

# SEN

**SPECIAL EDUCATIONAL NEEDS**

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# When autism diagnosis goes wrong

**Mark Chapman and Kirsty Stubbs** look at the implications of autism misdiagnosis and how to help the professionals get it right

**T**his article explores what happens when autistic spectrum disorder (ASD) is misdiagnosed – either when a child receives a diagnosis even though their behaviour can be explained by other factors, or a child not being diagnosed or being wrongly diagnosed when they are on the spectrum.

Children are usually referred for a diagnostic assessment – commonly carried out by a neurodevelopmental team found in local or specialist child and adolescent mental health services (CAMHS) – if there are concerns regarding their social interaction, social communication or rigidity in thought, all of which are potential indicators of ASD. Evidence of a child's behaviour across different settings (including home and school) is collected from parents and teachers and combined

with behavioural observations and their developmental history following a face-to-face assessment. All of this evidence helps the assessing clinicians to reach a conclusion regarding a diagnosis.

Giving a diagnosis is, unfortunately, not always as clear or as easy as we would all hope. There are no medical tests that can help diagnose ASD, so it can often be a complex process. It is possible that certain behaviours typical in autism (for instance, a lack of eye contact) could be explained by a different cause (in this case, potentially, social anxiety or cultural norms). It is therefore possible, although not common, to misdiagnose ASD.

## The cost of misdiagnosis

If a diagnosis of ASD is given in error, when in fact the presenting behaviour could be explained by other factors –

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such as attachment difficulties, trauma or social anxiety – the implications can be significant. A child given an autism diagnosis will carry that “label” with them for the rest of their lives, and it is therefore important to make sure it tells the correct story for that individual. A diagnosis of ASD can mean an individual does not qualify to enter specific professions (for example, the army or being a pilot) or enjoy certain types of training or employment opportunities.

Sometimes, parents believe that once their child is diagnosed, a world of resources will open up for them. However, being diagnosed incorrectly or for the wrong reasons would not guarantee additional support or, indeed, the correct support.

What's more, multiple ongoing assessments with different professionals and extra support or special treatment at school can be tiring for both parents and the child involved. Young people can also develop a degree of nervousness about health professionals and assessments or, conversely, a reliance on the professionals involved (especially when it comes to classroom support). The impact of misdiagnosis on a child has not been well documented; however, an ASD diagnosis can have a serious



Being diagnosed with autism can have a big impact on a child's self-esteem.

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impact on a child's self-esteem and their feelings of belonging to their peer group. Even if a misdiagnosis is rectified, the impact of this may involve psychiatric problems for the child concerned, and it could lead to a medico-legal conflict.

If a diagnosis is not given, when in fact a child meets the criteria for ASD, this can have serious implications for the level of support offered by the education system and later in life for the individual's chances of finding and maintaining employment. It is, of course, possible for an individual to display traits of ASD without meeting the criteria for diagnosis and this should always be taken into account when outlining a need for additional support.

### How can schools help?

Unexplained psychological symptoms in young people are some of the most common problems in today's schools, accounting for a lot of the concerns about pupils held by teaching staff and SENCOs. In addition, without a diagnosis, a child is currently unlikely to receive significant extra support at school. This often means that a child's difficulties can be represented in an incorrect or misleading way in order to create a sense of urgency within the system to assess them. The information presented to those who are conducting an assessment does not therefore always provide the best, most accurate picture of the child's needs and difficulties.

When asked for information to support an assessment schools should provide clear objective descriptions of a child's behaviour. So rather than just saying "John has good social skills", it is better to provide a fuller, more accurate account, such as: "John is able to initiate and maintain conversations with known peers on a regular basis across contexts, including the playground and classroom, but finds it more difficult with new peers and adults."

Schools should also avoid using school-specific acronyms or jargon when

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explaining the support they provide and their behaviour management strategies. They should also present information about the child's strengths, not just about their difficulties.

### How can families help?

Parenting a child with complex and challenging behaviour can seem like a journey with many mountains and obstacles. Often, a parent may feel they need to find an answer as to why their child displays difficult or odd behaviours. Parents can easily stumble upon check lists of behaviour that almost mirror their child in exact detail. On occasion, parents can attend an ASD assessment and recall information which is, in fact, a direct replica of these checklists. This is not always a helpful and does not provide a genuine account of the child's difficulties. Similarly, parents can also reach conclusions about their child by listening to what other parents have to say (for example, "maybe it's actually undiagnosed autism").

Parents contribute a great deal to the assessment process and it is important that the information presented is clear, accurate and not influenced by the opinions of others. Sometimes, prior to an assessment, parents are adamant that their child does or does not have autism; this can lead to them, however unwittingly, providing biased information which makes it hard for the professionals glean the real facts of the case.

If you are a parent wanting to support the autism assessment process as best you can, it would be useful to:

- remind yourself of your child's developmental milestones beforehand
- bring along any previous reports from assessments your child has already had, perhaps from an educational psychologist, speech and language therapist, occupational therapist or behavioural support professional
- be as clear and as factual as you can about your child's presenting difficulties, using particular examples of their behaviour in certain circumstances, as opposed to presenting your (or somebody else's) opinion as to what caused the behaviour
- compare your child and another child of the same age, as this can be useful in order to understand whether you believe your child is able to do the same things as someone of the same developmental level
- come to the assessment without a set agenda and provide information about your child in the form of direct answers to the questions asked, rather than building a picture of your child's presentation in advance. **SEN**

### Further information

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