More than a diagnosis

What families with ADHD and Autism need to thrive

Contents

November 2025

Healthwatch Wakefield is a registered charity and company limited by guarantee registered in England and Wales. Registered charity number 1166797 and Registered company number 09907848.

Executive Summary

This report shares the experiences of 5 local families as they navigate the emotional and exhausting journey of Autism and ADHD with their child.

When a parent first notices differences in their child's development or behaviour is the start of a process of understanding their child's needs. At this time, they may face challenges in having their questions and concerns taken seriously by family, friends and professionals.

For children, these differences may be felt but not always understood, sometimes leading to a sense of being set apart from their peers.

Nurseries and schools can play a key role in identifying needs and providing. However, experiences are varied. While some families find schools helpful, others encounter limited understanding, and additional pressures. Children may also try to fit in at school and behaving differently causes a strain which emerges in behaviours in the place they feel safe, which is at home.

Families who feel that their concerns aren't believed feel isolated and unsupported. Staff at schools, family hubs, and community services have access to neurodiversity training delivered by Wakefield Metropolitan District Council 's specialist teachers and this has led to over 5,000 individuals receiving the training. The aim in providing this is for individuals who have contact with children to be better able to understand presentations of young people who may be neurodivergent and care for them equipped with skills and tools to help families throughout the child's development.

A diagnosis assessment for Autism or ADHD is not a simple process, requiring varied assessments by different professionals, and this can seem inconsistent and confusing to families. The complexities of assessment and the numbers requesting this process have led to long waits to be seen.

It is important to note that while a diagnosis may bring recognition and access to some support, such as medication, in itself it isn't therapeutic. Many families feel that getting a diagnosis is the first and most important step in helping their child to flourish, but it isn't a requirement of many offers in Wakefield, and so it is possible to seek support earlier and it isn't reliant on having completed the process in full to get help. Alongside this report we have produced an information pack with information on how to access lots of these offers.

Parents can access external support while waiting for assessment to support their child however the pathways to support are not clear or understood by families which means they are managing on their own which can impact on family life, work and finances.

Families and children require support to manage the challenges they face; however, a diagnosis may not be the outcome of the assessment process and therefore support needs to be based on needs and not diagnosis. Additionally, it must also be recognised that where a child does receive a diagnosis this may not change or increase the support they receive if the child's needs are already being met.

Families often find strength in increased knowledge, peer networks, and supportive environments outside of clinical pathways.

Families with greater capacity, time, or financial means can often navigate the system more successfully, raising issues of equity and fairness in current support models.

This report is clear: disability is not the barrier. A diagnosis alone will never be enough. What matters is how families are supported, empowered, and included. Families shouldn't just survive the process; they should be able to thrive.

The pathway must put families at the centre. It must build their capacity, protect them, and nurture them through what is often a difficult journey. Families are not just carers or a safety net - they are the foundation. If we want children to flourish, the pathway must focus on the whole family, not the child in isolation.

Our Recommendations

Our recommendations are based on the lived experiences of five families shared with Healthwatch Wakefield during this project. We also spoke with service leaders who helped us to understand the challenges being faced and how they are working to continuously improve and be needs led, not just focussed on diagnosis.

They will be shared with relevant organisations and progress will be monitored over the coming months.

The full recommendations can be found on page 13.

There is a need to create consistent and clear information of the support available and the referral processes for families, GPs, schools, and community services. This information needs to be accessible for all, including those who are digitally excluded. There is a need to strengthen needs led support and signposting. There is a need to build on and continue to recognise parents and carers as essential partners in the child's journey. There is a need to embed targeted, ongoing training on neurodiversity for professionals; and to canvas nationally for training to be universal in both education and social care training and education.

The purpose of a system is what it does, and families need more than assessments. They need a system that helps them stand tall, navigate the journey, and support their children to flourish.

Lewis Smith-Connell

Chief Officer

Introduction

In recent years, growing awareness of neurodiversity has significantly influenced how we understand and support individuals with neurological and developmental differences.

Neurodiversity refers to the natural variation in the human brain and cognition, encompassing conditions such as Autism and Attention Deficit Hyperactivity Disorder (ADHD).

Rather than viewing these differences as deficits or disorders, neurodiversity recognises individuals as part of the broad spectrum of human experience and functioning.

Many people have reported negative experiences while waiting for a diagnosis. Recent data from Healthwatch England[1] on ADHD support highlights this issue. People said they experienced poor communication from services, received no support during the diagnostic process, and felt that services could be improved by offering clearer advice and better information about ADHD.
Waiting times for ADHD and Autism assessments in England have reached critical levels. As of March 2025, around 549,000 people were on the ADHD[2] waiting list, and 224,000 people were on the Autism[3] waiting list. With around 90% of people waiting longer than the NHS recommended 13 weeks, and 144,000 people reported waiting two years or more.

These long delays[4] have serious consequences, impacting education, employment, mental health, and quality of life. The data highlights a national shortfall in diagnostic capacity and underscores the urgent need for expanded services and timely support for neurodivergent individuals.

The latest available data for September 2025 shows 1,592 children were waiting for the initial appointment with a Paediatrician in Wakefield. This first appointment is known as the Social Communication Clinical assessment and the average wait time for this is currently 41 weeks.

Once the child has had this initial appointment, and there is evidence of need for a full assessment, they move on to the Multi-Disciplinary Pathway. Currently there are 1,560 children waiting for their first appointment in this pathway, and the average wait is 53 weeks.

Background

Understanding and effectively responding to neurodivergent needs is more pressing than ever. Local data from the Wakefield Joint Strategic Needs Assessment (JSNA) highlights the rising prevalence of neurodevelopmental conditions in local children and young people.

