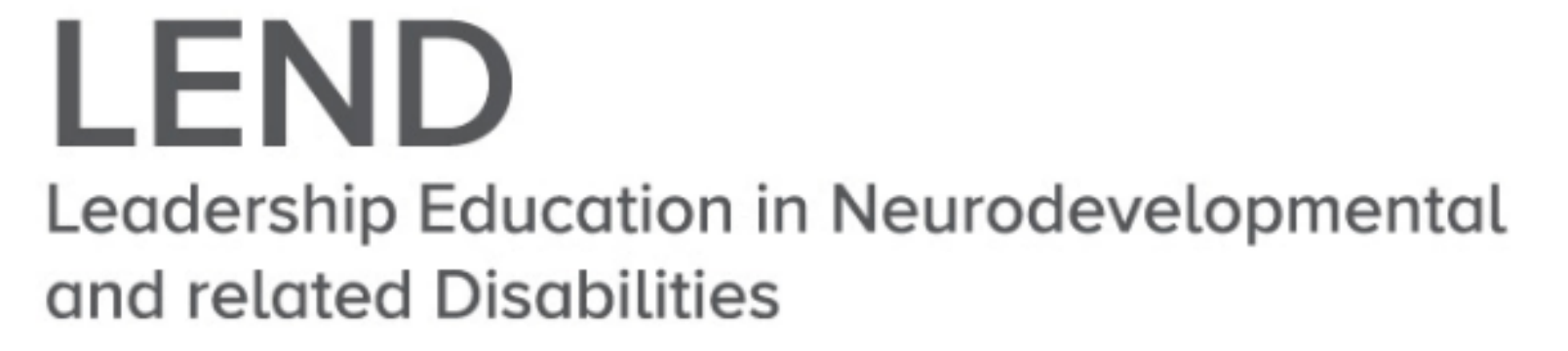


# FAMILIES' EXPERIENCES WITH THE PATH TO AN AUTISM DIAGNOSIS



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Understand caregivers' experiences with the diagnostic process, looking at potential racial differences

### INTRODUCTION

- Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social-communication deficits and restricted, repetitive, or stereotyped patterns of behaviors or interests
- There is significant variability in families' experiences with the diagnostic process
- Importantly, children of color are...
  - Diagnosed later
  - Misdiagnosed
  - Lacking culturally responsive care
- Studies examining dissatisfaction with diagnostic process have underrepresented families of color

