

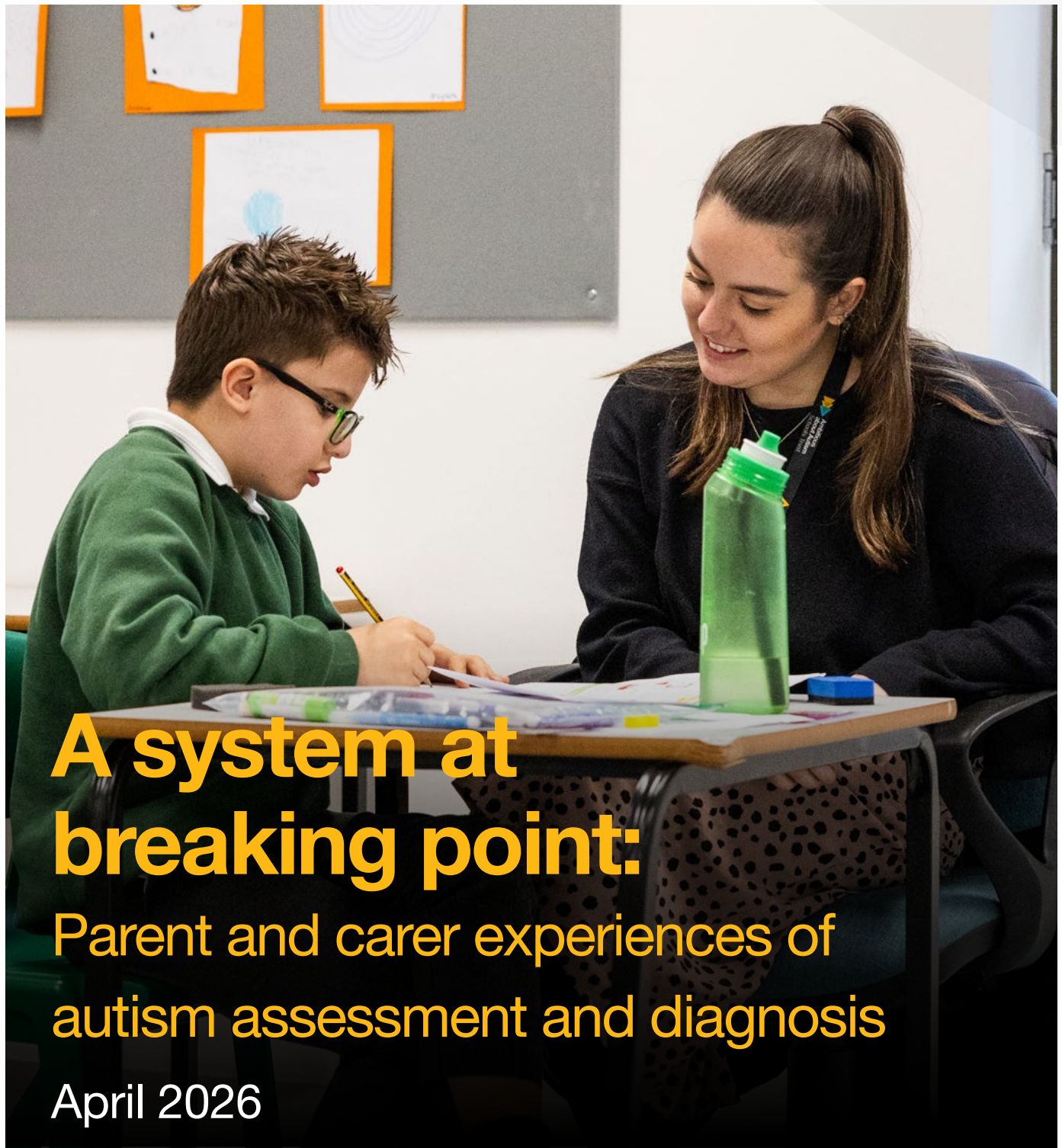


UNIVERSITY OF
BIRMINGHAM

The Autism Centre for
Education and Research



**Ambitious
about Autism**



A system at breaking point: Parent and carer experiences of autism assessment and diagnosis

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Executive summary

A system at breaking point:
parent and carer experiences
of autism assessment
and diagnosis



“

We aren't doing this as parents because we want attention, we are trying to make sense of our neurodivergent children in a neurotypical world.”

Background

The current system for autism assessment and diagnosis is struggling to meet the needs of autistic children and young people and their families. Autism diagnoses have increased by 784% over the last 20 years, driven by greater awareness and improved clinical understanding of autism ([Abdelnour et al., 2022](#); [Russell et al., 2022](#)).

However, autism assessment and diagnosis services have not expanded to meet this rising demand.

As of December 2025, over 250,000 people were waiting for an autism assessment, with over 90% of people waiting longer than guidelines recommend ([NHS England Digital, 2025](#)).

Previous research has shown that parents and carers find the autism assessment and diagnosis process as lengthy, complicated, and stressful, with little or no post-diagnostic support ([Crane et al., 2016](#); [Howlin and Moore, 1997](#)). Around 34% of autistic adults and 46% of parents and carers have reported receiving no support at all ([Department of Health and Social Care and Department for Education, 2021](#)).

We conducted research to provide up-to-date evidence on parents' and carers' experiences of the autism assessment and diagnosis process, and their views on a potential alternative or complementary pathway: a strengths and needs assessment.

This research is particularly timely given ongoing SEND reforms (led by the Department for Education) and an autism, ADHD and mental health prevalence review (led by the Department for Health and Social Care).

Key findings

The assessment and diagnosis process

- Parents and carers seek an autism assessment primarily to protect their child's mental health, not to gain advantage. Many reported that their children and young people reach serious "crisis points" while waiting for support in a system that is not meeting their needs.
- Families faced long waits for an autism assessment: 9 in 10 waited longer than the 13-week recommended guidelines, around 1 in 3 waited more than two years, and 1 in 8 waited more than four years.
- Parents and carers describe the process as stressful, isolating, and hard to understand.
- Nearly a third of families paid for private assessments due to long delays, not being believed by professionals, or difficulties navigating the system. Some reported taking out loans, demonstrating the financial barriers that stop many families from accessing timely assessment.
- Post-diagnostic support was very limited: 62% rated it as bad, and 17% reported receiving no support at all. Families were left to rely on schools and charities for support.

Views on a strengths and needs assessment

- Just over half of parents and carers felt that a strengths and needs assessment could be helpful: by providing quicker, more personalised information that could improve understanding for the individual; at home, in education settings or at work.
- However, the other half of parents and carers were unsure whether it would improve or limit access to support. They were also concerned that it could reduce the value of an autism diagnosis, dismiss autistic experiences, or create an unfair two-tier system.
- Many parents and carers wanted a formal autism diagnosis instead of, or alongside, a strengths and needs assessment.
- Overall, parents and carers noted potential benefits of a strengths and needs assessment but felt that any assessment pathway needed to prioritise meaningful support for the autistic child or young person.
- Implementing approaches for assessment of needs requires detailed and careful consideration.

Policy recommendations

Autistic children and young people, and their parents and carers, need access to a timely and effective diagnosis. The following recommendations set how to achieve this:

- 1. Deliver assessment and needs-led support together** with a stepped approach so that people receive early help that continues at every stage of the process. Ensure that additional pathways complement formal diagnosis, are evidence-based, and provide meaningful support.
- 2. Centre lived experience** in policy and practice decisions around assessment and diagnosis.
- 3. Invest in clear, well-resourced assessment and diagnosis services** so families understand pathways and professionals can work together.
- 4. Prioritise mental health and wellbeing**, ensuring support is offered proactively, not only once children and young people reach crisis point.
- 5. Strengthen post-diagnostic support** across education, health, and social care.



About the research

A total of 779 parents and carers of autistic children and young people completed an online survey about their experiences of the autism assessment and diagnosis process.