---

[1] How to improve ADHD support for people, Healthwatch England, May 2025
https://www.healthwatch.co.uk/report/2025-05-28/how-improve-adhd-support-people
[2] NHS Digital, Data, Publications, ADHD Management Information, ADHD Management Information, May 2025
https://digital.nhs.uk/data-and-information/publications/statistical/mi-adhd/may-2025
[3] NHS Digital Data Publications Autism Waiting Time Statistics Autism Statistics, April 2024 to March 2025
https://digital.nhs.uk/data-and-information/publications/statistical/Autism-statistics/april-2024-to-march-2025
[4] The rapidly growing waiting lists for Autism and ADHD assessments, Jessica Morris, Nuffield Trust 4 April 2024
https://www.nuffieldtrust.org.uk/news-item/the-rapidly-growing-waiting-lists-for-Autism-and-adhd-assessments

In Wakefield in the 2024/25 academic year a total of 11,751 school age pupils had been identified as formally requiring extra help at school due to having special educational needs (SEN). This is 20% of the pupil population, about 1 in 5 pupils[5].

There is a trend of increasing numbers of children identified with special educational needs over the last five years in Wakefield as well as nationally. For example, in Wakefield there have been increases over time from 2017/18 to 2024/25 for pupils with an EHCP in a number of primary need groups, the largest number of pupils are in the Autism category (920 pupils), this has increased from 443 in 2017/18, an increase of 477.

Historically, interventions to improve the diagnosis pathway which were put in place in 2020 have not kept pace with the increase in ADHD and Autism referrals, which are continually growing, but if these improvements hadn't been made, things would have been worse. Long waiting times remain and families tell us there is limited communication and support from services, which makes families feel the wait is frustrating and like nothing is happening. The situation has been compounded by increasing referral backlogs and limited assessment capacity.

Recent data from NHS England[6] for West Yorkshire Integrated Care Board, which includes Wakefield District, shows that as of March 2025 there were 5,190 open Autism referrals for children and young people aged 0–17 years. Of those, the number receiving a first appointment after more than the recommended 13 weeks was 1,415.

However, there have been improvements made to local services recently. Funding of around £900,000 was given to the Wakefield District Health and Care Partnership to improve the Autism pathway. This has funded and recruited more Paediatricians, Speech and Language Therapists, Occupational Therapists, Psychologists, and Assistant Psychologists, who act as Pathway Coordinators in the service.

Over the past 12 months, an over-12s Autism pathway has been introduced. This is a shorter pathway designed specifically for children aged 12 and above. All parts of the pathway aim to provide a comprehensive assessment which is NICE compliant, but the over 12 assessment is adapted based on the understanding that if a young person continues to present with traits or symptoms beyond the age of 12, it is considered less likely that these difficulties are the result of another medical condition.

A new pilot scheme is underway in which Speech and Language Therapists and Occupational Therapists are based within family hubs. At present, this is still in the trial stage and has not yet been rolled out across the whole Wakefield District.

Neurodiversity training is also being delivered across schools, family hubs, and through the Parent and Carer Forum. So far, around 5,000 people have taken part in the training, including staff, professionals, and parents and carers.

---

[5] Wakefield District Joint Strategic Needs Assessment (JSNA)
https://www.wakefieldjsna.co.uk/

[6] Autism Statistics, April 2024 to March 2025, NHS England, 15 May 2025, https://digital.nhs.uk/data-and-information/publications/statistical/Autism-statistics/april-2024-to-march-2025.

What we wanted to find out

The project sought to explore the experiences of local families with children who are waiting for a diagnosis or have been diagnosed with ADHD and/or Autism.

Our focus was understanding how these experiences can affect families, what could help to improve their experience, and what gaps and barriers there are to accessing these services.

The key aims and objectives of this project were to:

- Speak with families about their journey before, during, and after diagnosis.
- Gather their perspectives on the accessibility, quality, and relevance of available support services.
- Identify common gaps, barriers, and challenges faced by families.
- Highlight examples of services, interventions, or approaches that worked well.
- Summarise key findings to inform potential service and pathway improvements and identify potential support for local families.

What we did

We conducted five interviews with families who have children with ADHD and/or Autism and live in Wakefield District. We used semi-structured, open-ended questions, and conducted these either online or in person. All interviews took place in May 2025 and June 2025.

The project was advertised at engagement events using leaflets and posters and was also advertised through word of mouth at family hubs. Because of this, this was not a diverse group and does not represent all families within Wakefield District.

Five families took part. Each family was made up of two parents and two children.

The children were aged between 4 and 13 years old.

Four children were waiting for an assessment. Four children had a diagnosis of Autism. Three had a diagnosis of both Autism and ADHD.

> “We’re grateful for the time the families have given in being part of this work, sharing their experiences and their story to develop this report. It’s the lived experience of families, children and young people which drives us to continually try to improve our services in partnership across health, social care and education.”
>
> Jo Rooney
>
> Children and Young People’s
> Senior Commissioning and Transformation Manager (Wakefield)

Findings

From our interviews we found six main themes:

- Inconsistent referral experiences
- A lack of post-diagnosis support
- The emotional impact of parental advocacy
- Barriers to support
- The positive impact of community and peer support
- Challenges at school and misunderstanding behaviour

Theme one: inconsistent referral experiences

From the interviews, it was apparent that all families experienced significant delays in the process, often ranging from over a year to several years. Parents repeatedly described long waiting times for assessments, with one family waiting more than a year after referral without any communication, and another reporting multiple years of uncertainty before finally receiving a diagnosis.

> “We have filled in the forms and school has sent the referral, but we are still waiting, a year later, with no communication since the referral.”

Families also spoke of the lack of clarity in the diagnostic journey. Once referrals were submitted, many felt the process was ‘never ending’, and that updates were only possible if parents themselves chased services for information.

