

Children's emotional wellbeing and neurodiversity engagement report – Sutton

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Contents

1. Executive summary	3
2. Introduction.....	4
3. Background	4
4. Methodological approach.....	5
4.1 Research method.....	5
4.2. Demographics	5
5. Findings.....	6
5.1. Behaviours and emotional challenges.....	6
5.1.1 Section summary	6
5.1.2 Early behaviours	6
5.1.3 Current behaviours.....	7
5.1.4 Triggers to behaviour.....	8
5.1.5 Behaviour differences in home and at school.....	9
5.2 Experiences of diagnosis	9
5.2.1 Section summary	9
5.2.2 Experiences for those with a formal diagnosis.....	10
5.2.3 Experiences for parents without a formal diagnosis.....	11
5.2.4 Long waiting lists	13
5.2.5 Stigma and judgement when seeking support.....	13
5.2.6 Challenges navigating the health system	14
5.3 Support	15
5.3.1 Section summary	15
5.3.2 Support during and following a diagnosis.....	15
5.3.3 Support for families without a diagnosis	16
5.3.4 Key observations that could improve support for families	17
5.4 School experiences and support.....	20
6. Next steps	22
7. References	22

1. Executive summary

This report presents findings from engagement with families living in Sutton with primary-aged children with diagnosed or suspected neurodiversity. The report builds on a south west London-wide literature review that identified long waits, lack of inclusive support, and challenges navigating Special Education Needs and Disabilities (SEND) pathways, as key concerns and barriers. This focused on engaging directly with parents of primary school-aged children to help understand the early triggers and barriers that influence escalating behaviours and their access to support.

Key findings have been outlined below:

- **Confusion and frustration in navigating support** - Families described the health and care system as overwhelming and fragmented. Parents reported feeling “*lost in the system*”, with a lack of clear signposting and uncertainty about access to support, particularly for those without a diagnosis.
- **Masking behaviours lead to overlooked needs** - Children presented as settled or compliant at school but expressed different behaviours at home. Survey data showed 67% of parents saw differences between school and home behaviours. Parents felt their concerns were dismissed when schools reported “*no issues*”, creating barriers to diagnosis and support.
- **Need for practical advice and trusted resources** - Parents expressed a desire for practical strategies, early advice, and reliable information tailored to their child’s behaviours. Families felt face-to-face support was important and opportunities to learn from others with lived experience.
- **Fear of judgement and stigma delays help-seeking** - Survey data reflected 66% of parents felt judged when raising concerns. Parents feared being dismissed by services, leading to delays in seeking support.
- **Long waiting times and lack of support while waiting** - Parents described waits of 9 to 18 months for assessment, leaving families in “*limbo*.” Delays were reported to worsen children’s struggles and family wellbeing. Families without a diagnosis often felt “*stuck*” and unsupported, with little guidance or practical help during the waiting period. Some parents said they had no choice but to go private to avoid delays.
- **Challenges in early years and identifying early signs** - Parents described noticing differences from infancy or toddler years, such as delayed milestones, emotional sensitivity and heightened reactions. While parents were often unsure at the time what was “*typical*” behaviour, these patterns emerged across accounts as early signs that their child might need additional support.
- **Opportunities for early intervention** - Parents raised the lack of post-diagnosis follow-up, leaving them feeling “*neglected*.” Families without a diagnosis described being “*stuck*” with no formal support. Health visitors were frequently mentioned as a missed opportunity to share strategies or signpost families to help at an early stage.
- **Parents acknowledged that schools need more support to meet children’s needs** - Parents shared mixed experiences of schools, with some describing positive relationships and others highlighting gaps in understanding and limited resources. Families recognised schools are under pressure and emphasised the need for more staff training, practical strategies, and additional classroom support. Survey findings echoed this, with 11% of parents identifying a need for more in-school support.

The findings will be considered by Sutton Place Leads and will inform the refresh of the Sutton Health and Care Plan. Findings will also be used to help shape future strategies, ensuring that services reflect the lived experiences of families.

2. Introduction

Discussions at the Sutton Health and Care Executive meeting in January 2025 and with Sutton Place Leaders highlighted the need to focus on the emotional wellbeing of children and young people with neurodiversity, SEND, particularly where there are behavioural challenges.

In March 2025, we published a [literature review](#)¹ which reviewed existing insight across South West London - analysing 15 reports from our local NHS team, local authorities, Healthwatch and voluntary community organisations, published between 2020 and 2024. This gave us a strong evidence base, capturing mental health experiences from children, young people, and their families, especially those affected by SEND and neurodiversity. Key challenges we heard included:

- Long waits for assessment
- Lack of inclusive support and activities
- Mixed experiences with Education Health and Care plans (EHC plans)
- Difficulties navigating complex SEND pathways
- Many families felt isolated or had to 'fight' for support without clear guidance.

These findings shaped this next phase of our engagement, using an evidence-based approach to test key themes and the support which to avoid behaviours escalating with families living in Sutton. This report therefore outlines the approach we took following the publication of our literature review and shares the findings from this second phase of our engagement.

3. Background

The emotional wellbeing of children and young people in south west London is a growing concern, with increasing rates of mental health difficulties, self-harm, and suicide reflecting the urgent need for enhanced support services.

In south west London, around 16% of children and young people are identified as having Special Educational Needs (SEN), which is higher than both the London and national averages. Many of these children need additional help with their social, emotional and mental health².

In Sutton, the number of children and young people needing formal support has risen quickly. The borough supports 318 children and young people per 10,000 with an EHC plan, which is higher than the London and national averages³. The total number of EHC plans has nearly doubled in recent years, increasing from around 1,100 in 2015 to more than 2,100 by mid-2023⁴.

