



Neurodiversity – the hidden value of diagnosis

The benefits of a diagnosis – experiences shared with us by parents, children and young people who are waiting for or who have received a formal diagnosis of ASD, ADHD or other conditions relating to neurodiversity

March 2023

Neurodiversity

- the hidden value of diagnosis

Experiences shared with us by parents, children and young people who are waiting for or who have received a formal diagnosis of Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), or other conditions relating to neurodiversity.

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Executive summary

Background and objectives:

In the light of long waits for diagnosis and increased needs-based support for children and young people, we set out to explore what families perceive to be the benefits of a formal diagnosis.

We interviewed 15 parents and three children/young people, some waiting for diagnosis and some with a formal diagnosis.

Interviews lasted between 30–90 minutes and were loosely structured to enable people to explore the issues important to them.

This was a qualitative project, and findings are illustrative of themes present in the population represented by our sample.

Key findings:

Every journey to referral and diagnosis was unique: none could be described as easy but some had been less traumatic than others. Two variables impact the speed and quality of people's journey to assessment and support, and ultimately to diagnosis:

- Their school's knowledge, experience and resources relating to neurodiversity. Some schools and some individuals within schools were more able to identify possible neurodiversity and offer support than others.
- The parent's existing knowledge and ability to identify the possibility of their child's neurodiversity. For some the presentation was clear and they were able to engage with the school to access support; for others their child's challenges were a distressing mystery. Ability to fund diagnosis privately obviously made a substantial difference.

Almost all interviewees felt a formal diagnosis would make a significant difference to their child, or had found the diagnosis had been of great value; one was neutral, none were negative.

Our conversations with parents and with young people were emotional; they

spoke often and passionately about the benefits of diagnosis on their and their child's mental health, peace of mind and family life. They also spoke of the value of a diagnosis when searching out non-statutory support from grassroots upwards.

People told us a formal diagnosis can help access the right statutory support, but few expected a diagnosis to automatically open doors to new levels of support.

The benefits of formal diagnosis that people shared with us fell into four thematic areas:

1. **Certainty:** knowing for sure what condition the child or young person has. While some were very sure before going in to diagnosis, many were unsure what the diagnosis would be or received additional/detailed information about their child's specific presentation. Diagnosis took them from a state of ignorance or uncertainty to firm ground.
2. **Understanding and forgiveness:** often the first and most passionately expressed benefit area. Diagnosis moves people from confusion to understanding, from blame (often self-blame) to forgiveness. People also told us of the alleviation of loneliness – a move from “not like the others” to “here are the others like me”, and the benefits of losing negative labels.
3. **Developing Strategies:** with the formal diagnosis and the understanding that diagnosis brings, people can research and implement more effective strategies to reduce difficulties and unlock the potential of the diagnosed person.
4. **Accessing support:** we heard a wide variety of expectations and experiences relating to support after diagnosis, but we did not consistently hear expectations that diagnosis would immediately result in an ECHP. Many either already had an ECHP or understood that whatever the diagnosis, their child's needs meant they would not qualify for one.

Some did expect diagnosis to open a pathway to condition-specific support and were disappointed when this did not materialise. But for most a formal diagnosis was seen as an addition to their evidence

base when negotiating for statutory support; a strengthener more than a deal-breaker.

The diagnosis is also a valuable signpost when searching for invaluable non-statutory (VCSF, informal) support groups, and a 'ticket of entry' to some of those groups.

Recommendations

This project was undertaken to shine a light on the thoughts and experiences of Surrey residents; to share their voices in a way that can provoke discussion and enrich strategy. We know there is no magic solution to long waits for diagnosis; we know the new needs-based approach will reduce some of the detriment of long waits.

We recommend all organisations consider our findings and share reflections with partner services as well as Healthwatch Surrey.

We encourage all services to

- Continue to listen to families waiting for referrals or diagnosis; work with them to develop support that meets their wider needs
- Use our insight to reflect on the support being offered – are there any additional benefits of diagnosis that could be delivered pre-diagnosis?
- Continue to work with schools at an individual level – even in our small sample schools seemed to vary in their resourcing and approach
- Empower grassroots and community groups – recognise their value to families, and ensure they have the information and support they need to thrive
- Ensure those willing and able to fund private diagnosis have the information they need to ensure their diagnoses are valid across all statutory services (we did not hear any direct experiences of diagnoses being rejected, but most parents had heard of ADHD diagnoses that had not reached the required standards).