### METHODS

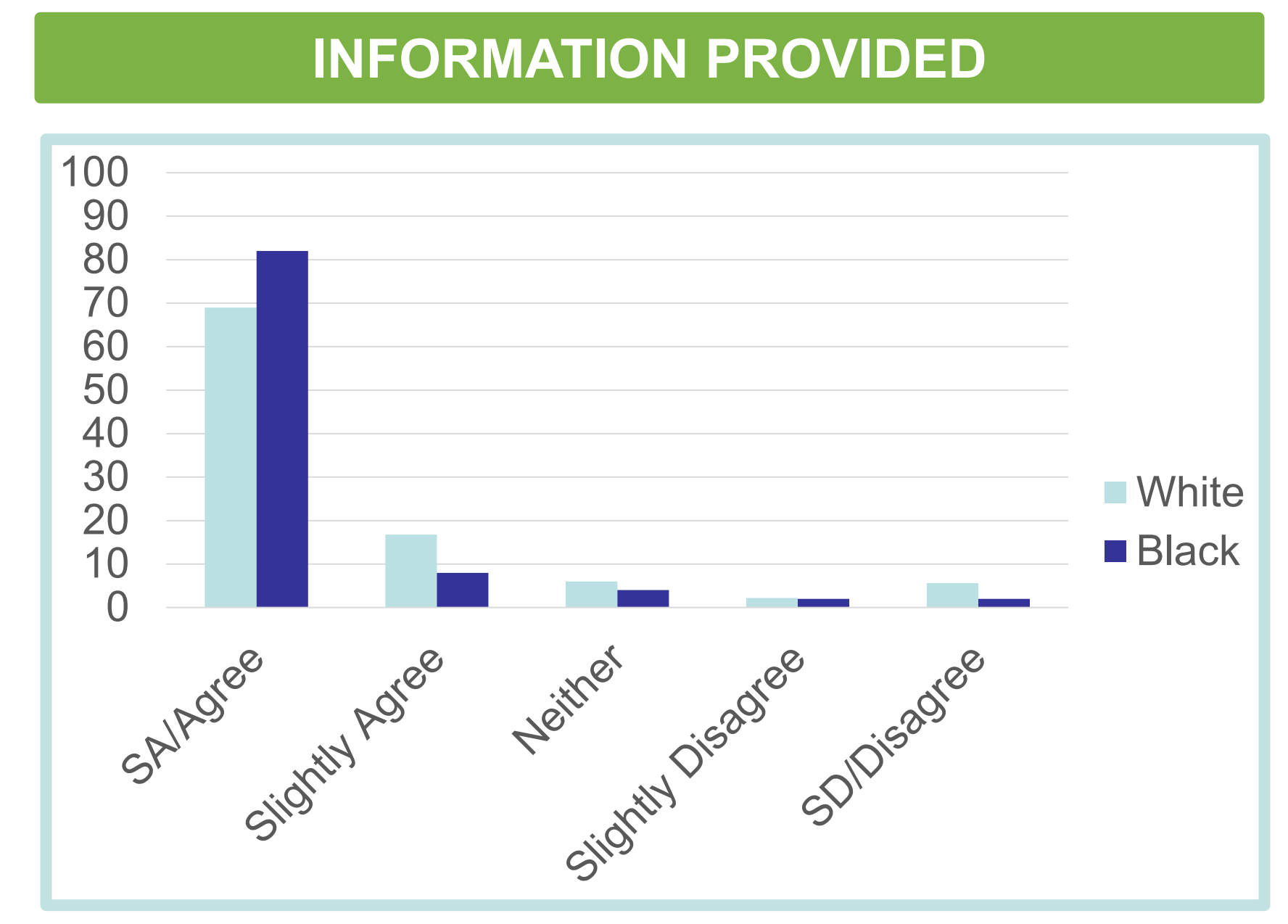
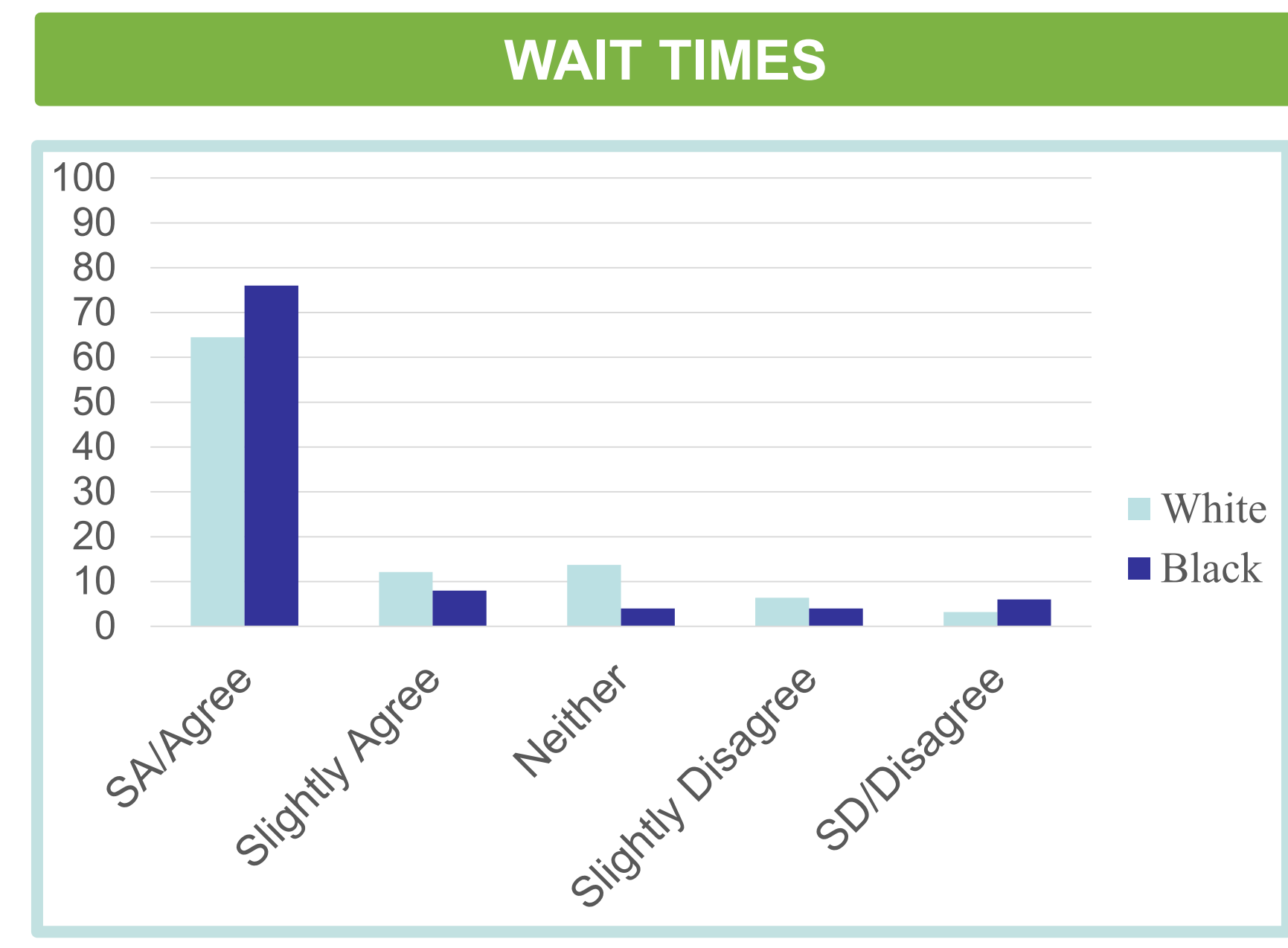
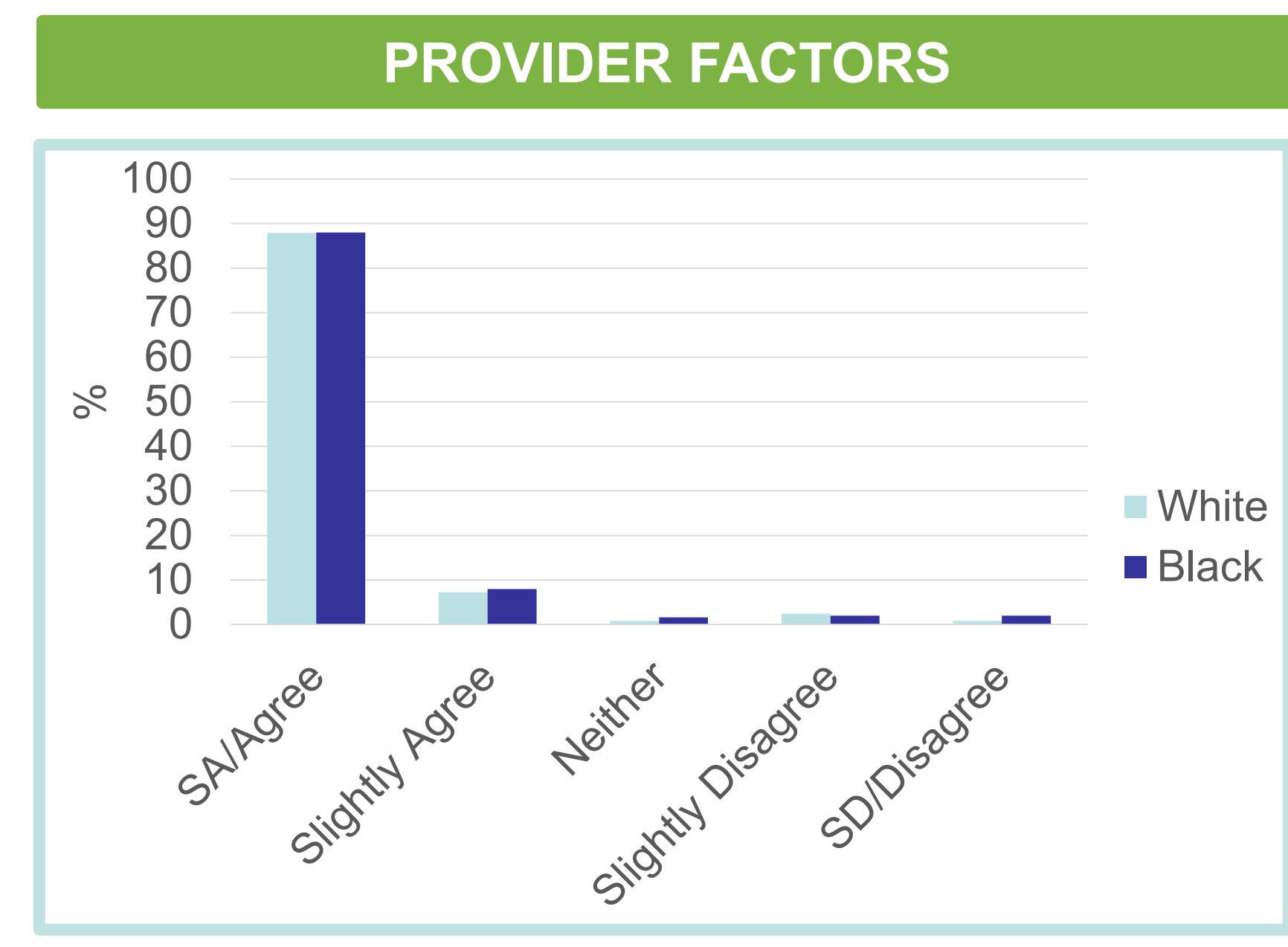
- Participant pool
  - Patients diagnosed with ASD through CCHMC DDBP in 2018 (n=439)
- Patients diagnosed under 1 of 3 evaluation models:
  - Developmental Behavioral Pediatrician, Psychology, and Speech Pathology
  - Developmental Behavioral Pediatrician at earlier date, then Psychology + Speech Pathology at later date
  - Psychology + Speech Pathology "arena" evaluation
- Initial chart review to identify resources/referrals provided to families
- Developed research questionnaire with interdisciplinary team and input from community partners
- Questionnaire comprised of 2 surveys:
  - Family demographics
  - Family experiences with ASD diagnostic process
- Outreach efforts to families of color were done through community partner and with an enrollment video



