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## Introduction



- ❖ Black children with autism are diagnosed 1.6 years later<sup>1</sup> and are 2.6 times more likely to be misdiagnosed than White children.<sup>2</sup>
- ❖ Black families with a child with autism are only half as likely to receive family-centered care from a health care professional than their White counterparts.<sup>3</sup>
- ❖ Parents of minority toddlers are more likely to refuse services even when they are available, not actively advocate for services, and may end treatment early.<sup>4,5</sup>
- ❖ Strategies are needed to increase engagement in services and earlier access to care.

## Objectives

- ❖ Use Community Partnered Participatory Research (CPPR) to understand the challenges Black mothers of children with autism face during diagnosis, early intervention, and in critical transitions during school.
- ❖ Use themes to recommend systems change interventions to bridge the gaps for Black families and help them engage in services and become effective advocates for their children.

## Method

### Focus Group Participants

- ❑ 8 low-income parents of Black children with ASD.

### Focus Group Meetings

- ❑ Participants met in two separate focus groups
- ❑ Researchers used structured interview questions to understand:
  - How first concerns were identified
  - Barriers and facilitators to diagnosis
  - Barriers and facilitators to service access
  - Intervention recommendations

### Data Analyses

- ❑ Themes were extracted by the research team based on the focused questions.
- ❑ Focus group transcriptions were coded for themes.
- ❑ Transcripts were coded with at least 90% inter-rater reliability.

## References

1. Mandell, D.S., Listerud, J., Levey, S.E. Pinto-Martin, J.A. (2002) Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children with Autism. *Journal of American Academy of Child & Adolescent Psychiatry*. Vol. 41(12), pp.1447-1453.
2. Mandell, D.S., Ittenbach, R.F., Levy, S.E., Pinto-Martin, J.A. (2007) Disparities in Diagnosis received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders*. Vol. 37(9), pp.1795-1802.
3. Montes, G., & Halterman, J.S., (2010). White-Black Disparities in Family-Centered Care Among Children with Autism in the United States: Evidence From the NS-CSHCH 2005-2006. *Academic Pediatrics by Academic Pediatric Association*. Vol. 11 (4), pp. 297-304.
4. Pierce, K., Carter, C. et al. (2011). Detecting, studying and treatment autism early: the one-year well-baby check up approach. *The Journal of Pediatrics*, 159, 458-465.
5. Kazdin, A.E., Holland, L., & Crowley, M. (1997). Family experience of barriers to treatment and premature termination from child therapy. *Journal of Consulting and Clinical Psychology*, 65, 453.

## Focus Group Results

### Silenced by Medical Professionals

"So, this whole time I'm talking to the doctor and she's saying, well, he's fine."

"I ended up going to a doctor's appointment and the doctor told me that he was probably just stimulated, self-soothing himself. And it just didn't feel right"

"We finally got the diagnosis but it took the pediatrician telling me I needed a nanny, not an assessment, being kicked out of pre-schools."

### Silenced by Family and Community

"Yeah, I couldn't talk to my parents."