Main Report

Context

We have listened to families talking about the value of a formal diagnosis for children and young people for conditions relating to neurodiversity – their expectations and hopes, and the reality of their experiences since diagnosis. This report shines a light on their view of diagnosis and their lived experience in their own words.

Even before the pandemic, waiting times for assessment of neurodiversity in Surrey were long. Since the pandemic, demand has continued to increase to the extent that children and young people may wait years for a diagnosis.

To reduce the detriment to the wellbeing and educational attainment of children and young people and ensure they are not left without support, a new approach has been implemented. Children and young people's needs are assessed and services or support are put in place to meet those needs with no requirement for a formal diagnosis: if there are still concerns after this support has been embedded a review considers further support or the need for a diagnostic assessment.

Pilots have indicated the success of this approach in general, and have hypothesised this approach could reduce the demand for formal diagnosis.

While the move to earlier support is welcomed, it is recognised that the benefits of formal diagnosis are much broader than access to formal support. Without a formal diagnosis these benefits may not be realised – but it may be that some of these benefits can be delivered under the new approach without the need for a formal diagnosis.

Purpose

In light of intractable waiting times for formal diagnosis, our aim has been to highlight the benefits of a formal diagnosis, in order to inform the development of strategies that can deliver those benefits to those waiting for a diagnosis.

Approach

This was a qualitative, listening project. What we heard represents themes that are present in the population, rather than the extent to which they are present. Our aim was to deliver insight that can provoke reflection and enrich strategy.

We listened to 15 parents and 3 young people in individual interviews lasting 30–90 minutes. The interviews were very loosely structured, encouraging the interviewee to tell their family's story with only minimal questions for clarity. More focussed probing was introduced around their expectations, experience and feelings about referral and the diagnosis¹. Interviews were audio or video recorded, and some were transcribed. Respondents all consented to our inclusion of anonymised verbatims in our report.

We used a thematic analysis approach to develop our findings and report.

Who we listened to

Recruitment was undertaken through a combination of social media and networking with partner organisations. Respondents were selected to deliver a breadth of situations, diagnoses and demographics, but this was not a scientific exercise. While we are confident our respondents represent a broad spectrum of experiences, we are aware there is a bias towards more engaged, articulate and connected families.

- 15 parents (two fathers, 13 mothers); one adoptive family; mix of single and two-parent families
- 3 young people aged 12–14
- Parents represented 9 children aged 6–11
- Parents represented 6 young people aged 12–15

¹ All interviewees were aware of the interview content before the interview took place and were encouraged to prioritise their own mental health and wellbeing during the interview.

- 3 families waiting for diagnosis
- 4 with one condition formally diagnosed, waiting for a second diagnosis
- 8 having been diagnosed (all in the past 18 months)

- 8 state funded diagnoses
- 1 with one state funded diagnosis and one private diagnosis
- 6 privately funded diagnoses

- 14 waiting for or diagnosed with ASD
- 8 waiting for or diagnosed with ADHD
- 1 waiting for or diagnosed with another condition

Additional conditions experienced by the children and young people included:

- Anxiety
- Eating disorders
- Self-harm
- Suicidal ideation and attempts
- School refusal
- Tourette's
- Hypermobility Disorder
- POTS
- Chromosomal abnormalities
- Development delay
- Speech and Language delays

Main Findings

Family stories and the varied pathways to diagnosis

Across our interviews we heard a wide range of pathways and approaches to diagnosis. Every family's story is unique, but the drivers of difference that were most apparent across our families were:

