwest, SENCO and hospitals).

Contact with professionals is an important part of the process. People told us they were looking for someone to listen to their concerns and that of their child. However, for the most part, contact with professionals seems to become problematic as parents are seeking an understanding of their child and family's needs and an early referral within a system where access to services is based on a diagnosis. People often referred to their interaction with professionals as a 'fight or battle'. The parent's role becomes that of an advocate or as Abrahamson et al (2021)<sup>4</sup> suggest, parents need to make 'a polite nuisance of themselves in order to traverse barriers to referrals'.

<sup>1</sup> In Birmingham, Birmingham Community Healthcare Trust has responsibility for the neurodevelopmental pathway (NDP). The NDP team is a multidisciplinary (MDT) professional service that assesses children and young people for neurodevelopmental disorders such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD). It includes speech and language therapists, consultant community paediatricians, specialist nurses, occupational therapists, psychologists, paediatricians, and clinical assistants with NDP administrators, secretaries and co-ordinators.

<sup>2</sup> School Nurses and Allied Health Professionals, Hospital Paediatricians and Allied Health Professionals, GPs, Social Care Services, Education – Schools, Educational Psychologists, Special Educational Needs Co-ordinators (SENCo's), Forward Thinking Birmingham (CAMHS), Voluntary sector – Bernardo's, NCH Action for Children and others.

<sup>3</sup> <https://www.bhamcommunity.nhs.uk/download.cfm?doc=docm93ijim4n5833.pdf&ver=10673>

<sup>4</sup> <https://bmjopen.bmj.com/content/bmjopen/11/12/e051241.full.pdf>

## Barriers to being referred

### Length of wait for a referral and professional support

At least 49% of people told us they had been waiting between one and three years or more to get an initial assessment. Most told us that their experience was not positive, and they struggled to get a referral. Some people felt defeated before the process had even begun as professionals often discouraged them.

*Nursery at aged 2 spotted signs, I had to fight the primary school for 3 years to get a referral. School quoting[stating], "we won't even be accepted for assessment and even if we were we won't get a diagnosis and even if we did they won't put nothing else into place".*

*Went to GP to report concerns that we suspect that my child might be Autistic due to the symptoms she is experiencing that seem to be worsening. GP informed me that he will refer my daughter for an assessment but there isn't much that the NHS can do after a diagnosis is made. It felt like even obtaining a diagnosis would be a waste of time.*

People talked about the battle for a referral and the impact it has on waiting times leading to a diagnostic delay.

*Autism was query by the Health Visitor and ADHD was spotted by school but took years to get an assessment.*

*The school originally raised concerns and we've been on the waiting list for a year*

*I approached school first with my concerns about my child. But it's taken 1.5 years for the school, before the school formally got to the stage that they sought out telephone assessment with psychotherapy services which identified autistic and sensory deficit traits. This has finally initiated an autism assessment.*

*After 2 years on the waiting list, we decided to pay for a private diagnosis. Our son is still on the NHS waiting list.*

People spoke about professionals not submitting documents on time and referrals being missed, further delaying the assessment and diagnostic process.

*The referral was sent to CAHMS who were supposed to assess for Autism. Instead, the Psychologist we saw was frequently off sick and lied to us. She claimed she'd put our daughter on the list for an assessment, but she hadn't. We waited 2 years and were then told no paperwork had been submitted. After a huge complaint, my daughter was prioritised, and an assessment was carried out.*

*I asked school to complete a referral to the ADHD/ ASD service. This referral from school was missed by the ADHD service and remained in the email inbox for 8 months unopened. It was only when we chased up the referral it was discovered. The system is broken.*

Restrictive criteria and thresholds were another problem with the ASD and ADHD pathway, further exacerbated by changes to the criteria (e.g. age), which meant that parents were told a child is too young for a diagnosis.

*No one listens, thresholds are too high. Unless a child is disruptive in school then no one cares.*

*ASD diagnosis through Clinical Partners was done 1st – this was after a 2.5 year wait on list and then there was a long wait (1.5yr) for 2nd diagnosis of ADHD due to both my child being under the age required when had initial diagnoses of ASD.*

### **Case Study 1**

*My child's first referral for ASD assessments was put in when he was 2 years old following failure at the 2 year development check. That was declined, another was sent and declined.*

*We were then told the age limit had gone up to 2 and a half so we had to wait until he reached this age, then another referral was sent by the health visitor which was declined. My GP sent a referral next and was declined.*

*Back to the health visitor to try again and that was also declined. Another GP sent it again, which was again refused. The first GP sent another referral and I'm still waiting to hear if this one has been successful or not. I've been back to the GP to chase it, the nursery he attends has tried to chase it, I've called the children's centre that has the referral to chase it just to be told the wait is long and they can't give a time frame.*

*Just since the last referral we've been waiting 9 months, just to see if they accept or decline! We haven't even started the waiting for the actual assessment, which is heartbreaking. I get upset just thinking about it.*

*My son has extremely limited support because he has no diagnosis. I have thought about going to a private company to get his diagnosis just so I can get more support for him.*

### **Professionals' knowledge of the referral pathway**

People's views show that there might be a lack of clarity for referrers on how, when, and who to refer to, including who should refer a child for an assessment. These issues contribute to the increased waiting times, leading to a lack of early identification of autism and ADHD and delays in the provision of support.

