

African American Parents' Journey Through Autism Diagnosis and Treatment

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Abstract

The CDC reports that 1 in 68 children will be diagnosed with ASD. However, African American (henceforth, Black) children with autism are diagnosed 1.6-5 years later than White children (Mandell et al., 2002). This poster will discuss the results from focus group research that investigated the challenges that Black parents of children with autism face during diagnosis, early intervention, and in critical transitions during school.

Objective

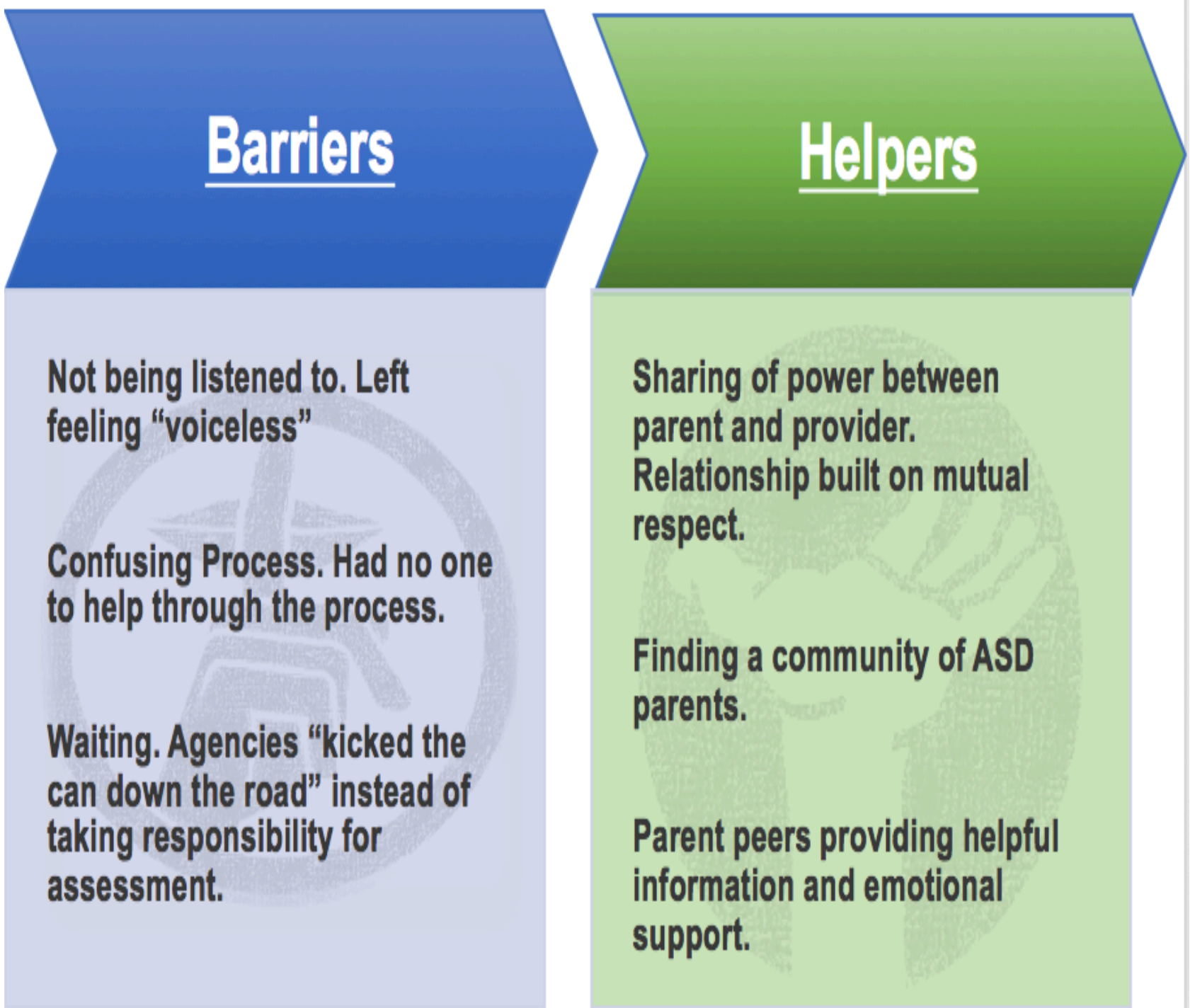
To examine barriers for Black families with children with autism.