- the contribution of school. Parents depend on schools to be knowledgeable, identify problems, provide support and facilitate access to services. While GPs and CAMHS do play a part, we heard far more about the contribution of schools, both good and not so good
- the school position is complex. We heard of
 - school staff that had recognised the possibility of a child's challenges being rooted in neurodiversity
 - schools that had provided excellent needs-based support, but had not recognised the needs as rooted in neurodiversity
 - “she had support at school, ELSA and the Chill Out Club and extra support for maths. I was beginning to suspect ASD so I went to speak to the teacher who spent most time with her and the pastoral care worker and they couldn't pinpoint any behaviours” (D, P, 13F, ASD)²
 - schools that had been unsupportive – examples given were not current but may have been very recent – ranging from the previous year teacher to previous schools or older siblings
 - Where schools had been less knowledgeable/supportive we heard about
 - inexperienced/junior teachers

² **Verbatim quotes are formatted as follows:**

W: waiting for diagnosis D: have received a diagnosis

P: parent CYP: child or young person

Age and gender of child/young person e.g. 11M = 11 year old male

Primary Diagnosis = ASD, ADHD, Other + signifies additional conditions

Hence (W, P, 12M, ASD) indicates a verbatim quote from a family waiting for diagnosis; the quote is from a parent; the child/young person is a 12 year old male, and the expected diagnosis is Autism Spectrum Disorder

- specialist/support staff vacancies or long term sickness
- lack of focussed oversight of/familiarity with a child (larger, secondary schools in particular)

“They started to give her a bit of support but the follow through across all the different curriculum teachers was really patchy” (D, P, 13F, ASD)

- inexperience/lack of understanding of neurodiversity/behavioural challenges (often experienced as parent blaming)
- inflexible approaches to SEN/SEN focussing on learning difficulties at the expense of neurodiversity
- low expectations of children
- focus on children with the most overt challenges at the expense of the managing-strugglers
- “ninja-level masking” (D, P, F11, ASD). We heard several experiences of parents approaching schools for help to be told “we’re not seeing any of this at school”.

- Parents’ pre-existing knowledge of neurodiversity:

- Some parents had a good understanding of neurodiversity and/or had recognised neurodiversity in their child from their early days: for example where an older sibling was already on the pathway to diagnosis, or their child’s presentation was classic, where this was a second or third child with very obvious differences to their other children, or they had professional insight. They were in a better position to drive an assessment/referral for neurodiversity.
- For others the idea their child may be neurodiverse was a surprise or a shock, often coming later in the child’s life and from a seed planted by school or by peers: they had little pre-existing knowledge, or their child’s presentation was unusual or distracting (eg diagnosis of anxiety in girls). They were less able, less confident or slower in the drive to assessment.

“I knew very little about [autism], I’d heard the term, I’d heard of Aspergers ... I knew very little about it at all to be honest, it’s been a massive learning

curve for me” (D, P, 13F, ASD)

“We knew absolutely nothing. And I’d never heard of PDA” (D, P, 6F, ASD+)

- Parents’ ability and willingness to pay for a private diagnosis.
 - Six of our families had accessed private diagnosis to avoid a lengthy wait. While these may be overrepresented in our sample they have valuable insight to offer – by definition they were highly motivated to access a diagnosis as quickly as possible

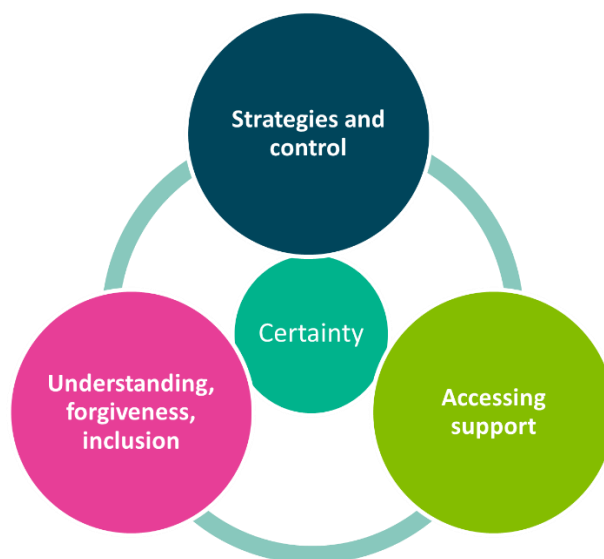
The children and young people themselves are of course completely dependent on the adults around them to recognise and act on their child’s experiences.