*I saw the health visitor first who put in a referral for ASD testing, which was refused. Child was also referred to a speech play group. Through the play group we also had a hearing test referral. I've since had three health visitors try to send separate referrals, all failed. 2 GPs have sent referrals one of which was declined and I'm still waiting to hear about the second referral 9 months on. The nursery also tried to send a referral but couldn't.*

*I went to health visitor first that referral was refused as they only had parental say so and no evidence. The school nursery then put a referral in and 16 months later we are still waiting for assessment.*

*Originally requested referral in February 2023 but was not completed until October 2023 after chasing up a few times GP had not followed the correct process therefore it meant that we are waiting longer.*

*The Dr sent the referral to the paediatrician instead of the ADHD team which delayed the process. Then the ADHD team lost the referral meaning I had to start the process again. This led to nearly a 2 year delay.*

*As part of the EHCP process a paediatrician said my son needs an autism assessment. The referral had to be from the GP, the GP was not happy as he said it was the paediatrician who would do the assessment. It took us six months to get our son on the waiting list for assessment. Initial form he used was wrong, it came back to us to complete. We then had to get the school to complete part of the form. The referral form kept going backwards and forwards. It was also very long and assessment not a referral form.*



*School referred me to my doctor. Doctor said it should be school doing referral as they suspected. It was going back and forth. Eventually doctor did referral.*

### **Professionals' knowledge, training and ability to recognise the signs and symptoms of autism and ADHD**

A professional's knowledge and training, particularly within healthcare, is crucial for the provision of the best care for children and young people with autism and ADHD. Professionals need the knowledge and training required to screen, diagnose, and refer children and young people with autism and ADHD.

Some people told us they felt professionals lacked knowledge and awareness of autism or ADHD.<sup>1</sup>

*The GPs refusal to refer our child at my 1st request met almost 8 years of awful increased anxiety and feelings of not belonging. Then about 3 different Psychologist [names redacted] failed to assess correctly our child's ASD & ADHD because she masked her symptoms, and they didn't consider smart or academically managing kids can have ASD & ADHD.*

*Gp did not make referral properly- no real knowledge of system. GP was very unhelpful and said it would be quicker to go private or get school to do it- when pressed for a referral GP did not do it correctly. Lack of knowledge in this area.*

*It was one year after diagnosis OT booked an initial appointment to see me child, the person who attended knew nothing about autism, and subsequently sent a letter to reflect the appointment with another child's name on it.*

*Yes, the primary school refused to help as they didn't recognise need despite post adoption social worker, ed psychologist and clinical psychologist all supporting an assessment.*

*I did speak to the GP, but they said it's not their area. So, school Senco helped me with both diagnoses.*

Some felt professionals lacked knowledge and awareness of autism or ADHD.

*I went to our GP when our child was about 7-8 years old. I asked for a referral to a psychologist. The GP refused saying my child was articulate & seemed very bright.*

### **Focusing on the parent and child or young person's identity**

People felt that when a referral is requested there is often a focus on the child or young person's behaviour and the family's parenting style motives rather than the child and their symptoms. Parents' competence and children's behaviour are often blamed prior to assessment and diagnosis. People felt criticised by professionals for their child's behaviour and that their ability and expertise was questioned or critiqued, thus blaming either on the parent or child rather than the condition. In some cases, parents were told that their child just needed discipline for things to change and were therefore denied a referral to a specialist, resulting in a delay to assessment and diagnosis.

*We initially contacted with Health Visitor with concerns about my child regressing and losing skills, every single day I was committing to supporting my child socially, developmentally and sensory. I was told by the Health Visitor it was impossible for a child to regress and that it must be my fault for not 'doing enough with my child'.*

<sup>1</sup> <https://www.nature.com/articles/s41390-021-01465-y>

*The GP fobbed us off twice and said it's just a 'bit of anxiety', lots of girls are experiencing this ATM.*

*I wasn't aware that my son was suffering with ADHD and his school was just pushing us away and calling him the naughty terrible child.*

*It was awful, they tried to make out I was lying, only saw [my son – name redacted] for 20 minutes etc and we have been pretty much left to our own devices.*

*We have changed our parenting and lifestyle to accommodate our kid's needs, we have tons of coping mechanisms in place but have had no help from the experts in the field at all.*

*Was advised to attend parenting course even though, daughter had verbal dyspraxia and clear additional needs. CAMHS would not help or refer further so I needed to pay for a private assessment.*

*So, it's the attitudes, they more tend to go after the parents who's trying to get things put into place as opposed to let's support the child and work together and do what's best for the child.*

*Waiting for the ADHD assessment was the hardest, because all the professionals say ADHD. But no one wanted to refer us. Everyone says oh just wait until he is older. Things may change. Well things did not change.*

In some cases, a diagnosis was a relief for parents as it shifted blame from parents and the child or young person to the condition.

### **Poor communication and partnership working with families**

The stress of going through the assessment and diagnostic pathway can be reduced through improvements in communication and partnership working, yet people said they were not provided any explanations throughout the process. In many cases people do not feel included in decision making. The process is not seen as transparent, which further impacts people's understanding of the diagnostic process and exacerbates feelings of not being supported.

*Our son was referred by school soon after he started in reception. We eventually paid for a private ASD assessment at the end of year 3 as we still hadn't heard anything about an assessment via the NHS. We'd had 1 initial consultation where they talked through everything on the referral form (so totally pointless) and we were told they'd be in touch, no one told us anything.*

*Delays in various steps along the way, not enough emphasis on input from Family not listened to.*

*We have had no information not even to acknowledge referral or let us know our son is on the waiting list. As far as I am aware the ADHD team and NDP report only on waiting times from the date a referral is classed as received and triaged. At the moment the wait for triage is in excess of 6 months. As far as I am concerned this is smoke and mirrors as there is no transparency of information sharing to patients, families, and commissioners.*

*Waiting times are so long and no communication about where we are in the queue or how long we expect to wait.*

*Lack of communication and updates and huge waiting times have been incredibly stressful for our family.*

## Diagnostic assessment

NICE guidance recommends that an autism diagnostic assessment for children and young people starts within three months of the referral to the autism team.<sup>1</sup> For ADHD, waiting times for assessment are more difficult to determine as the assessment requires that a period of watchful waiting (10 weeks) and a referral to group-based ADHD-focused support or parental training (under 5s) takes place before a formal assessment is conducted.<sup>2</sup> BCHC states that it can take up to 12 months from referral to decision or diagnosis of ADHD.<sup>3</sup>

