

## How Did the COVID-19 Pandemic Affect People with Autism and their Caregivers?

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

### ■ Study Title

Impact of COVID-19 on Individuals with ASD and their Caregivers: A Perspective from the SPARK Cohort

### ■ What was the study about?

The COVID-19 pandemic caused many schools, clinics, and community programs to close in early 2020. SPARK researchers wanted to find out how these disruptions affected people with autism spectrum disorder (ASD) and their families.

### ■ How was the research done?

SPARK sent online surveys to parents and caregivers of children and dependent adults with autism who were enrolled in SPARK. A dependent adult is one who has a legal guardian. A total of 3,502 people completed a survey in March 2020 and a follow-up questionnaire a month later. Most study participants were women and had an average age of 43. Their children's average age was 11.

### ■ What did the researchers learn?

- In March, more than 75 percent of the parents and caregivers who responded reported disruptions to their child's special education, speech and language therapy, physical or occupational therapies, or applied behavior analysis (ABA) services. Less than 40 percent reported disruptions to medical services.
- By April, a majority of the children and dependent adults were not receiving online or telehealth services in most categories.
- Among those people who received online services, only mental health and medical services were rated as moderately or significantly helpful by a majority of caregivers. Online mental health services helped adults the most, followed by children aged 6 to 17. Children under age 6 had the least benefit, parents said.
- Compared to older children and adults, children aged 5 and under had the most severe disruptions to services, and also had the least benefit from online or telehealth services.
- Less than half of parents reported moderate or significant benefits from online or telehealth special education, and ABA, speech, and occupational or physical therapies. Adults received the most benefit from telehealth ABA services, of all the age groups.
- Almost two-thirds of parents said service disruptions had moderately or severely affected their children's autism symptoms, behaviors, and other challenges.
- Three out of four parents said that they had moderate or extreme stress from service disruptions. Stress was greatest among parents of preschoolers (80 percent), followed by parents of children aged 6 to 17 (73 percent), and the guardians of adults (68 percent).

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

When SPARK launched the study, the pandemic's effect on the autism community was unknown. SPARK developed questionnaires just for this study. The research provides new information about how caregivers view telehealth therapies and services for autism.

## ■ What do the findings mean?

Early in the pandemic, most children and dependent adults experienced disruptions to their services. Parents reported a worsening of autism symptoms and moderate family stress as a result. Some online services were not very helpful to many who received them. This suggests that strategies to support the autism community should be developed and implemented.

## ■ What are parents and scientists saying?

### Parents:

"The greatest impact on our family has been the cancellation of school. My [child] started a private autism school this year and all of the children were finally in a good place and routine there. This has impacted them the most, not being on routine or seeing their friends."

"Special education children have not had a coordinated effort. Instead, typically developing children can benefit from remote learning while special ed children do not have the independence to do this."

**SPARK Principal Investigator Wendy K. Chung, M.D., Ph.D.:** "We have not found any evidence that children with ASD are more likely to catch the virus causing COVID-19 or to have more serious medical complications once infected. However, disruption of services, including therapies and educational supports, has been widespread and particularly impactful on young children. I hope we can get back to normal in 2021 with widespread adoption of the vaccine for the virus. The vaccine is demonstrating excellent safety and efficacy in adults, and hopefully in children too in the near future."

**SPARK Researcher L. Casey White, M.A., M.S.:** "We wanted to highlight the need for researchers and clinicians to get creative and work with families to improve continuity of care. Improving remote and telehealth services may also have general benefits for service delivery — for example, by providing better quality of care for individuals in rural or underserved communities — that would extend beyond the pandemic."

## ■ What's next?

SPARK's research is continuing. Researchers have surveyed parents at additional points in time about disruptions to schooling and therapies, and about the benefits of telehealth services.

## ■ References

1. White, L.C. et al. J. Autism Dev. Disord. Online 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.