“throughout primary school I remember feeling anxious but I didn’t realise how anxious I was because my parents didn’t realise” (D, CYP, 13F, ASD)

Diagnosis – four benefit areas

This report focuses on what people (parents, children and young people) told us they hoped to gain, or had gained, from a formal diagnosis.

To provide structure for this report we have categorised these benefits into four broad themes, discussed fully below. These themes are qualitative, and the benefits are often emotional and intangible: there is considerable blurring and overlap and a complex web of connections between them.



Many spoke first and most passionately of personal, emotional benefits such as understanding, forgiveness and confidence – these were a powerful hope and expectation before diagnosis, and often the most valuable benefit to those who had received a diagnosis.

Certainty

For some people it seems as if there is little to learn from the formal diagnosis; the presentation is clear and the outcome almost certain.³

“if she could have her diagnosis for ASD then...” (W, P, 14F, ASD)

“He was on the waiting list for his ASD diagnosis. We saw a behavioural psychiatrist for his behaviour and I told her that and she said oh I’m happy to do the diagnosis for that for you now from what I’ve seen, so that was great. But we’re still waiting for his ADHD diagnosis” (W/D, P, 10M, ADHD/ASD)

“having filled out those forms and knowing how these things work there’s no question in our mind she’s got ADHD” (D, P, 6F, ASD+)

But for many families waiting for a diagnosis there is genuine uncertainty as to whether the child or young person does have the condition they have been referred for:

“we really weren’t sure she would be diagnosed as autistic” (D, P, 11F, ASD)

“he’d never met enough of the things on the checklist to warrant a referral” (D, P, 12M, ASD)

“it wasn’t clear what the issue was, he wasn’t classically anything” (D, P, 14M, Other)

“she was so challenging, but her background was so traumatic, we didn’t know what the root of it was” (D, P, 6F, ASD+)

³ The information that has been shared with us suggests around 2/3 of those initiating the process for diagnosis of ASD do receive that diagnosis; and 4/5 for ADHD.

“we were thinking is this mental health, goodness, are we looking at something different like autism. Is that what this is?” (D, P, 14NB, ASD)

Detail within the diagnosis may also bring fresh knowledge: any traits, strengths, weaknesses or possible additional conditions may add information that parents find invaluable.

“She was diagnosed with ASD with a PDA profile” (D, P, 6F, ASD+)

For these families the first benefit of diagnosis is that the nature of the child’s condition is identified and they can start the next phase of their journey.

“the earlier you get the diagnosis the earlier you get the support the earlier you get the management techniques for it” (D, P, 14M, Other)

Understanding, forgiveness, inclusion

Pre-diagnosis, both parents and children/young people told us they felt different, separate, lost, confused. There was often anger and distress; they felt alienated and misunderstood; parents were at a loss to understand why their child was behaving or developing in ways so different to their expectations and to their children’s peers.

Diagnosis led to a better level of acceptance and inclusion for both children and young people and their parents: people told us the benefits under this theme, directly or indirectly, often made a substantial contribution to improvements in mental health for both children and parents.

Understanding

When asked “why did you want a diagnosis” often the first, most spontaneous response was “understanding” – knowledge that helps make sense of what is happening

“I wanted to understand what’s going on” (D, P, 6F, ASD+)

“it would explain how I act in a certain way; it would tell me and it would tell other people what was going on. And sometimes I wonder why I do things, it would explain to me” (W, CYP, 14F, ASD)

“it tells you who your kids are, why they are as they are” (D, P, 10M, ASD+)

“A lot of things I thought were just behavioural for him suddenly made sense” (D, P, 14M, Other)

Several of the children and young people suffered significant mental ill-health including self-harm and suicide attempts. The diagnosis had helped identify a root cause for their struggles:

“I want to understand, is there something underlying this anxiety? Is it just that she's anxious because she's an anxious person, or is there another reason that's underlying it? It doesn't cause it, I know, but I know the two now that they coexist very frequently. And I just thought I just want to get some explanation as to whether there's more to it than her feeling anxious, are there other things that are involved? So, I think that was it, and it was at that point very much, I don't want to have a label, but it's just more of an understanding” (D, P, F12, ASD)

“She feels it helps her a lot (child self-harming, suicidal plans and actions) because it's not just anxiety, there's some kind of explanation and better understanding of herself” (D, P, 13F, ASD)

“there were periods of illness, like glandular fever, that kind of thing, which with the benefit of hindsight were somatic illnesses – she'd sleep for a week, it was burnout from the masking” (D, P, 14NB, ASD)

Self acceptance and forgiveness

For many parents the diagnosis allowed them to forgive both their children and themselves: pre-diagnosis many children's most noticeable symptoms appeared to be behavioural – meltdowns, anger, school refusal, difficulties socialising, food refusal – or mental health problems such as anxiety.