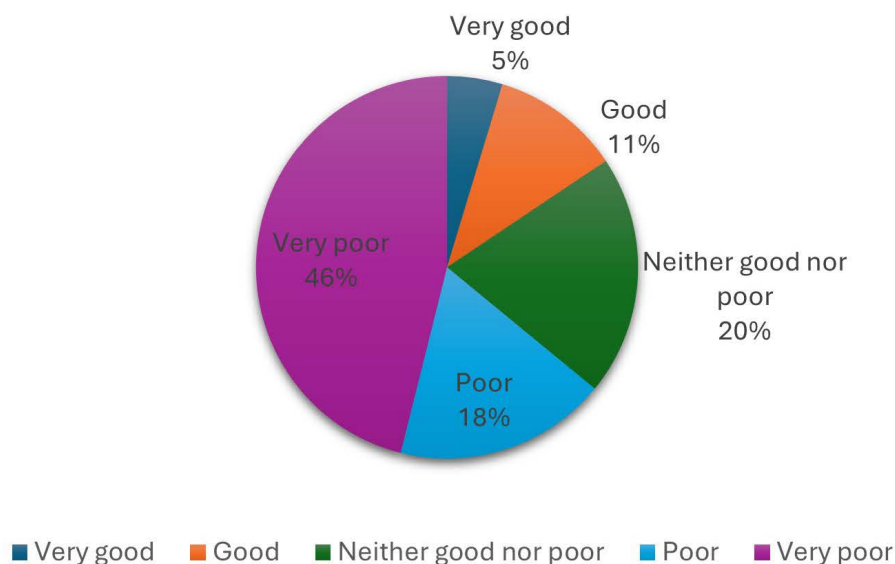
Forty-four percent of people told us that they are currently waiting for an autism or ADHD assessment while 50% had already been assessed. Twenty-eight percent had had an initial assessment and 40% a full assessment. Nineteen percent were not sure whether they had had an initial or full assessment, while others had waited for so long that they were not sure anymore.

Over half (58%) of people were not told how long they must wait to have an assessment; only 20% have been told an estimated waiting time. People that were given an estimated time had requested this at the time of their appointment or called the service after a long wait. The estimated time given ranged from 12/18 months for initial assessment to three years for a full assessment.



For 64% of people, their experience of waiting for an assessment was rated poor or very poor. Only 16% of people rated their experience of waiting for an assessment as good or very good, while 20% said it was neither good nor poor.

**Fig 1: Experience of waiting for an assessment**



<sup>1</sup> Recommendations | Autism spectrum disorder in under 19s: recognition, referral and diagnosis | Guidance | NICE

<sup>2</sup> Recommendations | Attention deficit hyperactivity disorder: diagnosis and management | Guidance | NICE

<sup>3</sup> <https://www.bhamcommunity.nhs.uk/download.cfm?doc=docm93jjm4n5833.pdf&ver=10673>

People who rated waiting for an assessment as poor or very poor described a nerve-racking, lengthy, confusing process, lacking in communication and engagement, and with changing thresholds leading to increased waiting times, lack of support and feeling alone.

***No one tells you anything, just that it can take 3 years. Takes a year for initial questionnaires to be sent out, no support offered in the meantime while you wait!***

***The long wait for an assessment has been stressful for us and our son as we were unsure about how best to proceed and support our son.***

***No interventions whilst waiting for the assessment, crucial time lost in early intervention.***

***Took too long and we waited nearly 4 years for an assessment and diagnosis and it's not good enough that my daughter had to suffer without support or an explanation to her behaviour.***

***Only received an initial assessment over the phone. Completed and returned all the paperwork sent by the unit. No further contact from the unit, I have contacted them for an estimate on when she will be seen, told up to 12 months before she will be seen.***

### **Case Study 2**

***Very slow, the process just kept having steps added to it. Services had long waiting lists where initial screening was used to pretend waiting lists were shorter than they were by then adding you to another waiting list with an even longer wait.***

***No support or help was provided. The service repeatedly asked for the same information from myself contrary to the SEN code practice and nice guidance. The repeated requests for the same information by the NHS led school to accuse us of chasing a diagnosis- we were not but needed to send back information at each stage under the threat of discharge if we did not do so.***

***This ultimately led to them refusing to supply more information when the actual assessment started citing teacher workloads and they then accused us of over medicalising the child and doing a safeguarding alert. This was not us but the NHS repeated requests to us as parents for info from school.***

***Despite us asking clinicians to contact school they refused, saying schools should be aware the process was to ask parents to ask school. This exacerbated the situation. Then when school would not supply information without the NHS directly contacting them, we were left at risk of being dropped off the whole pathway for something completely outside our control. I***

***In the end school got a supply teacher who had been in the school a week and who had never met my child to send back the forms minimally completed.***



People felt that the delay in assessment and diagnosis left their child in limbo with no support.

*I feel the long delay in getting referred and assessed for almost 8 years has robbed my child and me of enjoying her Secondary School years. Mainly due to having no support and no diagnosis until aged 16 yrs. My teenager has told me she feels she didn't reach her full potential, solely due to not having support in the years from Year 7 onwards especially. She felt her Secondary School was a horrible experience where she was sometimes eating lunch in the toilet or with the Assistant Head of Year & kids from an Inclusion Unit in an I.T classroom. It led to school refusal and restricted attendance at school.*

*It took 8 months from first referral by GP for my child to be assessed and then 5 months later to get a response that my child had been found with Neurological issues. Over a year later to be given notification that with the waiting period and backlog of referrals, that my child's diagnosis assessment could take up to another 2 yrs. They specified up to 3 yrs from first initial assessment. We have been waiting currently over 2 yrs since referral through GP and now possibly another 2 yrs before diagnosis before my child can receive the appropriate support specifically for her health issues?*

Delays also affected access to support in the education system.

