

# When children with autism grow old

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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.

In the public consciousness, autism spectrum disorder only affects children. In truth, ASD is a lifelong condition. But how it affects older adults is a gaping unknown in autism research. Now, a new and significant grant from the National Institutes of Health (NIH) will help researchers at San Diego State University understand how the disorder plays out across the lifespan.

"Developmental disorders do not end after childhood," said Ruth Carper, a neuroscientist at SDSU and a co-investigator on the project.

"Development is a lifelong process, and there is a real need to know what happens later in life for people with [autism](#)."

## Young diagnosis

For a variety of reasons, it's a subject sorely in need of study, added SDSU psychologist and principal investigator Ralph-Axel Müller. For one, autism spectrum disorder (ASD) was only recognized as a unique disorder about 70 years ago. Over the years, what we now describe as autism has been referred to as childhood schizophrenia or the catch-all, mental retardation. Only in recent years has medical and public awareness grown to the point where it can be reliably diagnosed.

"It's hard to even find older adults who have been diagnosed with autism," Müller explained. "Diagnostic criteria have changed enormously over the decades."

Another reason is that research and treatment has typically focused on children, Carper added. Part of this has to do with the instinct to protect children, which plays out in research and funding, she said. But it's also because behavioral treatments and interventions seem to work best in young children, making childhood autism a natural research target.

Educational systems also tend to serve as de facto mental health support systems, meaning children who are still in school receive more institutional attention. Once people with autism leave school, their welfare falls to their families and to the California Department of Developmental Services. Many wind up living with family members or in care facilities for the rest of their lives and those who are able to live independently often struggle with employment or social acceptance, but don't qualify for support services.

"Fortunately, there's nothing about autism that shortens the lifespan, as far as we know," Carper said, but this also means that adults with ASD may require care and special assistance for many decades.

It remains completely unknown whether some of them may be at risk for accelerated cognitive or neurological decline later in life. This has been seen, for example, in the case of people with Down syndrome, who almost always develop Alzheimer's disorder as adults, as well as in some people with Fragile-X related disorders.

## **Calls for help**

For years, families and advocates have been calling for more research into older adults with autism so that caregivers can ground their support services in hard data and understand what's happening cognitively and emotionally with their loved ones and patients.

"There's really no literature to guide hypotheses in this area," Müller said.

To that end, Carper and Müller recently were awarded a five-year, \$3.5-million NIH grant to recruit older adults with autism and perform a series of cognitive and neuroimaging studies. In collaboration with scientists and health workers at the University of California, San Diego, and Alliant International University in San Diego, they are seeking to recruit 70 adults between the ages of 45 and 65 with [autism spectrum disorder](#) and an additional 70 control participants.

Using a variety of functional and anatomic brain imaging techniques, the researchers will explore the brain connections of adults with autism to see how they might differ from younger people with the disorder and from adult peers without ASD. They will also give participants assessments of cognitive, social, and language abilities, and measure

their executive functioning, motor functioning and memory. Participants' families and caregivers will respond to questionnaires about their daily living skills.

Though this work is still in its earliest stages, Carper said that people are excited about the research's potential.

"Families are excited that anyone is looking into this," she said. "A lot of them feel like they've been forgotten."

## **Disorder progression**

Even though very little scientific research has been done in adults with autism, there are smatterings of anecdotal reports that suggest certain aspects of the disorder might improve over time. For example, Carper noted, some parents have reported that their children's language abilities continue to improve into older age, as do their social skills. Determining whether these improvements are related to normal aging or the natural course of the disorder could help guide therapeutic and [support services](#) and suggest new avenues of research.

"We don't know what's in the future for these folks," Carper said, "but we know they need support. Understanding the brain mechanisms at work in [older adults](#) with autism can help us improve their lives and the lives of those who care about them."

Provided by San Diego State University

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