In Sutton, autism is the most common reason children and young people have an EHC plan. This reflects national data, where almost a third (31.5%) of all EHC plans are for autism. Other common reasons include speech, language and communication needs (21.3%) and social, emotional and mental health needs (20.7%)⁵.

With the rising demand and increase in complex needs, this report outlines our findings into the experiences of families, to help shape support and services that reflect their needs.

4. Methodological approach

4.1 Research method

To inform our approach, we held conversations with local partners including Sutton Council, South West London and St George’s Mental Health NHS Trust (SWLStGs), Cognus and Sutton Place Leads. These discussions highlighted the importance of early prevention and helped shape the scope of this project, leading for us to focus on primary school-aged children. Focusing on this age would enable us to better understand the early ‘trigger points’ that can escalate into a mental health crisis if left unaddressed, and the support families would find helpful to avoid behaviours escalating. Alongside these conversations, we also shared and reflected on the findings from our literature review, which further guided the direction of our engagement work.

We worked with local primary headteachers to design and test our approach, holding a coffee morning with parents at a local school. This provided an opportunity to test our questions, ensure language was accessible and check that the issues we planned to explore resonated with families. Feedback from the coffee morning informed the development of both our survey and one-to-one interviews.

Interested schools helped to promote our survey and one-to-one interviews with parents on our behalf and encouraged involvement. This approach enabled us to reach families who may not usually engage with health and care services. The NHS SWL engagement team’s contact details were also provided so that families could request support or alternative formats if required, ensuring that our methods were accessible for all families and views were not excluded.

4.2. Demographics

In total, we heard in-depth feedback from 23 local families raising children. Families who were interested in being involved had children with diagnosed or suspected autism and Attention Deficit Hyperactivity Disorder (ADHD) as well as wider neurodivergent behaviours. This included families whose children who had a confirmed diagnosis, those who were awaiting assessment or diagnosis, and others who were noticing early signs. This demographic allowed us to capture a broad perspective on early behaviours, pathways to support and the varying challenges families face in accessing help and support.

At the end of the survey, participants could choose to provide demographic information, which helped us understand who we had engaged with and assess how representative the sample was.

Data regarding ethnicity and year group has been outlined in the tables below.

Ethnicity	Number of people
Asian or Asian British	2
Black Caribbean	1
Black African	1
Black Caribbean and White	2

Year group	Number of people
Reception	2
Year 1	2
Year 2	2
Year 3	7
Year 4	2
Year 5	3

White British	12
White European Mixed	1
White Other: Polish	1

5. Findings

5.1. Behaviours and emotional

challenges

5.1.1 Section summary

This section explores parents' experiences with their child's behaviour, including early and current behaviours of children, triggers to behaviour challenges and differences in behaviour at home and at school. Key findings have been outlined below:

- Behaviours:** Parents noticed differences from infancy or toddler years, often linked to delayed milestones (speech, language, learning skills) or behaviours such as withdrawal from social contact, repetitive/obsessive interests. Many were unsure what was *"typical"* behaviour. Other behaviours include impulsivity, mood swings, meltdowns, difficulties with friendships and challenges with attention and routines. Survey data supported this, showing strong emotional reactions, difficulties with transitions, resistance to tasks, and challenges with routines and cooperation.
- Triggers:** Behaviour was often affected by changes to routine, sensory overload (e.g. noise, busy places), school environments, social situations, or unmet expectations. Some behaviours were unpredictable, leaving families feeling anxious and restricted in daily life.
- Masking:** Many children masked behaviours at school, appearing regulated, quiet, or compliant in school and behaving differently at home. Parents felt this made it harder to access support, with needs overlooked when schools reported *"no concerns."* Quiet or well-behaved children were particularly at risk of being missed. Survey findings confirmed this with 67% stating their child's behaviour was different at home to being at school.

5.1.2 Early behaviours

Parents described how the first signs appeared gradually, sometimes as early as infancy or during their toddler years, when developmental milestones such as walking, talking or social play were delayed or seemed different to other children. For many, these were delayed milestones including speech, language development and learning skills: *"At around 2 ½ years I started noticing something wasn't quite right. It was more purely development and behaviour - their reaction and how they were handling things. It just wasn't quite there."*

Some parents described behaviours that seemed different to what they expected in very young children. These included early signs of being obsessive or repetitive (e.g. fixation on particular things or objects). Others noticed that their child seemed to withdraw from social contact or avoid people, even at a very young age:

“I noticed my child’s behaviour changed when they were 2 years old. They hated people and would sit in their room and not engage. They didn’t want to talk to people and sometimes would cry and be unhappy about someone else being at home.”

Parents spoke about uncertainty, wondering what was “normal” or “typical” behaviour for their child’s age: *“It’s hard with your own child as you’re not entirely sure what’s normal and what’s not. I did have concerns when they first started.”* Another parent added: *“It’s difficult to differentiate between what’s normal behaviour. To know what a typical way to respond to things.”* For some parents, concerns grew as children reached school reception-age. Parents noticed difficulties with focus, “*lashing out*”, short attention spans, meltdowns and other challenging behaviours: *“Around reception I noticed their ability to focus and their retention. They were suddenly lashing out. Having breakdowns, meltdowns. Loud screaming and compulsive behaviours. I just knew that it wasn’t normal.”* Some parents referenced how teachers initially raised concerns about their behaviour: *“In year 3, the teacher noticed my child was struggling in class and struggling with their attention and retrieval.”*

Survey responses reflected these findings, with parents identifying early signs of emotional sensitivity, challenges with adaptability and heightened reactions.