Some parents described diagnostic experiences as ‘inconsistent and fragmented’. Multiple professionals were involved, yet families felt there was little coordination or follow-through. One parent explained that a referral was delayed because their child did not fit all the criteria for Autism, despite clear traits observed by both school staff and community paediatrics.

Another concern raised was the dismissal of children’s traits as ‘learned behaviour’ from siblings already diagnosed. This was particularly distressing for families who felt that their children’s needs were not being taken seriously.

Parents also described professionals attributing behaviours to alternative causes, such as prematurity, rather than recognising neurodiverse traits. One family reported being told by their GP that a referral would only be accepted if the school initiated it yet their school said they did not believe in Autism.

> “They told me that he doesn’t look or act autistic so he can’t be. How is an autistic person supposed to look and act?”

The inconsistency of diagnostic outcomes was stark. While a small number of families reported efficient processes with same-day feedback, others waited months for letters, and some were even removed from pathways for missing appointments they were never informed about. These inconsistencies left families feeling powerless and frustrated, with many questioning the reliability and fairness of the system.

Theme two: lack of post-diagnosis support

Once a diagnosis was confirmed, many families described being left to figure it out themselves. Parents reported a sudden drop-off in professional involvement, with little to no structured post-diagnostic support.

There are different treatment options for ADHD and Autism, with ADHD having medication and therapy treatments. Autism has therapy treatments. These services can often take months to years to access.

Families consistently described the absence of follow-up appointments or practical support. In many cases, the only resource provided was an information booklet, which parents felt was inadequate in preparing them to support their children.

Several parents noted that occupational therapy services offered some support, but these were often limited to suggestion-based guidance, leaving families to carry out strategies independently without ongoing help.

In response to this lack of support, parents described taking matters into their own hands. Many turned to self-directed research, seeking out resources online, compiling lists of symptoms, and pushing for support services.

Some families identified charities or community services that offered valuable guidance, but these were inconsistent or difficult to access.

> “All they did was add another lane to the motorway, but the traffic was still there.”

The lack of accessible post-diagnosis support left many families feeling abandoned by the system, amplifying stress, and forcing them to become their own coordinators of care.

Theme three: the emotional impact of parental advocacy

Across the interviews, families consistently described the need to take on the role of advocate for their child. Parents felt they had no choice but to research conditions, learn Special Educational Needs and Disabilities (SEND) law, and prepare themselves to challenge professionals and schools.

In many cases, parents felt they knew more about their child’s condition than the staff responsible for supporting them.

This constant battle was reported as exhausting and emotionally draining. Several parents described the impact on their own wellbeing and family relationships.

One family explained that the strain nearly caused their marriage to collapse, while others spoke about the stress of attending frequent meetings with schools, feeling constantly on edge and overwhelmed.

> “At one point, we were at school every week having meetings because of her behaviour, it was draining.”

Parents also spoke of isolation, describing how their experiences set them apart from friends whose children were developing typically. The constant comparison to other families deepened feelings of stress, sadness, and exclusion.

> “It’s been very stressful and isolating. Our friends’ kids are hitting all the milestones, ours aren’t, and we’re left asking: what can we do?”

The recurring theme of ‘having to fight’ emerged strongly. Parents explained that even when progress was made, new battles always followed. This ongoing cycle left families exhausted and fearful about the future.

Theme four: barriers to support

Support was not experienced equally across families. Those with financial resources were often able to seek additional support such as access to private diagnostic assessments or therapies, while families without such means were left waiting or going without. Parents described how income and location determined the level of help their children received.

Some families spoke of significant financial costs related to sensory tools such as toys and kindles which help their child self-regulate and improve focus. The organisation KIDS has a sensory toy library and the Parents and Carers Forum also have resources they can provide or loan, to help address this, but this offer could be publicised more widely.

Others highlighted the hidden costs of lost income due to reduced working hours or the need to leave employment to provide care, which is an issue that has been well documented across all areas of children’s disability in the last few decades.

> “I’ve had to change my working hours. My husband’s got flexible working, thankfully. But we’ve got no social life, it’s just not possible.”

Even when community support was available, access varied depending on local provision. Some families benefitted from initiatives like gym access or swimming sessions, which provided much-needed respite and wellbeing support, while others described a lack of opportunities nearby. With different parts of the district having limited access to public transport, the ability to take part in initiatives further afield becomes restricted.

A family shared that they’ve been using free Max Cards for both of their children. These can be applied for through the Local Offer, a directory of services and information for children and young people with SEND. You don’t need a formal diagnosis to get a card, and it can be used at a range of venues and attractions.

Parents also highlighted the social impact of inequality. Families often lacked downtime or the ability to build social lives due to the intensity of caring responsibilities and the absence of affordable support.

This illustrates how financial means, geography, and local service provision can combine to create a system of unequal access to support, leaving some families better resourced while others were left behind.

Theme five: the positive impact of community and peer support

In light of ongoing service limitations, community and peer-based support networks were described as transformative for many families. When accessible, charities, family hubs, and neurodiverse-friendly environments provided both emotional and practical help.

Parents highlighted the sense of belonging and relief that came from connecting with others who understood their struggles. Peer-to-peer networks were especially valued for reducing feelings of isolation and providing reassurance that families were not alone in their experiences.

> “We seek out friends with families similar to ours, because they understand what we are going through.”

Some families shared examples of how supportive nurseries or hubs made a tangible difference in their child’s progress and wellbeing. Parents explained how their children thrived in these settings, where staff were more understanding and supportive.

Community services also provided essential outlets for parents themselves, offering safe spaces to express emotions, share experiences, and access informal advice.

This highlights the significant role that community and peer support can play in alleviating pressure and improving family resilience, even when statutory services fall short. Families often don’t know where to look and so miss out on many of these great offers, we identified that more could be done to help provide families with this information, and so we have created the information pack alongside this report which helps connect with local community initiatives.

