

With autism numbers rising, how best to provide support?

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Credit: UCSF

Recently released [data](#) from the Centers for Disease Control show childhood autism rates are at their highest level since the CDC began tracking data in 2000. About 2.3% of U.S. children, or one in 44, were diagnosed with autism spectrum disorder in 2018, compared to one in 150 children in 2000. For boys, the ratio rises to nearly one in four.

Autism spectrum disorder (ASD) is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. The disorder is marked by difficulty with communication and interaction with other people; restricted interests and repetitive behaviors; and symptoms that affect the ability to function in school, work, and other areas of life.

While [autism](#) affects all ethnic and [socioeconomic groups](#), people of color tend to be diagnosed less often and at an older age. About one-third of people with autism also have an [intellectual disability](#), and one-fourth have an IQ in the borderline range (between 71 and 85, where 100 is the average).

As Autism Acceptance Month draws to a close, we spoke with autism expert Somer Bishop, Ph.D., an associate professor in UC San Francisco's Department of Psychiatry and Behavioral Health Sciences and the UCSF Weill Institute for Neurosciences, about the latest research regarding autism and life outcomes, and UCSF's approach to care for the neurodiverse population.

Q: Given the rising prevalence of autism, how can health professionals best support children and adults with this disorder?

Autism is a really heterogeneous condition, so it's important for clinicians to know how somebody's autism symptoms manifest when they are thinking about how to help them. And the symptoms will change over time—as a person grows up, one set of symptoms may disappear only to be replaced by another. For example, repetitive motor behaviors might diminish after childhood, but be replaced by anxiety or depression in adolescence or adulthood. Difficulty in social communication, one of the core deficits in autism, can be affected by

lots of individual variables like how old the person is, where they live, what kind of family they come from, and what their IQ or language level is.

This applies to prognosis too—one of the most common questions I get from parents, whether I am seeing a two-year-old or a 20-year-old, is what is going to happen to my child when they grow up? And the answer depends on some things we can predict, and some things we can't. Some of the answer lies in level of language impairment and cognitive difficulties, but not all of it.

So for clinicians to help, they need to know where the biggest challenges are at a given time and help to address them. And that includes helping the individual and their family with coordination of care—because often there are multiple specialists involved—speech therapists, behavior therapists, occupational therapists, neurologist, etc.—and that can be very overwhelming.

Q: What does the research say in terms of adult outcomes for children with autism?

Before I answer that, it's important to understand that much of the adult literature, and [longitudinal studies](#) in particular, is on kids who were diagnosed 30 or 40 years ago, and this is a totally different group than the kids being diagnosed now. Kids have access to different services now, too, so it really limits the conclusions we can draw. What we see in those older studies is pronounced decreases in [repetitive behaviors](#) and certain kinds of social difficulties, but stable impairments in things like nonverbal communication and difficulty with social interactions and friendships.

Existing data also suggest people with autism have much lower than

optimal rates of functional independence as [adults](#), and low rates of traditional adult success milestones such as employment, or ability to live independently or have meaningful social relationships. Many people are surprised to learn that [young adults](#) with autism are less likely to work for pay than adults with intellectual disabilities or learning disabilities, and they are less likely to have activities during the day, like adult day services or school. Nearly 25% of [autistic adults](#) are just at home not doing anything.

Q: How do you explain the fact that autistic adults are less likely than other disabled adults to have daytime activities?

Some of it is that the group of autistic adults who are more capable in terms of language and cognitive abilities often has access to fewer community services in adulthood than those with intellectual disability. Also, this group is very vulnerable to depression—nearly half of autistic adults are clinically depressed, and the rate of completed suicide in autistic adults is 8–10 times that of the general population. Unemployment is a big risk factor for depression in autistic adults, and these adults often have a hard time keeping jobs due to their social impairments.

Q: Is there any room for hope in the face of these grim statistics?

We tend to talk about autism in terms of individual factors, but I think it's time as a field and community that we start to think about all of the things that happen outside the individual, like their family and community sources of support, whether that's support groups, social groups, church, or other things.

One of the most hopeful adult studies in the last 20 years found that half of the autistic adults had good or very good outcomes in terms of active social lives and employment. They were part of a Latter Day Saints community in Utah, so they had a community around them to support them. Social groups or community groups that give people a place to go once a week where people care about you can lifechanging.

So let's get people more hangouts with friends, more social interactions. And at the same time, let's recognize that while quantity may be important to some people, we need to consider what the individual wants in terms of social interaction.

The other thing is that most adults without disabilities have jobs. And when you have a group of people who are very capable in many ways and they don't have gainful employment, how could we not think that this is going to be associated with depression? So we need to think outside the individual about how to get folks employed in a way that is meaningful for them. And even if the job isn't a favorite activity, the act of earning and being able to contribute to your own livelihood can be meaningful. One research study found that autistic adults who worked in high school had higher rates of employment as adults, so looking for opportunities to practice working in high school is good.

Q: How does UCSF approach care for autistic patients?

One of the big problems autistic people face is that, when they age out of the school system and out of the pediatric medical system, their services and treatment often drop off. People talk about it as "a cliff," where suddenly they have no support. At UCSF, we are a lifespan care center, which means we provide care across the life course. So, once someone is getting care at UCSF, we will hold on to them and see them

through, including as adults. That way, we know the care we are giving is quality care when, typically for people with autism, the care is so fragmented. We also help to coordinate the care, which can be a big hassle and strain on families and autistic individuals.

Provided by University of California

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