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Dr. Mirza has an interdisciplinary background in occupational therapy, disability studies, and health services and outcomes research. Her research agenda addresses disparities in access to rehabilitation services for people with disabilities and chronic health conditions. She currently serves on the Illinois Refugee Health Task Force and the Illinois Minority Health Committee.

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BLACK AND LATINO PARENTS MANAGE THEIR CHILDREN'S SPECIAL HEALTHCARE NEEDS
Introduction

How do low-income African American and Latino parents of children with special healthcare needs (CSHCN) navigate the often complex network of healthcare services?

CSHCN are children with chronic physical, developmental, behavioral, or emotional conditions who require extensive support services (e.g. cerebral palsy, ADHD, cystic fibrosis, autism, etc.); they represent approximately 20% of US children. Research shows that African American and Latino CSHCN experience disparities in healthcare access, utilization, and quality compared to their White counterparts. Furthermore, disparities are heightened for racial and ethnic minority children from low-income families as they are the least likely to receive needed services. Responsibility for coordinating care falls largely on parent caregivers and often calls for complex skills (e.g. understanding medical terminology, evaluating treatment options, locating community-based resources, etc.). Despite their central role in managing their children's needs, parents receive little preparation or guidance to navigate the web of healthcare service options. Low-income African American and Latino parents are particularly disadvantaged as education and language can further isolate them from healthcare services and information networks.

This project used focus groups to understand the experiences of low-income African American and Latino parents of CSHCN as they managed and coordinated their children's healthcare needs on a daily basis.

Preliminary Findings

- To secure healthcare services for their child, parents had to take on the roles of researcher, organizer, case manager, advocate, and networker.
- The responsibility of fulfilling the above roles affected other spheres of parents' lives. It impacted their employment, social relationships, and their physical and mental health. Sources of support varied; some parents found support in friends, family, and their spiritual community, others preferred support from professionals.
- To gain access to healthcare information networks, parents joined support groups or volunteered at their child's school or rehab facility. Parents found that connecting with another parent who could provide useful information and resources played a pivotal role in their ability to gain access to much needed services for their child.

Recommendations

There is a critical need for accessible and effective interventions that allow these parents to increase their knowledge, skills and confidence in managing, coordinating, and advocating for their child's healthcare needs. Support interventions for parents should include information on finding and seeking resources, training in advocacy skills, parent-peer mentoring, and mobile technology (i.e. an app, website, or text messaging) to disseminate information regarding healthcare services. Such interventions would be successful in helping parents of CSHCN navigate complex healthcare systems and achieve better health outcomes.