Theme six: challenges at school and misunderstanding behaviour

Schools were central to many families’ accounts, often as sources of both support and difficulty. Before diagnosis, many children were misunderstood and labelled as ‘naughty’ or ‘disruptive.’ Parents recalled instances where schools threatened exclusion, failed to recognise behaviours as signs of unmet need, or dismissed concerns outright.

> “She would sometimes lash out and refused to sit down, the school threatened to expel her before she was diagnosed.”

Even after a diagnosis, support was inconsistent. Some schools implemented effective interventions that allowed children to thrive in mainstream settings, while others continued to lack adequate training or empathy. Parents described frustration at schools dismissing their insights, despite parents often being the most knowledgeable about their child’s needs.

> “The staff only had basic neurodiversity training… so they didn’t know how to deal with him.”

Some children were able to thrive with additional support in mainstream environments, while others masked their difficulties during the school day only to ‘explode’ at home.

“He bottles up his behaviours at school, and then when he gets home, he’s like a shaken bottle of coke, he explodes.”

Parents described ongoing challenges with navigating Education, Health and Care Plans (EHCPs), with processes occurring without meeting the child directly. The SENART service doesn’t meet the child in person although they do pull together the reports and evidence into the plan. This can be challenging for families to understand, but is a limitation of capacity, and is how the service manages the high demand.

Overall, this demonstrates the critical role of schools in shaping family experiences. While good practice was evident in some cases, some families faced barriers due to inconsistent staff training, punitive behaviour policies, and a lack of systemic understanding of neurodiversity.

Recommendations

These recommendations are based on the lived experiences of five families shared with Healthwatch Wakefield during this project. These recommendations will be shared with relevant organisations and progress will be monitored over the coming months.

1. Create a consistent referral process across GPs, schools, and community services

Families should not have to chase information or repeat their stories. The referral pathway should be clearly explained, accessible to all, and include a single point where families can check progress and next steps.

2. Strengthen pre-diagnosis and post-diagnosis support and signposting

Commissioners and services should recognise the vital role of community organisations, creating stronger and more visible pathways to community and peer support so families can easily find support. Families should receive structured follow-up after diagnosis, including signposting to practical advice, emotional support, and opportunities to connect with other families.

3. Recognise parents and carers as essential partners in the child’s journey

Professionals should strengthen communication, set clear expectations, and ensure families are well informed at every stage. Families should be able to access up-to-date, plain language information on what to expect before, during, and after diagnosis, alongside details of local and national sources of support. Families should also be recognised as assets and focus should be given to empowering and enabling families to be active participants in the care pathway, as well as essential parts of ongoing care beyond diagnosis.

4. Provide targeted, ongoing training on neurodiversity for professionals

SENCOs, pastoral teams, and relevant staff in schools, family hubs, and other services should have regular training on ADHD/ASD awareness, masking, and understanding behaviour. This training should be part of a continuous development programme, not optional or one-off.

Conclusion

This report shows the strength of families and the need for clearer, fairer, and more supportive pathways. A diagnosis is only one step; lasting change comes from better communication, consistent processes, and inclusive support that helps children and families thrive.

We would like to say a huge thank you to the families who shared their experiences and to all those working to improve support.

Your voices and efforts make change possible.

Case Studies

All names have been changed to protect family identities.

Case Study One

Daniel, 13, and George, 9

Mum and Dad first noticed subtle symptoms with their eldest son Daniel when he was around 18 months old - poor eye contact, the way he played, and what he played with. They used to go to the family hub stay and play sessions and other people also mentioned these things to them.

When he was around three, they spoke to a friend, who also worked at the family hub, and she offered to come out as a favour, to reassure them. She went through a tick sheet, which the hubs use and said there was nothing to worry about, but suggested they try getting Daniel into nursery a couple of days a week, to help him socialise, which they did. About six months later, his key worker approached his Mum and said they'd noticed some things too, his Mum felt relieved that someone else had noticed.

From there, nursery started putting things in place. They helped with transition and even supported Daniel's move into school, and his key worker even went with his Mum to meet the new teachers. They describe the school as fantastic.

Daniel went to Sunbeam Nursery, which his parents describe as brilliant. He started speech and language therapy after the nursery identified this need. He didn't grasp sharing or playing with other children, he'd play alongside but not with them. He had a few sessions with the Speech and Language Therapy team and then the nursery referred them to Pinderfields Hospital to see the Paediatrics Team and have an Autism assessment.

Daniel was three when he was referred and six when they finally got the diagnosis. In this time, they had a few appointments with a Community Nurse, just for support and to chat about what might help. Even though it was a long process, it was relatively easy and smooth.

When Daniel was diagnosed, they received a report that was around three or four pages detailing the diagnosis, but they were also lucky enough to be told in person, shortly after he had his assessment. His Mum described crying with relief when she was told.

Daniel's brother, George, is nine and has had his referral dismissed. His Mum feels that this is because he masks his symptoms very heavily whilst at school, so teachers have not seen his behaviours fully. His Mum described how George bottles up his behaviours at school, and then when he gets home, he's like a shaken bottle of coke - he explodes.

His Mum told us that George can become quite chaotic at home; he doesn't understand his emotions and his family have to deal with the results of this. For example, his Mum has had to switch to contact lenses, as he keeps accidentally breaking her glasses.

His Mum and Dad asked the school to view videos of George at home, so they could understand his behaviour when making the referrals, but they refused because of safeguarding issues, even though his Mum had given her permission. They had been keeping a diary of his behaviours and gave this to the Assistant Head Teacher to read, which is when they finally listened. They also went to the family hub in desperation because he had threatened his parents with knives. The Family Hub staff suggested that the parents join a parenting course, but this was for neurotypical children.

George was also referred to CAMHS but was dismissed again because it 'wasn't a mental health issue.'

