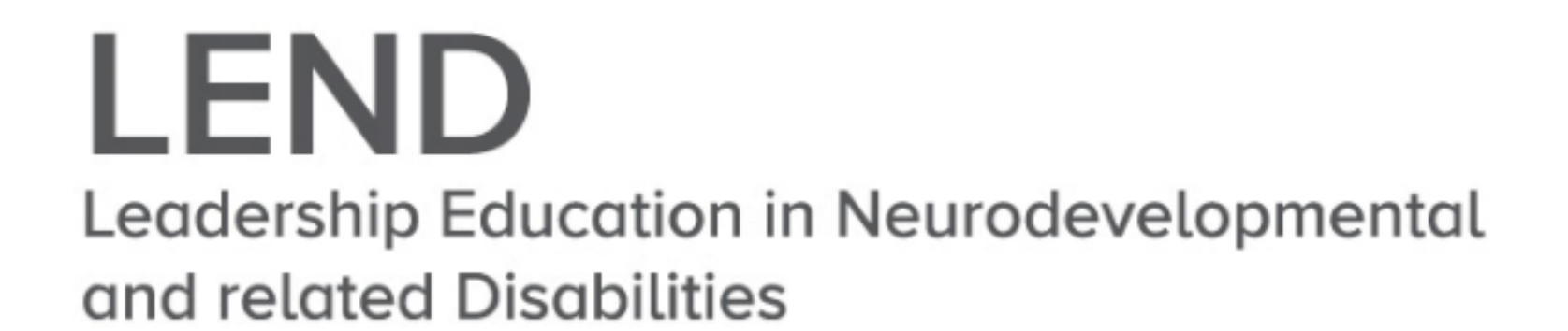


FAMILIES' EXPERIENCES WITH THE PATH TO AN AUTISM DIAGNOSIS



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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 than white children
 - More likely to be misdiagnosed
 - Less likely to have culturally responsive care
- Studies examining dissatisfaction with diagnostic process have underrepresented minoritized families