*My son missed on getting his EHCP because of the pathetic waiting time to get diagnosed.*

*There's many places and even education wise where my child is missing out on appropriate support for her needs, as she has not received diagnosis and without the diagnosis. There are not many places that will support. So basically, my child is stuck in limbo waiting until we can receive an official diagnosis to help.*

## Diagnosis

A timely diagnosis enables children and young people to get an intervention and support. A diagnosis is helpful in clarifying how neurodevelopmental differences may be impacting an individual and the interventions, support and adaptations required (NCBI, 2021).<sup>1</sup> Some argue that a lack of a diagnosis has implications for patient safety as people do not receive the needed support, affecting their wellbeing and mental health.<sup>2</sup>

The number of people receiving a formal diagnosis under 12 months is low in our study. Only 9% of people told us they received a diagnosis between 1-12 months. Fifty-nine percent waited over one year to receive a diagnosis. The long waits led some people to go private for a diagnosis *'I was told it would be 4 years, so I paid to go private'* while another said, *'I paid for a private ASD diagnosis because I was told 2 years minimum wait'*.



### Case Study 3

*Too much time is waiting on doctors. First wait for an appointment. Second long wait for the next appointment. Third waiting for diagnosis. Long waiting. Everyone can agree this child has Autism. But yet you must wait 2 or 3 years to get the official diagnosis. The pain and trauma we parents go through in the waiting is mind boggling.*

<sup>1</sup> Development of a Pathway for Multidisciplinary Neurodevelopmental Assessment and Diagnosis in Children and Young People - PMC (nih.gov)

<sup>2</sup> Long waits for ADHD diagnosis and treatment are a patient safety issue - Diagnosis - Patient Safety Learning - the hub (pslhub.org)

Following a diagnosis, a majority of people told us they were given a written report about the diagnosis. For some, the report outlined the support they would receive, information about follow-up appointments and medication.

**Table 1: Following a diagnosis, did you receive:**

Answer Choice	Response Percent	Response Total
A written report about the diagnosis	74%	69
A follow up appointment	35%	33
Information about post-diagnostic services and support	29%	27
Nothing received	12%	11
Other (please specify):	8%	7

When we asked people to rate their experience of getting a diagnosis, the views were almost equally split between those that rated their experience as good or very good (39%) and poor or very poor (41%). Twenty-two percent said their experience was neither good nor poor.

The length of time waiting for an appointment with a specialist is a key issue for people who rated their experience of getting a diagnosis poor or very poor.

***The waiting time to see the paediatrics and occupational therapist was awful.***

***I would rate the whole pathway, the excessive waiting time and the absences of any form of support or communication as dreadful and very poor but the clinicians who assessed my child were excellent.***

For those who said their experience was good or very good, the things that worked well was the quick diagnosis they received from a specialist.

***Had to wait for consultant appointment to come through but diagnosis was given after 1 appointment, did not have to go back and forth with school as they had given letters.***

***Ignoring the wait time (because it shouldn't be such a long wait!) the assessment was done by Healious and they were great. Clear communication & they did what they said they would, when they promised to.***

**Table 2: Satisfaction with the diagnostic process**

Answer Choice	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
The overall diagnostic process (referral to 1st appointment, duration of assessment, wait from assessment to final diagnosis)	14%	23%	30%	17%	16%
The information given at diagnosis	18%	32%	29%	11%	10%
The manner of the professional disclosing the diagnosis	37%	34%	18%	6%	4%
How involved you were in making decisions	22%	33%	29%	10%	6%
The support offered post-diagnosis	6%	12%	27%	22%	33%

## Access to support

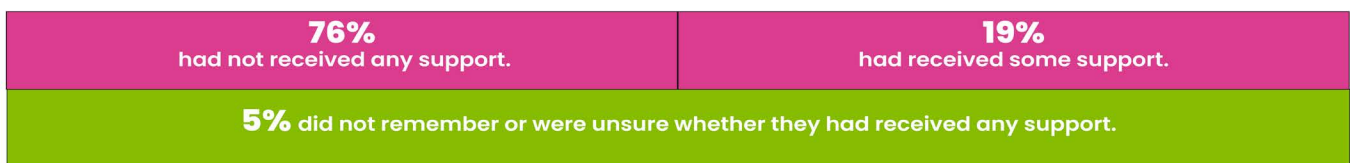
After long waits and struggles to receive a diagnosis, people feel that getting support during and after the diagnostic process presented its own challenges. People felt that they had to fight to get support for their child *'There was a feeling of having to fight every inch of the way for the help that these children need and are legally entitled to'.*

### Case Study 4

*Waiting lists are generally years long. Clinicians are not properly trained. Services are gate kept by discriminatory criteria that disadvantages certain autistic presentations and is dependent on the knowledge and good will of schools having knowledge and putting effective SEN support in place.*

*There is no support pre diagnostically and little to no support post diagnostically. Access to mental health and educational support is poor and again professionals are not always neuro informed.*

When asked whether they received any support during the diagnostic assessment process, a majority said they were not given any support while waiting for an assessment and a diagnosis.



*The length and the waiting time for prognosis leaves the family and the child in limbo of distraught and distress. There should be some support system in place for waiting children.*

*There was 14 months between seeing the Community Paediatrician and the assessment – in these 14 months, as my child was not diagnosed, he was not entitled to the correct early intervention. They have been waiting to see an NHS Speech and Language Therapist since Feb 2023 and has yet to receive an appointment.*

*No advice or support offered during waiting time. No direct access to OT or speech and language. No guidance on how the process works or what to expect.*

Some people felt let down following a diagnosis as most saw a diagnosis as a way of getting the support their child needed. Having a diagnosis without the needed support was described as pointless for some people as it did not change anything. People stated they received a *"Bog standard letter stating they had seen him in clinic and received diagnosis"* but no other support *"I received a written report from clinical partners but no other support after that"*.