The parents say that they feel judged constantly, and those who haven't been through the same thing just don't understand. They told us that: "People from the outside look at you like you can't parent your child."

Since Daniel's diagnosis, they've had six-monthly check-ins with the community paediatrics team. The Community Nurse sent letters to the school about what they could do to support him. He doesn't have an EHCP, but the school is doing what he needs. "He gets some extra help and attends a mainstream school where he's really thrived."

His Mum and Dad were worried about the transition to high school, but his teachers were incredibly supportive and understanding. Daniel enjoys school and has a nice group of friends.

For George, they were told his behaviours were 'learned' and that it was attachment issues because he was born very prematurely.

They didn't access support services for Daniel as they didn't feel the need to. The help from school was enough. But with George, they have searched for support. WASP has been great, and their coffee mornings are helpful. They did the 'Riding the Rapids' workshop, sessions for parents. There's a waiting list, and they're often on Zoom or Teams, but they would prefer to do these in person.

Mum signed up to the Parent Carer Forum online and said that they send useful information and signpost to the Local Offer, a directory of information.

You don't need a diagnosis to sign up for the directory and they have used it mainly for the Max card which Mum told us is good for taking the kids for days out. They haven't accessed everything else but have made a referral to the Early Help Hub. Sometimes, just threatening to call the police can stop George's violent behaviour. They have also made a PCSO referral to have someone talk to him calmly. He struggles with talking to people and can be very shy. The parents feel that there needs to be more training around masking and a serious rethink on waiting times for diagnosis.

The occasional phone calls from the community nurse since Daniel's diagnosis have stopped so now have no real input from the NHS since his diagnosis. For George, they are now going through the right to choose at a clinic in Harrogate. They feel that he needs a diagnosis, and he needs medication to manage his anxiety. All of this has put pressure on the parents.

Mum's doctor suggested talking therapies for her, although she didn't take this up, as she has tried counselling before and it didn't work. They manage to offload to their friends and family and have a good support network. They go to a support group on Mondays at Castle Family Hub, which does help them.

This has massively impacted their lives. They don't go out much. Grandparents are their only babysitters but they worry about their (Grandparents) safety if George had a meltdown with them, so they avoid leaving them. They sometimes come to their house and babysit, which works. Daniel doesn't mind who looks after him, but George finds this difficult without his Mum.

Case Study Two

Olivia, 12, and Teddy, 8

Olivia and Teddy's parent started on their assessment and diagnosis journey for the children over five years ago. They describe this experience as mostly positive, but also stressful, isolating, and often soul destroying.

Olivia's ADHD traits were the first to surface. She struggled to sleep, and some behaviours were hard to manage. It was hard to distinguish early on but whilst they noticed signs in her, her brother Teddy's needs were so 'in-your-face', there was no room for them to just see how it went. "I threw myself into research, made lists of traits, and began seeking support."

Olivia's ADHD referral was delayed as the paperwork didn't tick enough boxes, but she wasn't discharged either. Eventually, she was picked up by community paediatrics. By then, they were seeing more autistic traits. They were worried about having to change the paperwork to include this, and whether this would delay diagnosis further, especially amid the chaos of lockdown. Fortunately, her school re-referred her, her file was already well established, something many families don't get.

Her ADHD doctor at Pinderfields was excellent; they started assessing for both conditions straight away and her parents said they walked out of appointments feeling good. However, there were still gaps. After diagnosis they didn't have disability nursing teams, only the ADHD medication reviews. For example, they had a good review with occupational therapy, but suggestion based, which meant they felt they were then sent off on their own to figure out.

The support found has been down to the parents reaching out. They felt that her primary school really failed her, but since starting at secondary school she has thrived. "She's thrived, made friends, eating more, doing really good."

With Olivia's brother, Teddy, it was a very different story. For the first 6 months, he slept and was the 'perfect child'. Olivia's behaviour was described as difficult and challenging, so this felt like a relief to them. But very suddenly, his behaviours changed, he was so sad with everything and became aggressive. The house was in permanent chaos. "It felt impossible to do anything, it was so draining."

Nursery reported escalating behaviours. He'd scream the school down and throw bricks and toys. A trial without the parents present was attempted, but they walked into what looked like neglect with Teddy in a soiled nappy, shut down, not eating, not sleeping. "It became clear I needed a diagnosis for my son, not for labels, but because nobody would take us seriously without a piece of paper."

They started the referral process. They had two very different experiences with the health visitor. With Olivia it wasn't a good experience. Her health visitor was reading from print outs, discussing only the negatives, telling her Mum and Dad what they shouldn't do. They saw her once. Teddy had a really lovely health visitor, she came multiple times and really engaged with the whole family. She even helped Mum with her health.

To start the Autism Diagnostic Pathway, in early 2019, we were advised we needed to attend the communications clinic. This was to rule out if there was any speech and language barriers to his behaviours. We were told that it was first come first served for an hour clinic, so get there early. We arrived at Castle Family Hub promptly. Teddy struggled waiting in any situation, and the waiting room was full. It was a stressful hour but luckily, we were seen before they closed the clinic, I don't know if I could have faced having to try again. The speech and language therapists were good, gave us a vital tool, a hand signal, and communication at home improved immediately and he was finally responding to his sister! From this session our referral continued through the system and he received his diagnosis at the end of nursery before starting reception.

He was diagnosed at four and a half, but ADHD can't be formally assessed until over six. Now they are two and a half years on and still waiting for the assessment and formal diagnosis and communication has been poor. Despite this his parents felt that his needs are understood and met without the diagnosis. "I've come to have peace with this."

The anxiety he carries can be crippling and this stops him from going out. The parents think he would benefit from ADHD medication, as his behaviour suggests sensory and ADHD overlap. He sees everything as a threat, and this is hard when doing things like assessments as every answer is a straight 'no'.