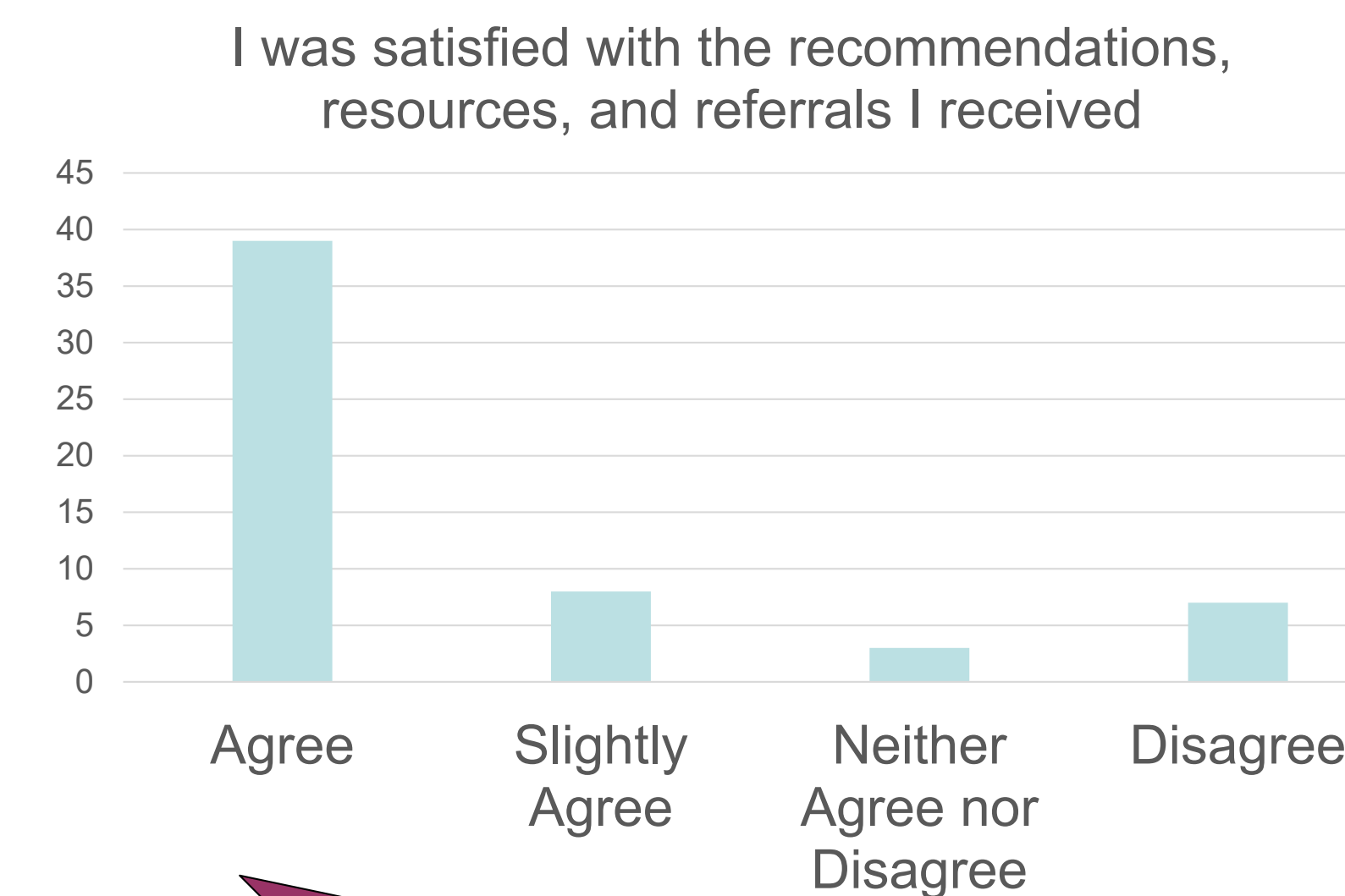
METHODS

- Participant pool: patients diagnosed with ASD through CCHMC DDBP in 2018 (n=350)**
- 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 community partners
- Questionnaire comprised of 2 surveys:
 - Family demographics
 - Family experiences with ASD diagnostic process
- Participants to date: n = 58