*I was lucky he was diagnosed just before he was 4. Diagnosis doesn't change anything still no support.*

*Long waiting times, then lack of support after. Just a discharge letter and a Google this, go to this website.*

***My daughter was about 4 or 5 when she was diagnosed. She is nearly thirteen now. Once diagnosed and discharged from the CDC, that was it! No help and no idea how to get help. It has been very difficult and still is. I'm still learning about Autism.***

After a diagnosis was made, only 29% of people told us they received information about post-diagnostic services and support. Although some (35%) of the respondents were given a follow-up appointment (see Table 1) they felt that following diagnosis they were then discharged with no further contact ***"the doctor just wrote Autistic on my daughters red book, then discharged! We were left to fend for ourselves!"***.

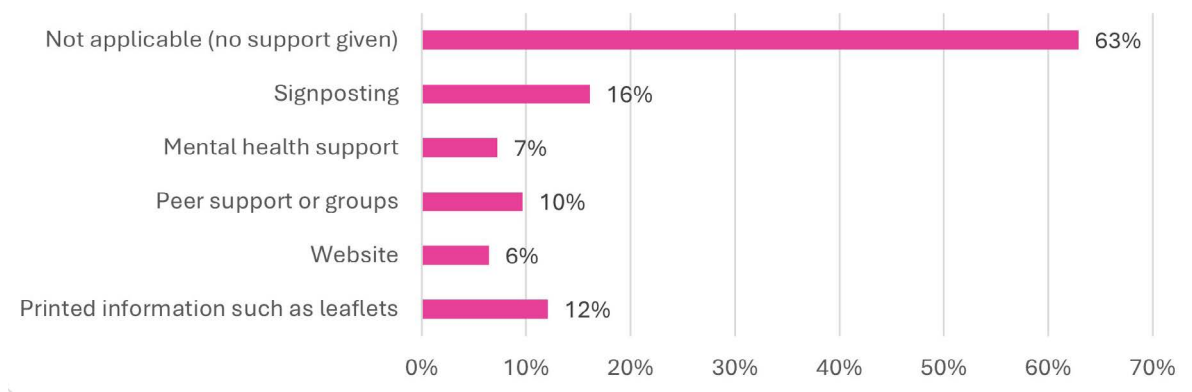
***I got a follow up appointment to discuss the report and then also a course about autism but then since then there has been no further contact about anything. I think we were discharged.***

***Unbeknownst to me - once my child was diagnosed, they were discharged from Community Paediatrics, despite severe issues with other elements of their health and despite third party services such as SLT and OTs not having seen them. I had to contact BCHC Pals and complain in order to make sure a follow-up appointment was arranged.***

***Although we waited just over 12 months from referral to diagnosis, I appreciate that we are very fortunate as other children have to wait much longer. The lady that carried out our diagnosis was very kind and professional and provided me with lots of information, but I feel that after that appointment, very much on my own trying to understand how best to support my son and where I would go for help now if needed.***

We further asked people who had received support to tell us what type of support they received. Many (16%) people said they were signposted to support, 12% were given printed information (e.g. leaflets), 10% had peer support or joined support groups and 7% were offered mental health support.

**Fig 2: What support were you given while waiting for an assessment?**



***We had the introductory course on Autism. Courses on Autism and what to expect and how as parents how we can support our children. Carers group sessions. Very important.***

Some noted that support mainly came in the form of medication with no other practical support.

***Received a letter for appointment with ADHD nurse. All that they could offer was medication. Had a letter with a diagnosis on.***

***Was shortly discharged from their care when I refused medication. No other support given.***



Even where support was offered, people told us they waited a long time to receive it.

*We were left to ourselves until a letter about 18 months later referring to some support agencies and then discharging us.*

*Follow up appointment with ADHD nurses booked 7months after diagnosis to discuss what support is needed and medication.*

We asked the respondents how they rate the support they received throughout the assessment and diagnostic pathway. Only 12 percent rated the support they received good or very good while 20% said it was poor or very poor. Nineteen percent said the support was acceptable.

### Case Study 5

*Every single element of the diagnostic/ assessment and early intervention process in Birmingham is horrific, unfair and disenabling for children with autism and ADHD.*

*No proper care*

*No proper school facilities*

*Disinterested Healthcare Professionals (80%)*

*And a Council that does not want to spend money supporting these children*

### Case Study 6<sup>1</sup>

*1. Acknowledgement of referral.*

*2. Reassurance that there is a triaging system in place so that children in crisis are prioritised.*

*3. Info on What to expect (including waiting times)*

*4. A list of providers that Birmingham ICB would be prepared to sign a contract through I/ already have a contract with via right to choose pathway.*

*5. A dedicated phone number for Birmingham ICB right to choose queries (the only way I could get hold of anybody who knew about right to choose was through the complaints number).*

*6. List of support organisations to help whilst on waiting list e.g. occupational therapy for sensory issues (we had to tell the gp that our daughter was eligible for support via OT).*

*7. Capacity for gp to support with paediatric medication that whilst waiting to be seen (gp refused to reactive melatonin for our daughter).*

<sup>1</sup> These are the improvements one of the respondents told us they would like to see in the neurodevelopmental pathway.

## Key improvements people want

Overall, most (71%) people rated the ASD and ADHD assessment and diagnostic pathway in Birmingham as poor or very poor, 21% said it was average, while only 8% said the pathway was good or very good.

People told us they would like to see the following improvements:

### Work in partnership with parents and more communication

Families want to be provided with a key contact, ensure that they are provided with explanations throughout the process and participate in decision-making. Parents want to be listened to and not to be blamed for the child's or young person's behaviour.

Consider their experience and that of the child. Professionals should be transparent and ensure that the information shared with parents is also transparent. Keep communication open about waiting times but most important acknowledge receipt of referral and inform parents of a time frame. Write to people periodically (every few months) to acknowledge that they are still on the list and how much longer the wait is. Consider parents as the experts of their children and ask for more qualitative information from them not just from schools.

Support parents through the process and help them understand the diagnosis. More support, advice and information about what ASD/ADHD is, how it affects the child and what support is available for parents. Parents feel that they are helping each other through word of mouth and not evidence-based information.

