

## Autism study finds later diagnoses for girls, high rates of co-occurring disorders

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Quinn, an autistic boy, and the line of toys he made before falling asleep. Repeatedly stacking or lining up objects is a behavior commonly associated with autism. Credit: Wikipedia.

A new study analyzing the first 1,000 participants in the Rhode Island Consortium for Autism Research and Treatment (RI-CART) identifies key trends in the presentation and diagnosis of autism spectrum disorder. The study was published in *Autism Research* on Monday, Jan. 20.

The first finding was that girls with [autism](#) receive a [diagnosis](#), on average, nearly 1.5 years later than boys. This is likely because parents and clinicians tend to notice language delays as the first sign of autism, and girls in the study exhibited more advanced language abilities compared to boys, said study authors Stephen Sheinkopf and Dr. Eric Morrow.

Autism is far more common in boys. The RI-CART study found more than four times as many boys as girls with autism; however, given the large size of the sample, the study was well-powered to evaluate girls with autism. The finding that girls with autism are diagnosed later is clinically important, said Morrow, an associate professor of molecular biology, neuroscience and psychiatry at Brown University.

"The major treatment that has some efficacy in autism is [early diagnosis](#) and getting the children into intensive services, including behavioral therapy," Morrow said. "So if we're identifying girls later, that may delay their treatments."

Sheinkopf, an associate professor of psychiatry and pediatrics at Brown, emphasized the importance of early recognition.

"We need to think about how we can improve recognition of autism in individuals—including many of these girls—who don't have the same level of primary language delay but may have other difficulties in social communication, social play and adapting to the social world," he said. "And as we improve diagnosis for the full range of individuals in the early years, we must also rethink early interventions to make sure they're designed appropriately for children who might need assistance on more nuanced elements of social adaptation. We need to refine treatments so they cater to individual needs."

Based at Bradley Hospital in East Providence, the team behind RI-

CART represents a public-private-academic collaborative—a partnership between researchers at Brown, Bradley Hospital and Women and Infants—that also involves nearly every site of service for families affected by autism in Rhode Island. The study team also integrated members of the autism community, family members and particularly the Autism Project, a family support service for autism in the state.

By engaging both the community and treatment providers, the study enrolled more than 20 percent of pediatric-age individuals with autism in Rhode Island. Participants were recruited from all geographic regions of the state, and as part of the study, they were given rigorous in-person assessments.

Most participants had received an autism diagnosis prior to entering the study (a community diagnosis), and their diagnosis was subsequently confirmed by an in-person assessor, meaning that they also received a research diagnosis. The study also included individuals whose diagnoses were less clear cut. For example, some individuals received either a community diagnosis or a research diagnosis, but not both. Other individuals were referred to the study but did not have evidence of autism from either a community evaluation or the research assessment.

"The group that was diagnostically less clear-cut represents the complexity that clinicians encounter on a daily basis, so it's a realistic sample in that sense," Sheinkopf said. "This full range of heterogeneous autism presentation is rather unique to our study."

The other major finding of the study was that people with autism frequently exhibit co-occurring psychiatric and [medical conditions](#).

Nearly half of the participants reported another [neurodevelopmental disorder](#) (i.e., attention-deficit/hyperactivity disorder (ADHD) or intellectual disability), while 44.1 percent reported a psychiatric

disorder, 42.7 percent reported a neurological condition (i.e., seizures/epilepsy, migraines, tics), 92.5 percent reported at least one general medical condition and nearly a third reported other behavioral problems.

"These co-occurring conditions need also to be a focus of treatment for patients," Morrow said.

"Many people with autism need support for the psychiatric and emotional challenges that are prevalent in people who share this one diagnosis," Sheinkopf added. "These are clinically complicated individuals who deserve strong, sophisticated, multidimensional, multidisciplinary care."

Sheinkopf and Morrow say they're encouraged by the support and collaboration of a variety of health care providers, community members and particularly, by the level of commitment shown by the families who participated in the study. Going forward, they're hopeful that the RI-CART registry will lead to more studies that will improve the lives of people with autism and their families, particularly because the cohort currently involves such a wide age range of participants, including individuals with autism ages 2 to nearly 64.

"Given that autism is a developmental disorder, the field really needs to focus on longitudinal studies: following people's development and transitions," Morrow said. "I think we're going to learn even more when we follow children from a very young age as they develop, including into adulthood."

**More information:** Carolyn E. B. McCormick et al, Autism Heterogeneity in a Densely Sampled U.S. Population: Results From the First 1,000 Participants in the RI-CART Study, *Autism Research* (2020). [DOI: 10.1002/aur.2261](https://doi.org/10.1002/aur.2261)

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