5.1.3 Current behaviours

As children grew older, most parents said the behaviours they first noticed either continued or became harder to manage. Impulsivity, mood swings and concentration difficulties were recurring themes: *“My child is very impulsive. Their emotions can change... they can be happy one minute and then angry the next and find it’s very hard to concentrate on one thing.”*

Meltdowns were described as frequent and overwhelming: *“My child has meltdowns which is hard to deal with. Their anger and meltdowns are being channelled at you.”* Parents highlighted the intensity of some meltdowns: *“Meltdowns are bad – they have threatened to throw furniture at me and across the room.”*

Parents also raised concerns about safety and social behaviours, with some describing a lack of danger awareness: *“I’m constantly having to monitor my child as they have no sense of danger.”* Another parent added: *“When we go out it is very challenging. You really have to stay on top of it. I can’t have them out of my sight and they need constant supervision.”* Others spoke about clinginess and attachment: *“My child is very fixated on me... they ask me ‘where I’m going’ if leaving the house and has meltdowns when I would leave the house.”* Social interaction and difficulties with friendships was also highlighted: *“My child plays on their own and copies other children rather than playing with them”.* Another highlighted challenges with friendships: *“They’re constantly arguing and fighting with their peers.”* Other ongoing difficulties included communication and understanding plans and routines, needing prompts or instructions, hyperactivity, not listening and being a “fussy eater”.

“They were finding it hard with friendships, impulsive behaviour and social cues. I know this was having an impact on my child as they were getting frustrated.”

“Parents who live this life can become quite isolated because their children have meltdowns in public... It can be mortifying and make parents not want to go out.”

Survey findings supported interview findings, with parents reporting strong emotional reactions (16%), difficulties with focus, transitions and bedtime routines (12%), resistance to tasks (14%), challenges at mealtimes (10%), and difficulties following instructions or cooperating (8%).

5.1.4 Triggers to behaviour

Parents described a wide range of triggers which impacted their child's behaviour. Survey findings highlighted that changes to routines, whether at home or at school, was a frequent trigger. One parent explained, *“My child likes to know what we're doing. If we're not going somewhere until the evening they will have a meltdown.”* Difficulties settling into new environments were also highlighted: *“My child struggled to make friends when they moved school as it was a big change. They've had lots of issues with school and not wanting to go even though they're really keen on learning.”*

“Sensory overload” came up frequently, with parents referencing noise, busy places and sudden changes as triggers: *“Noises are a trigger e.g. ambulance, sudden moment. Sometimes people talking to my child or when someone smiles at them when walking on the street, this can make them really upset.”*

Attention and learning environments were also common triggers. A parent said, *“Not having any attention on them is a trigger like if I'm talking to their siblings and not them.”* Another parent highlighted attention within the school environment: *“If a subject isn't engaging or the teacher's not engaging it's a trigger. They struggle with supply teachers - having breaks help.”* This was supported by the survey, where school environment was found to impact behaviour, alongside friendships and bullying.

Some triggers were linked to obsessions or routines: *“If they're not obsessed with the video games, it's something else. They wake up with it on their mind and can't get back to sleep.”* Expectations were also noted: *“If my child has an expectation of something and then the outcome doesn't meet their expectations then they get really frustrated - like losing at a sport.”* One parent stated how saying “no” was a trigger in itself: *“They flip out if they don't get their way. It's not a case of being spoiled... they genuinely struggle.”*

Some parents indicated that not all behaviours could be explained by a clear trigger:

“Sometimes behaviours are not predictable. Sometimes there's no trigger and that's what makes it really tough.”

For some families, this unpredictability had a wider impact: *“This is why a lot of people do hideaway in their houses with their children because their behaviour is very unpredictable and anything can trigger them in their environment.”* Lastly, parents also worried about their behaviour as they grew older: *“My child's anger scares me a lot for when they are older.”*

5.1.5 Behaviour differences in home and at school

Masking of behaviours was strongly indicated when speaking to parents, particularly in those who struggle getting a diagnosis. Many parents described how their child masks behaviours and difficulties while at school and then acts differently at home. Parents felt this makes it harder for their needs to be recognised, impacting access to support and diagnosis. As one parent explained: *“Behaviour is different at home than at school. The school says my child listens and plays and is generally well behaved... then as soon as they get home they let it all out. It’s like their safe space.”* Others described how difficulties were not always seen in the classroom: *“At school they sit in the corner when they’re upset. They don’t fit in with people and no one sees them misbehaving.”* Masking could also work in different directions: *“It’s like where they can mask it and where they can’t. If sad at school then they’re good at home or good at home then have a bad day at school.”*

Several parents felt their child’s ability to mask in school settings meant their needs were dismissed or overlooked: *“Just because they look OK, it doesn’t mean that they are... They’ll mask it quite well and then be bottling up all these thoughts and feelings. And then I would deal with it outside of school. They’d say, ‘No, it’s fine, it’s fine, it’s fine’, when really it’s not fine.”* Another parent added, *“Behaviours don’t ever get noticed in school because they so abled. They aren’t disruptive.”* Parents highlighted that quiet or well-behaved children can easily be missed:

“My child is quiet and can just sit in the corner. There needs to be more of a holistic approach and look at everything else and that they’re different at home. It’s about taking mum’s word for it.”

Survey responses also reflected these findings, with 67% of parents stating their child’s behaviour was different at home compared to being at school. Among those who saw differences, parents highlighted masking at school appearing more regulated due to routine and social interaction or holding things in until they return home. Others saw differences in concentration levels or emotional expression, with one parent suggesting their child *“does not feel safe or supported at school and therefore cannot show emotions.”*

5.2 Experiences of diagnosis

5.2.1 Section summary

This section explores parents’ experiences of diagnosis, divided between those who had received a formal diagnosis and those who had not. Key findings have been outlined below:

- **Mixed experiences of diagnosis** - Parents described different journeys depending on whether their child had received a formal diagnosis. For many, diagnosis was essential to unlock support at school and with services being a *“gateway”* that provided validation and opened doors. Some found the process frustrating and dependent on which professionals or services they saw.
- **Families felt “stuck” without a diagnosis** - Parents who had not yet received a diagnosis often felt *“stuck”* and described being dismissed by professionals. They reported barriers such as needs not being recognised by services and services relying

heavily on school reports. Parents emphasised the need for professionals to take a more holistic approach and to listen to their concerns.