Ensure that parents understand the assessment and diagnostic process and feel involved. This would make the process less stressful.

### Ensure professionals are trained in neurodevelopmental conditions and understand the assessment and diagnostic process

People want to see an understanding of the training needs of professionals, ensuring that they have access to training that meet their needs, competencies and role. Ensure that services that work with children and young people who may have autism and ADHD ensure that they have the professionals with the right skills and experience. Make sure professionals are suitably trained to identify and support neurodivergent children and young people (e.g. GPs, health visitors, mental health professionals, speech and language therapists, occupational therapists, paediatricians, school welfare officers, social workers). As some people suggested, the professionals who do the MDT assessments could all do reports that not only speak to their views on ASD/ADHD, but also the things the child will benefit from. If that means onward referrals for sensory support, mental health or other AHPs, they should be sorted out proactively, instead of parents having to fight each service separately. They could see how important it is for children and young people to get the diagnoses they need in a timely manner and act to ensure they get what they need.

***"If frontline health and education professionals (e.g. GPs, teachers) are confident in recognising the signs and symptoms of autism, are cognisant of referral pathways and listen to parents, taking their concerns seriously then CYP will be referred to an appropriate service, in a timely manner, reducing parental frustration" (Abrahamson et al 2021)<sup>1</sup>***

<sup>1</sup> [e051241.full.pdf \(bmj.com\)](https://www.bmj.com/content/363/e051241.full.pdf)

## Improve diagnostic assessment

People want to see assessments drawing on information from parents and educational settings in addition to professional assessment. Have a one stop shop where children can be seen by all professionals that are required for a diagnosis (e.g. do joined up assessments like that done at Spectrum Northwest). People believe engagement with parents and children or young people can be improved by having a key contact. Also offer a single point of access for ASD and ADHD to professionals with the necessary skills and expertise. It is important to have a neurodevelopmental understanding rather than focusing on single condition – this reduces waiting times. Make other NHS support available for referral e.g. physio, OT, paediatrician. Train and enable other staff (e.g. SALTs, Paediatricians, Educational staff etc) to conduct some aspects of the assessment and also enable some healthcare professionals to diagnose straightforward cases.

*“If a structured, consistent and multidisciplinary approach to service delivery is adopted, making best use of available staff and clinical expertise, then the number of assessments per individual may be reduced. If a balance of interview, observation and recognised tools are used, alongside an assets-based approach, this will ensure a comprehensive and family-friendly diagnostic experience. If the same Trust manages both community paediatrics and mental health services, this potentially allows for a seamless transition, avoids duplicate waits and enables families to see all relevant professionals at the same time.” (Abrahamson et al 2021)<sup>1</sup>*

## Referral, assessment and diagnosis

People want professionals referring children and young people for a diagnostic assessment to be clear about the guidelines for a referral. To understand what information is needed, how and who to refer to thus reducing delays and waiting times.

They would like a move away from a diagnosis led model where emphasis is on a diagnosis in order to receive support. People want support throughout the assessment and diagnostic process. Support should be varied to include practical as well as medical support/ educational support/speech and language and simplify the process of the received support

Change the assessment and diagnostic system so that it is geared towards support for children and young people rather than being geared towards getting people to give up. Improve the waiting times, barriers people face, and inefficient use of time by reducing assessment appointments

Get rid of referral criteria which results in the assessment services being gate keepers with a focus on only externalised autistic/ADHD behaviours that are noticed and supported in schools. Make the screening questionnaire relevant to current evidence and include symptoms for girls.

## Improve support for ASD/ADHD in education

Increase the number of professionals such as Communication and Autism (CAT) workers. Improve training on ASD/ADHD recognition and support in schools. Make it easier for schools to apply for funding before a diagnosis and ensure that all relevant school staff know how to support children while they wait for a diagnosis.

<sup>1</sup> [e051241.full.pdf \(bmj.com\)](https://www.bmj.com/content/363/e051241.full.pdf)

*There is obviously very high demand for these services – schools work on a ‘one hat fits all’ system of education which is impossible as everyone is different, and all children have different needs. There seems to be far more awareness of ADHD, ADD and Autism these days and a broad spectrum for each for levels of support and help needed. The length of time taken to get a diagnosis hinders the children’s education and acknowledgment they need support or help. It’s a no-brainer that improvement of the assessment and diagnosis pathway would be to make it far quicker and more efficient than waiting with no updates for 18–24 months. This is a long, long time in the journey of a child’s development at school and just hinders their potential and development.*

## Improve access to ASD/ADHD services

People note that there appears to be an enormous funding gap and feel the service is clearly overwhelmed. They believe there needs to be more resources in order to bring the waiting times down so people can get on with their lives and get the support that they need.

People suggest that to reduce the waiting list and waiting times, outsource to private companies earlier on. This has clearly already been done as a ‘last resort’ when people have been waiting over two years. This can be done earlier. If the NHS do not have capacity, they should be using private companies as routine.

People would like to see an introduction or increase in the number of hubs that could offer interim support specifically catered for children and young people with spectrum issues and for the families who are in care of their children, particularly during the waiting period.

Improve interagency working. If ‘experts’ including people with autism, carers, professionals and specialist organisations work in partnership, and the knowledge generated is effectively embedded into local services, this will build capacity, improve parent and children and young people’s satisfaction and support planning of services both locally and nationally.<sup>1</sup>

## Conclusion

Whilst we acknowledge the amount of work taking place in the system to improve the neurodevelopmental assessment and diagnostic pathway, as outlined above, people told us that the ASD and ADHD assessment and diagnostic pathway in Birmingham is stressful. It is a long battle and a burden on parents, made up of lengthy and multiple assessments, lacking in support for children and young people as well as parents. Delayed diagnoses have had a negative impact, as without a diagnosis children and young people are living without the support they need. Long waiting times delay intervention which not only prevent people from getting vital care and medication but also affects the management of ASD and ADHD. This leads to academic and social struggles, emotional distress, and prolonged periods of unmanaged symptoms. Living with undiagnosed or unmanaged ADHD and autism has an impact on people’s mental health, resulting in anxiety, depression, and self-esteem. It also leaves a strain on families left to manage the day-to-day challenges posed by ADHD and autism symptoms.