Participants were eligible if they had a child or young person aged 0–25 who, in the last five years, had received, was seeking, or was considering an autism diagnosis.

The survey collected background information to understand who was taking part and the stage families were at in the assessment process. Parents and carers were then asked about their experiences and views of the assessment process, including proposed alternatives, through a combination of multiple-choice and open-ended questions.

This research was conducted by Ambitious about Autism, with support from the Autism Centre for Education and Research (ACER) at the University of Birmingham.

Contact

Ambitious about Autism

Ambitious about Autism stands with autistic children and young people so they can be themselves. We run services and campaign for change.

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Introduction

“

...evidence suggests that the system as a whole needs to be improved to better support autistic children and their families.”



Background

In the UK, the current system for autism assessment and diagnosis struggling to meet the needs of autistic people and their families. There has been a 787% rise in autism diagnoses from 1998 to 2018, often attributed to greater awareness and improved clinical understanding of autism^{1,2}. However, assessment and diagnostic services have not evolved to meet demand.

At the end of December 2025, over 250,000 people were waiting for an autism assessment³. National Institute for Health and Care Excellence (NICE) guidelines recommend that an autism assessment should begin within 13 weeks (3 months) from initial referral⁴. However, over 90% of people are consistently waiting more than 13 weeks for an assessment^{5,6,7}, with many waiting years⁸.

Deciding whether to seek an autism assessment involves balancing potential benefits (e.g., accessing supports and services, better understanding a young person's needs) with potential challenges (e.g., stigma and discrimination). Parents and carers are often the first to notice signs that their children might be developing differently from same age peers⁹. As parents and carers often navigate the assessment and diagnosis process on behalf of their children, it is important to understand their direct experiences. Existing research with this group has highlighted the following themes:

1. Assessment and diagnosis is pivotal for support

Although a formal diagnosis is not legally required to receive the right support^{10,11}, in practice diagnosis and access to support is closely linked, making it hard to get help without a formal diagnosis. For example, a formal diagnosis can entitle an individual to an assessment of specific needs across education health and care and it also enables access to specialist autism services^{12,13,14}. Autistic people and their families report that a diagnosis is often needed to access meaningful support and to provide “proof”, or recognised evidence, of their needs¹⁵. As a result, it is a key reason why people seek a diagnosis^{16,17}.

2. Lengthy delays and confusing pathways

Large-scale surveys of parents and carers have reported consistently long delays – usually of several years – to access an autism diagnosis for their children^{18,19}. Longer delays were associated with lower parental satisfaction²⁰. Navigating this lengthy process was reported to be challenging and confusing for parents²¹.

3. Dissatisfaction with the current assessment and diagnostic process

After experiencing lengthy delays, parents and carers find the time that practitioners spend assessing their child to be disappointingly short^{22,23}. As such, parents and carers may feel that certain characteristics or needs are ‘missed’ or misrepresented²⁴. Parents and carers also report that their concerns or insights into their child’s experiences and needs can be dismissed by professionals, which negatively impacts parental wellbeing and yields further delays^{25,26}. While the manner of the diagnosing professional is crucial to how parents and carers process and understand the diagnosis²⁷, some parents and carers report that professionals can be insensitive when speaking about autism²⁸.

Many professionals recognise that the diagnostic journey can be stressful and emotional for parents and carers to navigate. At the same time, professionals may find it challenging to deliver the best possible care against a backdrop of service constraints^{29,30}.

4. A stressful, emotional experience

Parents and carers often describe the assessment and diagnostic process as stressful and dissatisfying^{31,32,33,34,35}. Receiving an autism diagnosis for their child can result in mixed emotions, including blame, guilt or concern for their child’s future, but also relief or validation^{36,37,38}.

5. A lack of post-diagnostic support

After receiving an autism diagnosis, parents and carers are often not provided with appropriate guidance as to how to access services to support their child^{39,40}. The extent of post-diagnostic support varies widely across the UK; 34% of autistic adults and 46% of parents carers have reported receiving no support at all, and many regions offer only a single follow-up appointment to signpost to other resources^{41,42}. This lack of meaningful support can lead to feelings of isolation, particularly if broader family support is lacking⁴³.

It is also important to recognise that some families might exist the process without their child meeting criteria for an autism diagnosis. Parents and carers in this position can be disappointed with this outcome and feel abandoned by the system when alternative support is not offered^{44,45}.

6. The impact of intersecting identities

Each family experiences the autism assessment and diagnosis process differently, and some families might face more difficulties than others. For example, differences in how autism can present in girls can make the diagnosis journey more complex for some families⁴⁶. Further, fathers in the UK can experience unique struggles during the assessment and diagnosis process, even feeling dismissed or unsupported as more attention is placed on mothers⁴⁷.

Families from ethnic minority backgrounds may face additional barriers, including systemic racism, historical mistrust of institutions, and language and cultural differences. Professionals are more likely to dismiss the concerns of Black parents and carers, which can further delay identification and access to support^{48,49}. In addition, differences in how communities understand autism and mental health can lead to traits being misinterpreted, inconsistently recognised, or overlooked altogether^{50,51}.

Autistic parents and carers may experience unique challenges during the autism assessment and diagnosis process. For example, the negative, deficit-based language used by diagnosing practitioners could be particularly upsetting for autistic parents and carers to hear⁵². These parents and carers were also worried about disclosing their own autistic identity in case it would be used against them or their child during the assessment and diagnosis process.

The current research

While there are excellent examples of practice in autism assessment and diagnosis across the UK, evidence suggests that the system as a whole needs to be improved to better support autistic children and their families^{53,54}.

The recently published Schools White Paper⁵⁵ and ongoing reviews and consultation relating to autism assessment and diagnosis in the SEND system⁵⁶ and further emphasise the need for decisions to be underpinned by lived experience.

Therefore, Ambitious About Autism – with support from the Autism Centre for Education and Research (ACER) at the University of Birmingham – surveyed parents and carers to inform recommendations for assessment and diagnosis in the UK, to best meet the needs of autistic young people and their families.

Aims

We wanted to understand parents' and carers' current experiences of autism assessment and diagnosis (i.e., within the last five years) and their views on proposed alternatives. Key questions were:



1. Why do parents seek an autism assessment and diagnosis for their children?
 - a. What are their top motivations?
 - b. What benefits do they expect for their child and family?
 - c. What risks or downsides do they perceive?
2. How do parents experience the assessment and diagnosis process?
 - a. What challenges and barriers do they face?
 - b. How do they view concerns about 'overdiagnosis'?
3. How do parents view alternatives/ accompaniments to a formal assessment and diagnosis?
 - a. What are their thoughts on a Strengths and Needs Assessment instead of, or alongside, a formal assessment and diagnosis pathway?
 - b. If Strengths and Needs Assessments were adopted, how could any concerns be mitigated?

What we did

A total of 779 parents and carers of autistic children and young people completed an online survey about their experiences of the autism assessment and diagnostic process.

In the UK, a “child or young person” with special educational needs or disabilities (SEND) can be any age from 0 to 25 years. As such, parents and carers could take part if they had a child or young person age 0–25 years and, in the last five years, they:

- had received an autism diagnosis
- were seeking an autism diagnosis, or
- were thinking about getting an autism diagnosis

The survey began with background questions. These helped us understand who was taking part, how well different groups were represented, and what stage people were at in the autism assessment or diagnosis process.

Parents and carers were then asked about their views and experiences of the autism assessment and diagnosis process, including proposed alternatives. This included multiple choice questions and open questions where they could describe their experiences in their own words.

Ethical approval for this research was granted via Ambitious about Autism’s Research Ethics Committee.



