



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

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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."

Executive summary

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.

A full report of the research is available [here](#).

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

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