

Development of a Community Informed Approach for Implementing Support Network Trainings for Children with Autism Spectrum Disorder in Western Kenya

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Background:

Autism spectrum disorder (ASD) impacts a large global community, with a prevalence of nearly 1 in 100 children. However, little is known about the educational experience of children with ASD and other neurodevelopmental disorders (NDD) in low- and middle-income countries (LMICs). Guidance from local communities is essential when developing a cultural inquiry into this educational landscape. Our project objective was to evaluate community perspectives on ASD and areas of development for future support network trainings.

Methods:

This qualitative study was performed within the Academic Model Providing Access to Healthcare (AMPATH) program in Eldoret, Kenya. Using group discussions, this approach engaged stakeholders from three areas: medical personnel, educators, and caregivers/families. Kenyan professionals in child psychiatry, occupational therapy, and special education guided discussion and led the recruitment of key informants for interviews. Within this qualitative analysis, brief thematic analysis of dialogue elucidated key themes.

Results:

Four focus groups were held, with 87 total participants (group size = 12-29). Four main themes were identified in the data: beliefs about causes, treatment options, barriers to education, and a need for community advocacy. Advocacy was a major focus of discussions, due to a sentiment of fragmentation and poor acceptance from the community. Stigmatization carried over into local beliefs about causes of ASD, which included poor nutrition, witchcraft, and genetics. Finding resources to access education and therapy was a challenge, especially for families in rural settings. These viewpoints informed study protocol adaptation by expanding recruitment to include community-based service providers and staff from additional schools, and integrating themes into interview questions.

Conclusion:

This project prioritized dialogue with stakeholders to gain insights to inform the development of a cultural inquiry into the special education landscape in western Kenya. Themes elucidated from this project provided critical feedback to inform future study protocol and an expanded recruitment plan.