

Ensuring Equity in Early Childhood ASD Services in North Carolina

Ainsley Buck (Co-PI), Sophie Hurewitz (Co-PI), and Michelle Franklin (Mentor)

Background

- Children from racial and ethnic minorities are diagnosed with Autism Spectrum Disorder (ASD) at a significantly later age and with more severe symptoms than their White counterparts.¹
- Being Black, Latinx, or poor is associated with decreased access to ASD services and interventions.²

The NC Early Childhood Action Plan (NC ECAP) aims to ensure all young children in NC are:

- healthy
- · safe and nurtured
- · learning and ready to succeed

Goal 2 of the NC ECAP (Figure 1) focuses on preventative health services, including screening for developmental disorders like ASD.³

Figure 1.



Objectives

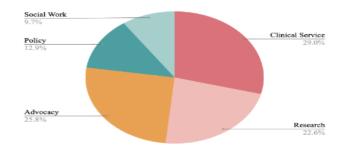
- Understand the barriers and facilitators to early childhood diagnosis of ASD among Black and Latinx children in North Carolina.
- Apply findings to develop specific implementation recommendations for providers and policymakers.

Data & Methods



- 25 informants in various sectors including clinical service, research, policy, advocacy, and social work. (Figure 2).
- Semi-structured interview domains: disparities in ASD diagnosis, disparities in ASD referrals, parent and family engagement, cultural humility strategies, and policy recommendations.
- Utilized rapid analysis for health services research and qualitative descriptive approach.⁴

Figure 2. Focus group informants (N=25) interviewed from a range of sectors



Key Findings: Diagnosis



Key Findings: Referral & Intervention







Referral Bias

Workforce Shortage

Stigma

Key Findings	Informant Quote
Provider Bias	"I cannot tell you enough how many times [Black and Brown] families say, "I've gone to the provider I've asked for this," and they're just going in circles. So yes, it's access, but it's also systemic issues, right? It's also implicit and explicit biases, it's also discrimination, it's also racism, right?"
Lack of Access	"in the more rural communities, there's nobody to provide those services"
Limited Family Awareness	"if you don't have any knowledge of the diagnostic terminologyit's a daunting taskthen you have the issue of where people are getting their information, and unfortunately there's a lot of misinformation out there"
Referral Bias	" Hispanic families were experiencing a delay in referrals they actually got screened at the same time, but for some reason the providers were actually making a referral a little bit later"
Workforce Shortage	"there's not enough providers, there's not enough understanding of autismBecause there's not an understanding of autismthen the kids aren't getting the services they need for school"
Stigma	"stigma around label and disability related to historic experiences, historic discrimination in schooling, tracking, fear and stigma not wanting to have my child labeled or placed in special education for fear of outcomes"

Recommendations

- Cultural humility strategies in higher education and the workplace (medical school, training + fellowship programs, clinics, hospital networks)
- Workforce development via incentives for providers in rural areas (NC Community Practitioner Program⁵) and diverse providers (SCRD Caucuses⁶, DBPNet⁷)
- Increased follow-up to improve successful referrals and use of data-sharing and tracking platform
- Community-level ASD education and awareness initiatives to reduce stigma