They managed to secure Disability Living Allowance (DLA) for both children, Personal Independent Payments (PIP) and a Blue Badge for Mum, because of her hip displacement, and fought for Teddy's EHCP. "I had to go to tribunal twice to make that happen."

They now use Aspire cards, offered by the council. This scheme offers several types of memberships for accessing different leisure activities, depending on what each individual is looking for. Memberships are standard, no discounts are offered for ADHD/Autism, but children get a discounted rate.

They have had mixed results with support services. The learning disability team was only offered for Teddy, and never for Olivia. However, Wakefield Awareness Support Project (WASP) did some good sessions that Olivia enjoyed. Future in Minds gave school sessions but they had no depth to them and didn't support the children's mental health needs. However, this was useful for the parents; they attended zoom workshops which they found useful still use elements of this learning now.

They said they wouldn't bother with Child and Adolescent Mental Health Service (CAMHS) or attempt to use their service again. CAMHS had suggested that Olivia's level of worry was 'normal', despite her being bullied at school and struggling to make friends.

They have found some good support services, which have been a 'lifeline' for them. The Wakefield Parent Carer Forum were described as 10/10. The support was still there during the COVID-19 lockdown, where they still put on coffee mornings and had regular meetings. "I knew I could turn up on a Wednesday and they would be there." They said that it was great to learn from other people's experiences and were able to understand and ask questions.

West Yorkshire ADHD Support Group were also great. The knowledge and experience, help and support they received was described as invaluable to the children. The parenting courses are good, and they do stay and play sessions for the children, where they can find other children with ADHD to play with and make friends with. Beat Autism were brilliant and were very understanding and would do anything for the community. Compass were great, especially for Olivia, they helped her in school and through the holidays to help with the transition to high school. Short Breaks were very good and tried their very best to support them the best they could.

But ultimately, the support system is patchy and overwhelming. They said that the ADHD diagnosis process just feels like a path to get medication and then you are left afterwards.

They describe themselves as being geographically isolated. Family support is limited as there are communication differences between the children and their families. They don't get support from friends either as the children don't always get on.

Mum is primary carer of the children and Dad works nights and shifts so she doesn't get time to herself. "I struggle with fatigue, a mix of caring, admin, chronic pain, and ADHD on-the-go-ness leaves very little time to work."

The impact on the whole family has been huge. Their communication styles clash and both children have similar, but very different needs. If one child has a day off school, then the other one wants a day off too. This then affects how the parents manage day to day. "I think my ability to get fully onboard with understanding and accepting the children and making drastic changes to our home has meant we've been able to meet their needs where possible."

One thing they would like to change about their experience would be to have more information from the start. Information about traits and the assessment and diagnosis process would have been extremely helpful. The parents spent a year wondering whether the traits were in line with ADHD and Autism or whether it was 'the terrible twos', and there was no one to speak to about this.

They also felt it would be better if schools had more confidence in speaking up to parents about traits and referrals. They thought maybe school staff didn't want to approach parents about what they had witnessed. It might not be bad behaviour or the child 'acting out' because they don't like school. They said it would be nice If they did approach parents, because it might affirm things the parents had also noticed over the months or years.

Case Study Three

Freddie, 13, and Lucy, 10

Freddie was in nursery when the staff and his health visitor started noticing his speech was delayed. He was able to speak but not understand it. This was brought to the attention of Mum and Dad who had not noticed anything yet. “The nursery was a godsend; they were very supportive.”

Everything seemed to change when he went to primary school. The school didn’t recognise Autism as a health condition, they didn’t ‘believe’ in it. They used to ‘train’ Freddie to act a certain way, a ‘normal’ way and did not support any of the referrals for Freddie to be assessed. Mum and Dad had to get a referral through the community team instead.

Whilst he was in school, they started pushing back. The school told Mum that she was making things up and blamed this on being a foster child, her mental health, and the fact she had just had a new baby. They then called in child protection services. This process lasted around two years where services looked into Mums family history, including her being a foster child, how they were bringing up their daughter Lucy, and possible attachment issues from being a foster child, despite Mum mentioning she had a wonderful childhood. “They blamed his behaviour on my ‘poor childhood’ and ‘attachment issues’.”

They had told his Mum that he couldn’t be autistic because he didn’t look or act like he was autistic. After Freddie left primary school, Mum and Dad found out that he had spent around four years behind a privacy screen, away from the other children because the staff deemed him naughty.

For both Freddie and Lucy, it was all dependent on what the school said and their referral. The consultant paediatrician would not accept a referral unless the school did this. It was slightly better for Lucy going through ‘Right to Choose’, but for Freddie he went through Pinderfields.

Freddie was on pathways for both ADHD and Autism and once referred, he got his diagnosis quite quickly, he was diagnosed around age nine and they were given a big information pack explaining his diagnosis and what it meant.

Daughter Lucy was also diagnosed with ADHD and Autism; however, this took around seven years. It was up to the school whether they were referred and assessed due to funding. She was eventually referred, and the school funded an additional staff member to help her with her learning. The Special Educational Needs Coordinator (SENCO) rang Mum and told her that the school couldn’t deliver what Lucy needed, so she was without schooling for a short while and then offered a place at a Special Educational Needs school.

Before homeschooling, Freddie was put into a mainstream school and had an Educational Health and Care Plan, (EHCP), written without meeting him or Mum and Dad. They wondered how you could develop a plan without meeting the child.

Freddie really struggled at this school and had panic attacks going through the entrance gates. He completely shut down. His Mum said: “They told him that I would go to jail if he did not attend school.”

They contacted CAMHS who refused to work with Freddie as he did not have a mental health condition and discharged him but Mum said he was diagnosed with severe anxiety and wondered why was this not taken into consideration alongside his neurodivergence. She felt that nobody seemed to understand what he needed and everything was brushed under the carpet.

