Study Titles

- Perceived helpfulness of depression treatments among young adults with ASD
- Depression in Independent Young Adults on the Autism Spectrum: Demographic Characteristics, Service Use, and Barriers

What was the research about?

Previous research suggests that depression is common among autistic adults. Researchers wanted to find out:

- How common is depression in the broader autism community?
- How many people get treatment?
- Are some people more likely than others to get treatment?
- What are the most common barriers to getting treatment?
- Do people feel that treatments are helpful?

How was the research done?

Researchers sent online surveys to independent autistic adults who were enrolled in SPARK. The survey measured participants’ current symptoms of depression. It also asked whether they had been diagnosed with depression in the past, what types of treatments they had received, and how helpful they found the treatments. More than 300 people participated in the two studies.

What did the researchers learn?

- Rates of depression: About two-thirds of the people in the study had been diagnosed with depression in the past. About one-half met criteria for depression when they took the survey. More than three-quarters of people who were depressed at the time of the survey had been diagnosed with depression in the past.

- Women vs men*: The number of people who had current depression was similar between men and women. But women were more likely to have a formal diagnosis of depression.

*Findings are based on biological sex.
• **Treatment:** More than one-half of those who were depressed when they took the survey were getting treatment. More than two-thirds had received treatment in the past. The most common treatment was medicine, followed by therapy. Barriers to getting treatment included financial and insurance challenges, lack of access to care, and provider’s lack of understanding of depression in autism.

• **Helpfulness:** Most people receiving treatment, such as medicine and therapy, found it helpful. Women and people with milder symptoms were more likely to find therapy helpful than men and people with more severe symptoms.

### Rates of Treatment

- **Present:** More than 50% were getting treatment.
- **Past:** More than 66% had received treatment in the past.

### What was new and innovative about the studies?

Most previous research on depression and autism focused on people at specialty clinics. These current studies surveyed people in the broader autism community. Few studies have looked at how many autistic people with depression are getting treatment and who is getting treatment. This information is important to improve access to care.

These studies are also the first to look at whether people with autism find it helpful to get treatment for depression. This is important because people who feel that treatment is helpful are more likely to continue and benefit from it.

In the general population, women tend to have higher rates of depression. Previous autism studies had not found sex differences in rates of depression. These current studies found that men and women were equally likely to report symptoms of depression. But women were more likely to have been diagnosed with depression by a doctor. The researchers think that doctors may be more likely to screen women for depression.

### What do the findings mean?

The findings suggest that most autistic people with depression are being diagnosed, but some are not. Only one-half of the people who were depressed when they took the survey were getting treatment. Decreasing financial and other barriers to treatment is important, as is training providers to recognize and treat depression in adults with autism.
What are participants and scientists saying?

Participants:

• “Please keep up the research, us autistic adults need help finding better coping mechanisms.”

• “I would love to be able to make others more aware of current research and why it’s important for the autism community.”

• “I originally had a therapist, but since I am unemployed, I could not afford to continue therapy long-term. Especially with my insurance doubling this year, [...], I cannot afford to receive help anymore. I just take my anti-depressants and struggle through it, since I cannot get access to any other helpful sources.”

Scientists:

Shuting Zheng, a researcher at the University of California, San Francisco, who led the study:

“The high rate of depression in ASD is alarming, but findings from our two studies show that we are doing a relatively good job identifying depression in adults with ASD. Moreover, adults who have been receiving depression treatment in the community perceived the treatment as at least moderately helpful. However, more research is needed to address service barriers and possible service disparities that we observed in our study and to understand the processes and mechanisms of depression treatment responses.”

What’s next?

Researchers plan to contact participants four times a year to monitor depression symptoms, treatment, and other changes. Researchers also want to understand what types of treatment are most helpful, and whether participants who feel that treatment is most helpful also improve the most.

The surveys were limited to autistic adults who had been diagnosed with autism as children. Researchers say that more studies are needed to understand depression and mental health in people diagnosed with autism as adults. More than three-quarters of the participants in the studies were white. More research is needed on racial disparities in diagnoses and access to treatment.

References


About SPARK Research Match

This SPARK program matches families with research studies that they may want to join. These studies have been evaluated for scientific merit and approved by a scientific committee at SPARK. The program is free to researchers and families. SPARK does not endorse or conduct these studies. Families choose if they want to participate in a particular study.