Exploring referrals and waiting times for autism and ADHD assessments and treatment is crucial to understanding the problem. However, many children and young people are blocked from getting care and support until they get a diagnosis. A report by the Child of the North initiative (2024) set out several recommendations. Key was a move away from a diagnosis led to a needs-led approach where care and support are offered in a timely way without waiting for a diagnosis. Given the long waiting lists, many children and young people with ASD and ADHD are not receiving the support that they need.

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8672008/>



## Acknowledgements

We would like to thank everyone who shared their experiences. We are also grateful to NHS BSOL ICB, BCHC, BCC, Birmingham Parent Carers Forum, Accord and all community organisations that helped us access service users. We are particularly grateful to all third sector or community organisations who allowed access to service users through their events.

## About 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 take into account, 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/>

### How do we select the issues we collect evidence about?

Some of the issues we hear about from patients and the public may require deeper exploration in order to present a comprehensive report to those who commission, design and deliver health and social care services in Birmingham. Members of the public select these issues as part of our Topic Identification and Prioritisation System. By involving members of the public in decisions about our future activities, we ensure we are operating in an open and transparent way. It also ensures that we understand the public's priorities.

### Who contributes to our evidence collection?

We explore selected issues with the help of our volunteers, Healthwatch Birmingham board members, patients, members of the public, service users and carers. They share relevant experiences, knowledge, skills and support. Healthwatch Birmingham also talks to key professionals providing or commissioning the service we are investigating. This helps us to form a deeper understanding of the issue from the perspective of these professionals, and encourages them to take prompt action to implement positive changes for patients and the public.

### What difference do our reports make?

We follow up our reports to see if our findings have made services better for patients and service users. We hold service providers and/or commissioners to account for changes they stated they would make in response to the report. If Healthwatch Birmingham finds no improvement, we may decide to escalate the issue to Healthwatch England and local regulators. We also monitor the changes to see if people experience sustained improvements.

### How to share your feedback about the issues heard in this study

If you are a service user, patient or carer, please do share your experiences with us via our:

- Online [Feedback Centre here](#).
- Information and Signposting line on 0800 652 5278 or by [emailing us](#).

## Appendix 1

### NHS BSOL full response

We would like to thank Healthwatch Birmingham for their work gathering this important feedback. We understand how frustrating a lengthy wait can be for parents and children alike and in recent years, the numbers of children and adults referred for assessment for autism and ADHD has grown significantly.

Put simply, there are now many more people referred each month than there are assessment appointments while funding remains largely the same. The lengthy waiting list is unacceptable and we know that we must, as a health and care system, think and organise ourselves differently to ensure that children and young people get quicker access to the support they need.

We must be clear that there are no quick fixes and be open about the scale of the challenge. We are committed to making significant changes to ensure faster diagnosis and better support for our children and young people and will listen to those who use our services to help us identify the changes we should make.

We agree wholeheartedly with the recommendations made in the report and are committed to taking action in these areas:

#### **Support families, children and young people to 'wait well'**

We are developing better resources for parents, carers and young people explaining the support available to people while they wait for assessment.

#### **Increase training and support for professionals referring children and young people for assessment.**

We will take steps to ensure that we have a clear understanding of the training needs of professionals and explore how these needs can be met. We are currently working with 40 schools across Birmingham and Solihull as part of the Partnership for Inclusion of Neurodiversity in Schools (PINS) Project. The project is being run in collaboration with the Birmingham Parent Carer Forum with the aim of developing bespoke training plans for individual schools based on their own priorities.

#### **Improve the assessment and diagnosis process.**

In September we are launching a quality improvement programme focused on improving this process and reducing waiting times. The programme will bring together parents, carers and young people, schools, local authorities and the NHS to develop clear plans for meaningful change.

<b>Area of Focus in the Report</b>
Support families, children and young people to 'wait well'
<b>ICB Response</b>
We are developing better resources for parent carers and young people explaining the support available to people while they wait for assessment.
<b>Further questions and ICB Response</b>
<p><b>a) What resources will you produce to inform and signpost children, parents and carers?</b></p> <p>It is important that information, advice, guidance and support is available as soon as a child's need is identified. Children shouldn't have to wait to be assessed or diagnosed before they receive support.</p> <p>There are already a range of resources and information available to help parent carer and others support children (please see the links below). However, we have heard that many parent carers are not aware of the resources available and feel that what is available could be improved.</p> <p>We want to make it as easy as possible to get reliable and straightforward information. This would include:</p> <ul style="list-style-type: none"> <li>• Practical strategies to help support your child.</li> <li>• Information about support that is available to everyone, regardless of whether a child has a diagnosis.</li> <li>• Information about the process of assessment and diagnosis and what this means.</li> <li>• Myth busting information.</li> <li>• Information about how long you might have to wait for an diagnosis and the choices available to you.</li> </ul> <p><b>Information, Advice and Guidance</b></p> <p>There is more information about the Birmingham Local Offer for Special Educational Need or Disability (SEND) <a href="#">here</a></p> <p>Birmingham Community NHS Healthcare Trust (BCHC) have a range of information on their <a href="#">website</a> about neurodevelopmental needs like ADHD and Autism.</p> <p><b>b) How will you collaborate with parents and carers and involve them in developing these resources?</b></p> <p>We have asked the Birmingham Parent Carer Forum (BPCF) to be part of the group of people that will develop and progress our detailed plan of action. We will work with BPCF ensure the actions in the plan are coproduced wherever possible.</p> <p>We want to produce information resources with parent carers and children so that we are confident that it will be helpful. We will work with BPCF to develop these resources. If you would like more information about BPCF you can <a href="#">find it here</a>.</p>

**c) Detail how the local support offer will change to ensure families receive the help they need while they wait for assessment or diagnosis?**

There was a consensus at the Quality Improvement workshops that focus should shift from offering support based on diagnosis, to identifying need and offering that support as early as possible. Work has commenced to ensure that there is a full picture of all the services currently available so that we can identify the gaps and areas of duplication.

