

VIEWPOINT

Listening to parents can curtail autism's diagnostic odyssey

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Those in the medical field struggle to screen and diagnose autism. Our standardized screening tests are not perfect: They often **erroneously flag children** who turn out not to have autism and **miss many of those who do**. What's more, there are far **too few autism specialists** to evaluate all those suspected of having the condition. As a result, many autistic children and their families find themselves **waiting a long time** — sometimes even years — for an autism diagnosis.

Fortunately, there may be a simple way to address the problem: surveys that ask parents about their impressions of their child's behavioral problems.

Parents often already complete such surveys — they are a part of the litany of forms families fill out during their quest to see a specialist. These forms ask parents about their child's autism traits, challenging behaviors and ability to perform daily tasks, something known as adaptive functioning.

In a new study, we found that paying attention to some questions on these forms can help make autism screening more accurate and could get children diagnosed and in therapy sooner¹.

The questions concern behaviors known collectively as 'emotional and behavioral problems.' These problems include attention difficulties, aggression and excessive worry or anxiety.

The presence of these problems in a child can confound how a parent describes the child's autism traits on screening tools, research shows^{2,3,4}. Much of this prior work, however, focused on children who already had an autism diagnosis — another factor that can influence how a parent responds to autism screening questions.

We examined how the presence of emotional and behavioral problems may affect how parents fill out a screening tool for their first time.

Survey says:

We analyzed the autism screening results of 115 children, all 18 to 30 months of age, who had been referred to any of three clinics for an autism evaluation. To aid in the triage process and diagnostic differentiation, these clinics had parents fill out a widely used autism screening tool called the **Modified Checklist for Autism in Toddlers** (M-CHAT-R/F). Parents also completed the Child Behavior Checklist (CBCL), an established survey of emotional and behavioral problems, prior to their child's evaluation by experienced autism specialists.

We explored how emotional and behavioral problems impacted the M-CHAT screening results. As we suspected, the parents who reported frequent externalizing behaviors, such as aggression and overactivity, on the CBCL tended to also report high levels of autism traits on the M-CHAT. As a result, twice as many children who have these behaviors as those who do not crossed the screener's threshold for autism.

When we excluded children with externalizing behaviors, the accuracy of the M-CHAT screening results improved: The test's positive predictive value (the probability that a toddler with a positive screen truly has autism) increased from 69 percent to 87 percent, and the false positive rate dropped from 30 percent to 10 percent. Within this smaller group of children, the traits parents acknowledged on the M-CHAT were more often accurately attributed to autism rather than to emotional and behavioral problems.

This finding presents an opportunity: Combining data from the two screeners, the M-CHAT and the CBCL, creates a more accurate M-CHAT result that could lead to a better triage and diagnostic differentiation. For example, if a child does not screen positive for clinically significant externalizing behaviors on the CBCL but does screen positive for autism on the M-CHAT, our results would suggest that this child has a 'high' likelihood of having autism. Conversely, if a toddler screens positive for both externalizing behaviors and autism, the clinical picture is likely complex and may require further evaluation.

We have since put these results into clinical practice. We have created an automated algorithm that uses an M-CHAT score, along with parent responses to survey questions about their child's language abilities and emotional and behavioral problems, to produce a quantitative score indicating a child's chances of having autism. Toddlers who score high are immediately triaged into a clinic that is able to streamline the evaluation process. The algorithm replaces what was once a time-consuming triage process, which called for a highly trained intake specialist to painstakingly sift through charts and forms. Using it has enabled us to repurpose critical resources while also streamlining the intake process.

Our field is ever challenged to increase efficiency while maintaining best-practice care for children and their families. Like many aspects of healthcare, the field of autism seeks to leverage technology, including automated intelligence and telehealth medicine, to expedite screening and

diagnostic services. As we write this, the world is experiencing an unprecedented pandemic of coronavirus disease. The situation has forced clinicians to think even more creatively about how to continue to provide excellent patient care, including conducting evaluations, in nontraditional ways. We would like to challenge clinicians to think more broadly about the information they collect prior to evaluations and to examine whether other creative opportunities might exist to expedite diagnosis and access to therapies.

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