

NEWS

Long-term studies track how autism changes with age

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Autism is a lifelong developmental disorder, but paradoxically most studies of the disorder are cross-sectional: They provide only a snapshot of what it looks like at a single point in time.

There are good reasons for this. Following individuals with autism over long periods of time can be expensive and require enormous effort on the part of both the families and the researchers.

Still, it's the only way to understand what early-life factors help some children with autism do better than others over the long term, something that cannot be assessed in cross-sectional studies.

A handful of long-term studies, each including up to several hundred participants, have now followed people with autism for close to two decades. As the children in some of these studies come of age, researchers are piecing together the disorder's trajectories.

For instance, one of the largest studies has followed about 300 children from age 2 to 21, and has found that about ten percent of children improve dramatically by their mid-teens. Another 80 percent of the children have symptoms that are **remarkably consistent over time**.

"We were surprised that such a high proportion of the kids' trajectories were stable," says lead investigator **Catherine Lord**, director of the Institute for Brain Development at New York-Presbyterian Hospital in New York City. "I would have expected more of them to improve, and I would have expected more variability from year to year."

Meanwhile, a crop of smaller, more targeted longitudinal studies of autism, the result of a surge of interest in this type of study design about a decade ago, is also beginning to bear fruit.

"It's taken the field really until the last ten years to **invest the time and effort** into conducting longitudinal studies," says **Tony Charman**, chair of clinical child psychology at King's College

London in the U.K. Charman is part of a research team that has followed a group of about 170 people with autism from age 12 to 23, and some of them beginning at age 2.

Varied vectors:

Thanks to new statistical techniques, scientists can now group their study participants based on shared characteristics that unfold over time¹. Lord's team used this approach to divide the children in her study into four groups, based on the trajectory of their symptoms from age 2 to 15 years².

The small proportion of children who improve tend to both start out with a high verbal intelligence quotient (IQ) and improve their verbal skills early on. This is in line with other studies suggesting that language skills and IQ are the **strongest predictors** of a child's outcome.

Studies that focus on more cognitively able children may help researchers to home in on more specific predictors of outcome, says **Elizabeth Pellicano**, professor of psychology and human development at the University of London.

For example, Pellicano assessed cognitive skills in 37 children with autism and average IQ. She found that children between 4 and 7 years of age who have the strongest executive function skills — required for planning and carrying out complex tasks — also have the strongest **theory of mind**, or ability to understand others' thoughts and beliefs, three years later³.

The study suggests that improving executive function skills in children with autism may also yield benefits for theory of mind, Pellicano says.

Another longitudinal study, conducted by researchers in Canada, tracked 39 children with high-functioning autism or **Asperger syndrome** from about age 4 to age 19. Analysis of some of the data suggests that building theory of mind skills may help children who start out with poor language skills overcome their deficits⁴.

These findings are typical of the way researchers are using longitudinal studies to parse how changes in one area of development influence another. "That gives us clues with respect to leverage points for intervention," says **Alice Carter**, professor of psychology at the University of Massachusetts in Boston, who was not involved in the studies.

Carter's own work tracked 170 toddlers with autism, assessed at three annual visits starting between 18 and 33 months old. Her team found that children who show more sensory sensitivity as toddlers are more likely to have anxiety as preschoolers⁵.

Data from longitudinal studies also reveal how the interplay between children with autism and their families or their environment can influence how they fare.

For example, an unpublished analysis of Carter's data shows that a 'responsive' parenting style — meaning that parents are attuned to what a child is paying attention to and often join in — has benefits for children with autism. The children of these parents show greater gains in language skills, Carter's team found.

Parental engagement:

Lord's study has yielded similar data: One analysis showed that children whose parents are more engaged in their treatment early on have better verbal and daily living skills as teenagers⁶. Lord also has unpublished data showing that the children with the best outcomes — who were able to attend college with no extra support — all had parents who had been involved in their treatment beginning at age 2, Lord says.

Because of the small size of most longitudinal studies, it's especially important for this sort of validation from multiple studies, Lord notes.

Both researchers caution that this should not be interpreted as assigning blame to parents if their children do poorly. But the results do suggest that it's important to involve parents in interventions for autism. Also, Carter adds, "Longitudinal studies are critical for trying to learn more about the kinds of supports parents really need over time."

One of the other surprises to have emerged from longitudinal studies is the relative ease of the teen years.

"We anticipated that adolescence would be a time of great difficulty, but in fact it's a time of behavioral and symptomatic improvement," says **Marsha Mailick**, director of the Waisman Center on Mental Retardation and Human Development at the University of Wisconsin, Madison. Mailick leads a longitudinal study of autism in adolescence and adulthood that includes more than 400 families of people with autism, who were age 10 or older when the study began in 1998.

However, this improvement slows down around the time that the teens leave high school⁷. That may be in part because the structure and routine of school is beneficial for people with autism, she says. Teens with autism also frequently **lose access to services** around the time they finish school.

As adults, Mailick has found, many people with autism are able to hold down jobs, but few have **opportunities for career advancement**. Although many adults with the disorder have a stable place to live, only about five percent **live completely independently**.

On the other hand, Mailick says, "Having a full-time independent job and living in one's own place is not necessarily the only metric or the only way to think about quality of life." Mailick says she hopes to continue the study for as long as possible, to find out how people with autism fare as they

age.

Lord echoes those ideas. “We just haven’t figured out,” she says, “how to represent in the scientific literature [that] there are young people who have minimal verbal skills who do lead, at age 19 or 21, quite happy lives.”

References:

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