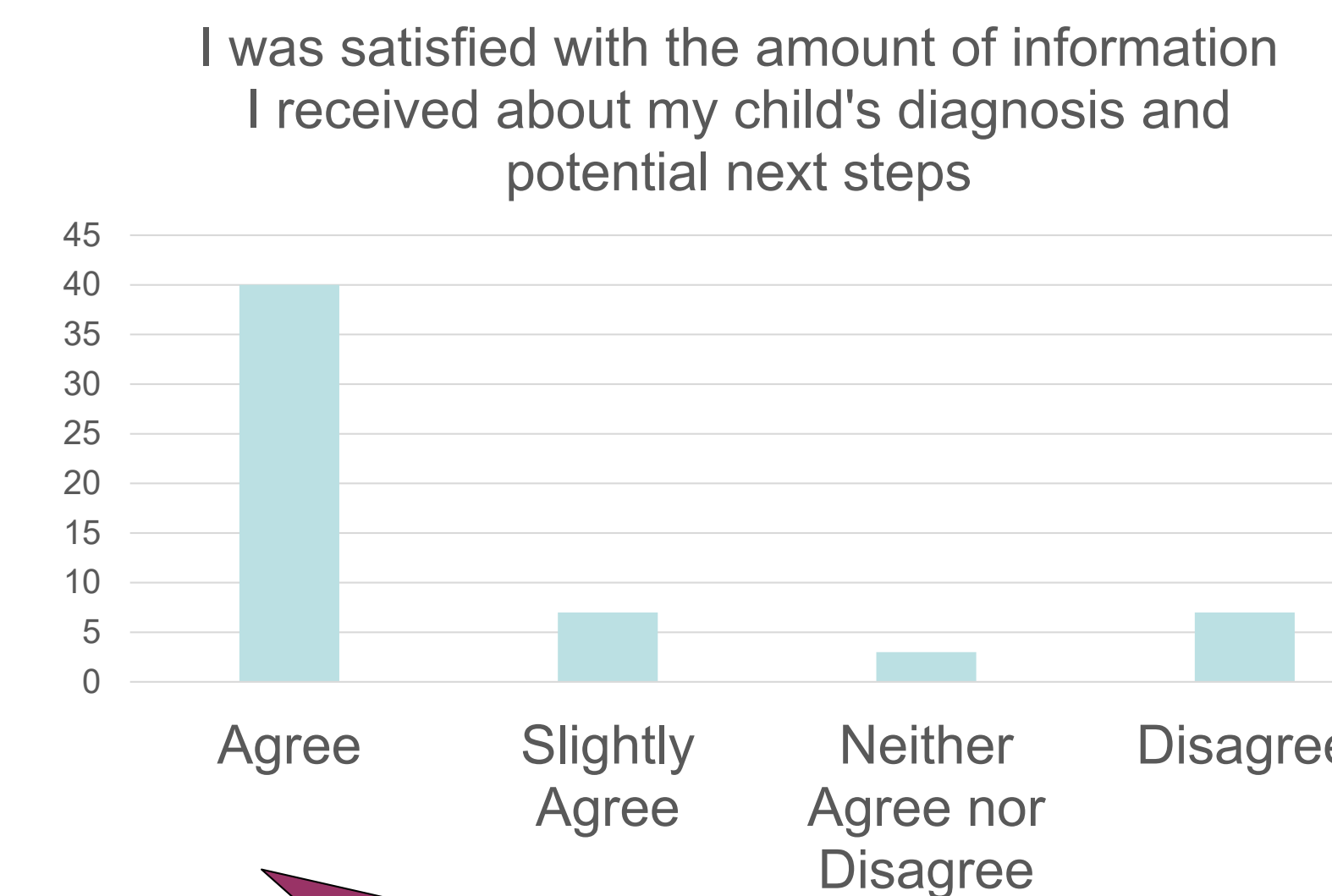
Table 1
Participant demographics from questionnaire.

	M	SD				
Age	37.6	9.25				
	N (%)					
	<\$30,000	\$30-59,999	\$60-99,999	>\$100,000		
Income	16 (37%)	11 (26%)	5 (12%)	11 (26%)		
	Caretaker					
	Mother	Father	Grandparent	Other		
	53 (91%)	3 (5%)	1 (2%)	1 (2%)		
	Parent race					
	African American/Black	Asian	Biracial	Hispanic/Latino	White	
	9 (15%)	2 (3%)	3 (2%)	4 (7%)	43 (73%)	
	Child race					
	10 (17%)	1 (2%)	7 (12%)	2 (3%)	39 (66%)	