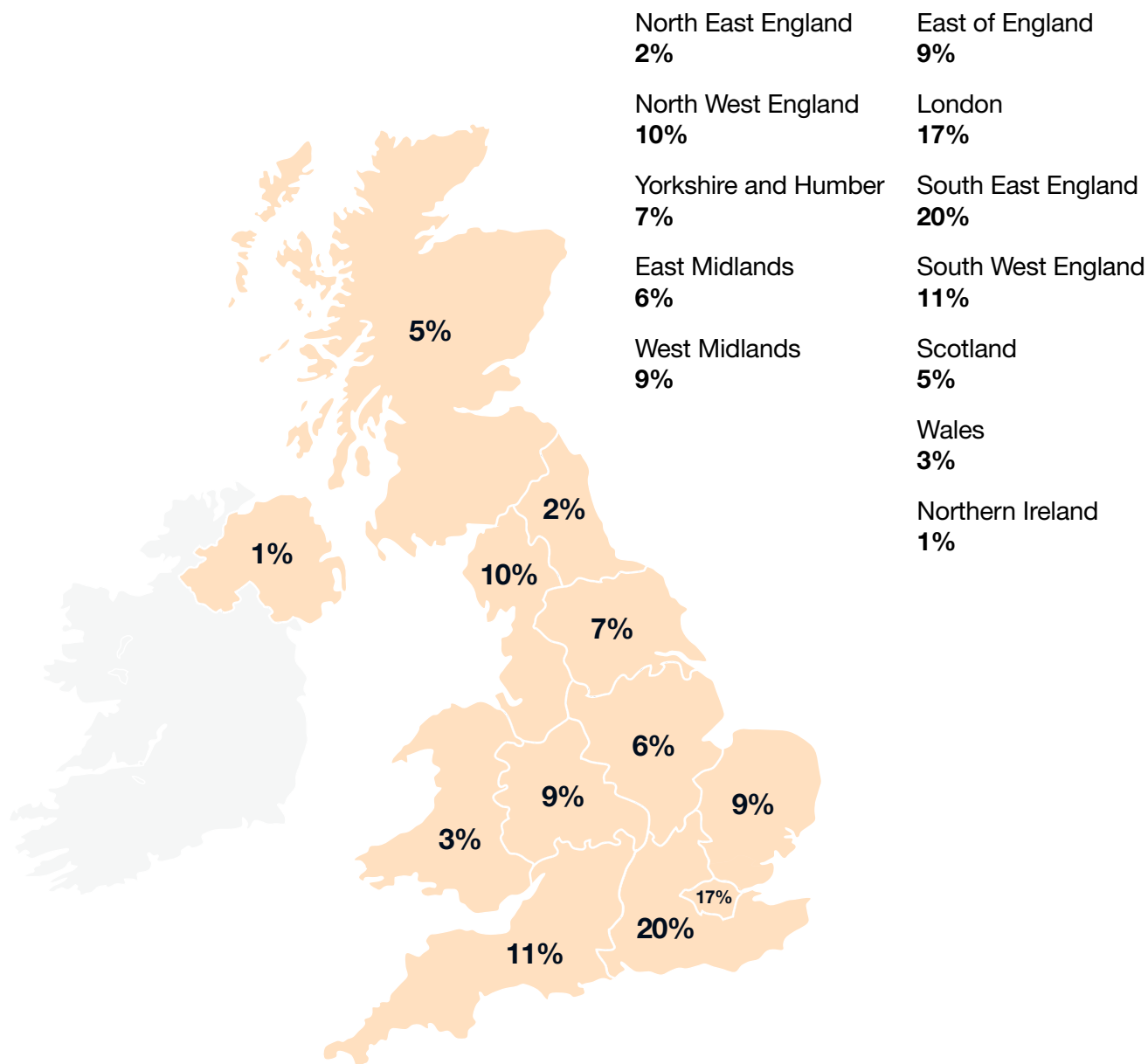
Who completed the survey?



About the parents and carers

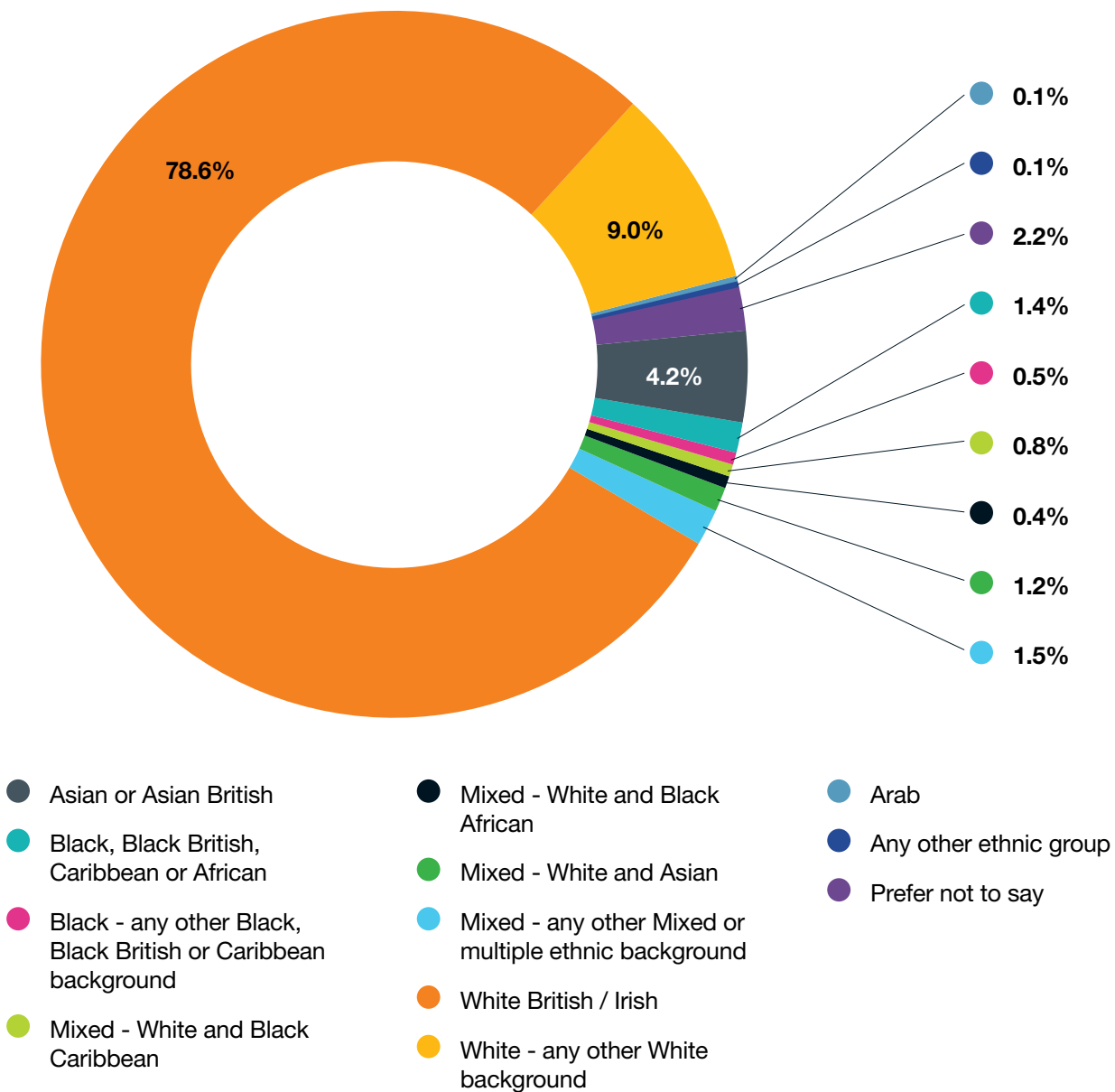
779 parents and carers from across the UK completed the survey. Parents and carers lived throughout the UK, including the South of England (37%), the Midlands (22%), and the North of England (18%).

Figure 1: Where respondents live



Most parents and carers described their ethnicity as White British or Irish (79%) or any other White background (9%). This was followed by Asian or Asian British (4%). Two per cent of respondents preferred not to disclose their ethnicity. Full details of ethnicity are shown in Figure 2.