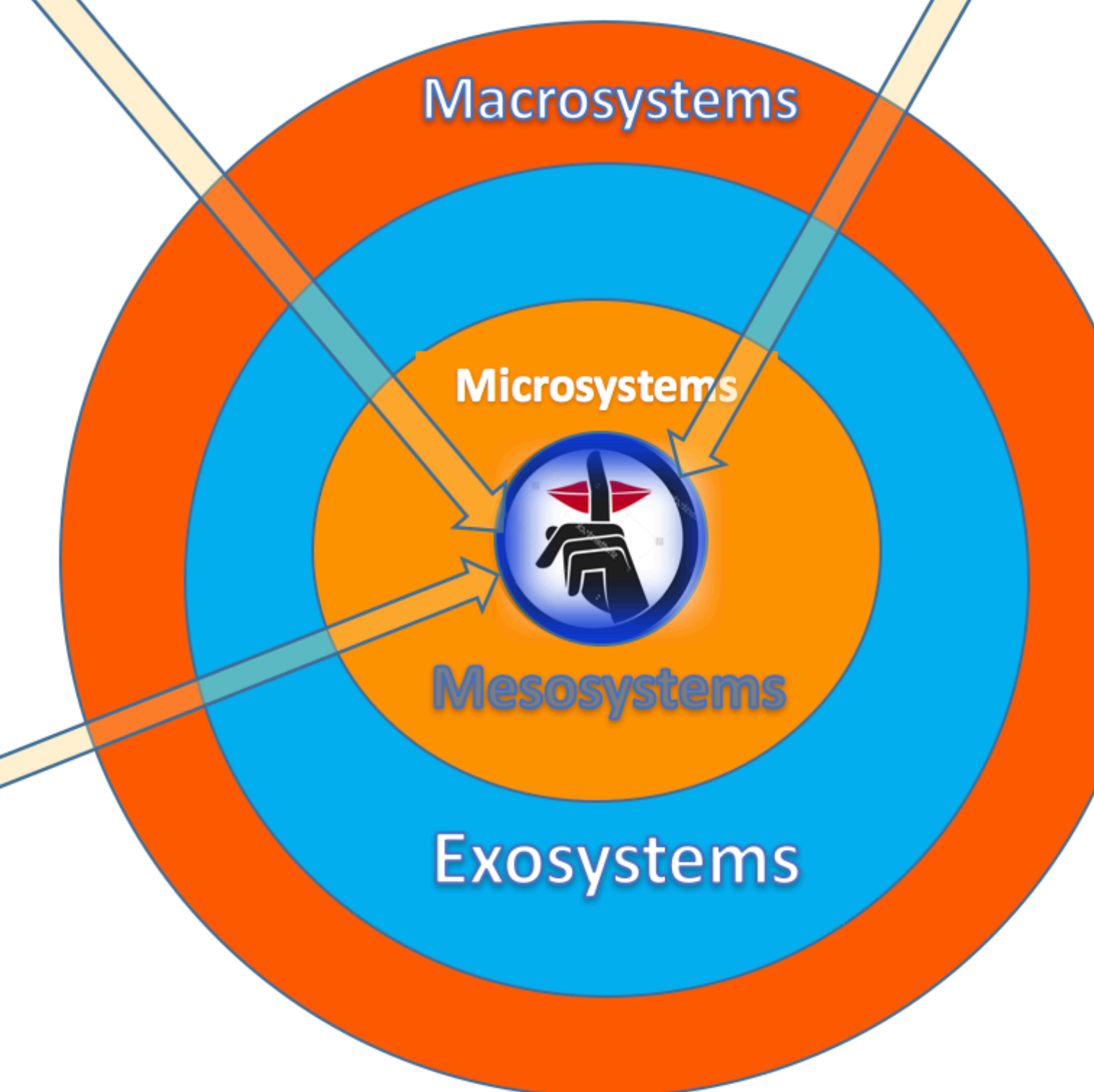
"And talking to people in your family about it, I know as a person of color, it's – there's a stigma attached to it".

### Silenced by School Professionals

"So, they called me to pick him up, the Principal was like, his teacher's going on maternity leave, we don't know what we're gonna do with him."

"And they said, "your son, something's wrong with him and we don't have the capacity to – he needs additional support and we just don't have the capacity, so he's not gonna be coming back here."

"And going to the school, and the school wanted to kick it back to Alta [EI]"



**Microsystem**  
The immediate environment of the developing child.

Data indicate that when providers silence a mother's voice she loses her ability to be an effective advocate for her child.

**Mesosystem**  
The interconnections of two microsystems.

Focus group provide evidence of weak mesosystemic connections which can impact child outcomes.

**Exosystem**  
Indirectly influence a child.

Families that experienced the frustration navigating the system and interpreting policy and procedure felt silenced.

**Macrosystem**  
The overall ideologies and social constructs that influence development.

Race/ethnicity, societal beliefs about disability, and social stigma influence their ability to advocate for their child.

## Implementation Implications

### Overall Results

Feeling that their ideas and concerns were not heard was a strong and consistent theme across all focus group participants. Participants felt silenced by people they went to for help, and this led to negative outcomes for the child, in both immediate and extended time periods.

### Immediate Outcomes:

Focus group participants expressed interest in participating in a culturally sensitive support group. As a result, the UC Davis Center for Excellence in Developmental Disabilities partnered with Warmline Family Resource Center to co-sponsor the founding of the African American Developmental Disability Parent Alliance (AADDPA). The group has been meeting monthly since August 2016.

### Extended Outcomes:

Further research needs to be done to determine specific interventions and approaches to promote family-centered care within the Black community. The following diagram is a conceptual model for future study to compliment these qualitative data.

