

Effects of Barriers to Diagnosis and Treatment for Black Families of Autistic Youth

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

■ Study title

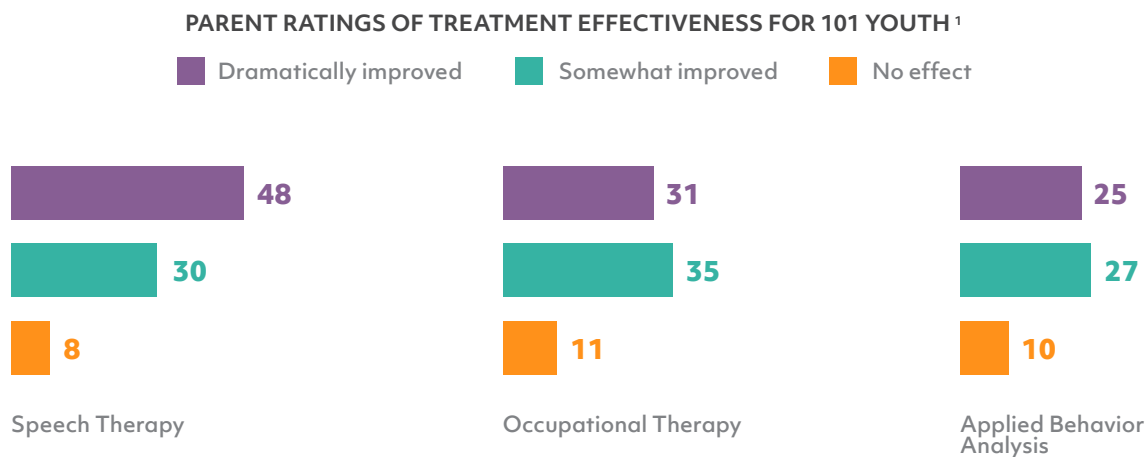
Racial and Practical Barriers to Diagnostic and Treatment Services for Black Families of Autistic Youth: A Mixed-Method Exploration

■ What was the study about?

Researchers explored barriers that Black families face in receiving an autism diagnosis and treatment for their children. They wanted to learn the effects of barriers on parents' stress, satisfaction with treatment services, and views of treatment helpfulness.

■ How was the research done?

Researchers enrolled 101 parents and guardians of Black autistic youth, who had an average age of 9. Study participants completed online surveys about barriers, treatments, and stress. Researchers also interviewed 20 of the parents about their experiences on video calls.



■ What did the researchers learn?

- The barriers that Black families experienced when seeking help raised their stress levels and negatively affected their perception of the quality of autism treatments. These barriers included experiencing racial bias and stigma, as well as trouble finding autism therapies that they could access or afford.
- More than 70 percent of the parents said that their child improved from treatment, and more than 60 percent were satisfied with the treatment.
- Speech therapy was tried the most often and had the highest parent rating.
- In interviews, many of the 20 parents reported barriers, such as denial and fear (65 percent each), poor knowledge about autism (50 percent), lack of support (45 percent), and mental health challenges (30 percent). Seventy-five percent said that the COVID-19 pandemic made it harder to get help, as did being treated differently than white families (60 percent), and insurance and finances (45 percent).

- Parents who were interviewed said that providers should show more “humility, compassion, and understanding.” They also recommended having more support groups for Black families and more Black professionals.

■ What was new and innovative about the study?

This study used two methods – online surveys plus video interviews with 20 of the parents – to study the effects of diagnosis and treatment barriers on Black families.

■ What do the findings mean?

The researchers concluded that Black families’ experiences with autism diagnoses and treatments may be worsened by barriers, and improved by advocacy, community support, and greater knowledge about autism.

■ What are people saying?

STUDY PARTICIPANTS:

- “Thank you for taking the time to conduct this important research. Thank you for the opportunity to have a voice in the process and share our experiences. I hope that these findings will help teach parents – especially Black families – how to best advocate for their children.”
- “I am a biracial mother and it has been interesting to me to notice differences in how I feel about autism vs. my white peers, and how providers treat me and our family based on whether they know my race and family of origin or not.”
- “Thank you for recognizing and understanding the inequalities that Black families may have when trying to receive help or information from medical professionals and thank you for trying to find out how to improve the areas that are lacking.”

STUDY RESEARCHER:

- **Study researcher Harlee Onovbiona, Ph.D. candidate, University of Arkansas:**
“Because Black families are very understudied and we rarely hear their perspectives, a lot of the autism supports, services, and interventions we’ve created are not necessarily fitting these families’ needs and values. Studying their experiences helps us better understand ways that we can improve.”
- **Study Researcher Lauren B. Quetsch, Ph.D., assistant professor, University of Arkansas:**
“Thank you to all the families who participated. Research and improvements in mental health care cannot happen without those who are willing to share their experiences and their voices.”

■ What’s next?

Onovbiona and Quetsch are preparing a paper about a support group for Black caregivers of autistic youth that Onovbiona led. Onovbiona is also helping to create a website with resources for people of color at www.village-autism.org.

■ References

1. Onovbiona H. *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.

© Simons Foundation | Published February 2024