

How Has the COVID-19 Pandemic Affected Independent Adults with Autism?

Summary Reports describe results from newly published research using data from SPARK participants.

■ Study Title

Early Pandemic Experiences of Autistic Adults: Predictors of Psychological Distress

■ What was the study about?

The COVID-19 pandemic caused disruptions in daily life for many people beginning in March 2020. Researchers wanted to find out how these disruptions affected adults on the autism spectrum.

■ How was the research done?

Researchers sent online surveys to independent autistic adults who were enrolled in SPARK. Almost 400 people ages 18 to 74 completed the first survey in April 2020 and a second survey in late May to early June 2020. The average age of the participants was 37. Before the pandemic, two-thirds had a job, 20 percent were students, and 70 percent were receiving at least one service or therapy. Most had attended some college or had a college or graduate degree.

■ What did the researchers learn?

- By April, 93 percent reported that the pandemic had a negative effect on at least one area of their lives, such as employment, school, social life, services, home, or finances.
- Forty-five percent had a moderate to severe amount of psychological distress. More than one-half of the participants had two or more symptoms, such as anxiety, loneliness, or depression, at least three days in the previous week.

LEVELS OF PSYCHOLOGICAL DISTRESS



- Some people reported more disruptions to their lives, and greater difficulty coping. These participants were more likely to be younger, female, to have had a mental health diagnosis before the pandemic, and to know someone with COVID-19 symptoms.
- More than one-third said that they felt hopeful about the future three or more days a week. This group also reported better coping and less psychological distress.
- Almost 100 people received online services in April, and about three-fourths said that those services provided a moderate to significant benefit.

- People who did not see as much benefit from online services, and people who felt less hope over time, reported more distress by May or June.

■ What was new and innovative about the studies?

When the research began, the pandemic's effect on independent adults with autism had not been studied. The study provides data on how these adults viewed their experiences during the pandemic.

■ What do the findings mean?

A higher percentage of autistic adults had moderate to severe psychological distress, when compared to the general population who were surveyed around the same time by other studies. The results suggest that autistic people need more supports during the pandemic. Ways to increase "hopefulness may be a particularly important area to explore," researchers say.

■ What are participants and scientists saying?

Autistic adults:

"My anxiety and stress is way up. This is forcing me to change my routine and messing up my life. I'm taking it harder than NT [neurotypical] people, but it is very hard to explain to them and have them understand its effect on me."

"I think this is hitting the autism community especially hard and the impact going forward will have lasting effects, especially in terms of trauma and PTSD."

"We feel very forgotten about in a time when we shouldn't be. It also is scary because hospitals do not have in place very good adult autism awareness and the thought of going in without an advocate if we need to be seen right now is very scary too."

Researcher Vanessa H. Bal, Ph.D., associate psychology professor at Rutgers University: "We know from other studies that, under the best conditions, many autistic adults do not have the supports they need. Here we are in the middle of a pandemic, and they're struggling even more. I feel it's important to show that with data so that we can advocate for supports on their behalf."

■ What's next?

Researchers have continued to send surveys to the study participants to document their experiences at different points in time.

■ References

1. Bal V.H. *et al.* *Autism Res.* Epub ahead of print (2021) [PubMed](#)

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.