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For the First Time, a Census of Autistic Adults

By Claudia Wallis

Among the many great mysteries of autism is this: Where are all the adults with the disorder? In California, for instance, about 80% of people identified as having an autism spectrum disorder (ASD) are 18 or under. Studies by the Centers for Disease Control and Protection (CDC) indicate that about 1 in 150 children in the U.S. have autism, but despite the fact that autism is by definition a lifelong condition, the agency doesn't have any numbers for adults. Neither has anyone else. Until now.

On Sept. 22, England's National Health Service (NHS) released the first study of [autism in the general adult population](#). The findings confirm the intuitive assumption: that ASD is just as common in adults as it is in children. Researchers at the University of Leicester, working with the NHS Information Center found that roughly 1 in 100 adults are on the spectrum — the same rate found for children in England, Japan, Canada and, for that matter, New Jersey.

This finding would also appear to contradict the commonplace idea that autism rates have exploded in the two decades. Researchers found no significant differences in autism prevalence among people they surveyed in their 20s, 30s, 40s, right up through their 70s. "This suggests that the factors that lead to developing autism appear to be constant," said Dr. Terry Brugha, professor of psychiatry at the University of Leicester and lead author of the study. "I think what our survey suggests doesn't go with the idea that the prevalence is rising."

In England, where there is widespread suspicion that the childhood vaccine for measles, mumps and rubella has led to an explosion in autism cases, the study was hailed as part of a growing body of evidence that the vaccine, which was introduced in the 1988, is not to blame.

Brugha's study was part of a larger national survey of psychiatric disorders among adults. In the first phase, researchers conducted 90-minute interviews with 7,461 people in 4,000 randomly selected British households; the interview included a 20-item questionnaire designed to screen for autism. (Sample yes-or-no questionnaire items: *I find it easy to make friends. I would rather go to a party than the library. I particularly enjoy reading*

fiction.) Based on their answers in the first phase, investigators further assessed 618 individuals, using a battery of psychiatric measures, including a state-of-the-art autism diagnostic tool. (About 200 of these participants had been selected for scoring high on the autism screen; the rest had been selected to sample for other disorders.) In the second phase, researchers identified 19 adults with ASD. But had they been able to evaluate all 7,461 in the survey, they estimate that they would have found 72 cases, or roughly 1% of the total.

One limitation of the study is its relatively small size, says Brugha. Being the first of its kind, it also needs to be confirmed by other studies. Another issue, notes Richard Roy Grinker, an autism researcher and professor of anthropology at George Washington University, who was not involved in the work, is that the study looked only at adults in the general population. Had it included people living in institutions, which is where the most severely autistic adults are likely to be, the estimated rate of ASD may have been even higher than 1%.

Michael Rosanoff, an epidemiology specialist with Autism Speaks, emphasizes that "the small sample size for estimating prevalence requires caution about interpreting this finding on a population-based scale."

Despite its limits, the new study does begin to fill in the profile of high-functioning adults who are on the spectrum but living in an ordinary home in the community. Researchers found that they are primarily male and unmarried: about 1.8% of men surveyed were on the spectrum — among never-married, single men, an estimated 4.5% had ASD — compared with just 0.2% of women. (Brugha notes, however, that autism screening tools may be poorly adapted for identifying autism in adult females.) People with autism are less likely than average to have finished college but about as likely to be employed. Only 0.2% of adults who had finished college were on the spectrum, but the rate was 10 times higher among those without a high school degree. And, in contrast with people with depression or anxiety disorders, autistic adults were unlikely to be receiving any sort of mental health services.


Why has it taken so long to do a study of this sort? For one thing, you need an enormous sample size — at an enormous cost — to find significant numbers of people with autism. Second, it's more difficult to detect autism in adults than in children. Children often have glaring symptoms, like delays in learning to speak, extreme social withdrawal and terrible tantrums. Less is known about how autism looks in adults. "To diagnose autism, you need to have good information on people's behavior," says Brugha. "It's much more straightforward to get that with children because you've got parents and teachers as observers. Adults with autism are not the best people to describe their own behavior."

The Irish-born psychiatrist and epidemiologist says he sees a lot of adults with ASD in his own clinical practice, and "they have so much difficulty saying what their own difficulties are." He suspects that this lack of insight and inability to communicate emotional issues also reduces their ability to seek professional help.

Efforts to identify and help adults with ASD have lagged far behind efforts to help children. And yet, Brugha notes that just having an ASD diagnosis to explain their troubles can be enormously beneficial to his adult patients, who often struggle with relationships at home and at work because of difficulty reading social cues. "Once you help

them to understand that they are not the only person on the planet who is like this, and help their families understand, it can be a breakthrough. People also have a better chance of staying in their work, if their employer understands why they are the way they are." Moreover, Brughra says it is not expensive to provide services to adults with relatively mild autism. "The cost of treating a child with autism is phenomenally high. We are not talking about this. We are talking about support, helping people adapt their lives" with help from a social worker.

Grinker, who has a teenage daughter with autism, finds the study to be in some ways comforting. "I would think that a study like this would encourage people that children with autism could grow up and have futures that are meaningful and that they are not going to end up in institutions."

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