

Title: Co-Developing and Piloting Culturally-Responsive Informational Materials About Autism for Families of Young Children: Employing a Train-the-Trainer Implementation Model Within a Nonprofit Setting

NCT number: NCT06314438

Date: 3/6/2025

Study Protocol

Background:

Access to early, evidence-based autism-specific treatment can profoundly improve long-term outcomes for children with Autism Spectrum Disorder (ASD). However, current estimates reveal an eight-month to three-year gap between caregiver first concerns about their child's ASD-related behaviors and receipt of ASD-specific services. This prolonged time-period between caregiver first concerns and receipt of ASD-specific services is characterized by elevated parenting stress, increased child behavioral challenges, and reduced quality of life, even compared to families of children with non-ASD developmental concerns. Unfortunately, culturally and linguistically diverse (CLD) communities experience lengthier time-periods between first concerns and receipt of services, report increased difficulty accessing timely diagnostic and treatment services, and ultimately experience worse health outcomes compared to White communities.

Objectives:

The investigators partnered with Mother Africa, a local non-profit organization, to 1) co-design culturally-responsive caregiver-focused educational materials to support CLD families with young children who have social communication delays or ASD and 2) develop a novel route for dissemination of information and materials within non-profit organizations, which are often the preferred entry-point for accessing healthcare information and services for underserved populations, rather than traditional medical facilities. The educational materials aim to support caregiver and child well-being by increasing caregiver knowledge and use of ASD specific parenting strategies as well as increasing caregiver awareness and use of local ASD resources. This research has the potential to effect programmatic changes in the services and settings available to support CALD communities during the early years of a child's ASD condition and thereby improve child and caregiver outcomes.

Methods/Design:

Participants included 6 non-specialist providers working at a local non-profit organization and 35 caregivers. Caregivers were affiliated with the non-profit organization and met the following inclusion criteria: has a child who screened at likelihood on the Ages and Stages Questionnaire; and speaks one of the following languages: Arabic, Mai Mai, Swahili, French, Tigrinya, Dari.

This project utilized a three-stage development and implementation process informed by the literature on bridging cultural adaptation with implementation science to ensure that our end-product (i.e., culturally-responsive caregiver education materials) is relevant for consumers and feasible for deployment. Co-design methods (e.g., treating community members as equal collaborators in the design process, synthesizing feedback from target users into actionable insights) were used to ensure that caregivers, ASD specialists, service providers, and program supervisors are actively involved in the design of the curriculum and its implementation needs.

Stage 1: For the co-design phase, a working group of caregivers, Mother Africa supervisors (i.e., program managers), Mother Africa providers (i.e., administrators of developmental screeners who are matched to the culture and language of their clients), and ASD specialists were assembled and met to culturally adapt existing caregiver-education materials for a total of eight co-design sessions over 6 months. Stage 2: Using a web-based tutorial, Mother Africa staff were taught to deploy the

culturally-adapted curriculum. **Stage 3:** Providers piloted the curriculum to groups of caregivers. Supervisors, providers, and caregivers completed self-report surveys during Stages 2 and 3 to provide feedback on the cultural adaptation, implementation, and caregiver and child outcomes. The current study registered on clinicaltrials.gov focuses only on this third stage of our project (i.e., the pilot feasibility trial).

Statistical Analysis Plan:

The primary goal of our analyses was to measure change in caregiver knowledge and service usage before and after participating in our program. As such, paired samples T-tests were used to test for differences before and after implementation of the Family Care Project on the following dimensions: Staff Competence in Assisting Families with Children at-autism Likelihood Survey (self-report); The Maternal Self-Efficacy Scale Questionnaire; and Caregiver Knowledge and Use of Behaviors that Support Children at autism-likelihood Survey.

Additional, secondary surveys were analyzed using descriptive statistics for Likert scale measures and those using discrete variables (i.e., received/not received), including Staff Competence in Assisting Families with Children at-autism Likelihood Survey (self-report), The Maternal Self-Efficacy Scale Questionnaire, Caregiver Knowledge and Use of Behaviors that Support Children at autism-likelihood Survey, Current Services Utilized by Families to Support Children at autism-likelihood Survey, and Family Care Project Feedback Survey of Implementation Properties. All surveys except one were analysed using mean and standard deviation. Current Services Utilized by Families to Support Children at autism-likelihood Survey was operationalized as number of families who received or did not receive diagnostic and intervention services before and after implementation of the Family Care Project.