- **Long waiting times** - Delays for assessment and support were a major source of stress. Parents described waits of 9 to 18 months, leaving families in “limbo.” Many said delays worsened their child’s struggles and family wellbeing. Some felt they needed to go private to avoid long waits.
- **Judgement when seeking support** - 66% of survey respondents said they felt judged when seeking support. Parents worried about being dismissed as “over the top” or blamed for their child’s behaviour. Fear of judgement often stopped parents from seeking help in the first place.
- **Navigating the system** - Parents described the health and care system as confusing, and overwhelming. Many felt “lost” and unsure where to turn, with some saying support only came if they pushed persistently. GPs and schools were usually the first point of contact, but families reported being passed between services with little guidance. Some with professional or family knowledge of health and education found the process easier, but many called for better signposting and more accessible information.

5.2.2 Experiences for those with a formal diagnosis

Parents shared mixed experiences of the diagnostic process, with differences depending on whether they had received a formal diagnosis for their child or not. When asked about their experiences with assessments or diagnosis, survey respondents described feelings of “neglect”, “hitting a brick wall,” and “long waiting times.” Just over half of parents (56%) reported that formal support or assessment had been suggested for their child. Barriers to seeking assessment included not knowing how to begin the process (20%) and concerns about waiting times (10%).

Many parents with children who had received a formal diagnosis described it as essential for accessing support. As one parent highlighted: *“You don’t get the help and support until you’ve got that diagnosis. The doors open for support.”* Parents felt diagnosis provided the evidence schools required to put support in place: *“I’m desperate for them to get the support they need, especially when it comes to school. I know diagnosis is not a miracle cure.”*

“Life is very hard and you just have to hope that with that bit of paper in your hand, that diagnosis, it will make it a bit easier for you to access the services that might help your child.”

Some parents expressed relief from having a diagnosis, with one parent stating: *“it was validation of what I already knew, what we had already experienced”* and *“the validation of having it on paper and having difficulties addressed and recognised.”* Others described diagnosis as a gateway: *“Diagnosis opens the gates for conversations with people.”*

Parents’ experiences of diagnosis and assessment varied. Some described how early processes made a positive difference. One parent credited Dragonflies Assessment and Intervention Base in Sutton with helping their children access support: *“I went to Dragonflies assessment unit and I really credit them... we didn’t have to do it alone and it was done early. It made a difference to my children.”* They described how this allowed their children to have an EHC plan by the time they had reached reception, allowing the school to provide

early support. In contrast, some parents highlighted how they didn't feel supported in the diagnosis process, stating: *"It was me pushing every button to get what I needed."*

Others described how they found the diagnosis process challenging including previous rejections: *"Previously had two rejections after paediatrician put referrals into CAMHS for ADHD diagnosis. It was quite the fight, even the paediatrician had to appeal the decision."* Another parent described challenges during the assessment process for an autism diagnosis: *"I told the assessor that my child has problems speaking to people and we ended up sitting for an hour with my child being silent and crying. Their diagnosis was based on them acting like that for an hour."*

The quality of the diagnosis process was described as varied, depending on where families went and which professionals they saw: *"Support depends on who you see and which hospital you go to. It's a postcode lottery. The paediatrician at St George's was absolutely amazing."* Another parent also highlighted positive feedback on the paediatrician they had seen, referencing how they performed a *"very thorough assessment"*.

5.2.3 Experiences for parents without a formal diagnosis

Parents who had not yet received a diagnosis often described uncertainty, self-doubt, and barriers to accessing help.

The system not recognising behaviours raised at home was a reoccurring theme. One parent explained, *"I contacted our health visitor and asked for a referral and they wouldn't refer them. They would say 'from what they see the child looks okay' but it's when it's just me and my child on their own their behaviours are displayed."* Another referenced the importance of school views in the diagnosis process and how this could be a barrier: *"If the school haven't got an issue, then they [diagnosis services] won't look at you."* For some, barriers to diagnosis left them feeling stuck.

Feelings of being dismissed was evident in the parents we spoke to. One parent shared dismissal when talking to a paediatrician, *"It was so frustrating. Their manner was dismissive and I felt shut out the room. I was so angry and upset and I didn't feel listened to."* Some highlighted how they felt dismissed by the school: *"I feel dismissed like they're trying to make me feel like I want the diagnosis. It's very disheartening"*. Another parent added: *"I went to school with a few issues but it was just put to the side, like they don't do this at school so they must be OK. I wish they would have done the EHC plan from the get go and listened."* Some highlighted how a more holistic approach is needed to access diagnosis and support:

"I feel lost in the system, I don't know what to do."

"As a mother you just know when things aren't quite right, especially when you've had other kids as well. You feel like you're comparing in a way that you think something isn't quite right."

Parents described mixed experiences with GPs with some highlighting feelings of dismissal when addressing their concerns: *"I visited the GP for a diagnosis but nothing came out of it. My child would constantly fidget and wouldn't make eye contact so I thought the GP would*

pick up on that". In contrast, others described more positive experiences after seeing a different GP: "I wasn't really getting anywhere before I started seeing another GP, and now I just make sure I go to them". Fear of being dismissed by GPs was also highlighted as a potential barrier to accessing support: "I don't want to book a doctor's appointment and make a thing of it in case they turn around and go 'he's ok', 'he's doing well in school, 'he's got friends.'"