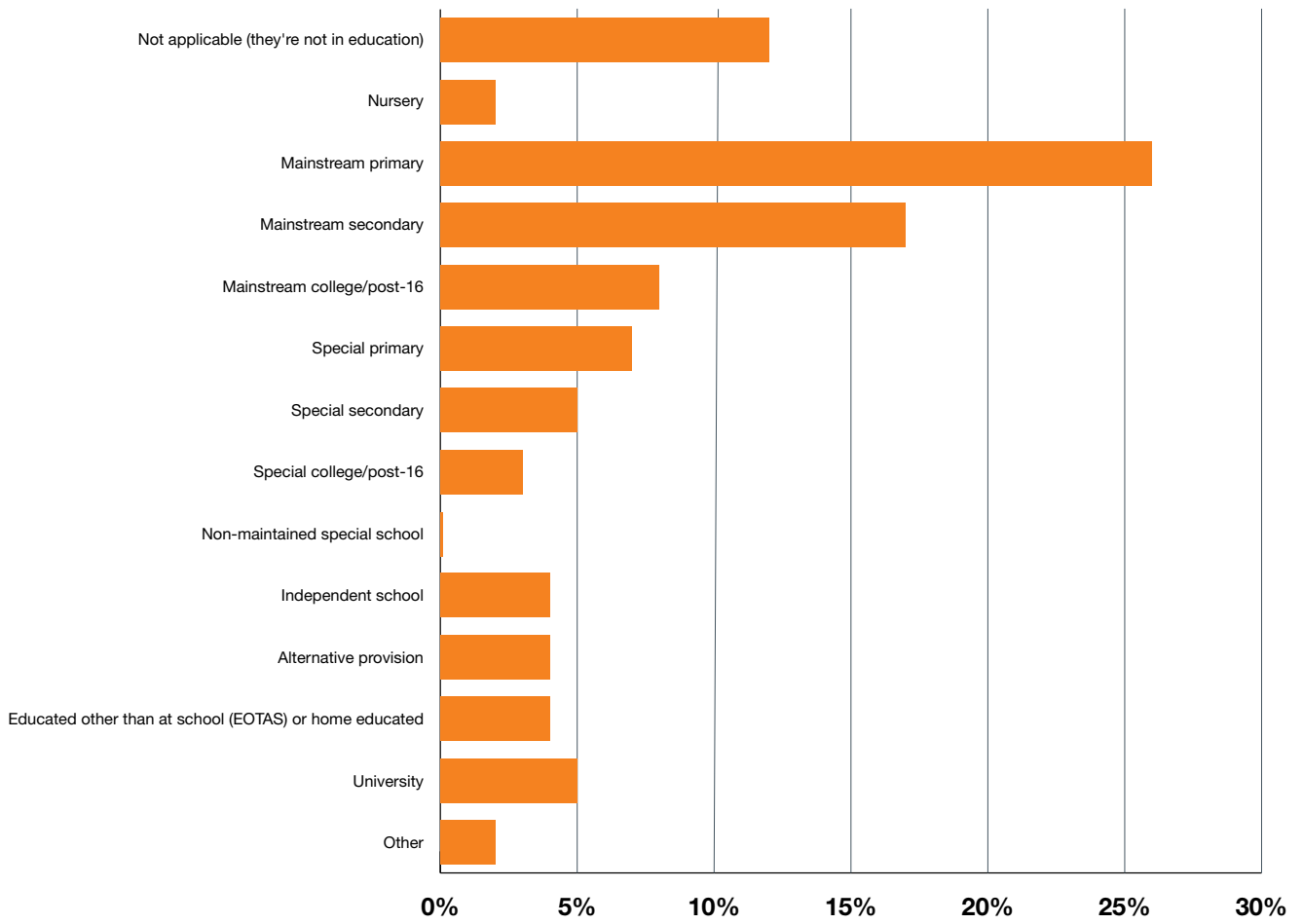
Figure 2: Respondents' ethnicity



Parents and carers completed the survey about their children, who were aged 2 to 25 years. The average age of the children was 13 years, but many were younger or older (largely between 8 and 18 years).

Most children and young people were attending mainstream schools, with 26% in mainstream primary, 17% in mainstream secondary, and 8% in mainstream college or post-16 education settings. Others were in a range of education settings, or were not in education because they were beyond compulsory school age (12%). Full details of education status are shown in Figure 3.

Figure 3: Education settings



What we found



Some also felt their concerns were not taken seriously by publicly funded services and therefore turned to private services to be heard.

The assessment and diagnosis process

Most parents and carers said their child or young person had received an autism diagnosis in the last five years (77%).

Twenty-one per cent were currently seeking an autism diagnosis, and 2% were thinking about getting an autism diagnosis, for their child or young person.

Most parents and carers said they were accessing assessment and diagnosis via the NHS (70%). However, 21% said they were following private routes, and 8% said they had pursued both routes (2% preferred not to say).

Those who used private services either instead of, or alongside, NHS services often attributed this to long NHS waiting times. Some also felt their concerns were not taken seriously by publicly funded services and therefore turned to private services to be heard.

“

(I) started the NHS route but it was too long to wait so took a loan out to pay to go privately.”

“

I asked both my GP and my son’s school to refer him for assessment. Neither took my concerns/request forward so I had to go private.”

The decision to move from NHS to private services was often described as a last resort and a difficult financial choice for parents and carers. Many reported having to take out loans or make other significant financial sacrifices to afford a private assessment. As not all families are able to access private services, this option can further exacerbate frustration for those navigating the diagnostic process.

“

We aren’t doing this as parents because we want attention, we are trying to make sense of our neurodivergent children in a neurotypical world.”

Parents and carers chose their reasons for seeking assessment and diagnosis from a list. The reasons, ranked from most to least common, are:

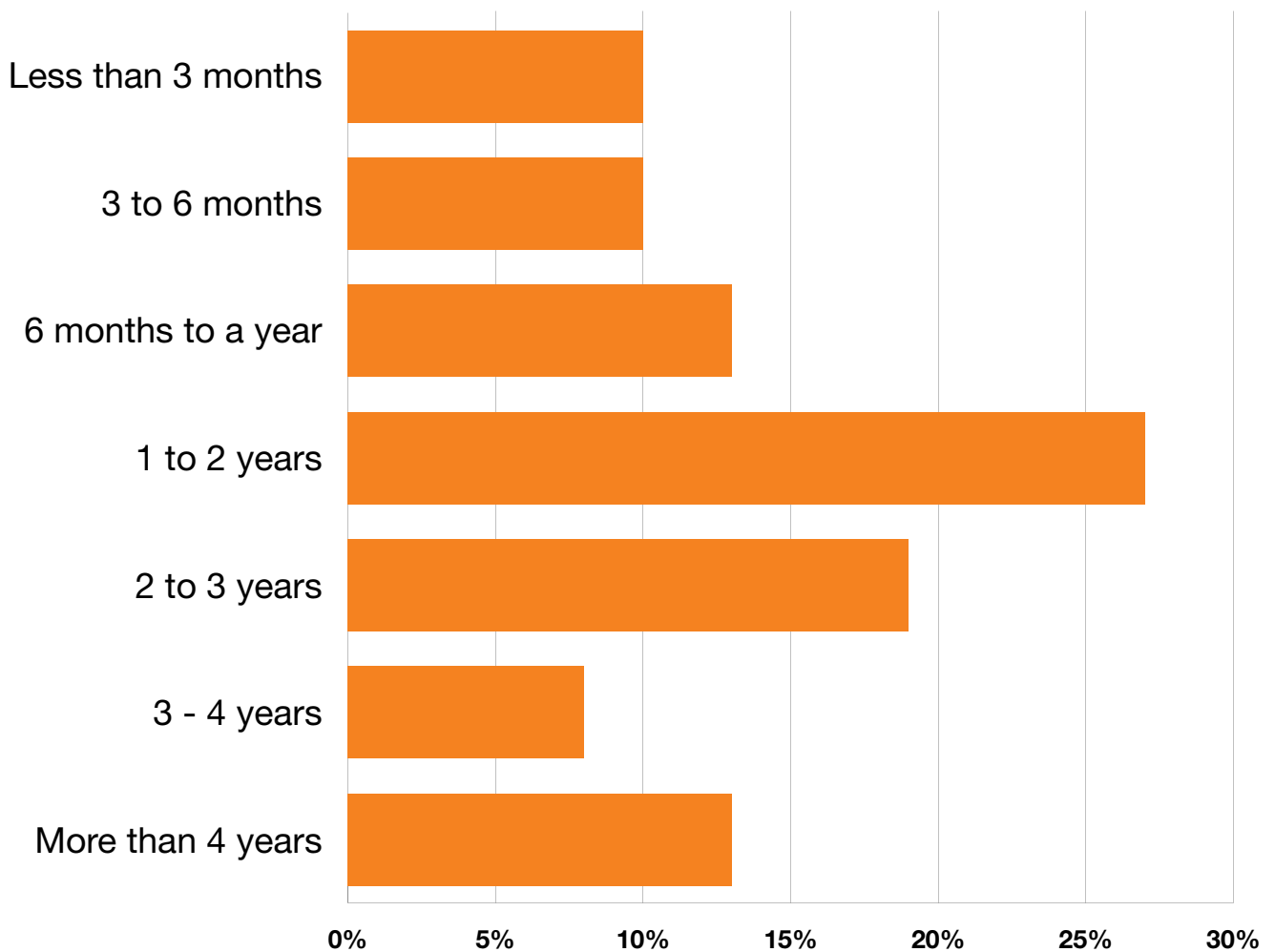
- 1. To support my child's or young person's mental health and wellbeing (78%)**
- 2. To get the right support, help and services for my child or young person (77%)**
- 3. To help my child or young person understand themselves (71%)**
4. To help the staff in their education setting understand and support my child or young person (60%)
5. To understand my child or young person better (59%)
6. To get adjustments at school or activities (52%)
7. To help my child or young person get the right educational provision (for example, getting a place in a special school) (39%)
8. To make daily life easier for our family (35%)
9. To help get an Education Health and Care (EHC) plan to help my child or young person get the right support (33%)
10. Because a professional suggested an assessment (27%)

Autism assessment waiting times

Of those who had been referred for an autism assessment, the most common waiting time from receiving a referral to having a formal autism assessment was 1–2 years (27%), then 2–3 years (19%) followed by six months to a year (13%) and more than four years (13%).

Overall, 90% of parents and carers had waited over the 13-week guideline for an assessment.

Figure 4: Autism assessment waiting times



Challenges of the assessment and diagnosis process

Parents and carers experienced a range of challenges when seeking (or thinking about seeking) an autism assessment diagnosis for their child or young person. These are listed below from most to least common.

- 1. Long waiting times for the assessment (70%)**
- 2. Limited support or services after a diagnosis (55%)**
- 3. Not being listened to (50%)**
4. Feeling anxious or stressed during the process (49%)
5. Lots of paperwork and appointments to manage (43%)
6. Concerns about how others (school, family, peers) will see or treat my child (36%)
7. Cost of private assessments (34%)
8. Balancing the autism diagnosis process with other conditions or diagnoses (30%)
9. Feeling like I'm adding to long waiting lists (22%)
10. The outcome might not give a diagnosis (18%)
11. Feeling like I'm contributing to an autism 'over diagnosis' (16%)
12. Stigma in my community (14%)

More on the autism assessment and diagnosis process...

Four key messages were identified from parents and carers' comments about the assessment and diagnosis process.

1. Dismissed

The decision to seek support and guidance, and to pursue an autism diagnosis, can be an emotionally difficult time. This vulnerability is often heightened when parents' and carers' requests or concerns are dismissed by the professionals they approached for help.

Many parents and carers reported feeling resistance and even discrimination from professionals (such as GPs, other healthcare practitioners, and school staff) when they raised the possibility of an autism assessment.

"Constantly got fobbed off."

"Constant gaslighting. Constant fighting. Constantly moving goal posts."

"The process also felt prejudicial and stigmatising."

Parents and carers expressed frustration when professionals dismissed their concerns because their child or young person's neurodivergence did not align with professionals' expectations.

"Daughter masks so it was hard to get professionals to listen to us."

2. Crisis points

Long waits for an autism assessment meant that children and young people experienced difficulties for extended periods. Parents and carers reported that their children and young people were only prioritised for an autism assessment after a critical incident occurred. For some families, these delays had serious, and even life-threatening, consequences.

"The process was long and painful and during that time my son had a breakdown as his needs were not being met."

"It was only when she started self-harming and missing school that our case was escalated."

"Both [children] had to be in crisis (suicidal for one over a year of emotionally based school avoidance for the other) before we made any progress in getting through the diagnostic process."

Parents and carers reported increased concern about securing an autism assessment during key transitions, such as changing schools, starting university, or moving from child to adult services.

“We paid privately because our daughter was going to “fall off” the child waiting list and have to join the adult waiting list.”

3. Lost in the system

Parents and carers expressed frustration with the complexity of the system, describing the assessment and diagnosis pathway as ambiguous and difficult to navigate. They noted that professionals themselves struggled to identify a clear pathway.

“We were bounced from pillar to post.”

Parents and carers also reported failures in service delivery, including misplaced forms, forgotten referrals, poor communication between institutions, and inadequate interactions between professionals and families. These experiences had tangible impacts on their experiences.

“My daughter got lost in the system. There were many forms that were lost and had to be redone, and she received her diagnosis almost after 4 years since we were first referred.”

Little communication was received during lengthy waits, so parents and carers felt frustrated and disappointed.

“Waiting time is endless and brutal.”

Parents and carers found completing paperwork and bureaucratic tasks difficult whilst balancing other responsibilities such as work and caregiving.

“Managing your own health and your other children too, whilst working, it is all very overwhelming.”

4. Stressful, isolating, and exhausting

Parents and carers described navigating the assessment and diagnosis process as a lonely experience. They often felt unsupported and unable to rely on others for support, compounded by a system that was not designed to make accessing support straightforward.

“I felt as if we were very much alone in our situation.”

Parents and carers were consistently burdened by worries about what an autism diagnosis might mean for their child or young person and its impact on their future. They were concerned about the number of appointments involved, the potential distress this could cause, and whether they were making the right decision.

“(I have) been very worried how it will affect him.”

“I’m not putting my son through it again.”

Parents and carers were also concerned about societal perceptions and feared being judged for seeking a diagnosis.

“I constantly worry that people don’t believe me when I say how hard it is to manage my daughter’s challenges.”

Overall, the assessment and diagnosis process left parents and carers physically and emotionally exhausted. They emphasised that improvements to the system are needed to support the wellbeing of their entire families.

