DEEP DIVE

Revealing autism's hidden strengths

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19 DECEMBER 2018

Working as a clinical neuropsychologist in a Montreal hospital a decade ago, **Isabelle Soulières** routinely administered tests of cognitive ability to autistic children. And the children routinely stumbled on questions she knew they should be able to answer.

For instance, to test if a child understood the word ‘dog,’ Soulières would ask him to point at a dog in a series of four pictures. But the autistic children she worked with, many of whom were minimally verbal, just stared at her or looked away — even when the parents insisted their child knew what a dog was. To test the children’s memory, Soulières would show a picture of one clown, then one of two clowns, and ask the child to identify the familiar clown in the second picture. One autistic girl she recalls didn’t point to either clown as many of her peers did — but then went on to demonstrate that she had an excellent memory, reaching into a drawer for a toy she had played with two weeks earlier.

After several months of this frustrating exercise, Soulières came to a simple conclusion: Some children with autism understand far more than they can say with words or show with gestures, and they are mistakenly thought to have low intelligence. “We know that they have these abilities, but we cannot get the answers from them,” says Soulières, now professor of psychology at the University of Quebec in Montreal, Canada.

Many clinicians and families share that idea, bolstered in part by high-profile stories in the media. Tito Mukhopadhyay, for example, is a 29-year-old nonverbal autistic man who has authored three books by way of a controversial technique called the ‘rapid prompting method’; his mother, Soma Mukhopadhyay, is credited with inventing the method to try to tap his latent language skills. Similarly, 22-year-old Ido Kedar speaks only a few words but writes a blog by typing on a tablet. He first learned to communicate using rapid prompting at age 7, his mother says.

Skeptics **question this method** and whether what these men write reflects their own thoughts. Regardless, over the past decade, research has confirmed that some autistic people — especially those who **speak few or no words** — have abilities that standard tests of intelligence **underestimate or overlook**.

The consequences extend far beyond problems of miscommunication: “Not being able to

communicate your knowledge or being treated like you do not understand things that you do would be extremely frustrating," says **Vanessa Bal**, Karmazin and Lillard Chair in Adult Autism at Rutgers University in New Jersey. "I think this could lead to depression and decreased life satisfaction."

It may also limit autistic children's access to treatments that would best help them navigate the world. "These kids who we think are very low functioning, very nonverbal, may have more going on upstairs than we're giving them credit for," says **Charles A. Nelson**, professor of pediatrics at Harvard University and Boston Children's Hospital. "But if we thought they had higher potential, maybe we could develop better interventions."

Misleading test results may also skew our understanding of autism itself. For example, studies often match autistic participants to neurotypical controls using intelligence quotients (IQ), measured through tests such as those Soulières administered. "If you get the IQ wrong, your IQ-matched group won't be accurate," Soulières says. And because researchers cannot get reliable data from individuals with severe autism, they often exclude them from their investigations. "I think most people dodge it by not studying kids at that end of the spectrum," Nelson says. "This is a big problem."

Some scientists have, over the past five years, been developing tests to assess the cognitive potential of people who are minimally verbal or need high levels of support. Some are adapting existing tests to make them more engaging and easier for autistic people to complete. Others are looking to techniques such as **eye tracking** and brain imaging to reveal hidden abilities. The results are preliminary, and the tests, many of which rely on unwieldy technology, may never be widely available. But they might still provide clues to autism and why some people with the condition struggle to speak.

Test battery:

There are a variety of reasons, none of them having anything to do with ability, for why an autistic person might do poorly on a standardized test.

In a **2015 blog entry**, Kedar describes his experiences with vocabulary drills. He recalls that an evaluator laid out an array of picture flash cards on the table and asked Kedar to point to certain pictures. "My mind might be screaming, 'Touch tree! Don't touch house!' and I would watch, like a spectator, as my hand went to the card my hand, not my brain, wanted," he writes. "And down in the data book it would be marked that I had not yet mastered the concept of tree."

Many autistic people similarly say they have poor voluntary control over their movements. A test's setup, the test-taker's **anxiety** or problems with attention can also interfere with the results.

Most IQ tests are administered verbally in a one-on-one setting. That setup may be difficult, if not impossible, for some autistic people due to their social-communication challenges. Restricted interests characteristic of autism can also affect test performance. For instance, if an autistic person is asked to define the word ‘telescope,’ and astronomy happens to be her special interest, she may talk at length about what she can see through a telescope without ever explaining what a telescope is. “You never get to the point of saying the key elements of the definition I’m looking for, so you may not actually get credit,” Bal says.

Even for tests that can be administered nonverbally, the test-taker usually needs to be able to understand or perform complex gestures such as pointing, something else that’s often difficult for people on the spectrum. Many evaluators don’t have the training to help minimally verbal people with autism work around such challenges.

Assessments of cognitive ability also typically take 45 minutes to an hour to complete, too long for autistic people with attention problems and hyperactivity to stay focused. Many lack the motivation to complete the tests in the first place. “You have to motivate them to do the tasks, and the tasks we have that measure cognitive ability are often boring,” says **Beth Slomine**, a neuropsychologist at the Kennedy Krieger Institute in Baltimore. As a result of all of these factors, she says, “the tasks don’t always measure what we think they’re measuring.”

