

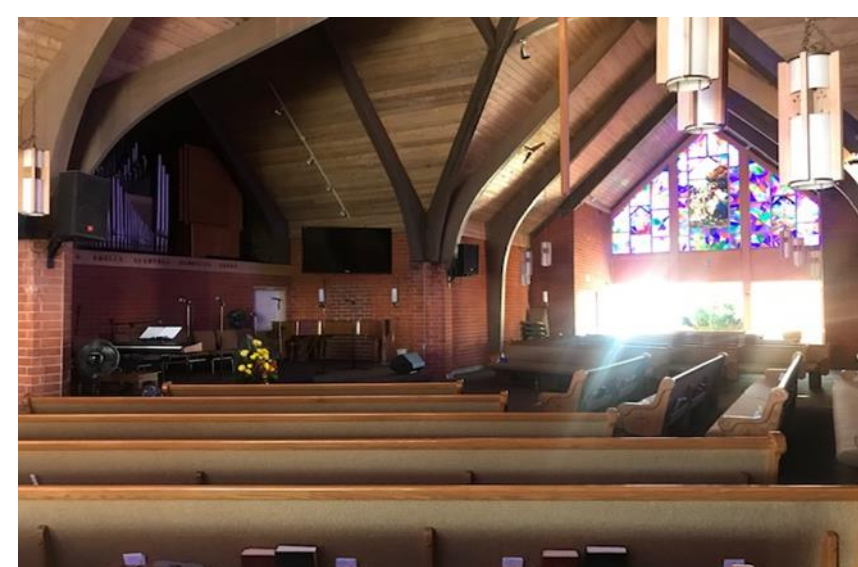
Introduction

Caucasian children have a 20% higher prevalence of an autism spectrum disorder (ASD) diagnosis compared to African American children.¹

African American parents have also been shown to report significantly fewer autism concerns compared to Caucasian parents.²

Extended families and churches are the most established, influential, and trusted, institutions within African American communities.³

The Black Church has been used in research to increase health promotion, prevention and behavioral changes.⁴



However, there has been only limited research to address how an African-American faith based organization can be used to increase ASD awareness and diagnosis.

Objective

Explore the perceptions and attitudes of ASD within the African American community in a faith-based setting.

Methods

Using the Community Partnered Participatory Research model,⁵ four focus groups were conducted at two Black Churches in Los Angeles.

Inclusion criteria:

- African-American
- Age 18 or older
- English speaking
- Parents of children with no developmental or behavioral problems.

Recruitment through in-person church announcements, with a follow-up phone screener to check participant eligibility.

Lincoln Memorial C. Church

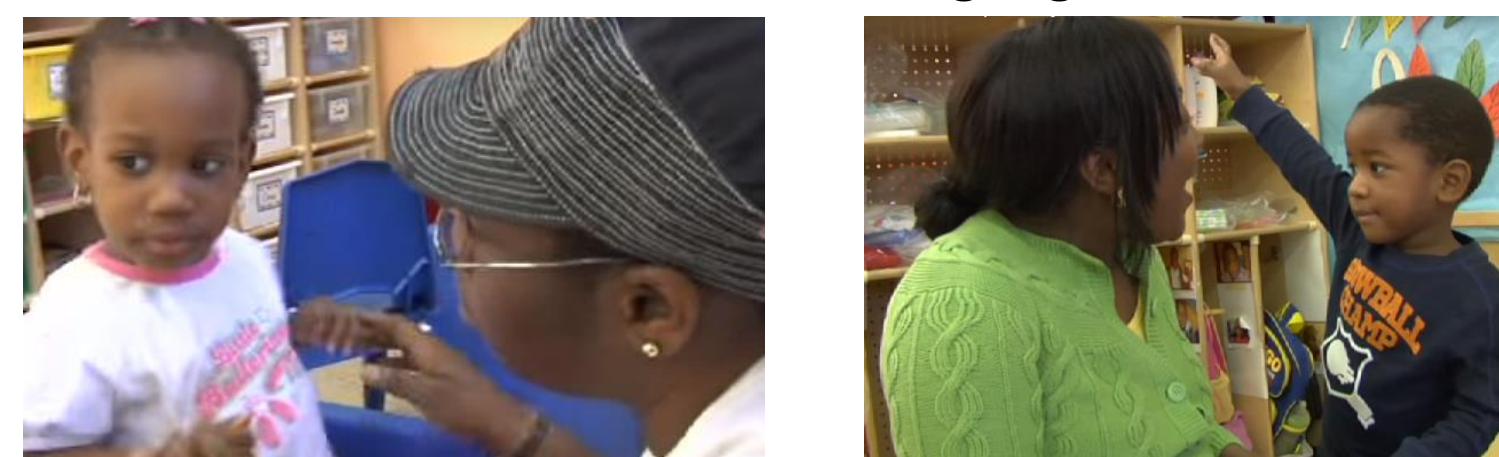
- Group 1: 9 participants
- Group 2: 11 participants
- Ages 35-85

Ward AME Church

- Group 3: 6 participants
- Group 4: 5 participants
- Ages 46-82

Two short videos were shown depicting African American children with ASD, unknown to focus group participants. They were asked open-ended questions in response to their observations of the children's behavior. Audio recordings of the participants were transcribed and analyzed using thematic analysis.

CDC Autism Case Training Vignettes



Results

Community Members' Interpretations of ASD Symptoms

- Hearing problems
- Introverted personality
- ADHD
- Child of a single parent
- Parent and child relationship
- ASD (2 participants)

"ADHD... her mind is wandering and she's just not there."

"The child may be an only child ...therefore, in a setting where there [are] other children they might be a little drawn to a corner."

Distrust in Healthcare Professionals

- Lack of diversity
- Racism and medical malfeasance
- Too quick to diagnose
- All too often developing programs to help underserved communities without actually consulting with those communities to determine their needs

"One of the things I'd love to see doctors do is develop relationships in the community... sometimes people don't want to go to 'The Doctor' or 'The Hospital.'"

"We need more Black pediatricians."

"I just really don't trust them [doctors]... you read the stuff in the media as well, you know the 'syphilis experiment.'"

Conclusions

Increase Awareness of ASD Characteristics

- Educate on the distinction of ASD versus other developmental disorders
- Provide credible Internet resources
- Disseminate information through trusted community organizations, such as churches (Autism Speaks National Black Church Initiative)
- Provide specific diagnosis screening questionnaire

Improve Trust and Access to Quality Care

- Provide appropriate specialist referrals, such as to a developmental-behavioral pediatrician
- Complete history taking, including home environment
- Treat the parent-child relationship as a patient, not just the child
- Invest in qualitative research within underserved communities
- Increase diversity of pediatric workforce

References

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3. Chatters LM, Taylor RJ, Lincoln KD, Schroepfer T. Patterns of Informal Support from Family and Church Members among African Americans. *J Black Stud.* 2002;33(1):66-85.
4. Brewer LC, Williams DR. We've Come This Far by Faith: The Role of the Black Church in Public Health. *Am J Public Health.* 2019;109(3):385-386.
5. Jones, L., & Wells, K. Strategies for academic and clinician engagement in community-participatory partnered research. *Jama.* 2007; 297(4), 407-410.