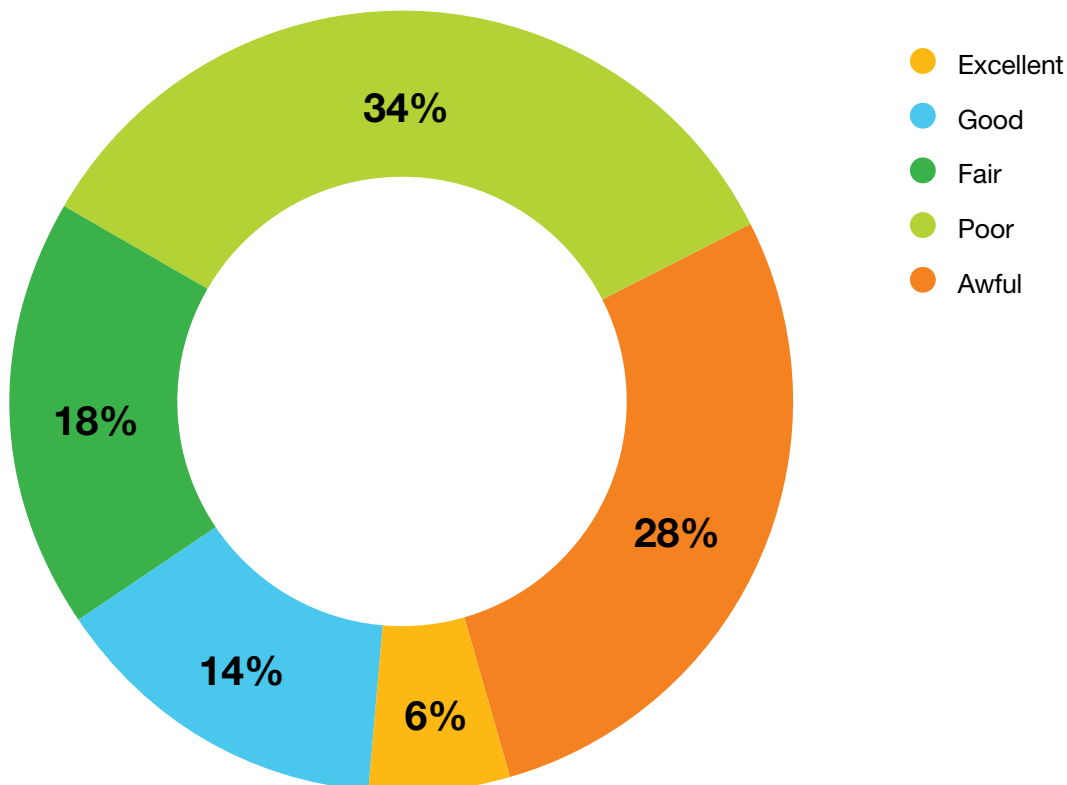
“It’s exhausting every step of the journey.”

“It has nearly broken me.”

Post-diagnostic support

Among parents and carers whose child or young person had received a formal autism diagnosis, 17% reported not receiving any post-diagnostic support. Among those who had received post-diagnostic support, only 20% rated it as good or excellent, but over half (62%) rated it as poor or awful (see Figure 5 for breakdown).

Figure 5: Parent and carers' views on the quality of post-diagnostic support, if received



More on post-diagnostic support...

Three key messages were identified from parents and carers' comments about post-diagnostic support.

1. Left in limbo

Parents and carers reported receiving little or no post-diagnostic support, and some were explicitly told by professionals to not expect any support.

"I was told I couldn't get support until he had a diagnosis, then when he got a diagnosis I was told there was no support available."

Post-diagnostic resources that were offered to parents and carers - leaflets, websites, online courses, and YouTube videos – were found to be unhelpful, as parents and carers had often found them during their own research during leading up to the diagnosis.

"Zero support offered. Zero follow-up. Here are some leaflets."

Parents and carers hoped that diagnosis would be a gateway to support. Facing the reality that support was not readily available was disheartening, leaving parents and carers feeling that the system failed them at their time of greatest need.

"It's like the system planted the seed but then forgot about us. We are left in limbo."

"You are left wondering where to go next, who can support you through this minefield"

2. External support

Parents and carers sought alternative support following a diagnosis, with mixed success. Some found schools and universities supportive, while others did not. Access to appropriate education health and care (EHC) plans also varied, with some parents obtaining them and others facing difficulties.

"The most support has come through school."

"There isn't any support after diagnosis, we struggled to get school to understand this and that the supports they suggested were not meeting needs."

When parents and carers received post-diagnostic support, it often came through charities. Parents and carers expressed gratitude to these organisations for providing some form of support.

"No support at all other than through charities."

Overall experiences

A third of parents and carers said they had a negative or very negative experience (33%). This was because the system felt complicated and bureaucratic, and because the assessment and diagnosis process left them feeling exhausted and alone with limited support.



The entire process was complicated and stressful ... The entire system is seriously flawed."



I know they're under pressure. But I feel let down."

Fourteen per cent felt there were both positive and negative aspects.

Around a quarter of parents (26%) described their experience as average.

A quarter of parents and carers (25%) said they had a positive or excellent experience.

Positive experiences were often related to getting an autism diagnosis at the end, and the validation and understanding gained from that.



Being diagnosed as Autistic has not been limiting or made either of us feel there is something wrong. Instead we now know she is just like many other children and adults in seeing the world differently and this is a strength she can take forward into the future."

Other positive experiences were from parents and carers who had sought private assessment and diagnosis and were satisfied with their decision.



I am glad we went private because diagnosis of any condition should not be a process drawn out for years ... a quick diagnosis has let us get on with life and try more strategies - and really educate ourselves about autism - rather than being stuck in limbo."

Views on strengths and needs assessments

Parents and carers were asked about their views on a strengths and needs assessment. The assessment was described to parents/carers as a comprehensive assessment that identifies what a child or young person is good at, what support they might need, and which goals are important to them. They were also told that the assessment could be shared across services to help professionals understand how best to support the child.

Strengths and needs assessment without a diagnosis

Just over half of parents (54%) said they would be happy for their child or young person to have a full assessment of their strengths and needs, even if it did not lead to an official autism diagnosis.

There were three main reasons why these parents and carers were supportive of a full assessment without pursuing an autism diagnosis.

1. Support and understanding matter more than an autism label

Parents and carers said their main priority was getting practical support for their child or young person, rather than receiving a formal diagnostic label.

“All we want is support for our daughter. It’s not about a label.”

What mattered most to parents and carers most was gaining a better understanding of their child’s strengths, needs and how to support them, which they felt a comprehensive strengths and needs assessment could provide.

“My primary aim is to understand how to better support my child’s needs... the diagnosis / label doesn’t matter as much as insight and evidence for support.”

Parents and carers noted that it was important that professionals recognised any potential solutions as ‘valid’ assessments in order for them to be helpful.

“It is still an assessment and as long as it is respected by schools and professionals it would help. Better than waiting several years.”

2. A strengths and needs assessment is more person-centred than a formal autism diagnosis

Parents and carers felt that a strengths and needs assessment could offer a fuller, more detailed and more individualised understanding of an autistic person than a formal diagnosis.

“More useful, child specific, result in proper tailored accommodations.”

Parents and carers also valued the focus on identifying strengths, which they felt was more positive and affirming for children and young people than a medical diagnosis alone.

“I think an assessment that shows strengths would be amazing. A lot of this process has been about discussing what my daughter can’t do, not what she can.”

Parents and carers noted that a more individualised approach may be particularly helpful for autistic children and young people with co-occurring conditions, such as attention deficit hyperactivity disorder (ADHD). They felt it allowed professionals to recognise and respond to overlapping and individual strengths and needs, rather than focusing on a single label.

“My child, 4, presents with sensory difficulties. This may be explained by ADHD or autism... [a] label is less important than need.”

3. Useful for those who ‘fall through the cracks’

Parents and carers said that a strengths and needs assessment could be particularly helpful for autistic people who mask a lot or might not fit stereotyped views of autism. This was seen as especially relevant for autistic girls and women, who may not neatly ‘fit’ within standard diagnostic criteria or may fall just below the threshold for a formal diagnosis.

“I think that females still could miss criteria by mere points under the medical model and leave parents hopeless.”

Parents and carers suggested that a more detailed and individualised profile could provide clearer evidence of a person’s needs. They felt this might be more convincing for professionals who hold narrow or stereotyped views of autism.

“I wonder if the assessment would have actually changed the teachers views that our child had no needs because she was not autistic?”

Ignorance and bias in professional circles exists, so even with a diagnosis we heard professionals say ‘she needs routine if she’s autistic’ when we were trying to explain the accommodation she needed to manage her overload and exhaustion from masking.”