Mum and Dad walked into school one day after being called in on account of Freddie having a 'melt down' and he was being restrained by the police. They had regular phone calls to go and take him home because of his behaviour, but this was recorded as they were voluntarily taking him home. If Mum and Dad refused, then that would be a suspension for Freddie. He has 12 suspensions over a one year period, with one being given 13 minutes after he returned from a previous suspension. "The staff only had basic neurodiversity training which that is optional anyway, so they didn't know how to deal with him."

Interestingly both Freddie and Lucy did well at school during the Covid pandemic as they were still attending in-person schooling, but at a reduced capacity because both Mum and Dad worked full-time.

Freddie was taken out of school and currently does all his schooling at home on a reduced schedule. He is thriving and has passed all of his SATS with top marks.

Mum and Dad went down the Right to Choose pathway for Lucy, and she had her assessment with Evolve Psychology. Lucy's diagnosis booklet was much more in depth than Freddie's was. Freddie's was three pages long and used negative language to describe the diagnosis. "It just kept mentioning all the things that he does wrong and was so negative and upsetting."

Lucy's was 33 pages long and used more positive language and included recommendations on how to manage the diagnosis. For Lucy, they suggested medication, but she is still on the waiting list and has been waiting around two years.

Since both diagnoses, they say they have received no support from the NHS, were given the information booklet and have heard nothing since.

They have received support from a few different organisations, but they don't qualify for much support unless Mum and Dad fund it. They tried to get support from Healthy Happy Holidays but were turned down because they didn't fit the criteria, as Dad works full-time.

They have received help from the Early Help Hub and have taken part in the Riding the Rapid's sessions, which are very good. They have had support from Riding for the Disabled who are also very good. Mum volunteers for KidsAware and says they are amazing. They have done all their parenting courses.

Mum and Dad enrolled both children into cubs and scouts, for a little while, they just sat at the back of the hall, but they now take part in activities and they both enjoy it.

Lucy was accepted into Short Breaks but Freddie was not at first because of his complex needs. He now has 1:1s with a member of the team and this is good.

WASP were really good and went into school and identified Freddie's needs but his school didn't accept the assessment of his needs. "It is so dependent on how schools view it and what their opinions are of it." Mum gave up her job to care for both Freddie and Lucy, but they see themselves as lucky as Dad still works full time. They feel they are doing okay, despite the challenges. "We nearly ended up divorced a couple of times because it was all too much."

They undoubtedly have gone through a tough time. They also felt scrutinised by healthcare workers and were told they had made their house too inviting and educational; both children will never want to go to school because of this. Mum said she would like to see healthcare professionals and schools not be so dismissive of parents because they are not professionals. Mum and Dad have done extensive research on ADHD and Autism and now have great knowledge on this but they felt they would be treated poorly in meetings because they weren't professionals. "We were looked down upon and viewed completely differently than those who wear lanyards and badges."

Overall, their experiences have had an effect on everyone's mental and physical health. Freddie has trouble with his anxiety and Mum ended up really poorly because she couldn't attend any doctor's appointments. Mum and Dad haven't had a proper social life in years. They lost a lot of family members during Covid, and there is no one to look after the children so they can have a break.

They do volunteer with KidsAware and this helps a lot. It is the biggest boost they have had since their children got their diagnosis.

Case Study Four

Mabel, 9, and Jennifer, 7

Mabel and Jennifer's Mum and Dad shared their experiences navigating the complex journey of assessment, diagnosis, treatment, and support for Mabel who has been diagnosed with ADHD and Autism, and Jennifer who is currently on the waiting list. Mabel was first diagnosed with ADHD in 2023, followed by an Autism diagnosis in 2024, after being on the waiting list since the age of six. Jennifer has been on the waiting list for around one year since she was six. "We have filled in the forms and school has sent the referral, but we are still waiting, a year later, with no communication since the referral."

Mabel's process of getting a diagnosis was drawn out and inconsistent. School first noticed signs during lockdown whilst she was taking part in school activities through online classes. School then helped with her referral and she saw a paediatric consultant and an educational psychologist to get her EHCP. Mum and Dad were informed of Mabel's Autism diagnosis on a phone call and a letter was sent out shortly after. However, for her ADHD confirmation, Mum and Dad were informed on the same day of her consultation, shortly after the assessment.

After Mabel's diagnoses, Mum and Dad were relieved as they had something in writing which explained her behaviour but: "We were both happy and sad after the diagnosis."

Straight away they started Mabel on medication for her ADHD, to help her focus and regulate. She was meant to have six monthly reviews for her medication, but this took around a year and a half to come through. She also has three monthly checks with an ADHD nurse to check her height, weight, and blood pressure because of the medication.

The pathway for Mabel's Autism diagnosis involved more communication and structure than her ADHD diagnosis and included better observations from both the school and hospital.

Unfortunately, there have been miscommunications about Mabel's medication with serious consequences for the family. Her paediatric consultant approved upping her medication dosage as the lower dose was not working for her and by dinner time it would start to wear off. They did this based on the consultant's guidance. They said they would review this with Mum and Dad after a week to see if this was working. They rang two weeks later and were told they had not approved upping the dosage and accused Mum and Dad of overdosing Mabel and that they would contact social services.

"This was a very stressful time for us, school noticed she was getting over stimulated after dinner time…… the higher dosage of medication was approved by the consultant, so we don't understand why he would say this. It was a nightmare."

Mabel can sometimes get overwhelmed and can become aggressive towards her sister and Dad. This can be both physical and verbal and Dad shared: "I think it is just easier to take it out on me."