Methods

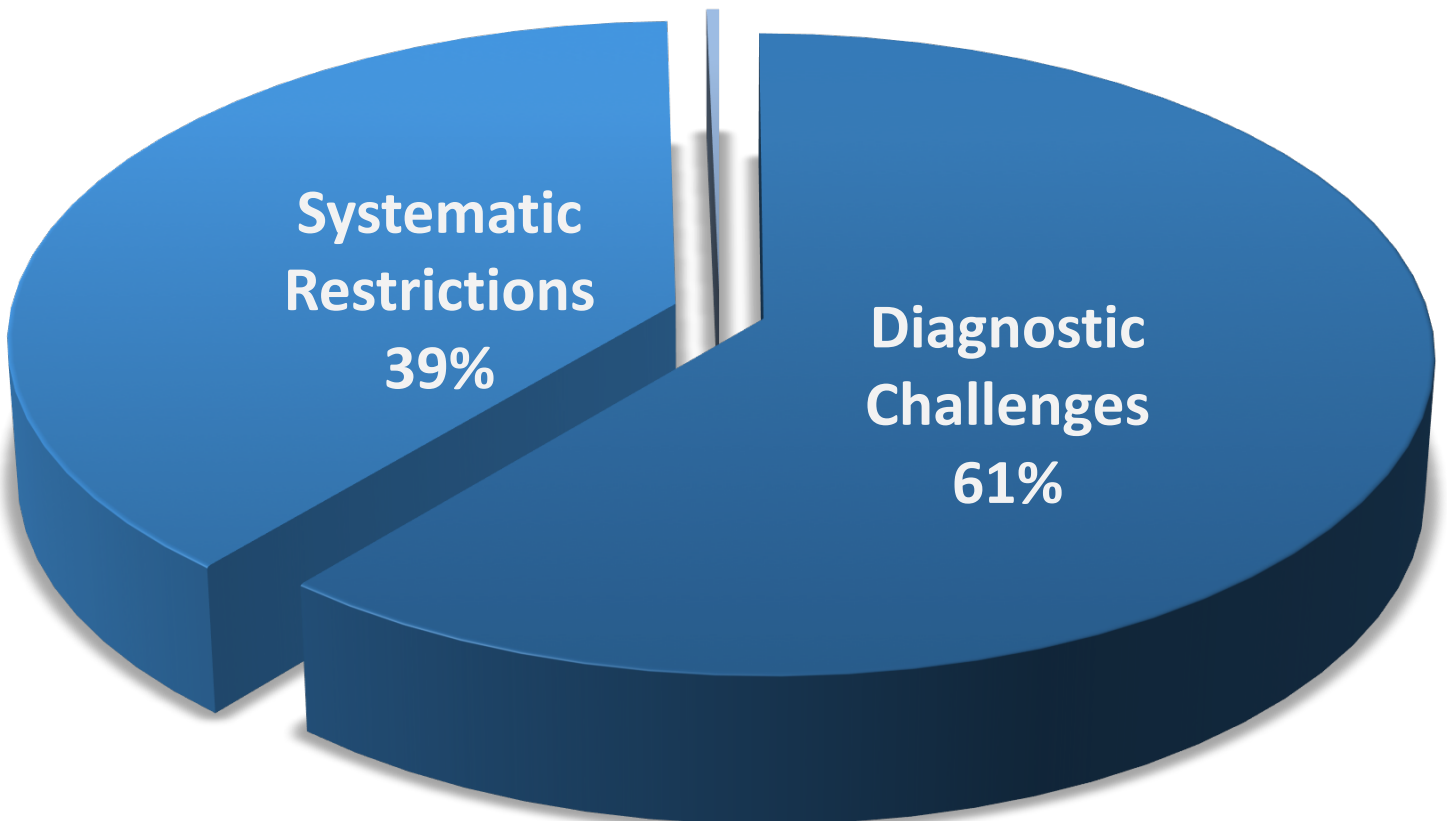
- Community Partnered Participatory Research (CPPR).
- Based on 37 Focus groups and interviews asking families about access to diagnosis and care.
- The current study extracted (N=19) Black parents responses for distinctive themes (18 mothers and 1 father).
- Transcripts coded with 90% inter-rater reliability.
- Frequency of statements coded in each theme recorded.