We will then work with parent carers to see how the local offer can be enhanced and take action to do this.

**Area of Focus in the Report**

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

**ICB Response**

We will take steps to ensure that we have a clear understanding of the training needs of professionals and explore how these needs can be met. We are currently working with 40 schools across Birmingham and Solihull as part of the Partnership for Inclusion of Neurodiversity in Schools (PINS) Project. The project is being run in collaboration with the Birmingham Parent Carer Forum with the aim of developing bespoke training plans for individuals' schools based on their own priorities.

**Further questions and ICB Response**

**a) Detail the intended outcome of the training needs analysis and the timelines for this? (e.g. training developed, or training updated, all professionals involved in the care of children with ASD/ADHD are trained?)**

Forty schools in Birmingham (25) and Solihull (15) completed a self-assessment to identify their training needs related to neurodiversity. Based on their feedback, a training and support plan has been developed by specialist education services, the NHS, and the Birmingham Parent Carer Forum. Schools will begin receiving this training in October 2024. The Birmingham Parent Carer Forum is also working with school leaders to gather input from parents carers, and will hold four engagement sessions at each of the twenty five schools between October 2024 and March 2025. Once the training is finished, NHS England and the Department of Education will evaluate the results. It's important to note that the PINS Project is not focused on any specific diagnosis but is based on the needs identified by schools.

**b) Detail what changes will be made to the PINS project as a result of our report findings?**

The aims of the PINS project support some of the findings of the Healthwatch report in relation to training an supporting professionals whilst also improving support for parent carers. The aims of the project are to:

- Provide training to schools around neurodiversity, build relationships between parent carers and school staff.
- Empower parent carers with knowledge around what neurodiversity is and how it can affect their child/children.
- Establish a parent carer group in all of the twenty five schools which will continue after the PINS project finishes.

**c) What action will the ICB take to ensure clarity around the referral process and support available whilst people wait?**

One result of the Quality Improvement session will be better communication through a single website that provides clear, simple information. This website will also offer guidance for professionals, helping them give clear support and information to parents carers. It will include training support for schools and GPs. The site will also feature videos to dispel common myths (like what to expect from a diagnosis and what it offers), along with standardized messaging and clear directions for finding help.

**Area of Focus in the Report**

Improve the assessment and diagnosis process.

**ICB Response**

In September we are launching a quality improvement programme focused on improving this process and reducing waiting times. The programme will bring together parent carers and young people, schools, local authorities, and the NHS to develop clear plans for meaningful change.

**Further questions and ICB Response**

**a) What is the timeline for the improvement programme and what progress has been made since the launch in September? (e.g. activities planned and/or conducted, developing or progress towards developing plans, and implementation of the plans).**

The Birmingham QI session took place on 23 September and we are working as partners to turn the change ideas into clear actions. We aim to have a more detailed plan available by December 2024 and will share this with Healthwatch.

**b) Detail how the findings of our report will shape the quality improvement programme.**

This Healthwatch Report is already helping to shape our work. The quality improvement programme will focus on the following areas which are informed by the Healthwatch report and the views expressed by our stakeholders including those representing parent carers:

- 1. Local Support:** Focus on providing help based on individual needs, offering early intervention, and integrating services like Family Hubs to reduce overlap.
- 2. Communication:** Create a single, easy-to-access source for information, personalized advice, and clear communication between professionals and the public.
- 3. Data & Technology:** Explore the use of digital tools, such as a shared care record, a single referral portal, appointment reminders, and improved data analysis.
- 4. Service Pathways:** Focus on meeting children's needs and improving outcomes, rather than just on diagnosis, and strengthen transitions between services.
- 5. Workforce:** Address recruitment and training for professionals and families, and provide more support in schools.



## Appendix 2

**Table 1: Index of Multiple Deprivation**

IMD decile	% of IMD	Count of IMD
1	38%	32
2	15%	13
3	7%	6
4	11%	9
5	9%	8
6	8%	7
7	4%	3
8	2%	2
9	4%	3
10	2%	2

**Table 2: What were the nature of your initial concerns? Select all that apply.**

Answer Choice	Response Percent	Response Total
Delay in starting to talk	48%	66
Delay in other milestones (e.g. walking)	26%	36
Social development (e.g. relating to people in the normal way)	72%	98
Rituals/obsessions/dislike of change/object attachments	60%	82
Failure to develop normal pretend play	38%	52
Behaviour problems (e.g. hyperactivity, tantrums)	68%	93
Schooling	42%	57
Medical problems (e.g. epilepsy)	11%	15
Hearing problems	9%	13
Sensory sensitivity	68%	93
Sleep problems	59%	81
No worries until a professional raised concern	2%	3
Other (please specify):	7%	10

**Table 3: How would you rate your experience of getting a diagnosis? Select one option**

Very good	11%	11
Good	28%	29
Neither good nor poor	21%	21
Poor	17%	17
Very poor	24%	24

**Table 4: Satisfaction with the diagnostic process**

Answer Choice	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
The overall diagnostic process (referral to 1st appointment, duration of assessment, wait from assessment to final diagnosis)	14%	23%	30%	17%	16%
The information given at diagnosis	18%	32%	29%	11%	10%
The manner of the professional disclosing the diagnosis	37%	34%	18%	6%	4%
How involved you were in making decisions	22%	33%	29%	10%	6%
The support offered post-diagnosis	6%	12%	27%	22%	33%

**Table 5: Overall, how would you rate the Autism and ADHD assessment and diagnostic pathway in Birmingham?**

Very good	11%	11
Good	28%	29
Neither good nor poor	21%	21
Poor	17%	17
Very poor	24%	24

# healthwatch

## Birmingham

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