Some parents described difficulties accessing support from services such as CAMHS, where evidence of challenges seemed to rely on school reports. One parent stated: *"Masking isn't taken into consideration - even if there are all these other reports from different settings, not just school. All feels a bit unfair."* For those without a diagnosis, the lack of recognition or progress risked leaving families stuck: *"If I don't see like a positive ending very quickly, I just give up."*

"What would make me feel more comfortable is a health professional listening to my concerns, not just looking at my child when and thinking there isn't anything wrong.

And not taking on board what teachers are saying because what they see isn't necessarily what I see at home. It makes it even more challenging because if the school haven't got an issue then they won't look at you. It's about taking a wider more holistic view."

"People are afraid to access help because they feel like they'll be denied or it's going to be a fight or they'll be scared how their child will be. It can be quite demotivating and exhausting so it's easy for parents to give up."

Parents reflected on the impact of not being heard by professionals: *"If they would have listened to me from the get go, I don't believe their behaviour would be so bad now."* Others referenced barriers linked to professional attitudes: *"I know that even in healthcare professionals, there's a lot of misconceptions about ADHD. I've heard some horror stories from people that they have a really outdated view of it all. They don't believe in it even."* Parents also referenced about the lack of specialism or knowledge in general health professionals: *"I thought maybe the GP wasn't specialised enough because they were a general practitioner rather than a SEND worker."*

"You don't get help until breaking point."

Lastly, some said their main concern was simply knowing how best to support their child: *"For me, a diagnosis isn't the be all and end all. It's just you want to know if there's any support you can give them. I want to know if they're neurodiverse and I don't know if there's anyone that can give me that answer."*

5.2.4 Long waiting lists

Long waiting times were a common issue. Many parents highlighted how they had waited months or over year for a diagnosis, with this being referenced as a barrier to accessing support. One parent explained: *“Some parents will cope with better than others, but it is a struggle. It’s a daily struggle - when you’re waiting a year, two years, then another couple of months... It’s endless, just endless waiting lists.”*

Parents also referenced how the long waits had impacted their child’s mental health: *“I know there is an 18+ month waiting list I was devastated, very angry and upset as I knew what impact their daily struggles were having on my child.”*

“The waiting list is killing us. It really is killing us parents who generally have neurodivergent children who need the help. You are sitting in limbo for a long, long, long time and you’re trying your best to help them.”

Because of long waits, some parents felt they had no choice but to pay for private assessments. One said: *“Going private for diagnosis because time is of the essence.”* Another parent who went private explained: *“the long waiting time could have impacted my child if I didn’t.”* Some parents described this as the only way to avoid delays and ensure their children’s needs were met: *“I went the private route as the wait just wasn’t fair on my child.”*

“We were absolutely stressed and worried sick for our child’s future and school journey. And out of desperation we decided to go private and get our son a diagnosis.”

“I was aware of the long waiting times, it’s under resourced and I haven’t got the patience.”

Delays were also noted following a diagnosis, with some parents saying they could not access the agreed support due to backlogs: *“There’s a waiting list/backlog for support and activities. It shouldn’t be awarded if there’s a big waiting list or can’t benefit. It feels like a checklist.”*

Survey responses echoed these concerns around waiting times. When asked what would help most right now, the most common answer was shorter waits for assessments and diagnosis (33%).

5.2.5 Stigma and judgement when seeking support

Many parents expressed how they felt judged when trying to access support. For some, this fear stopped them from seeking help.

“I just feel like I would get laughed off. They might think I’m exaggerating and it’s really hard when you’re trying to explain to people what it’s actually like because they

don't see it. I don't want to come across as an 'over the top' parent but if my child needs extra support then they need extra support."

Others spoke about fear of judgement from wider networks like peers and family. One parent described:

"Parents might feel like they will be judged and might hold it in because they don't want to feel like people are looking down on them."

Feelings about stigma and judgement was also reflected in the survey results where 66% of respondents said they felt stigma or felt judged when trying to get help for neurodiversity or additional needs. Parents reported being told things like *"just been told it's their age"* and highlighted that *"people think their behaviour is because of me."* Others felt ignored even when evidence was felt to be present: *"even though they tick all the boxes the doctors and specialists just don't want to help."* Some referenced about stereotypes: *"they don't understand ADHD and think it's stereotypical naughty boys running around the classroom."* One parent reflected about gender-specific stigma: *"I do feel there's a bit of stigma against girls not being diagnosed or accepted as having ADHD as readily as boys."*

The survey also showed that stigma shaped parents' decisions about whether to seek help at all. The most common concerns were a fear of being judged as a parent (33%) and worry about not being taken seriously (33%).

5.2.6 Challenges navigating the health system

Parents highlighted the challenges of navigating the health and care system. Many described how difficult it can be to know where to start when seeking help. As one parent explained: *"It was tricky like I don't know friends who have a child with autism. What should I do? Who should I call?"* Another reflected: *"A lot of people won't know what they're looking for."*

Some highlighted the complexity of the system: *"There are a lot of hoops you jump through. But there's no way I would have gone through the NHS because for me it just feels like you have to shout as loud as you can. You've got there's lots of obstacles, there's bureaucracy, there's lots of form filling."* Feeling *"lost in the system"* was also highlighted. One parent whose child displays signs of autism highlighted how they *"felt lost in the system"* and *"didn't know what to do"*. Others described the emotional impact of this: *"Navigating the system can be overwhelming, whether you need to go to your GP, CAMHS or the school."*

Parents described how the lack of early direction left them to navigate alone, particularly when waiting for or struggling to get a diagnosis:

"I feel like it can be easy if you know what you're doing. I find it can be quite long winded and it's not really easily accessible. Maybe if the school was able to provide more information, or maybe if it's the GP for a bit more support that would help."