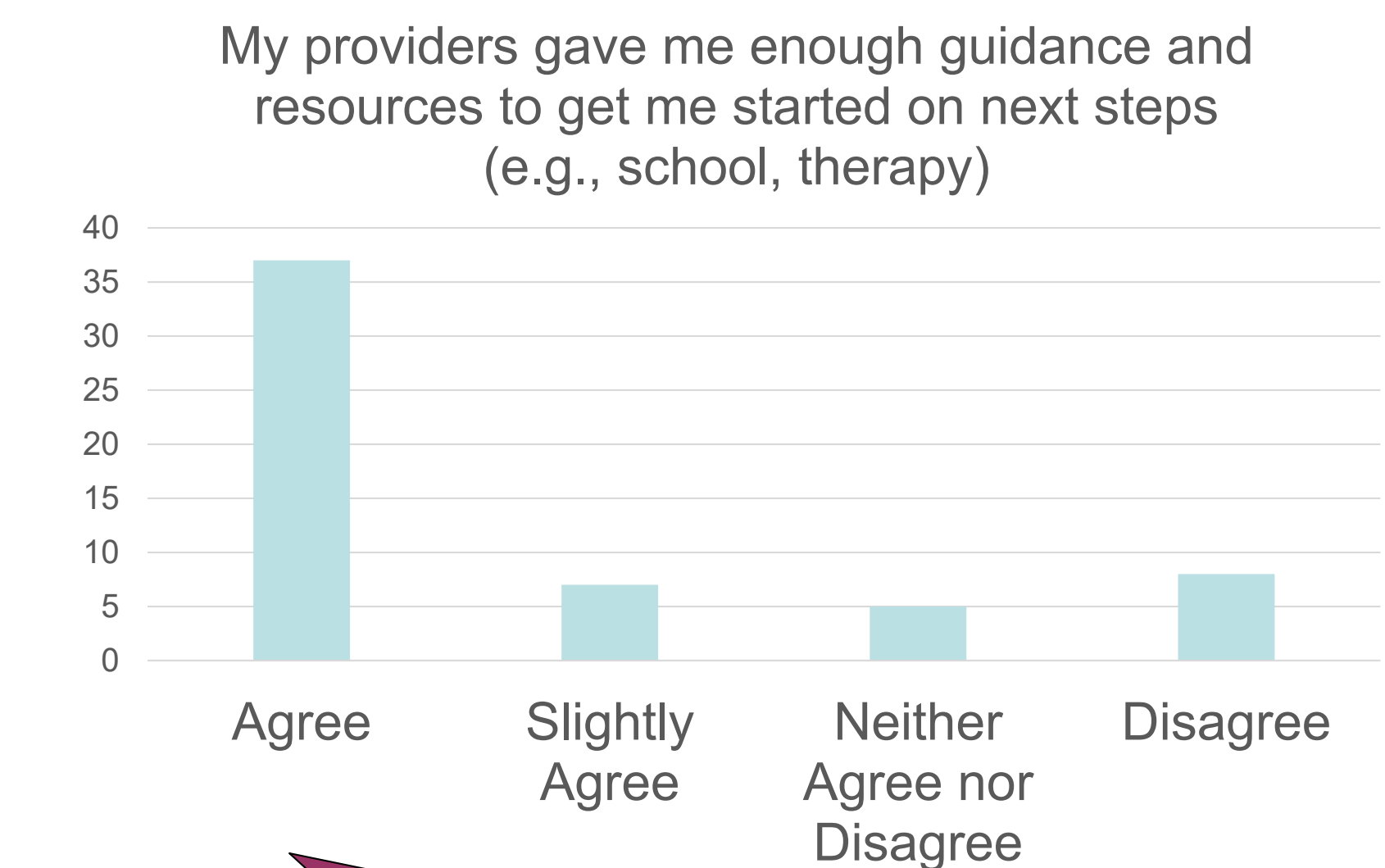
RESULTS



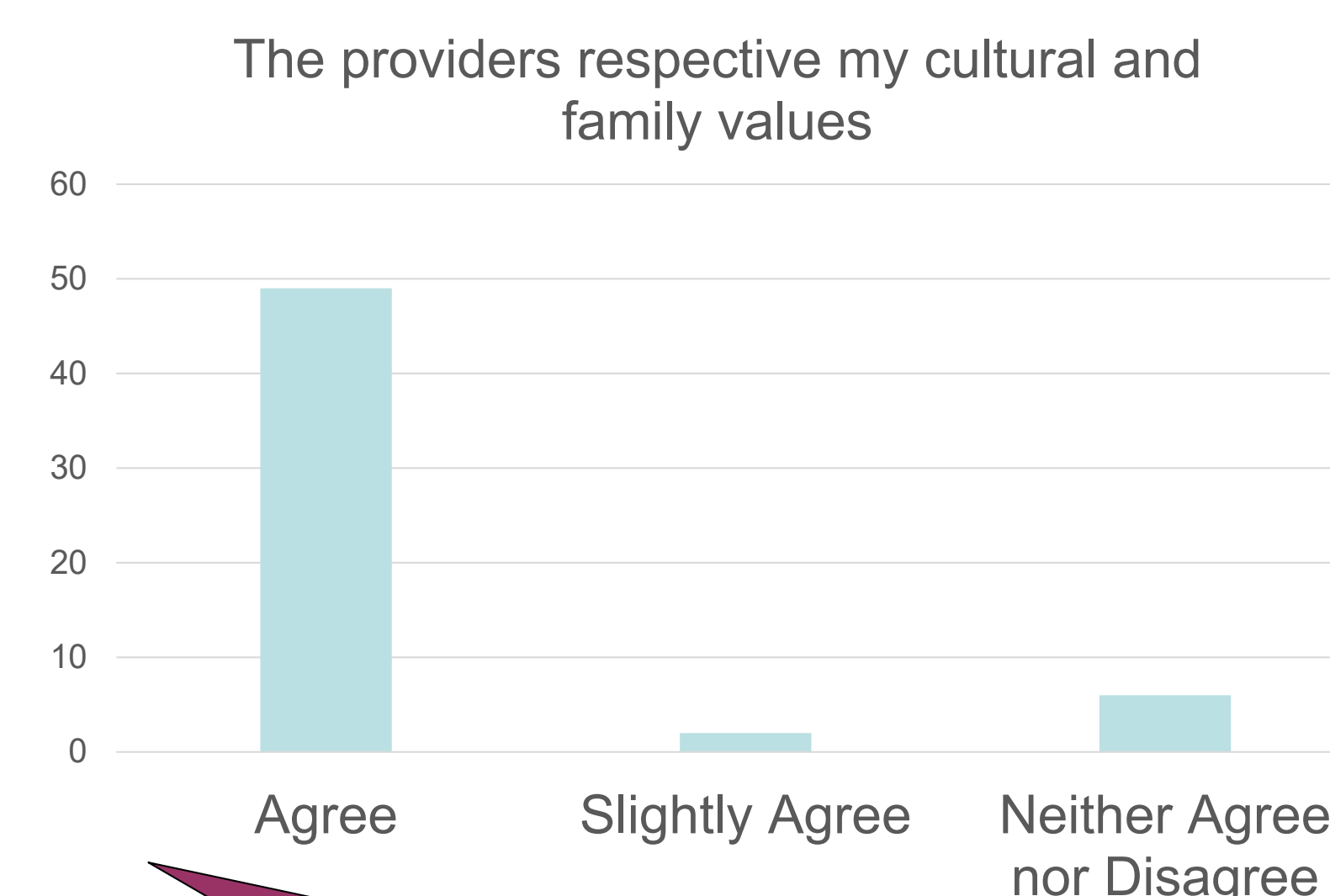
"All the resources I got were specific for area [near the hospital], but I live [far away]. An hour long drive one way is cost and time prohibitive."