Common Barriers and Helpers



Barriers

Frequency of Statement



Quotes

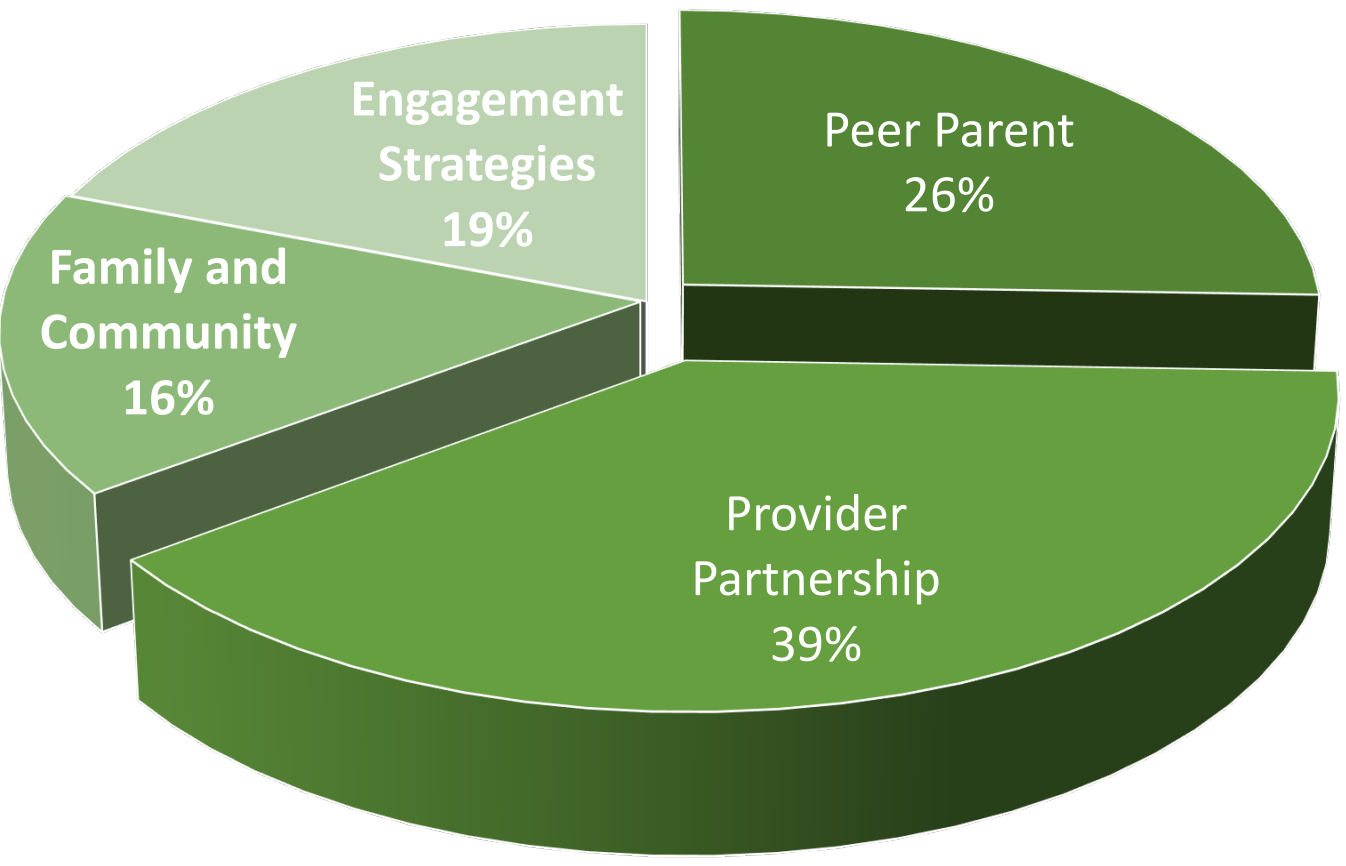
"The person that diagnosed him should have given me clear information on what my son had. Because I left her still the second time not knowing if he had autism."

"But that whole process gets a little confusing... But that's kind of a long process of waiting and waiting."

"And his school was like, "No, there's nothing wrong with him... He just bad."

Helpers

Frequency of Statement



Quotes

"So it was like two people who paved the way in an odd way. Where they probably wouldn't wanna be the road pavers in this sense, but they were"

"When I saw their willingness to tell me certain things then I just put my guard down...And that's when I was okay I let everything go, humbled myself. Then I could be open. I was ready to be taught. And so they showed me things. They opened up a whole new world for me."

"So, I think that that was probably my saving grace and the success of my kid was really part of being involved with a support group who had been there. To help me out."

Results & Discussion

- Data highlight themes related to Black parents' concerns about their children's development being dismissed by professionals. Parents reported feeling "voiceless." The parents were all told to 'wait to see' and had their concerns dismissed by professionals.
- Findings suggest cultural and linguistic competence training to support empowerment and inclusion of Black parents is needed.
- Black parents' well-being and feelings of self-efficacy were connected to their access to peer group supports and support groups.
- Findings support intervention efforts to help Black families to self-advocate and form social networks.

Acknowledgements

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