

“Ain’t nothing wrong with him”: family messages received by Black caregivers of autistic children

Dalia Marquez, Felicia Williams-Brown, Joseph Piven, MD, Kelly Caravella, PhD
The University of North Carolina at Chapel Hill

Background

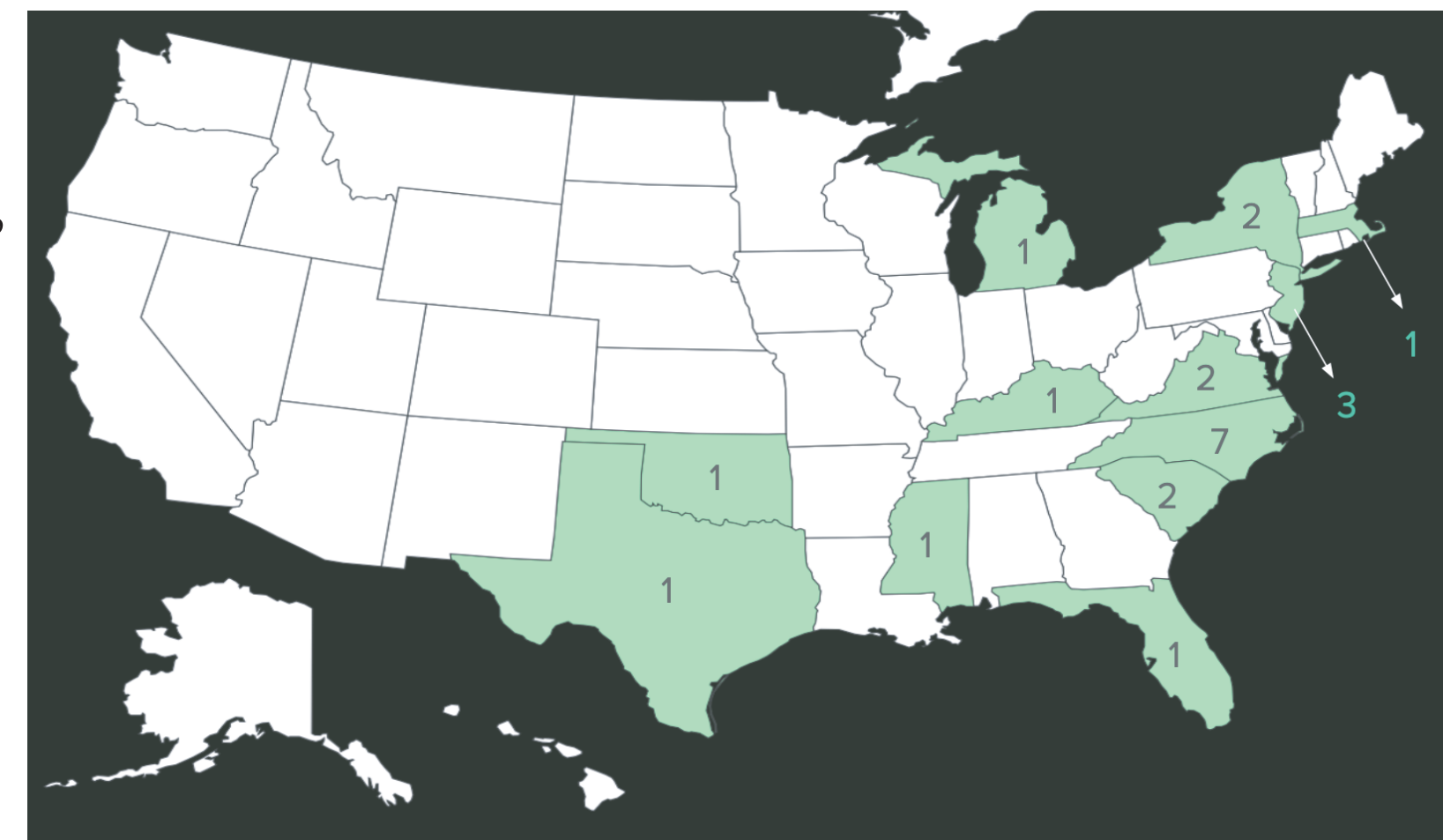
- Black children with autism experience disparities in both diagnosis and treatment¹
- This also impacts Black caregivers, who experience higher caregiver stress²
- Black caregivers of children with ASD also express that there are gaps in both knowledge and acceptance of disabilities within their communities³
- This lack of information and resources provided to Black communities can lead to tensions between families regarding autism diagnoses and how to support individuals with autism in their families⁴
- Although recent literature has discussed lived experiences and perspectives of Black caregivers of autistic children^{5,6,7}, the current study specifically examines messaging received from family members about their child’s diagnosis
- Examining family messaging surrounding autism diagnoses can inform strategies to develop culturally tailored interventions to support Black caregivers and their children with autism