**Table 1. Participant demographics**

	M	SD			
Age (years)	38.1	7.2			
Caretaker	Mother	Father	Grandparent	Other	
	150 (86%)	14 (8%)	3 (2%)	7 (4%)	
	African American/Black	White			
	50 (29%)	124 (71%)			
Child race	60 (35%)	112 (65%)			

## RESULTS



### PROVIDER FACTORS THEMES

- Lengthy Process and Emotionally Taxing Wait
- Lack of Individualized Care
- Lack of Emotional Support

### WAIT TIMES THEMES

- Positive and Negative Relationships with Providers
- Power Differential
- Impact On Services

### INFORMATION PROVIDED THEMES

- Lack of Follow-Up
- Varying Amount of Information
- Lack of Direction

"Sometimes I'm scared to ask for help and fear that [providers will think I am] incapable of taking care of my child"

"It's like waiting for a biopsy..."

"I've made it my number one mission [to figure out how to support my child] and it's my reason to live."



### FAMILY STRENGTHS

- Families did research
- Families pushed for therapy
- Looked for community resources
- Pushed for early evaluation

### CULTURAL CONSIDERATIONS

- Culture not discussed
- Culture affirmed
- Some families not bothered that culture not addressed
- Provider preferences

### DISCUSSION

- Most families describe positive experiences with diagnostic process
- Black and white families have similar levels of satisfaction
- However, not all families have positive experiences
- The qualitative comments provided rich information about both strengths and challenges that families faced
- Future provider training could include this feedback to improve culturally responsive care

### NEXT STEPS

- Presentation to Autism and We and other community partners for feedback on the study
- Implement the feedback obtained from community partners to improve the diagnostic process