“I think down the line it will explain behaviours. And by explain I mean forgive...at the moment she feels different, and she needs to know this is why you are different. This is why you behave this way. I suppose then it vindicates her” (W, P, 14F, ASD)

“all the things I thought were him just messing around and being

impatient and trying to get out of eating proper food suddenly made sense" (D, P, 14M, Other)

Many parents had felt to blame and questioned what they were doing wrong: some had experienced parent-blaming (often in the form of well-meant guidance and support, but occasionally not).

"there was a why – why he was doing these things, and why the things I did with other children didn't work...people don't see that, they think your child is bad, that he has bad behaviour and that you are a bad parent ... even your own family. Many times I felt judged" (D, P, 10M, ASD+)

The diagnosis provided a very different explanation for their child's challenges, and parents felt able to forgive themselves:

"For him, who at 11 can barely write, but he's so so intelligent, there's a reason why those difficulties are so huge" (D, P, 7F, ASD/ADHD+)

And from a parent who, because of her children's diagnoses, recognised ADD in herself and was formally diagnosed:

"Knowing I'm ADD has meant I can shut up and stop criticising myself for what I'm not doing, I'm so much kinder to myself. And that frees up space for me to actually do stuff". (D, P, 7F, ASD/ADHD+)

Find My Tribe

For both parents and children/young people, pre-diagnosis can be an 'outsider' experience defined by the 'difference' between themselves and their peers. The diagnosis changes this position, moving the person from being mostly "different to..." to being "one of people like this".

Parents described the formal diagnosis as a trigger for investigating a wider range of charities and groups, and connecting with local parents. Their children told us of using social media to connect with the worldwide community of neurodiverse people.

"now I'm diagnosed I follow this person who has an assistance dog in training. I just searched autism, just looked for stuff" (D, CYP, 13F, ASD)

"I've joined NAS coffee mornings...and there's a WhatsApp group for girls and teens and parents which is just brilliant" (D, P, 13F, ASD)

"Finding other families who have similar experiences – getting a diagnosis has been really helpful in that" (D, P, 6F, ASD+)

"I've got a support group through [a friend], again not about autism but totally coincidentally or not, all of the people in my support group, five of us, all had children with autism, and who have been through similar things to a greater or lesser extent" (D, P, F12, ASD)

A better label

The connotations of "labelling" are contentious and had provoked serious consideration for some of those we listened to.

"before, I was normal, I was unlabelled...now I'm not going to school and I'm going to go to a special school. If you'd told me that when I was in primary school I'd have been quite shocked" (D, CYP, 13F, ASD)

"It's difficult because you don't want him to be labelled, but my understanding is that without the label you don't get the support...a label helps him access the support he needs" (D, P, 14M, Other)

However, on balance the view was that while a diagnosis is a label, it can have positive value.

Before diagnosis many children and young people were carrying negative labels – even parents admitted thinking of their children as disorganised, difficult, disruptive; the children and young people had labelled themselves or been labelled by their peers; parents knew their children were identified at school as not achieving their potential, or having delayed language/written skills.

"I'd know why I'm so weird" (W, CYP, 14F, ASD)

"I had this image of her just being difficult" (D, P, F12, ASD)

“there were bullying episodes at school and xxx got labelled as a bully” (D, P, 10F, ASD/ADHD+)

A formal diagnosis cuts through the negative labelling – it legitimises a switch from something “bad” to Autistic, or ADHD, or dyslexic. While there are still negative connotations with the diagnoses there is a noticeable reduction in blame and shame.

“I’d rather be dyslexic than thick” (W, CYP, 14F, ASD)

Shorthand

In the circles that are important to those we listened to, most people have a good awareness and basic understanding of autism, ADHD and dyslexia. There is recognition that children will still be unique, but “my child is autistic” is an efficient headline that sets the scene for the listener.

