

NEWS

# Web-based autism screening service raises a host of concerns

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Neurona Health, a company in San Francisco, California, began marketing a web-based autism screening service last week that purportedly helps parents determine their child’s chances of having autism. The service — which costs \$299 annually and is not covered by health insurance — includes a genetic test, an autism screening questionnaire and telehealth visits (the company is currently offering a lower price for initial customers).

But experts say the genetic test may not be clinically useful, and the screening questionnaire is already a standard part of well-child visits.

The startup launched its website in 2021 with the promise of a polygenic score that parents could use to determine the likelihood of their child having autism. But **Neurona Health** walked back on that promise and instead began offering polygenic testing for other traits, such as anxiety or loneliness — while still marketing the platform as an autism screening tool — after *Spectrum* started reporting on the company this year.

“The site is written like a business,” says **Lisa Shulman**, director of autism clinical services at the Children’s Evaluation and Rehabilitation Center at Montefiore Medical Center in New York City, “with the top page being ‘Three Simple Steps to Keep Your Child Safe’ — that is quite an umbrella statement for this endeavor.”

Ross O’Hagan, a fourth-year medical student at the Icahn School of Medicine at Mount Sinai in New York City, co-founded the company with some of his student peers in August 2021. He says he decided to create it after observing a few cases of children receiving an autism workup “a bit

later than is really necessary,” delaying opportunities for early intervention. Neurona Health's website says its service “helps identify children at risk for ASD and allows for early intervention if necessary.”

Neurona Health released the service on 12 March, and there were about 400 families on the waiting list, O'Hagan says.

“We have people who are parents of people in the autism community; we have people who have family history; we have people who don't have family history but have other different statuses with neurodiversity, as well as people who aren't really impacted in any way but think that this platform might be valuable,” O'Hagan says.

When parents sign up for the service, the company mails them a kit to collect a cheek swab from their child. The company extracts DNA from that sample, sequences the child's entire genome and calculates various polygenic scores.

“We want to ensure that our messaging around [polygenic scores] is clear and interpretable before delivering a score for autism,” O'Hagan told *Spectrum* in an email.

With the scores in hand, parents meet via telehealth to discuss the results with a **board-certified behavior analyst** (BCBA), a therapist certified to provide an autism therapy called **applied behavior analysis**. The BCBA also collects demographic data and the family's medical history and, if the child is under 30 months of age, administers a 20-question autism screen called the Modified Checklist for Autism in Toddlers.

Four to six weeks later, the family meets with a BCBA again to take a video-based autism screening test called **TELE-ASD-PEDS**. During that 15-to-30-minute session, the BCBA evaluates levels of interactive play, imitation and joint attention between the parents and child, as well as the child's restricted interests and **repetitive behaviors**.

Based on the results of all three tests, the BCBA's deem some children to have an increased chance of having autism and advise that they see a diagnostic specialist.

Experts question the usefulness of Neurona Health's service, saying that its polygenic scores cannot make accurate predictions for individuals.

“The polygenic risk, when you apply it to a group, has an explanatory power, but when you apply it to an individual and say, ‘Well, your polygenic risk score is x, and therefore your risk is y,’ there are broad margins of error around that,” says **Jacob Vorstman**, associate professor of psychiatry at the University of Toronto in Canada.

A large population-based study **calculated polygenic scores for autism** in a Danish cohort in

2019, for example, and found that individuals who score in the top 10 percent have 2.8 times higher odds of having autism compared with those in the bottom 10 percent.

Those odds don't translate to a substantially increased chance of autism in an individual, Vorstman says, considering the prevalence of autism in the general population is only about 1 percent.

"Roughly speaking, if you identify this subset of individuals with the highest risk and go from 1 percent to, say, 3 or 4 percent, that is not a hugely high risk. So what do you do with that?"

Vorstman also cautions against having BCBAs, who are not trained genetic counselors or licensed to diagnose autism, relay genetic information to parents.

"There are a lot of risks involved with disclosing and communicating genetic risk. It is not necessarily only good — are they ready to discuss that and provide the necessary follow up?" he says.

Also, the polygenic scores are based on studies conducted primarily in populations with European ancestry, so the results may not translate to those of other backgrounds, Vorstman says.

"That's a limitation in the field as a whole, and it isn't unique to our approach," says Neurona Health co-founder and chief executive officer Ishan Paranjape. His end goal, he says, is to increase the diversity of his patient population and build larger datasets to improve the performance of genetic testing.

The Neurona Health team conducted outreach to family members, friends, medical colleagues and autistic people in the "low hundreds" to formulate the company's premise, O'Hagan says.

"They understand that it is not diagnostic and does not paint the full picture," he says, but "enjoy every data point they can have, especially if they are concerned."

And the additional resources and support Neurona Health offers, such as biannual meetings with a BCBA, can also increase equity in early intervention and diagnosis of autism, O'Hagan says.

Developmental telehealth monitoring for high-risk children could help parents understand their child's behavior while they wait on a diagnosis, Shulman says. Yet ideally, such additional monitoring should be folded into regular pediatric care, and not something parents pay for out-of-pocket. And there are existing companies already working to **support health-care providers** through telehealth monitoring programs, she says.

"The kind of parent I can see doing this is a parent with resources," she says. "Not everybody has access to [pediatric care]. I know that. This is a poor substitute for that. And that money is not

nothing. It's not a bargain for many families.”

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