Methods

Data Collection

- 23 Black caregivers of children with autism participated in qualitative interviews
- All participants identified as Black/African American (91% female, 9% male).
- One-third of participants lived in North Carolina (30.4%)
- 60-90 min interviews were conducted via phone or Zoom and followed a semi-structured interview guide (developed with stakeholder consultation) with four primary content areas: family/community, opinions about research, reducing barriers in research, and future directions in research

Geographic Distribution of Participants (n=23)



Sample Characteristics

Variable	n (%)
Race and Ethnicity	
Black or African American (non-Hispanic)	22 (95.7)
Black or African American (Hispanic)	1 (4.3)
Marital Status	
Married	4 (17.4)
Divorced	6 (26.1)
Never Married	9 (39.1)
Member of an unmarried couple	4 (17.4)
Income	
Less than \$10,000	2 (8.7)
\$10,000-\$29,999	7 (30.4)
\$30,000-\$59,999	11 (47.8)
\$60,000-\$99,999	2 (8.7)
\$150,000-\$249,999	1 (4.3)

Data Analysis and Coding

- PI, Study Coordinator, and senior RA independently coded 3 initial transcripts to develop a hybrid coding framework (i.e., a combination of a-priori and data driven codes) using qualitative coding software Dedoose
- Final codebook reviewed by study’s qualitative consultant and study’s community consultant- for purposes of this study only participant responses coded under “family views on autism” analyzed
- Coders instructed to use this code “when participants describe the opinions, experiences and beliefs of their family members about autism spectrum disorder or having a family member with autism spectrum disorder”
- Following higher-order themes developed by senior RA, PI, and study’s community consultant

Results

Theme	Example Excerpt
Lack of Understanding and Denial of Autism	
Lack of understanding of autism	“I have a lot of aunties and uncles that didn’t finish high school and stuff. They don’t really understand it. So when I’m around them and my son is doing certain stuff, they don’t understand. Like, ‘Oh, this is what people do with autism.’ Like, ‘No, you need to whoop him.’ Like, no... I don’t. I don’t. He doesn’t understand. This is why he’s doing that. So they don’t really understand.”
Lack of motivation to understand child with autism	“We were in a car going somewhere and the girls were in the car as well and my mother said uhm, she said something, it was a little disrespectful or whatever, and I said, hey, if CHILD was, if she had sickle cell, you would, you would research it. If she had some other kind of, like say disease or illness you would, you would look it up. ... I said though, because she has autism. You’ve never gone to a workshop about autism. You’ve never gone.”
Blame of challenging aspects of child’s diagnosis on the caregiver	“All I have to say is, as a Black family with a son that’s autistic, it was a horrible experience. Not just on a social level as far as like, outside of the home, as far as like school and stuff. But even within the family. For the longest time his grandparents on both sides- they tried to blame his condition on me and my husband, you know, by saying that we wasn’t raising him right. Especially when he would have a tantrum.”
Denial of child having autism entirely	“I had a few family members like, ‘Ain’t nothing wrong with him. He’s perfectly fine. They don’t know what they talking about. They always trying to diagnose somebody kid with something.” “...everybody’s like, ‘Ain’t nothing wrong with him! He alright.’ No, I don’t think something’s wrong with him, he just has a different way of learning and accepting things. It’s just different, not that something’s wrong with him.”
Supportive Acceptance and Inclusion	
Acceptance of child’s diagnosis and willingness to serve as a source of support	“So my family and my daughter, you know, they’re- they’re very supportive and I have to go to work and so forth. They’re watching and everything but uh. Yeah, we got a ton of support from my immediate family and they understand the situation. And some of the extended family also, they understand the situation, so they’re all supporters. And accepting of him.”
Treatment of child as any other child without a developmental disability	“We don’t treat him, they don’t treat him any differently just because he has autism because that’s not how it works in the real world, so I- they don’t treat him—they love him though. But we don’t treat him any differently, I treat him just as I would if he was a normal, functioning child.”

