

Half of Utahns with autism lead fulfilling lives, follow-up study shows

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Twenty years after first being assessed in a long-term autism study, 41 Utahns with the disorder had a higher social outcome than those in similar studies, University of Utah psychiatry researchers have reported in the *Journal of Autism Research* online.

Although the researchers can't yet explain why the follow-up study showed the Utah group fared better overall in living independently, developing [social relationships](#), and in some cases even showing higher IQs than 20 years ago, the results offer hope for many with a childhood diagnosis of [autism](#), according to Megan A. Farley, Ph.D., the study's first author and a research associate in the Department of [Psychiatry](#) at the U of U School of Medicine.

"This is an amazing group of people who, in many cases, did a lot more than their parents were told they would ever do," Farley said of those who participated in the follow-up study. "This gives a lot of hope for younger people with autism and average-range IQs."

Farley and her fellow researchers drew the follow-up study participants from an original group of 241 Utahns with autism who took part in a University of Utah and University of California, Los Angeles (UCLA), study from 1984-1988. The average age of participants in the original study was 7, while the average age at the follow-up study was 32. Participants in the current study had an average childhood non-verbal IQ of at least 70.

For the follow-up study, the researchers assessed the participants' overall [social outcome](#) by their ability to maintain paid employment, the existence of meaningful social relationships, and their degree of independence in daily life. From these criteria, an individual's overall social outcome was assigned to one of five categories: very good, good, fair, poor, and very poor:

- Very good meant the person held paid employment without extra support to perform job duties, had important social relationships, and a high independence in daily life.
- Good indicated the individual had a generally high level of independence at work and in daily life, requiring some extra support, and also had a friendship or some acquaintances.
- Fair reflected the need for regular support at work or home, but the person did not have to live at a special residential facility. The participants in this category had acquaintances through special activities but no particular friends.
- Poor showed the need for a high level of support, such as a residential living facility and planned daily activities for people developmental disabilities. Those in this category had no friends outside their residential living arrangements.
- Very poor meant the individual required a high level of care in a hospital setting with no autonomy and had no friendships.

By these measures, the researchers found that 24 percent of the participants had a very good social outcome; 24 percent had a good outcome; 34 percent had a fair outcome; and 17 percent were rated in the poor social outcome category. No one's social outcome fell into the very poor category.

About half of the 41 study participants were employed in full- or part-time competitive jobs. Six were living independently, including three who owned homes. Three were married with children, and one person also was newly engaged to be married. Eleven of the participants have driver licenses and the same number had a higher IQ than when assessed 20 years earlier.

"Adults with autism haven't received the attention from researchers that children have, but the few studies that have been done on similar groups showed 15 percent to 30 percent having good outcomes, compared to the 50 percent in our study," Farley said. "One early Canadian study showed similar results to ours, but other studies have had fewer people living and working independently as adults."

Although, Farley doesn't know why the Utah group fared better than those in other autism studies, she thinks it may be related to early intervention to help children with the disorder and strong social and family networks in Utah.

The most important factor in whether study participants had a better living outcome was their degree of independence in daily activities—being able to take care of themselves, hold employment, live on their own or at least semi-independently, and take part in meaningful social relationships, according to Farley. Although IQ significantly influences social outcome, daily independence plays an even greater role in determining how well people with autism function, the researchers said.

Although encouraging, the follow-up study results also show autism's devastating toll. About half the participants could not live or work independently, and the majority lived with their parents, although many of them had a high level of independence in their daily activities. Social isolation is a serious problem as well—44 percent of the group has never

dated. In addition, 60 percent of the study participants, even some of those who had achieved independent living and working, were prone to anxiety and mood disorders and worried about a social stigma attached to autism. The IQ of eight participants declined since they first were evaluated 20 years ago.

The 41 participants in the follow-up originally were identified through a statewide epidemiological survey between 1984 and 1988 conducted by the U of U and UCLA. The goal of that study was to identify every person born with autism between 1960 and 1984 and who lived in Utah during the four-year survey. The survey was one of the largest population-based autism studies in the world, meaning it tried to assess the whole population of Utahns with the disorder rather than a select group. By assessing participants from the original study, the follow-up gives a unique perspective on the long-term course of autism, according to Farley.

The long-term follow-up also will help researchers identify issues that affect the social outcomes of adults who were diagnosed with autism as children, providing information that can help determine services that will help these adults lead more fulfilling lives.

"Our current results have encouraged us to go further in following up the entire sample of 241 adults who were identified with autistic disorder in the 1980's," Farley said. "We now know that, with the help of the remaining adults and their families who are willing to give of their time and energy, we will be able to have a better understanding of the life course in autism. We're excited now to contact all of the families who participated in the original study."

Source: University of Utah Health Sciences ([news](#) : [web](#))

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