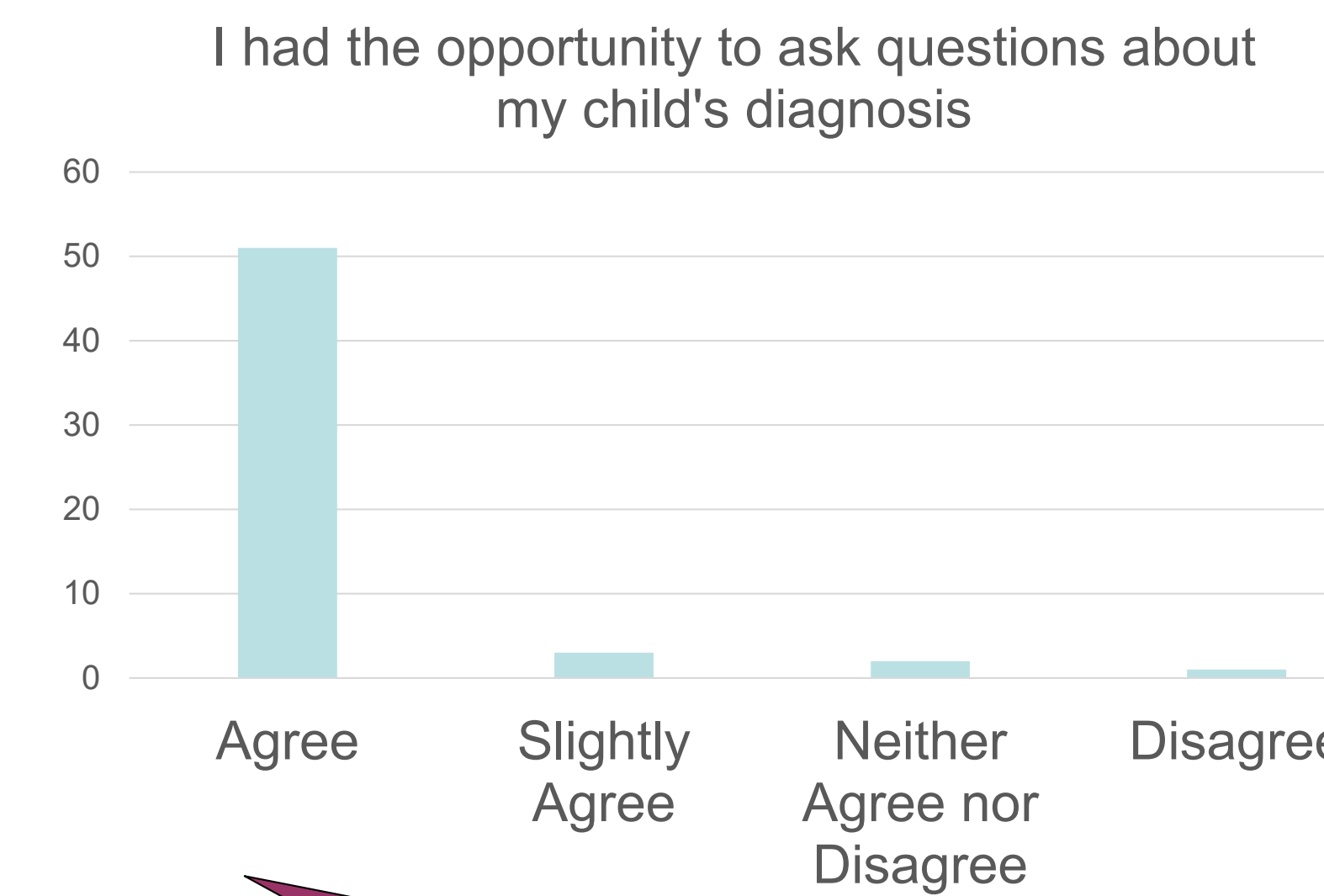
"I was provided with suggestions but there were so many things. It was overwhelming."



