

NEWS

Parental concern may skew scores on autism test

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A widely used test for diagnosing autism may miss children whose parents are not concerned that their child may have the condition, according to a new study¹.

The tool, called the Autism Diagnostic Interview-Revised (ADI-R), is a 93-item questionnaire that caregivers fill out. It is often used with another test, called the Autism Diagnostic Observation Schedule (ADOS), that clinicians complete. Results on the two tests usually agree, but children who score high on the ADOS sometimes score low on the ADI-R.

The study provides a possible explanation for this mismatch: Some parents do not recognize autism features in their children, or do not consider them to be problematic.

“There’s huge variation in how much parents are aware of the social deficits associated with autism,” says senior investigator **Catherine Lord**, director of the Center for Autism and the Developing Brain at New York-Presbyterian Hospital. Lord is co-creator of the two tests.

The findings drive home the importance of using multiple tools when diagnosing autism, says **Fred Volkmar**, director of the Yale Child Study Center, who was not involved in the study. “And regardless of which instruments you use, you have to have good clinical judgment,” he says.

Test mismatch:

Lord and her team worked with 697 toddlers aged 35 to 47 months whose parents agreed to autism screening, in many cases because the children showed some signs of behavioral or language difficulty. The children are all participants in the **Norwegian Mother and Child Cohort Study**, which follows more than 100,000 women and their children, starting when the children are in utero.

Separate groups of researchers administered the ADI-R to parents and filled out the ADOS. Afterward, a larger team of clinicians used the results, along with additional assessments, such as a physical exam and an expert's evaluation of the child's behavior, to diagnose each child.

The researchers excluded 16 toddlers already diagnosed with autism-related syndromes or who have severe sensory or motor impairments. Of the remaining 681 toddlers, 66 received a diagnosis of autism, pervasive developmental disorder-not otherwise specified or **Asperger syndrome**. (The latter two are not offered as diagnoses in the United States, but are still in use in Norway.)

About half of the remaining children were diagnosed with another condition, such as a language disorder or attention deficit hyperactivity disorder. The other half did not meet the criteria for any condition. The findings were published 22 June in *Autism Research*.

The ADOS results generally agreed with the clinicians' assessments. But when the team looked closely at the ADI-R data, they found an important distinction in how well that tool performed.

Among 48 toddlers whose parents reported being concerned that their child could have autism, 26 children received an autism diagnosis. The ADI-R correctly flagged 22 of these children, or 85 percent.

Among 400 children whose parents did not suspect autism, 37 received a diagnosis. But the ADI-R flagged only 21 of them (57 percent). In other words, clinicians would have missed 43 percent of the children with autism if they had used the ADI-R exclusively to make a diagnosis.

Keeping score:

Toddlers with autism who screened negative on the ADI-R generally have better intellectual and verbal abilities than those who screened positive, the researchers found.

Parents who are not concerned that their child has autism may be more likely to ascribe certain features of the condition, such as a **lack of eye contact**, to shyness or immaturity, the researchers say.

"If you've never really thought about autism, there are really subtle things that we [clinicians] all recognize but parents would not automatically think about," says **Connie Kasari**, professor of human development and psychology at the University of California, Los Angeles, who was not involved in the study.

The findings may help to explain why studies comparing the ADOS and ADI-R in the U.S., where autism awareness is relatively high, find better agreement than those in other countries.

Researchers should explore ways to adjust clinical tools to account for parental awareness and

other factors that skew screening test results, says **Donald Oswald**, director of diagnostics and research at Commonwealth Autism, a nonprofit organization based in Richmond, Virginia, who was not involved in the study. “The prospect of such an undertaking is daunting,” he says, “but progress in this area could have a substantial payoff in terms of improved utility of parent-report and parent-interview instruments.”

In the meantime, Lord and her colleagues recommend using multiple screening measures. They are revising the ADI-R to incorporate parental concern as a factor, and may adjust the scoring system for children whose parents are not concerned about autism.

REFERENCES:

1. Havdahl K.A. *et al. Autism Res.* Epub ahead of print (2017) **PubMed**