Schools and GPs were often the first point of contact for parents when navigating the process. This echoed the responses to our survey where parents said they would contact their GP if their child's behaviour became more challenging (33%), followed by contacting their school (22%).

While many parents felt the system challenging to navigate, some parents referenced using friends or family members to provide guidance: *"If I thought something wasn't right, I would speak to my family as there is a doctor and teacher in my family so I feel familiar with navigating the health system."* The use of AI was also referenced to help navigate local services and activities.

5.3 Support

5.3.1 Section summary

This section explores families' experiences of support for parents with and without a diagnosis. Key findings have been outlined below:

- **Support after diagnosis is inconsistent** - While some families benefited from CAMHS, speech and language therapy, occupational therapy, and parenting courses, others described support as *"one-off"* and not sustained. Parents repeatedly raised the lack of post-diagnosis follow-up, leaving them feeling *"neglected."* 44% of survey respondents reported low or no support from services such as GPs, CAMHS, hospitals, and schools.
- **Families without a diagnosis face additional barriers** - Parents often felt "stuck" with no formal support, uncertainty about their child's needs, and frustration that help is harder to access without a diagnosis.
- **Need for early and preventative support** - Health visitors were frequently described as a missed opportunity. Parents emphasised on early signposting, strategies, and guidance.
- **Trusted professionals and check-ins** - Families asked for regular follow-ups following a diagnosis with a trusted professional. Those without a diagnosis expressed informal contact with a professional to provide practical strategies, advice and reassurance.
- **Peer support is highly valued but not always accessible** - Speaking to other parents helped reduce isolation and were expressed as a mechanism to share experience and knowledge.
- **Community connections matter** - Parents wanted informal advice, drop-in spaces, and peer groups to reduce isolation and share practical strategies, supported by both professionals and trained parents with lived experience.
- **Signposting and navigation** - Families reported confusion about available services and how to access them. Schools were suggested as key points to provide signposting and links to community and NHS support.
- **Support must not depend on diagnosis** - A recurring theme was the need for advice, practical strategies, and peer groups accessible to all families, regardless of whether a child has a formal diagnosis.

5.3.2 Support during and following a diagnosis

Parents had mixed experiences of support during assessment and diagnosis with some parents finding forms of professional support and interventions helpful. Some parents referenced their access to support included occupational therapy, and speech and language

therapy which was found beneficial. One parent described how CAMHS made a difference: *“CAMHS under 5’s helped. It was an opportunity for me to talk about my concerns and issues and they gave me strategies to help.”* Parent courses were highlighted to be helpful for some, referencing how these helped understand their child’s behaviour. A parent said: *“The children’s behaviour class was the biggest help for me, it was a turning point, understanding that it wasn’t about parenting but actually understanding your child’s environment and why they’re reacting to a certain situation and understanding what we can do to help them cope”.* In contrast, some found that while groups or courses were initially helpful, these were often a ‘one-off’ rather than consistent: *“There was one group I attended was really great but then there was nothing else.”*

“It’s a collaborative process. It’s about everyone working together. Not being afraid to signpost here or there and getting other professionals involved.”

Many parents valued peer support and having other parents to relate to. One parent described, *“Speaking to other parents. It was just like therapy being able to resonate with other parents who might have similar experiences and share how they dealt/managed it. It helps you not feel so alone.”* However, some noted barriers to attending such groups: *“There’s no one there to mind the children... I can’t interact with people because I’m running after my child.”*

Parents frequently spoke about the lack of structured or ongoing support following a diagnosis, to prevent families from feeling *“neglected”*. One parent said, *“There’s a lack of post-diagnosis support. I knew what autism was and the ways to deal with it, but it would be great to have some support groups of mums.”*

One parent highlighted about the waiting lists for activities following a diagnosis and lack of activities during school holidays. They stated: *“On paper there is stuff, but in practice there’s very little and there isn’t a huge range of opportunities for us.”* Parents referenced the importance of inclusive activities and facilities which cater to their child’s needs with Playwise and Sutton Community Dance referenced as examples: *“Inclusive activities are really important. Going to safe places where you won’t be judged or stared at for being.”*

Families described mixed experiences of support, with some finding interventions from local services helpful and others highlighting the need for improvement. Our survey revealed that 44% of respondents do not feel supported or receive low levels of support from services including GPs, CAMHS, hospital services, and schools.

5.3.3 Support for families without a diagnosis

For families who had not yet received a diagnosis, the absence of support was evident. Many parents felt unsure about where to turn for support following attempts to pursue a diagnosis. Parents described uncertainty about how to help their child and whether what they were experiencing was *“normal”* or a sign of something more. Some parents referenced about feeling *“stuck”* and questioned where they could turn to for support.

“Is there anything for the average person who just might need a little bit of help to support their child?”

Survey results also indicated that parents most often turned to informal sources of help such as friends and family (21%) or online resources like NHS and parenting websites (17%). Some parents reported seeking support from GPs or health professionals (14%), talking to other parents (14%), using parenting books (14%), or approaching school staff (10%).

5.3.4 Key observations that could improve support for families

Parents highlighted the types of support that could make a difference to families. These focused on access to timely, practical support and having access to a trusted person or health professional in an informal capacity. This section explores parents' views on support which would make a difference to families with or without a diagnosis.