There is no consensus among experts on which tests are best to use with autistic people, especially those who are minimally verbal. Popular options include the Wechsler Intelligence Scale for Children, the Mullen Scales of Early Learning, the Leiter International Performance Scale and Raven’s Progressive Matrices, but researchers agree that none is a particularly good fit.

“These kids who we think are very low functioning may have more going on upstairs than we're giving them credit for.” Charles A. Nelson

There is also confusion over how to interpret the tests’ scores. IQ tests typically calculate an individual’s score by comparing her performance against hundreds, if not thousands, of randomly selected people of about the same age. Most designate the average score as 100, with 95 percent of the population scoring between 70 to 130. If an autistic person struggles to complete a test appropriate for her age or scores so low that it’s not plausible, the administrator may try a test designed for a younger age group. This strategy yields an age equivalence rather than a standard score: For example, a 19-year-old man who completes a test for school-age children and receives an age equivalence of 10 has performed similarly to the average score for a representative sample of 10-year-old children. Researchers often divide this age equivalence by chronological age and multiply the result by 100 to yield something called a ratio IQ score.

The ratio IQ for the 19-year-old would be roughly 52. But it's entirely unclear what that number means. "Is that 50 ratio IQ the same as a 50 standard score on a test for adults?" Bal says. "It's an open question."

The eyes have it:

Technology could help make cognitive tests for autistic people less demanding and, perhaps as a result, more accurate. Last year, Nelson and his colleagues adapted parts of the Mullen Scales of Early Learning, a standardized test of cognitive, linguistic and motor abilities typically given to children up to age 6, for minimally verbal children by using an eye-tracking device and altered instructions.

The team administered their modified **version of the test** to 47 girls with **Rett syndrome**, aged about 2 to 11. Rett syndrome is a rare condition characterized by intellectual disability and often autism; girls with the syndrome have fine-motor difficulties and are minimally verbal. Although the Mullen is untimed, clinicians usually allow no more than 20 seconds for each of the test's 159 items. In this case, though, the testers gave the girls up to one minute to respond to each item. They also adjusted some of the questions: In the conventional test, an examiner assesses a child's understanding of gestures and commands by holding out his hand and telling the child to pass him a nearby toy. In the adapted version, the examiner instead outstretches his arms and says, "Give me a hug," — which is physically easier for a child with Rett syndrome to do.

For a subset of the girls, Nelson and his colleagues also adjusted some of the test's items so that an eye-tracking device could help assess the children's responses. For example, on one item, an examiner typically gives a child a set of crayons, names a color and asks the child to point to the corresponding crayon. The team replaced the crayons with colored pieces of paper and monitored the girls' gaze as particular colors were named.

As expected, the girls performed poorly on tests of fine-motor skills and expressive language. But with the adaptations in place, some of the girls performed better than an average typical child on their understanding of words, pictures and symbols. "They actually looked better than we would have thought," Nelson says.

A team at Boston University has also used eye tracking to measure word comprehension in minimally verbal people with autism. In a 2016 study, the researchers asked 19 people with autism, aged 5 to 21 years, to view a series of two pictures side by side on a screen; 2.5 seconds after each pair of pictures appeared on the screen, the participants heard a recording that said, "Look!" followed by a word that matched one of the images. An eye-tracking device measured the amount of time the participants looked at either picture; the researchers interpreted more time spent looking

at the picture that matched the word as a sign of word comprehension.

The test avoids any direct interactions between the researchers and the participants, which may have made it less stressful for some of the participants. In between pairs of pictures, the researchers showed participants colorful pictures of an animated train called Thomas the Tank Engine or 10-second cartoon clips of rockets launching and fish swimming. “We did that to keep them engaged, to keep them looking — [so that] it doesn’t feel like a test,” says lead investigator **Helen Tager-Flusberg**, director of Boston University’s Center for Autism Research Excellence.

The study revealed that the participants’ eye movements were not random and that some of them had understood the words spoken. Their performance also tracked with their scores on other tests of word comprehension, including a conventional pointing-based vocabulary test involving flash cards, and a checklist on which their parents indicated the words they know. But the results were not always consistent. The participants saw each image twice — once when it matched the word and once when it didn’t — and only some performed correctly on both.

An Israeli team is also using eye tracking to test word comprehension, but their approach doesn’t require autistic people to control their movements. The team focuses on involuntary eye movements called microsaccades — tiny flicks of the eye as it jumps toward something of interest. They also look to see if these eye movements stop when an individual looks at something familiar. “Maybe the involuntary, the hidden things — the little movements of the head or the eyes and so on — will show the correct responses,” says lead researcher **Yoram Bonneh**, associate professor of vision science and optometry at Bar-Ilan University in Ramat-Gan, Israel. Bonneh says he became interested in this approach after learning about Mukhopadhyay and Kedar.