“I think it’s easier [post diagnosis]... I mean at least people know what Autism is...if I talk to someone who knows a bit about special needs I feel they have a better understanding, I don’t have to explain as deeply” (D, CYP, 13F, ASD)

“he’s on a SEN support plan, it’s just going, ‘He finds this difficult; he finds this difficult; he finds this difficult,’ but on his student pass at the top it says, ‘He has a diagnosis of ASD’. So when he responds to things in certain ways, there is a categorical reason.” (D, P, 12M, ASD)

Strategies and Control

Developing positive strategies

The understanding that comes with diagnosis can enable parents to research and put in place strategies to manage their own and their child’s behaviour:

“So [diagnosis and understanding] really helped, because then I was like, okay, this isn’t about... I can’t punish her for her behaviour because she’s not doing it on purpose” (D, P, F12, ASD)

“it’s teaching us what specifically his needs are ...someone being able to

draw up that report and this is what his needs are and how we can move on from that..." (W, P, 14M, ASD)

"I said to the school educational psychologist 'we've had this diagnosis, and I really struggle with his anger and how he manages his emotions,' she was the one that talked me through some theories around the emotional side of things, how we could manage that" (D, P, 12M, ASD)

"I wanted a diagnosis to tell me what to do next" (D, P, F12, ASD)

And there were many examples of how these strategies had improved the lives of the child and of their parents:

"I remember when I was younger and I got scared in situations my parents would talk to me and I wouldn't talk back and they'd say it's rude to ignore me, but for me I was overwhelmed but I didn't realise that, ... now they understand that when I do that I'm struggling" (D, CYP, 13F, ASD)

"We've been able to adapt our parenting style to a more low demand environment so we're not having the arguments ... that's probably the biggest benefit [of diagnosis]" (D, P, 6F, ASD+)

"when they play their way you understand why they play that way, and if they want to play that way I can play with them...you can put yourself to their level to engage with them" (D, P, 10M, ASD+)

"we've got her a dog, specifically to try to help give her some focus and responsibility, but they're very undemanding, they just want you" (D, P, 13F, ASD)

Control and predictability

We also heard that the understanding and direction that come with the diagnosis allowed parents who felt powerless or passive to regain a sense of control and confidence: parents felt empowered to take action for their children:

"I sort of waited for the diagnosis to tell me what to do next almost". (D, P, F12, ASD)

“I think that’s what diagnosis has given me. I think the things I am asking for for J are reasonable and I’m not being that awkward parent” (D, P, 10M, ASD/ADHD)

“So after we got the diagnosis, I was like, right I want a meeting at school to talk about the school refusal, to talk about the diagnoses, and the speech and language side of things”. (D, P, 12M, ASD)

Accessing Support

“You’re always going to fight for whatever you can get for your child aren’t you?” (D, P, 14M, Other)

Listening to service providers we heard the view that a formal diagnosis is seen as a golden ticket to an EHCP, and that this is a key driver for parents to seek a diagnosis for their child.

We saw little evidence for this across our sample.

- They are already engaged with or receiving services, including some with EHCPs
- They know there are no golden tickets
- EHCP is not their primary goal

Diagnosis – direct results

For the most part, people had realistic expectations of what a diagnosis would and would not deliver in the way of access to statutory support.

A handful of the people we spoke to *were* expecting access to better or different support as a result of diagnosis, or had been surprised that diagnosis did not open the door to a new range of services:

“then you can get like actual help because they know what you need help with” (W, CYP, 14F, ASD)

“so we got his diagnosis and then pouf! Nothing! There was nothing!” (D, P, 10M, ASD+)

“I did hope there would be some kind of pathway we’d be put on that

would mean she got some help” (D, P, 11F, ASD)

But many were under no illusion:

“I don’t expect a diagnosis to wave a magic wand” (W, P, 14M, ASD)

Many were benefiting from support before any formal diagnosis:

“I don’t think it’s necessarily going to change how school are treating her because they are pretty helpful, things are in place to help her anyway” (W, P, 14F, ASD)