School have been good with Mabel since her diagnosis. "She would sometimes lash out and refused to sit down, the school threatened to expel her before she was diagnosed." Their attitudes towards Mabel have now changed and she gets more support from them. Jennifer is experiencing similar issues but is still waiting for her diagnosis. She was suspended for one day for lashing out at a friend.

School have said it doesn’t matter if they have a diagnosis or not, they don’t tolerate bad behaviour. They said: “We understand not tolerating bad behaviour, but it isn’t entirely her fault.”

After Mabel’s diagnosis she was under the team at WASP. She is on the waiting list for Lego therapy, she has been on the list for around a year, and Jennifer has recently been put on the list too.

Mum and Dad have had no support. They have done some courses on Autism and how to deal with outbursts. They have also done their own research on ADHD and Autism.

They explained that: “School doesn’t like this because we know more about it than they do.” And that: “It is frustrating, they don’t listen to us at all when we give them tips on how to handle outburst and meltdowns.”

They have been to Cedars Family Hub and they couldn’t be happier with their services. “They are fantastic with both girls and really dote on the kids.” They were also with KidsAware for a short while who were great with the whole family. Mum and Dad have also done some of their courses for parents which were really good. “If there is anything you need to know, they know it…. they are great.”

They would like shorter waiting times for diagnosis and said there needs to be more information out there for parents. “When you become a parent, you sort of know what you are doing, but then there is a hell of a lot more to understand and do. You can’t understand what the child is going through, and there is no handbook given to parents to help them.”

After Mabel’s diagnosis, there was no support or guidance offered. They no longer see the consultant and only have appointments with the Speech and Language Team (SALT).

The diagnosis has not affected them financially, but they have had to buy certain things to help the children, such as sensory toys.

The have one family member that helps them, a grandparent, but it is a struggle to handle both girls. They do have a great support system with friends, as they have children who are also neurodivergent, so they can offer each other support and help. “We seek out friends with families similar to ours, because they understand what we are going through. “Neurotypical families don’t understand what we are going through and often judge us and assume our kids are spoiled brats when they lash out in public.”

Case Study Five

Bill, 6, and Ted, 4

Mum has spent the last several years navigating the complex and often disjointed system of trying to get an Autism diagnosis for her two young sons. Bill developed typically at first, meeting milestones such as walking and rolling over ahead of schedule. But at around 18 months, things began to change. “Up until about 18 months, he hit all the major milestones early, walking, rolling over… then he regressed, he stopped talking, he hyper fixated on Peppa Pig, started hand flapping and wouldn’t point at things or people.”

Concerned, Mum and Dad reached out to their Health Visitor, who made a referral just before he turned two. In contrast, Ted didn’t show signs of regression. He’s currently going through the diagnostic process, but the responses from professionals have been more relaxed. He didn’t regress like Bill did. Mum explained: “We’re still going through the process of diagnosis, but it’s harder because people think it’s learned behaviour from his brother.”

She said that the diagnostic pathway was long and difficult, particularly for Bill. His process involved speech and language therapists, occupational therapists, an educational psychologist, and a paediatrician. She explained that they had to chase and chase for appointment dates. The process was very difficult, especially during Covid. After more than two years, he was finally diagnosed with Autism and complex learning needs, particularly having issues with social communication. But the experience of dealing with different professionals was mixed. They saw the Speech and Language Team (SALT) a few times, contact with the occupational therapist was through phone calls and then they discharged him.

At one point, they were removed entirely from the service pathway for missing an appointment, despite poor communication from the service, and not receiving the appointment letter. She described how the process left her feeling unsupported, saying: “Once you get your diagnosis, it’s like, ‘see ya’.”

She felt there is no ongoing support, nothing out there for parents. They were lucky enough to be able to pay for private SALT appointments for Bill. However, this still comes at a steep cost, at £40 per 20-minute session, and a few hundred pounds for any reports writing up. This is something that they could not offer their eldest as he was going through the diagnosis.

Despite the challenges, they did find some support from early years settings and professionals. She explained: “The nursery was fantastic, really helpful.” And: “The health visitor was great; she did the referral.”

These individuals stood out as exceptions in an otherwise overwhelming process.

In addition, the financial and emotional toll has been significant. “It’s been very stressful and isolating. Our friends’ kids are hitting all the milestones, ours aren’t, and we’re left asking: what can we do?”

They have also made substantial changes to their lifestyle and home environment to accommodate their children’s needs. “I’ve had to change my working hours. My husband’s got flexible working, thankfully. But we’ve got no social life, it’s just not possible.”

Their home and garden now include a full-sized trampoline, a climbing frame, and a sensory garden in the driveway. “We’ve created a sensory garden, got a slide in the living room, anything to help them regulate. We’ve even got three Kindle charging all the time so one never dies.”

They have taken a proactive role in understanding Special Educational Needs and Disabilities (SEND) law and have become their children’s strongest advocate.

Support has also come from outside the district, through a Leeds based charity offering therapies and activities like 1-1 Rebound, a session using a trampoline, led by an experienced physiotherapist, to promote balance, relaxation, sensory integration, and improve muscle tone, fitness, and communication. “Without the Rebound sessions, he would have nothing.”

The parents' reflections are full of frustration with how little practical support exists for families like hers.

“The hardest part is constantly having to fight. When you think the fight is over, there’s always more. You’re fighting everyone just to get your child the support they need.”

They believe that clearer information, realistic time frames, and consistent post-diagnosis support could make a world of difference. “The information, the timeframes, the support, those three things could make such a difference.”

Despite all of this, both boys are energetic and happy. Their wellbeing is a testament to their parents’ commitment to creating an environment that allows them to thrive. “They’re happy because we’ve put their needs at the heart of everything.”

healthwatch Wakefield

Telephone 01924 787379

Mobile 07885 913396

Email enquiries@healthwatchwakefield.co.uk

Website www.healthwatchwakefield.co.uk

We are social people. Find us, follow us, message us.