5.3.4.1 Early and preventative support

Parents emphasised the value of preventative and early support, particularly around signposting, guidance and as a mechanism to share strategies at an early stage, helping to prevent behaviours from escalating. Many felt that having someone to guide them at the start would have made a difference, particularly helping to support navigating services: *"It's about having informal support from the start to help know where to go and the right direction."* Another parent stated, *"Parents knowing where to go is really important to being able to get their needs met early on. A lot of parents don't know or think that they're not going to be heard."*

"You don't realise what support is available. It's only available once you're at breaking point and before you know it, you've missed it – you're in too deep and it's too late. There needs to be support from the start."

Health visitors were frequently mentioned often as a missed opportunity for early intervention. Parents felt that while health visitors were in contact at an early stage, many did not provide practical advice or signpost to support. A parent highlighted *"It would be good if the health visitor could share strategies or signpost to support and guide to places that could support with strategies... I just wish they did something."* Another added, *"From early on a health visitor could be helpful as they don't really give information at that stage about signs to potentially look out for."* In contrast the benefit of having a health visitor support from early on was evident, with one parent stating how it helped to initiate the referral process for their child: *"I had a very good health visitor early on who took my concerns seriously. Health visitors are crucial in the process of picking up behaviours. Reporting my concerns to the health visitor resulted in a referral."*

"Health visitors are crucial in the process of picking up behaviours e.g. a child not meeting their milestones, not making eye contact and not speaking from early on."

5.3.4.2 Trusted professionals and check-ins

Regular check-ins with a trusted professional after diagnosis was a recurring suggestion. Parents felt this would stop families feeling forgotten: *“Having touch points is the main thing so parents don’t feel neglected after a diagnosis. Because people do feel vulnerable and isolated.”* Another added: *“I would love to talk to an actual person who is an experienced professional... have access to someone in person or virtual and have someone to check in with you every 3 months. Just to see how things are going and could offer some tips and hacks.”* Others emphasised the need for specialist expertise: *“Some kind of support from a psychologist or SEN support - someone who understands and can act like a link in between parents and those with autism.”*

5.3.4.3 Peer support and community connections

Parents also reflected on the importance of informal advice and community connections. One explained:

“I feel there’s a lack of community support and there’s nowhere to go for informal advice. There are no drop-in sessions where you can meet other parents but also have the right professionals in the room to ask questions and ask for anecdotal advice on an informal basis. It doesn’t have to be a health professional – just someone who has knowledge. There are parents out there who have neurodiverse children and are willing to share their expertise and can share what they found helpful, how they knew the signs and symptoms. With a bit of training, they could be appropriate.”

Parent groups and peer networks were repeatedly highlighted as vital for reducing isolation: *“Support from other people who are going through the same is vital. There should be more opportunities for parents to talk to each other like parent groups, coffee mornings. It’s knowing you’re not alone. Sometimes it can be very isolating and just knowing you’re not the only one.”* Parents emphasised that human contact mattered most: *“There’s a lot to be said with human contact rather than email and it being faceless... People feel isolated, people need to talk.”* Some parents highlighted accessibility of support groups: *“Saturdays are more ideal for parent groups - even if once a month. It’s more accessible for people who work long days.”*

“Parenting groups for people to listen and give constructive strategies to help us manage behaviours could be useful. Professionals must sympathise. As mums we just need that understanding and support. I had professionals say ‘try this, oh it works’ but as soon as you try it, it’s out the window. This can be frustrating.”

Schools were also seen as important touch points for bridging gaps between families and services. Parents suggested that schools could be a mechanism to link families to professionals and support: *“If the school had a go-to person that had access to professional in the community that could come in and help us in trying to understand.”*

Survey responses reinforced these views with 11% of responses stating they would value hearing from other parents with similar experiences.

5.3.4.4 Signposting

Others reflected more broadly on a lack of awareness or accessibility of local services. One parent said, *“I don't think that there's anything in my area in terms of health services that's either advertised or available to assist.”*

“Parents don't know where to go for information and that's the hard thing now knowing where to go. Maybe some people just fall through the cracks.”

Signposting was frequently mentioned, with parents referencing the school as a mechanism to potentially help with this, particularly those needing guidance and support navigating the system: *“What would have been nice is if the school could signpost us to somebody like within the NHS teams to talk to us and give us some guidance. What we can do. Because I've had to navigate it all myself and I don't really understand how it all works.”* Another parent explained: *“Signposting would be really, really helpful for parents. I guess it's how you communicate and making everything a bit more accessible for us as parents because I feel quite overwhelmed if I have to deal with the NHS and I don't really want to.”*

“Families need help to navigate the system to let us know what services are available and where to find help as to a lot of us. This is not common knowledge and we don't really know where to start to see what's available to get help.”

Survey responses also highlighted that 11% of parents wanted clear guidance on what support is available.

5.3.4.5 Information and online resources

While online resources were sometimes used, parents emphasised on the value of face-to-face support. *“Online resources are helpful but doesn't make up for face-to-face contact so you can explain to them what you're experiencing so they can give you honest feedback rather than just thinking about it and just looking online.”* Some used the NHS website and neurodiversity specific websites for information and guidance (e.g. ADHD specific websites). However, limitations of the NHS website were highlighted: *“I do look on the NHS website but the information is quite limited and just lists the symptoms”*. Suggestions for simple online resources was mentioned to help families. Parents also referenced using social media such as Facebook groups as a source of information and support, as a channel to reach parents in similar situations and with similar experiences: *“You get more context on Facebook groups.”* However, there were mixed views on the role of social media with a parent stating: *“Social media has been a saving grace and worst enemy. Facebook groups filled with mums who are supporting each other but also tearing each other down. But information isn't always helpful.”*

“It would be great if there was any support and not only me trying to find out the options.”