In one set of experiments, Bonneh’s team provides participants with a word (either spoken or shown on a screen), followed by a pair of side-by-side pictures, only one of which matches the word. An eye tracker monitors the participant’s microsaccades toward a picture as early as 200 milliseconds after its appearance, and it interprets those rapid eye jumps as an indication of comprehension. Preliminary results from three typical toddlers hint that the approach can accurately measure language abilities. Nonverbal autistic adults seem to perform as well as typical adults on this test. The team is assessing minimally verbal autistic children.

In another experiment, participants see a multiple-choice question on a computer screen, along with a series of possible answers; a highly sensitive eye tracker measures whether the eyes freeze briefly on the correct answer. Preliminary results suggest that the approach accurately measures cognitive abilities, Bonneh says. His team has used the technique to test a group of minimally verbal men with autism who were presumed to be illiterate; they found that most of the young men can, in fact, read.

Passive signs:

Some autistic people cannot complete even these modified forms of intelligence tests. For them, scientists are investigating a number of entirely passive ways of detecting their understanding. Researchers at Rutgers University-Newark, for example, are exploring the use of electroencephalography (EEG). In a 2016 study, they recorded electrical activity in the brains of 10 minimally verbal children with autism, aged 3 to 7, and 10 matched controls, all fitted with electrode caps. The children watched a series of images; half a second after each image, they heard a word that sometimes matched it.

The researchers looked for telltale patterns of brain activity that reflect the extent to which an individual recognizes the pictures and associates them with the correct words. In the auditory cortex, a brain region that processes words, both groups showed a peak in activity, called the auditory P1, about 100 milliseconds after they heard a word. And in the visual cortex, which processes images, both groups again showed a brief spike in brain activity, called the visual P1, about 150 milliseconds after each picture appeared. Both spikes occurred slightly later in the autistic children, indicating that sensory processing is in place, albeit slightly delayed.

“These very early perceptual processes were fairly intact,” says **April Benasich**, director of the Infancy Studies Laboratory at Rutgers University-Newark, who led the study.

Benasich and her colleagues saw more significant differences arise later in the sensory processing, however. In the visual cortex, the control group showed a longer-lasting boost in brain activity, called the positive slow wave, about 350 milliseconds after an image appeared. This wave is thought to reflect the brain’s attempt to call up memories related to an image, and it indicates more complex visual processing. The autistic children did not show this wave, suggesting that their brains may not connect the pictures they see to related information.

The controls also showed a large change in brain activity, called the N400, about 400 milliseconds after hearing a mismatched word. This response is thought to indicate the brain’s attempt to make sense of an unexpected or inappropriate word, and it is often taken as a sign of speech comprehension. Some of the autistic children showed less of a difference in the N400 after hearing a mismatched word versus a matching one. The smaller gap suggests that their brain has trouble relating the pictures they see to the words they hear, or that they simply do not understand the words. Alternatively, they may use other parts of the brain to process the information. “Even though they don’t look like typical children in the way that they’re processing the information, they may be actually putting it together but using very different parts of the brain and pathways,” Benasich says.

These differences might help researchers understand why some autistic children do not speak. “For some of these kids not showing a robust N400, maybe that is the reason why they’re not understanding or producing language,” says **Charlotte DiStefano**, clinical instructor in psychiatry

and biobehavioral sciences at the University of California, Los Angeles. “For other kids who do have an N400 but still aren’t talking, it must be a different reason,” she says. “There are probably a lot of different types of impairments that lead a child to be minimally verbal.” DiStefano was not involved in the 2016 study but has found similar, unpublished, results in 20 minimally verbal children with autism.

Kedar says his inability to speak more than a few words may be due to apraxia, a disconnect between speech plans in the brain and the motor plans needed to execute them. He was almost 7 before his mother, Tracy, first recognized how much he understood. The two were writing out invitations to his 7th birthday party — with her hand over his on the pen. She was spelling out loud every letter he should write. At one point, she noticed that she had omitted a word. Before she could tell her son, though, she says she felt his hand moving the pen to write the missing letters. “That’s when it hit me that he had it right, and that he had understood everything all along,” she says.

An alternative cognitive test, using eye tracking or EEG, might have identified Kedar’s hidden language abilities sooner. But before such tests replace standardized ones, researchers would need to validate their results with hundreds, if not thousands, of people. That may be tricky because the techniques are more expensive and less portable than traditional cognitive tests, says **Aaron Kaat**, research assistant professor of medical social sciences at Northwestern University in Chicago. Kaat is part of a team that has created a series of tests of cognitive and other abilities called the **NIH Toolbox** for tablets. The toolbox is being validated in people with Down syndrome, intellectual disability and an autism-related condition called **fragile X syndrome**. It is designed to be used even outside the confines of a lab.

Given the concerns the eye-tracking and EEG studies raise about the inaccuracy of conventional intelligence tests, some researchers say it is imperative to develop techniques for testing cognitive abilities in autistic people. That might be the only way to reach children who can understand language and read, but who cannot communicate. “Not everybody agrees what we should do,” Soulières says, “but at least we [should] be aware of the potential problem.”