The Pandemic’s Impact on Children with Autism and their Parents

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

Study Title

1. Psychological Distress Among Caregivers Raising a Child With Autism Spectrum Disorder During the COVID-19 Pandemic (Luther G. Kalb, Ph.D., and team)


What were the studies about?

Researchers wanted to find out how the COVID-19 pandemic affected children with autism, or their parents, when it began in 2020. Luther Kalb’s study compared the psychological experiences of parents in SPARK to those of parents in the general U.S. population. Anjana Bhat’s study looked at whether some segments of the autism community were more affected than others. Both studies used information from a COVID-19 impact survey that was sent to parents of children with autism in SPARK in March 2020. The children were under age 18.

How was the research done?

Kalb’s study compared survey responses from 3,556 parents in SPARK to the responses of 5,506 parents in the U.S. population who were contacted by the Pew Research Center. Bhat’s study analyzed the responses of 6,393 SPARK parents based on the severity of their child’s symptoms, level of developmental delay, family income, child’s age, and parent’s mental health diagnoses.

What did the researchers learn?

• At the beginning of the pandemic, almost half of the parents of children with autism reported psychological distress, compared to one-fourth of parents in the general population, according to Kalb's research.¹

• The SPARK parents were more likely to have feelings of panic, anxiety, and loneliness for at least three days a week. That was true even when researchers took into account parents' earlier mental health conditions.¹

• Compared to other parents, SPARK parents were more than twice as likely to report physical symptoms such as sweating, trouble breathing, a pounding heart, and nausea, when they were thinking about the pandemic. These symptoms are called hyperarousal and may be related to panic and trauma.
In Bhat’s study, parents reported disruptions in autism services, a worsening of their child’s symptoms, and a negative effect on their mental health from the pandemic. That was especially true for families who were low income, who have younger children, or who have children with more severe autistic symptoms and developmental delays.²

Low-income parents, parents of color, and parents of children with more repetitive behaviors were less likely to be receiving online services at the time. Other research has shown that there is a “digital divide in providing services to children,” Bhat says. A majority of families receiving online services did not report a significant benefit from them.

What was new and innovative about the studies?

Kalb’s study was the first to compare the pandemic’s effect on the mental health of parents who have children with autism with that of parents in the overall U.S. population. His team also took into account differences among the parents, including the higher rate of mental health conditions among the SPARK parents.

Bhat’s study looked at differences in the pandemic’s impact among families based upon factors such as income, health concerns, age, developmental delays, and autism symptoms.

What do the findings mean?

Mental health services should be made available to parents, particularly those raising children with autism, during and after the pandemic, Kalb says. “This study suggests that talking about parents’ well-being and their mental health is an important part of the conversation,” he says.

The pandemic caused greater problems for some parts of the autism community. Giving families the option to choose between in-person or online health care, and better access to family support services, could reduce such health problems in the future, Bhat concludes.

What are people saying?

Study participants:

- “My anxiety over COVID-19 is more about the economic, emotional, social, and clinical impacts on our family rather than contracting the virus itself.”
“Child care is a huge issue/concern; not only finding help, but the financial burden is taking a toll.”

Luther G. Kalb, Ph.D., assistant professor, Kennedy Krieger Institute and Johns Hopkins Bloomberg School of Public Health:
“Parents raising a child with autism have significant mental health needs. This is relevant during the pandemic as families lost a lot of supports. They lost educational supports, therapeutic supports, social supports, and emotional supports. This is a population in need. And we know, unfortunately, the pandemic is still with us. So this is as relevant today as it was when the data were collected.”

Anjana Bhat P.T., Ph.D., associate professor, University of Delaware:
“When the SPARK data became available, it provided a first opportunity to hear from parents what their challenges had been. They were also telling us what, within the telehealth/online format of services, was working versus not working, and how this was impacting their and their family’s mental health.”

What’s next?
Kalb and others are comparing the pandemic’s effect on families who have a child with autism, or who have a child with a developmental disability, or who have a typically developing child. That research is part of the U.S. Study to Explore Early Development.

Bhat’s lab is examining the survey data that SPARK collected at different times during the pandemic. She plans to publish findings on how the pandemic has affected access to autism services, how services are delivered, and parents’ mental health over time.

References

About SPARK Research Match
This SPARK program matches participants 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 participants. SPARK does not endorse or conduct these studies. Participants choose if they want to take part in a particular study.