Strengths and needs assessment alongside a diagnosis

Sixteen percent of parents and carers said they would only want a strengths and needs assessment if it could lead to an autism diagnosis.

There were four main reasons why parents and carers preferred a strengths and needs assessment only if it could lead to a formal autism diagnosis.

1. A formal diagnosis is a gateway to practical, long-term support

Parents and carers said that, in the current system, a formally recognised autism diagnosis is the only way to access support. They described a diagnosis as providing formal recognition and leverage that unlocks support in a way that a strengths and needs assessment does not.

“A diagnosis gives more legal [recognition]... it seems to be the only way to get help.”

Parents and carers said a diagnosis was often essential for autistic children and young people with complex needs, especially those attending specialist schools. It was also seen as critical for accessing wider educational support, such as Education, Health and Care plans and support in further and higher education.

“Diagnosis is needed when you have very high support needs and need a specialist school.”

“Support in education hinges on a diagnosis.”

Parents and carers also felt that a diagnosis provides access to support beyond education, including healthcare support, financial support, social care support, independent living support and support in the workplace (e.g., reasonable adjustments).

“A diagnosis was important to us to access medication. Our young person spent too many years suffering with anxiety, panic attacks, meltdown, etc, both in and out of school.”

The permanent nature of a formal diagnosis was seen as particularly important. Parents and carers valued how a diagnosis carries through different life stages and provides ongoing recognition of need. This gave reassurance that their child or young person would still be able to access support in the future, especially if parents and carers were no longer able to advocate on their behalf.

“We are unable to support our son financially once we are retired. This is extremely concerning for us for the future.”

2. An autism diagnosis is important for recognition in the system and society

Parents and carers said they were aware of their child and young person's strengths and needs, but added that a formal autism diagnosis was important for confirming or explaining these needs to others.

"My daughter's strengths and needs were fairly obvious, but we were only taken seriously with an official diagnosis."

A diagnosis was felt to address accusations of 'bad behaviour' or poor parenting, validated their experiences.

"I would prefer no labels, but unfortunately no one seems to understand you have needs when you don't have a label.

Services do not work with you, your kids' behaviour is just bad [and] attendance difficulties are just parenting problems. Until that changes, diagnosis is necessary."

Parents and carers argued that a diagnosis was especially important for children and young people who mask or do not have an additional learning disability, because some people may not recognise that they are autistic

"Because my son masks so heavily in school, it's important that he has a diagnosis... [the school] are more open to accepting a formal diagnosis.

It has been a struggle because he doesn't struggle academically - schools do not seem to understand the difference in people with a diagnosis of autism... we can't show he's autistic."

"There is little room for misunderstanding with actual diagnosis especially with looked after children whose difficulties are always referred to as trauma so the fight is even longer and more difficult."

Parents and carers framed this as a broader issue within services and society, noting that some services, particularly health services, fail to recognise or respond to the needs of autistic children and young people as schools do.

"Secondary school has been fabulous and know her strengths and weaknesses as we do at home. It is health services that don't know, understand or care. The NHS needs to do much more to align with the quality care schools are giving."

3. A strengths and needs assessment without a diagnosis can be an additional burden with uncertain outcomes

Parents and carers who prioritised a formal diagnosis often saw a strengths and needs assessment without a diagnosis as an extra step in an already stressful and lengthy process. They felt it could place additional strain on both children and families, particularly if the child had already experienced multiple assessments that were stressful or negative.

"I wouldn't want to put my anxious, overthinking child through an assessment more than once, and would only want to do one if it was leading to diagnosis."

They worried that a strengths and needs assessment alone could be confusing or upsetting for the child, and an effortful or resource intensive process for parents and carers. If it did not result in a recognised outcome or support, they felt the effort would not be worthwhile.

“The effort and energy and resources to commit to a test is too great to have a non-outcome.”

This fear was confirmed for the parents who had already gone through such assessments and had the results ignored.

“I paid privately for an assessment of strengths and needs for the annual review of the EHCP ready for secondary school. It was ignored and I only got additions to EHCP via tribunal.”

Finally, parents and carers expressed concerns about the expertise of the people carrying out these assessments. They felt that if the assessment was not conducted by someone with proper training, it could produce inaccurate, inconsistent, or even harmful results.

“I suspect that an assessment of strengths and needs would not be carried out by someone who is qualified to give a diagnosis. I’ve heard of these being carried out by teachers/SENCOs without sufficient training to even identify strengths or needs.”

4. A diagnosis is important for identity, validation, and system reform

Parents and carers described a formal autism diagnosis as psychologically important for the individual. They said a diagnosis helps validate the autistic person’s lived experiences, support better self-understanding, and can improve mental health.

“Diagnosis is extremely important... diagnosis is understanding.”

“It’s important to put an official name on lived experiences.”

This validation was seen as important not only at an individual level, but also at a societal level. Parents and worried that - if used concurrently – strengths and needs assessments and diagnostic assessments could contradict or invalidate each other, putting families in a weaker position.

“The diagnosis shouldn’t be undermined. It isn’t a label it’s an understanding and acceptance and it’s been professionally assessed. There is no ‘over diagnosis’ there is a lot of under acceptance and ableism.”

Parents and carers who were unsure or whose views depended on other factors

Just under a third (30%) of parents and carers were unsure about the relative pros and cons of strengths and needs assessments or said their decision would depend on other factors.

Several questions were raised by parents and carers who supported or opposed an assessment, with or without a formal diagnosis.

1. Will they work for all children and young people?

Parents said that the suitability of a strengths and needs assessment depended on the individual child or young person. They highlighted the importance of whether the assessment was a good fit for a child's specific profile and needs, including whether it was neurodiversity affirming and appropriate for children with presentations (e.g., pathological demand avoidance) where goal setting can be counterproductive.

Age and stage of transition (e.g., moves from primary to secondary school) were also key considerations, with parents and carers questioning whether a strengths and needs assessment could meaningfully support these transitions, and whether they would need to be repeated to account for changing needs.

“A diagnosis is important to help my child understand why they think the way they do. An assessment of strengths and difficulties would be valuable at the time it happened but would likely be irrelevant in a few years as my child grows and develops.”

Parents and carers also noted that the usefulness of a strengths and needs assessment varied depending on the education setting the child or young person was in, or hoped to enter.

“For my youngest child ([who is] non-verbal, [and has an additional] learning disability, [and] global developmental delay), more support is needed and this needs to be maintained in a legal document where I can hold the local authority and school to account.”

2. Will the strengths and needs assessment be recognised and unlock enforceable support?

Parents and carers felt that the usefulness of a strengths and needs assessment depended on whether it was recognised and accepted by key gatekeepers, such as schools and SEND teams, the NHS, exam boards, universities, and employers, and whether it could unlock enforceable legal support. This was particularly important where families needed evidence to secure support such as specialist placements or formal reasonable adjustments.

“Unless other organisations and the NHS were to start accepting private diagnosis and these needs assessments as proof of needing support then they're useless.”

3. Who conducts the assessment and how credible are they?

Parents and carers said confidence in a strengths and needs assessment was much higher when it was carried out by a suitably qualified and regulated professional who had enough time and context to understand complexity, including masking. Confidence was much lower when the assessment was perceived as light touch, rushed, or conducted by someone without sufficient expertise.

“It depends who is conducting the strengths and needs assessment. [They] must be a Health and Care Professionals Council registered for me to agree to this, [and there would need to be] a full report and as part of a wider assessment where the person has the opportunity to get to know the child.”

4. Will it lead to real-world action and funded follow-through?

Parents repeatedly questioned whether a strengths and needs assessment would lead to meaningful outcomes. They wondered who would implement the recommendations, who would fund the support, and what would actually change in practice as a result of the assessment. They expressed concern that the assessment would become another report that was ignored.

“It depends on whether support would be forthcoming without a diagnosis.”