Discussion

- Unsupportive family messaging negatively impacts caregiver well-being**
Caregivers frequently reported how this messaging impacts their well-being by ending with statements referencing their own emotions, such as “that was tough” or “nobody understood where I was coming from.”
- By centralizing equality in their treatment of children with autism, family members may unintentionally impact equity**
In an effort for inclusion and acceptance, treating an autistic child as “normal” may in effect be denial through a different lens and derogate from the need of essential supports
- Although negatively valenced family messaging is prevalent, caregivers also report inclusive and understanding family members that transcend passive acceptance into actions that improve the well-being of both the caregiver and their child**
Both caregivers and clinicians must be aware of the family messaging surrounding their child with autism in order to provide effective support

References

1. Constantino, J. N., Abbacchi, A. M., Saulnier, C., Klaiman, C., Mandell, D. S., Zhang, Y., Hawks, Z., Bates, J., Klin, A., Shattuck, P., Molholm, S., Fitzgerald, R., Roux, A., Lowe, J. K., & Geschwind, D. H. (2020). Timing of the Diagnosis of Autism in African American Children. *Pediatrics*, 146(3), e20193629. <https://doi.org/10.1542/peds.2019-3629>
2. Kim, I., Dababnah, S., & Lee, J. The Influence of Race and Ethnicity on the Relationship between Family Resilience and Parenting Stress in Caregivers of Children with Autism. *J Autism Dev Disord* 50, 650–658 (2020). <https://doi.org/10.1007/s10803-019-04269-6>
3. Burkett, K., Morris, E., Manning-Courtney, P. et al. African American Families on Autism Diagnosis and Treatment: The Influence of Culture. *J Autism Dev Disord* 45, 3244–3254 (2015). <https://doi.org/10.1007/s10803-015-2482-x>
4. Pearson, J. N., & Meadan, H. (2018). African American Parents’ Perceptions of Diagnosis and Services for Children with Autism. *Education and Training in Autism and Developmental Disabilities*, 53(1), 17–32. <https://www.jstor.org/stable/26420424>
5. Dababnah, S., Kim, I., & Shaia, W. E. (2021). ‘I am so fearful for him’: a mixed-methods exploration of stress among caregivers of Black children with autism. *International Journal of Developmental Disabilities* (Vol. 68, Issue 5, pp. 658–670). Informa UK Limited. <https://doi.org/10.1080/20473869.2020.1870418>
6. Dababnah, S., Shaia, W. E., Campion, K., & Nichols, H. M. (2018). “We Had to Keep Pushing”: Caregivers’ Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care. *Intellectual and Developmental Disabilities* (Vol. 56, Issue 5, pp. 321–336). American Association on Intellectual and Developmental Disabilities (AAIDD). <https://doi.org/10.1352/1934-9556-56.5.321>
7. Lewis, E. M., Dababnah, S., Hollie, K. R., Kim, I., Wang, Y., & Shaia, W. E. (2022). The creator did not give me more than I can handle: Exploring coping in parents of Black autistic children. *Autism*, 26(8), 2015-2025. <https://doi.org/10.1177/13623613211070865>