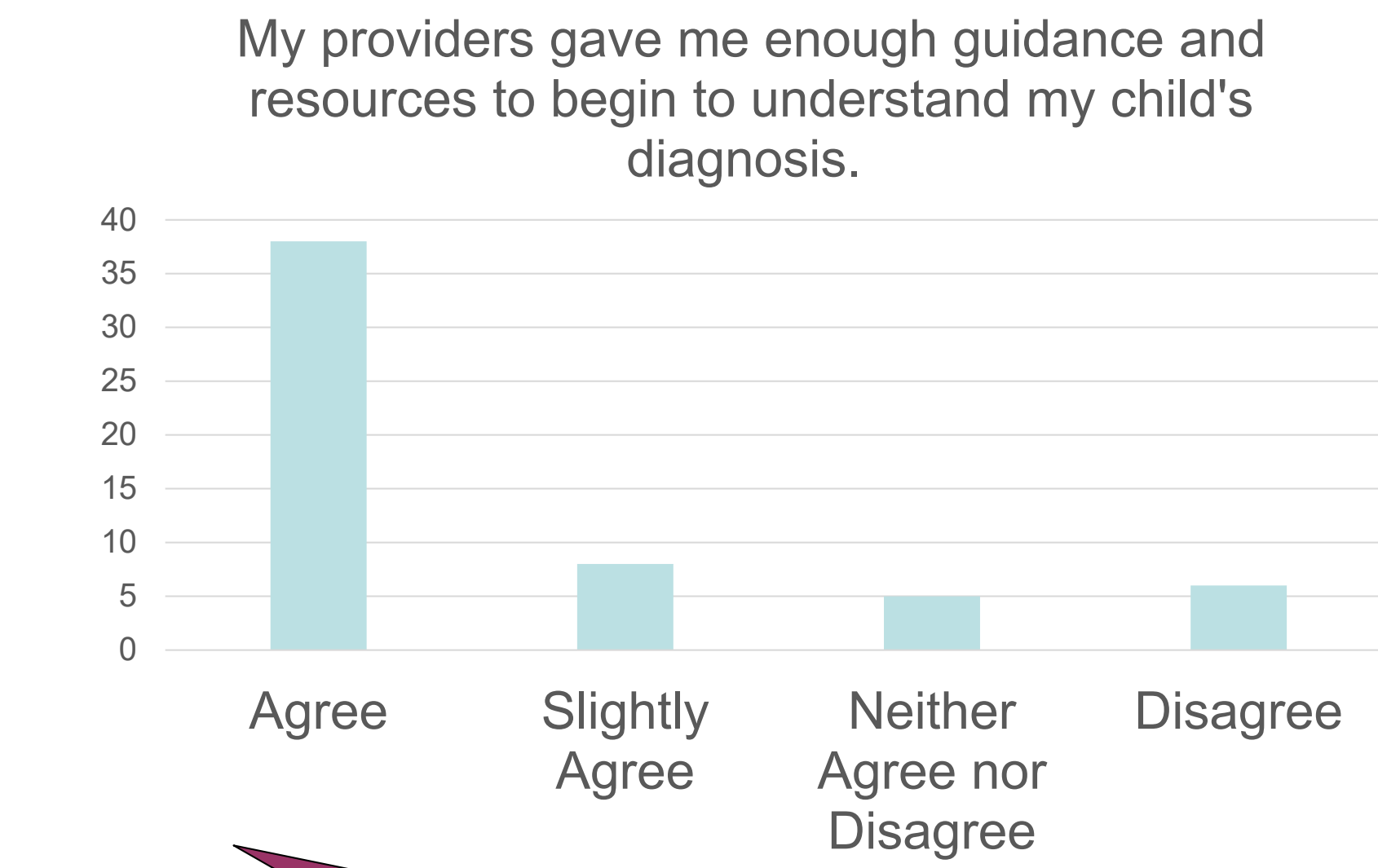
"They gave me resources, BUT I had to hunt everything down [...] It was like, here is a bunch of suggestions - best of luck. Again we felt lost and more confused."



"[The doctor] spoke to my wife and I like we were idiots [...] She spoke about my daughter like she wasn't in the room and used outdated and incorrect terms like mentally retarded and severe intellectual disability."



"A play based setting for the child in a large open space room would have [...] given us the chance to process and listen and ask questions."



"Everything I understand about autism, I've learned from my children or my independent research."

Race-based Differences

- Caregivers of color were less likely to report that their providers respected their cultural and family values ($t(54)=2.5, p<.01$)
- Caregivers of color were less likely to report that they had time to ask questions about their child's diagnosis ($t(54)=1.82, p=.075$)
- No other race-based differences in satisfaction with diagnostic process

DISCUSSION

- Most families describe positive experiences with diagnostic process
- However, **not all families have positive experiences**
- Some families are not satisfied with the referral, resources, direction, and information provided
- Some families "neither agree nor disagree" they received culturally responsive care, which was related to race

Next steps

- Continuing to recruit minoritized families to understand their experiences
- Analyze differences in recommendations and referrals by race