

The Experiences of Black and Multiracial Families Seeking Screening, Diagnosis, and Intervention for Autism

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

■ Study title

Screening, Diagnosis, and Intervention for Autism: Experiences of Black and Multiracial Families Seeking Care

■ What was the study about?

Black children with autism are often diagnosed later, and they receive fewer therapies and interventions, than white children with autism, according to previous research. For this study, researchers asked Black and multiracial families to share their experiences of receiving an autism diagnosis and intervention for their children, and ways that the process could be improved. The researchers received [SPARK funding](#) from the Simons Foundation Autism Research Initiative.

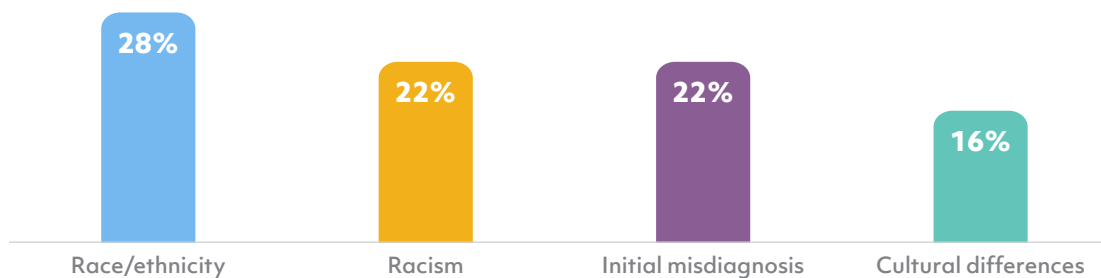
■ How was the research done?

Researchers enrolled 400 parents of children who were 1- to 8-years old and had an autism diagnosis. The families were SPARK participants who identified themselves as Black, African American, or multiracial. Parents completed the online Diagnostic Experience Survey.

■ What did the researchers learn?

- Twenty-eight percent of the families said that race or ethnicity affected their experience getting a diagnosis.

PERCENTAGE OF BLACK AND MULTIRACIAL FAMILIES AFFECTED BY FACTORS DURING AUTISM DIAGNOSIS PROCESS



- Sixteen percent said that cultural differences between themselves and health care providers influenced their experience.
- Twenty-two percent reported examples of racism and bias, such as a child’s behavior being attributed to race, and evaluations that did not have activities and toys that were relevant to their culture.
- Most parents (71 percent) reported that their pediatricians were helpful during the diagnostic process.
- Parents cited factors that would have improved the process, such as receiving an evaluation faster (51 percent), having professionals listen to their concerns sooner (42 percent), and having “someone explain what autism is” (35 percent).

- Families reported a need for more accessible and affordable therapies and school programs (21 percent) and better autism information (33 percent).

■ What was new and innovative about the study?

The study asked many Black and multiracial families across the country about their experiences seeking autism care and what could have been improved.

■ What do the findings mean?

Many families reported barriers to autism diagnosis and care. Their recommendations included more accessible therapies and faster evaluations, and having professionals who listen to them and who understand cultural differences.

■ What are people saying?

STUDY PARTICIPANTS:

- “I think this is a GREAT topic, as I have been very open about our Autism journey. This has allowed many of my friends to reach out to me and ask what steps to take, etc. especially those who would not have done anything. I will continue to be an advocate for [my child], and to let my people know that it’s ok to be Black and have/accept Autism.
- “Thank you for taking the time to care about what we go through to get help for our children.”

STUDY RESEARCHERS:

- **Amy S. Weitlauf, Ph.D., clinical psychologist and associate professor, Vanderbilt University Medical Center:**
“Parents shared very personal stories of struggles as well as success. This gave us important insight into what we can do to make the autism diagnostic process easier for families, especially families of color.”
- **Theodora Pinnock, M.D., developmental and behavioral pediatrician and associate dean, Meharry Medical College:**
“In addressing the racial disparity of Black children’s autism identification, it was critical to talk with parents. They shed light on several possible reasons of why their children were delayed in their identification and gave insight into how providers could ‘get it right.’”

■ What’s next?

Some researchers are working on additional tools that could improve the screening and diagnosis of children from diverse backgrounds. “It’s about trying to adjust and correct how we as diagnosticians interact with families, and how we listen to them,” Weitlauf says.

■ References

1. Weitlauf A.S. *et al.* *J. Autism Dev. Disord.* Epub ahead of print (2023) [PubMed](#)

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.

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