



Exploring the Experiences of Black Parents and Caregivers Raising Children with Autism Spectrum Disorder



Olivia Watson, Dr. Rose Skepple
College of Education, Florida State University

Introduction

Autism Spectrum Disorder (ASD) can be defined as a biological developmental disability that ranges from mild to severe and consists of deficiencies in social interaction along with “repetitive sensory-motor behaviors” (Lord et al., 2018).

Over the years, many services, resources, and strategies have been implemented to support children and adults with autism. Such resources include early interventions and further treatments, which have been reported to contribute to the academic and long-term success of individuals with ASD (Izuno-Garcia et al., 2021). Although such resources exist, parenting stress continues to be a major concern associated with raising a child with autism (Dababnah, Kim, & Shaia, 2021). One stressor that occurs among minority families involves the racial disparities that occur in the healthcare system. For example, studies have reported that children who are non-minority and of higher socioeconomic status are more likely to be identified and diagnosed earlier than children who identify as minority children or low-income, resulting in a lack of access to early intervention (Aylward, Gal-Szabo, & Taraman, 2021).

Additionally, previous literature has reported that parents and caregivers raising minority children with Autism Spectrum Disorder report feeling more stressed than others due to fear of police interactions, stigma, financial burdens, and the need “to fight for autism services” (Dababnah, Kim, & Shaia, 2021). While positive coping methods exist to mitigate such stress, more research is needed to understand how to reduce barriers or disparities experienced by Black parents or caregivers of minority children with ASD.

Research Questions

1. How does Autism Spectrum Disorder (ASD) affect Black families and caregivers raising children with ASD?
2. What barriers exist among Black families and caregivers of children with ASD?
3. What strategies can be implemented to support such families and caregivers, along with their children?

Research Design

- Articles concerning Autism Spectrum Disorder and how it has been addressed in diverse families were analyzed to gain a better understanding and discover common themes.
- A legal case was reviewed to understand how ASD among individuals has been addressed within the legal system.
- An interview with an advocate for Autism was conducted and transcribed.
- A Qualtrics survey was distributed to parents and caregivers raising children with ASD to understand their experiences and find common themes.

Results

Interview Findings

(Based on interview with an advocate for Autism)

- Three challenges of being a Black parent raising a child with ASD: education, stigma within our community, challenges from a system that minorities are not often included in.
- Cultural awareness is vital in the healthcare system and is needed to support the needs of racially and ethnically diverse families.
- Stigma: It is common for individuals from minority backgrounds to not address the concerns of autism or how it may affect families. ASD is not a common conversation.
- Caregivers still need support from other families or professionals within their community just as their children with ASD need support.

Survey Findings

- The results from the surveys are still in progress.
- I anticipate the results to present common themes that demonstrate that Black parents and caregivers face more racial disparities in the healthcare system compared to those who identify themselves as Caucasian (Dababnah, Kim, & Shaia, 2020).
- I also anticipate such themes to demonstrate that Black parents and caregivers of children with ASD experience cultural stigma when obtaining the services needed to enhance their child’s success, and they also experience more significant stressors compared to other parents (Pearson et al., 2021)

Discussion

Although there are various resources that support children and adults with Autism Spectrum Disorder, there are still major challenges that Black parents and caregivers face. Challenges may include cultural and health stigmas, which can be described as negative beliefs or shame against an individual with certain characteristics or attributes. Such challenges may also include educational and health services, racial disparities, and an external system that fails to understand and accommodate the cultural values of families from racial/ethnic backgrounds. Additionally, such challenges are key stressors affecting families and caregivers, along with their access to services that support the “unique” needs of their child. To mitigate such stressors or eliminate such challenges, more awareness is needed within multicultural communities. By creating more awareness, new families and caregivers of children with ASD will understand what services are available to support their child, along with how to navigate the healthcare system to obtain such services. They may also receive all the support that is needed from their community and not be hindered by cultural and health stigma.

Acknowledgements

I would like to thank Dr. Skepple for mentoring me and Alyssa Vougan for her assistance throughout this research process.

References

- Aylward, B.S., Gal-Szabo, D.E., and Taraman, S. (2021). Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder. *Journal of Developmental and Behavioral Pediatrics*, 42(8), 682-689.
- Dababnah, S., Kim, I., and Shaia, W.E. (28 Jul 2020). ‘I am so fearful for him’: A Mixed-Methods Exploration of Stress Among Caregivers of Black Children with Autism. *International Journal of Developmental Disabilities*. 68(5), 658-670.
- Izuno-Garcia, A.K., Jellinek, E.R., Rosenbrock, G.J., Keller-Margulis, M.A., and Mire, S.S. (4 Jul 2021). School Readiness for Children with Autism Spectrum Disorder: Critical Gaps and Call for Research. *Focus on Autism and Other Developmental Disabilities*, 37(1), 46-55.
- Lord, C., Elsabbagh, M., Baird, G., and Veenstra-Vanderweele, J. (2018) Autism Spectrum Disorder. *The Lancet*. 392(10146), 508-520.
- Pearson, J.N., Stewart-Ginsburg, J.H., Malone, K., and Avent Harris, J.R. (2021). Faith and FACES: Black Parents’ Perceptions of Autism, Faith, and Coping. *Exceptional Children*, 88(3), 316-334.