5.3.4.6. Inclusive activities

Some parents emphasised the need for more inclusive and tailored activities: *“On paper there is stuff, but in practice there’s very little. Not a huge range of opportunities for us... all the support we’ve been pointed towards are big groups, big sessions... my child doesn’t really fit into these and finds them overwhelming for his senses. Whilst they say these are for SEND, the spectrum is so wide and my child doesn’t really fit into these sessions.”*

Survey responses also indicated that 11% of parents wanted access to affordable or free activities.

5.3.4.7. Support that doesn’t depend on a diagnosis

A recurring theme was the need for support that does not depend on a diagnosis: *“Some support would have been helpful when dismissed e.g. signposted to parent groups, resources to help manage behaviour.”* Parents asked for spaces where they could share similar experiences with other families and seek guidance without judgment: *“Face to face groups for parents without a diagnosis or with a similar experience would be helpful and act as a space to ask questions.”* Another reflected on school-based courses: *“I find a lot of the parenting courses (through the school) are in school times or they’re just not convenient for like people that work.”* Parents highlighted about having informal access to a health professional for guidance and share their concerns: *“It would be helpful to have access to a health professional to get advice and guidance. Someone who can signpost and guide you on filling out forms and having a touch base weeks later to see how you’re getting on and if you’re having any issues.”*

“What would help me get support sooner is if I knew my child would get the help they actually need and not be just another forgotten child...”

Parents emphasised the importance of practical strategies for managing behaviour in the absence of diagnosis. One explained: *“Having those strategies to help you respond as a parent to situations.”* Another added: *“Strategies and tips in understanding behaviour would have been helpful. That has never really been available to me because they have no diagnosis... Even though I can look online forums to get an understanding there’s never really been like a ‘oh that’s what they have’ and ‘this is how it can help me.’ Do I? Don’t I? Is it normal? Is it not?”*

5.4 School experiences and support

This section explores experiences and views of schools. Key findings have been outlined below:

- **Mixed experiences** - Some families described schools and teachers as supportive, while others faced gaps in understanding, limited resources, or barriers to SEN support. 11% of parents highlighted a need for more in-school support.
- **Compassion and inclusion** - Parents felt children benefited when teachers showed empathy and used inclusive approaches. Some felt excluded or “*stuck in between*” mainstream and specialist provision.
- **Training and strategies** - Some parents raised a need for staff training and practical tools like visual timetables, calm spaces, and “*zones of regulation*” to support behaviour and emotions.
- **Resourcing pressures** - Families recognised schools are overstretched and felt teachers need additional classroom support and wider system funding to meet children’s needs.
- **Communication** - Some parents raised the need for more consistent communication and clearer signposting.

Parents shared varying experiences of schools. Some felt well supported and worked closely with teachers, while others said there were gaps in understanding, not enough resources, and challenges getting the right help for their child.

Compassion and understanding from staff were highlighted as important. One parent stated: “*My child would benefit from school understanding and compassion. They’re seen as being loud and a bit disruptive and it frustrates me. One teacher was fantastic and really understanding, but others could not cope.*” Another added: “*Of course my child doesn’t want to be told off and sent out, but they don’t have the concentration span and struggle to sit in a chair.*”

Some parents described situations where their child felt excluded or isolated: “*Being put in a room because they can’t go out and play because it’s too much for them, it’s not fair on the child.*” Others highlighted children who fall “*in between*”, where their needs are not severe enough to access specialist provision, but still struggle in mainstream classrooms:

“There are a lot of children who fall ‘in between’ where their understanding of the world and their behaviour doesn’t quite sit with mainstream. So these children are stuck in the middle and not quite sure where they’re going.”

Parents stressed the importance of training and classroom strategies to support neurodivergent children. Approaches such as “*visual timetables, timers to help with transitions, ‘now and next’ visuals, and zones of regulation to help children understand their emotions*” was suggested. Having a calm space or room was also described as essential in offering a safe environment for a child to “*re-regulate*”. Parents felt that with greater knowledge and practical strategies, teachers and support staff would be better equipped to manage behaviour: “*With SEN children entering mainstream ever increasing I feel basic courses for teachers and supporting staff should be included in their training. Understanding children’s behaviour is vital, with knowledge and understanding they will be better equipped to deal or handle behaviour.*”

At the same time, families recognised the pressure schools are under. Parents highlighted that teachers may find it difficult to manage lots of children and also meet complex needs without additional support: “*I don’t feel it is the sole responsibility for a teacher to manage*

behaviour within the class as their primary role is to teach 28+ children. I do feel adult support in the classroom to help manage behaviour is vital to help support the teacher. Without support it all becomes stressful for all and set for failure.”

Schools were also described as important partners in supporting diagnosis and care planning. Some parents praised schools that worked closely with them, accessed speech and language therapy, or helped secure EHC plans: *“It’s a collaborative process, it’s about everyone working together.”* Others described barriers, including difficulties reaching SEN support in busy schools with limited staff. For some children, specialist provision with smaller classes, one-to-one support, and sensory-friendly environments, was seen as better suited to their needs.

Parents valued workshops and in-school support, describing school-based speech and language support as *“brilliant.”* Communication between schools and families was also raised with some wanting more consistent dialogue: *“Having like a log, maybe a bit more of communication between me and the school... I feel like that possibly would have helped.”*

Finally, parents reflected on the wider system pressures schools face. One summarised: *“They’re so under pressure with other SEND children with more severe needs.”* Another added: *“We’re screaming from the rooftops to say these schools need help. But unless there’s government funding, the money, they don’t get the help. And that’s where the big problem lies.”*

Survey findings echoed these insights, with 11% of respondents specifically identifying a need for more in-school support for children.

6. Next steps

This report will be considered by Sutton Place Leads.

The report will also help to inform the SEND chapter of the refreshed Sutton health and care plan and will be shared with partners, to help shape system wide work and initiatives, helping to ensure that services reflect the lived experiences of families.

7. References

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