“the school were already pretty good [about phasing her return to school]” (D, P, 14NB, ASD)

It is known that there are some health and support services that can only be accessed by those with a formal diagnosis, such as ADHD medication and certain specialist education provision

“She’s at a new-build school for autistic children” (D, P, 6F, ASD+)

We heard a small handful of stories of other therapies requiring a diagnosis:

“when I approached them about equestrian therapy they said “oh no she needs a diagnosis for that” (W, P, 14F, ASD)

Diagnosis as Supporting Evidence

However, many parents told us the diagnosis had made a tangible difference in negotiations with schools and services. Even though they were aware services were designed on a needs basis, were already receiving support, and were clear that there is no direct link between a diagnosis and support, their experience had been that a formal diagnosis added weight:

“you can’t argue with a diagnosis” (W, P, 11F, ASD)

“put it like this. I applied for DLA for my middle child, got refused, went to mandatory reconsideration and basically we were told we were s**t parents, we should put some boundaries in place and all our problems

would disappear. 6 months later I applied with exactly the same information plus a diagnosis and we got high rate care” (D, P, 7F, ASD/ADHD+)

“ I don’t think[you need a diagnosis to get an EHCP], but I think it’s quite difficult to get EHCPs without one” (W, P, 14M, ASD)

“legally – there is a kind of legal protection in terms of discrimination, it makes it a legal requirement not to discriminate” (D, P, 13F, ASD)

“if she had her diagnosis I’d reapply for an EHCP. We’ve been rejected and been to a tribunal, and while they haven’t said a diagnosis would help it’s not going to hurt either” (W, P, 14F, ASD)

People told us a formal diagnosis empowered them during negotiations: both that they feel empowered, and that the diagnosis gave them a trump card in discussions with statutory services.

“rebalances power” (W, P, 14F, ASD)

“without a diagnosis you just have no credibility with the school” (D, P, F12, ASD)

Several parents told us the formal diagnosis gave them more confidence when advocating for their child. They feel the validation of “the system” is behind them and have more faith in their own judgement:

“it’s not just me being “that mum”” (D, P, I4NB, ASD)

“I feel more confidence when I’m advocating for J” (D, P, 10M, ASD/ADHD)

Access to charities, informal networks and social media

A formal diagnosis opens the door to an invaluable web of non-statutory networks and support groups, ranging from national charities to local groups and social media networks. The diagnosis gives direction (what to look for) and confidence (sense of belonging).

“I mean, we couldn’t really approach the Autistic Football Club until he had

a diagnosis of ASD" (D, P, 10M, ASD/ADHD)

"I've got involved with the local NAS to find events she will enjoy" (D, P, 11F, ASD)

"When we said we *think* she has autism it was "oh..."; when we had the diagnosis it was "oh! Welcome!" (W, P, 14F, ASD)

"join all of the groups you can...the support groups, everything" (D, P, 10F, ASD/ADHD+)

Parents, children and young people told us how important these grassroots organisations were to them for information, support, guidance and a sense of community and togetherness.⁴ We heard mention of networks ranging from specialist charities (eg Appeer), school WhatsApp groups and TikTok.

"just people that you meet, they say why don't you try this course or read this book..."(D, P, 10M, ASD+)

"I would advise parents to talk to other parents of children who have difficulties...you get a more balanced view from other parents and you can learn from their mistakes, what's worked and what's not worked" (D, P, 10M, ASD/ADHD)

⁴ The value of community support is a common theme across all the work Healthwatch Surrey do.

Summary and Thanks

Our report focusses on the value and benefits people associate with a formal diagnosis. Our key message is that a formal diagnosis is about far more than formal/statutory support. Diagnosis can have a far-reaching, holistic impact on the wellbeing of families and provide a foundation stone for achievement of potential. As such, the demand for formal diagnosis is likely to remain high even where support is in place before diagnosis.

We would like to thank all our interviewees for sharing their experiences with us. Their resourcefulness, courage, hard work and love are inspirational, and we wish them all the very best for the future.

We would also like to thank all those in “the system”, especially Surrey and Borders Partnership, Surrey County Council, and Surrey Youth Focus who enabled this project by responding so quickly to our questions.

Healthwatch Surrey – Contact us

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