5. What is the assessment burden versus benefit?

Families considered the burden of assessment on the child or young person. They were concerned about anxiety, stress, and potential re-traumatisation, particularly where assessments were lengthy or repetitive. Parents were reluctant to put their child through an assessment unless it led to a clear, practical, and usable outcome.

“The assessment process is incredibly stressful for the child. I would not be keen if it did not lead to a recognisable/ useful outcome.”

6. Does it complement diagnosis or become another barrier to diagnosis?

Parents and carers saw potential value in a strengths and needs assessment as an interim measure while waiting for a formal diagnosis. However, they expressed strong concerns that it could be used to delay or replace diagnosis, create a “two-tier system”, or add extra gatekeeping, especially in the context of wider narratives around ‘overdiagnosis’.

“On the one hand, this might be able to get children some of the support that they need now. But on the other hand, what if the government decides to stop the diagnostic process at this stage deeming the support given as ‘enough’.”

Conclusion

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More and more children and young people are being recognised as needing assessment and support, but assessment services have not developed at the same pace to meet this need.



Although obtaining a diagnosis is pivotal for autistic young people’s health, wellbeing and future prospects, the current system for autism assessment and diagnosis is not meeting their needs. Waiting times for autism assessments and diagnoses continue to be lengthy in the UK.

More and more children and young people are being recognised as needing assessment and support, but assessment services have not developed at the same pace to meet this need. At the same time, public debate has focused on the so-called “overdiagnosis” of autism, alongside forthcoming SEND reforms and ongoing reviews of autism, ADHD and mental health prevalence. In this challenging and evolving context, understanding the experiences of parents and carers – who often manage and navigate the autism assessment and diagnosis process for their child or young person – is essential.

Our research examined parents’ and carers’ views of the autism assessment and diagnosis process. It explored why families seek assessment and diagnosis for their children and how they view other types of assessment alongside formal diagnosis. The research aimed to provide up-to-date evidence on what works well and what does not work, to inform policy and practice.

Experiences of the assessment and diagnosis process

We found that 90% of parents and carers waited longer than three months for an autism assessment, which is beyond the 13-week guideline set by NICE. It was almost as common for families to wait more than four years for an assessment, as it was to be seen within 13 weeks. These findings provide further evidence of that the current autism assessment and diagnosis system is struggling to meet needs.

Some parents and carers reported switching from NHS pathways to private assessments because of unrealistically long waiting times and their young people being at crisis point. Many made this decision because they felt they were not being listened to or believed by health professionals. However, private assessments are costly, and some parents and carers reported having to take out loans to cover the costs. This highlights the financial barriers that prevent many families from accessing timely assessments, particularly in lower income areas⁵⁷. Even after receiving a diagnosis, post-diagnostic support was poor or non-existent.

Despite these challenges in the assessment and diagnosis system, parents and carers continue to pursue an autism diagnosis primarily to protect their child or young person's mental health and wellbeing. Our findings show that children and young people often reach serious "crisis points" while waiting for an autism assessment. This underscores that parents are not seeking a diagnosis to gain an advantage and "get ahead," but because their children are a serious risk of, or are experiencing, crisis due to systemic gaps in support.

Overall, these findings reinforce previous research: the assessment and diagnosis process remains lengthy, confusing, and stressful, with little support throughout the process, and limited to no support after a diagnosis. These issues have persisted for the past 20 years or more^{58,59,60}. Clearly, something needs to change.

Strengths and needs assessment

A strengths and needs assessment is a comprehensive evaluation of a child or young person's strengths and needs. Such an assessment could be shared with schools, social care, and health services to help them understand and support the child, plan adjustments, and access services. This type of assessment is proposed as a valuable option for parents and carers navigating the lengthy assessment and diagnosis pathway, but would not provide a formal diagnosis.

About half of the parents and carers in this research saw some benefits to a strengths and needs assessment. They felt it could provide a more immediate, personalised understanding that families, professionals, and wider services could use. This was viewed as particularly helpful for autistic people who mask their difficulties or fall just below the formal diagnostic threshold.

However, a similar number of parents and carers indicated that they still wanted a formal autism diagnosis or needed additional reassurance. They argued that a diagnosis remains essential in the current system to secure practical support across education, health, and social care throughout a person's life. They added that a formal diagnosis validates the autistic experience and helps society recognise their needs.

Some parents and carers expressed concern that alternative assessment pathways could create a two-tier system. Families who can afford a private diagnosis might receive different recognition than those who follow an alternative process, whose needs may not be taken seriously within the current SEND system.

Parents and carers agreed that any pathway should prioritise supporting the child or young person and facilitate access to services. Implementing alternative pathway options requires careful consideration, including how they would integrate with wider SEND provision and education health and social care systems, and whether these systems functions effectively.

Research by the autism research charity Autistica is investigating the real world outcomes of a standardised strengths and needs assessment based on the International Classification of Functioning (ICF) with families and staff across eight schools⁶¹. Early findings indicate that parents and educators want to better understand autistic young people's needs and highlight the benefits of this assessment in identifying practical, tailored adjustments that support participation and wellbeing. These insights suggest that structured strengths and needs approaches may help shift the focus away from diagnosis as the only gateway to support, towards earlier identification of functional needs that can inform practical adjustments in education and daily life. Evidence like this may be valuable in demonstrating the potential of developing parallel systems of diagnosis and needs-led support.

Recommendations

Autistic children and young people, and their parents and carers, need access to timely and effective assessment and diagnosis. This report concludes with five recommendations on how this can be achieved.

1. Deliver diagnosis and needs-led support together

The autism assessment system must develop to both reduce waiting times through investment and adapt to provide needs-led, stepped support so that people receive early help that continues at every stage of the assessment and diagnosis process. Additional pathways, such as strengths and needs assessments, should complement, but not replace, formal diagnosis. These pathways must be evidence-based, clearly explained to families, and used to guide support rather than restrict access. Families should understand how diagnosis and needs-led assessments work together and what support is available at each stage.

2. Centre lived experience

Parents and carers of autistic children are often not believed about their needs. This can lead to delayed, inadequate, or inappropriate support. Listening to families' experiences – alongside the voices of young people at the centre of the process – will help ensure services meet real needs and counter misconceptions about why families are seeking assessment and diagnosis in policy and practice decisions.

3. Invest in well-resourced, coordinated assessment and diagnosis services

Autism assessment and diagnosis services must be fully funded and staffed to reduce waiting times and prevent harm caused by delays. Services resourced to work collaboratively, minimise repeated handoffs between professionals and streamline processes in order to maintain good access to assessment. Families should receive clear communication from assessment and diagnosis services, including expected timelines and available support.


4. Prioritise mental health and wellbeing

Supporting autistic children and young people's mental health is a primary reason that families seek a diagnosis. Autistic children and young people should have early access to holistic mental health and wellbeing support throughout the assessment and diagnosis process. Education and mental health services should provide proactive support even before a formal diagnosis, rather than waiting until children or young people reach crisis point.

5. Strengthen post-diagnostic support

Resources should be directed to ensure consistent, evidence-based, holistic support is available to families as soon as needs are identified. Support should be accessible across the country and tailored to individual needs, so families are not left alone without guidance.

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About us

This research was conducted by Ambitious about Autism, with support from the Autism Centre for Education and Research (ACER) at the University of Birmingham.

Ambitious about Autism is the national charity standing with autistic children and young people. We believe every autistic child and young person has the right to be themselves and realise their ambitions. We started as one school and have become a movement for change. We champion rights, campaign for change and create opportunities.

The Autism Centre for Education and Research (ACER) develops evidence-based practice and provision for autistic people and those who support them, across the lifespan and globally. Working in partnership with the communities it serves, ACER aims to make a tangible difference to everyday lives and real-world practice. ACER is based in the University of Birmingham's School of Education.

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Ambitious about Autism is the national charity standing with autistic children and young people.

We believe every autistic child and young person has the right to be themselves and realise their ambitions.

We started as one school and have become a movement for change. We champion rights, campaign for change and create opportunities.

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