

Who will care for children with autism when they're adults?

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Limited resources and varying needs present a daunting challenge.

(HealthDay)—The vast majority of youngsters with autism will grow up to be adults with autism.

An estimated one of every 88 children in the United States has an autism spectrum disorder, according to the U.S. Centers for Disease Control and Prevention. That means that 45,000 to 50,000 kids with autism turn 18 each year, says autism researcher Paul Shattuck, from Washington University in St. Louis.

"This is an impending health care or community care crisis," said Dr. Joseph Cubells, director of medical and [adult services](#) at the Emory Autism Center at Emory University in Atlanta. "The services that are available vary from state to state, but often the resources just aren't there."

Public schools are required to provide services to people with an autism spectrum disorder until they reach age 22, according to the National Alliance on Mental Illness. After that, the responsibility shifts to the person with autism and family members to find educational or employment opportunities and appropriate living arrangements.

But experts note that a shortage of necessary programs for adults with autism already exists and is likely to worsen as the increasing number of children who are being diagnosed with autism spectrum disorders grow into adults.

One of the biggest challenges in providing services to people with an autism spectrum disorder is that the needs change from person to person.

"We say autism as if it's a single thing, much like we say cancer," Cubells said. "But, within the general category of things we call cancer are [brain tumors](#), [lung tumors](#), pancreatic tumors, and each requires different treatments. Autism is very individual. It varies from one extreme where someone needs custodial care for their entire life to the other extreme where someone is a highly functional, successful person who may be regarded as being a little quirky," he explained.

"There are some common themes," Cubells said, "but there's really nothing that applies to every single person."

Take higher education, for instance. An older child who's on the higher-functioning end of the spectrum may be able to go to college, but that presents challenges as well.

"There's often a substantial mismatch between verbal skills and performance skills," Cubells said. "You can be highly intelligent and able to do complex math and abstract reasoning, but you don't know how to

ask someone out for coffee. Having to make friends, schedule meals, and get to class without help can be like hitting a brick wall for a lot of people on the spectrum. I often tell people with Asperger's that they have to learn in words what most people learn intuitively."

He said a college's disability services office could be helpful in some cases, as could peer mentorship programs that pair someone with Asperger syndrome, for instance, with someone of the same age who's learned about the condition.

For those who don't go to college, navigating the world of employment can be a significant challenge. Both Shattuck and Cubells said that while some employers might be understanding, and some might even make certain accommodations, what employers are most concerned with is their bottom line—making it all the more important for people with an [autism spectrum disorder](#) to be placed in jobs that match their skills and interests.

A study done by Shattuck and his colleagues found that people on the autism spectrum are more likely to choose a college major in science, technology or math than people without autism. And, these types of careers may be just the ones where people on the autism spectrum find the most success.

"People on the spectrum can focus on the details," Cubells said. "In jobs that would be hideously boring and tedious to most of us, like jobs where you spend hours alone, having a social deficit can be a real strength." And Shattuck pointed out that people with autism aren't likely to waste work time looking at Facebook or socializing with co-workers.

But the overall picture isn't rosy for adults with autism. "A lot of parents describe the transition to adulthood as like driving over a cliff," Shattuck said.

In another study by Shattuck's team, the researchers found that more than one in three adults on the autism spectrum had no engagement in education or employment for the first six years after high school.

Those who are profoundly affected by autism generally end up staying with their families. Expensive, private options are often available but out of reach for many families. Services for housing options or vocational training are "very hit-and-miss," Cubells said. "There's a tremendous need for training about autism in the helping agencies."

For families with children on the autism spectrum, Shattuck said it's never too soon to start thinking about getting the child ready for the transition to adulthood. He suggested starting a conversation with your child's special education team at school during 8th or 9th grade to allow adequate time to investigate available resources.

"A lot of extra thought has to happen during high school to create a positive transition," Shattuck noted.

More information: Autism Speaks offers on its website a variety of [resources for adults with autism](#).

Read about one mother who worries about how her [two sons with autism will be able to handle adulthood](#).

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