

Project Title: Adaptation of World Health Organization Caregiver Skills Training for Caregivers of Children with Disabilities in Zambia

Developmental disabilities (DD), including intellectual disability and autism spectrum disorder, typically have onset in childhood, affect multiple functional domains, and persist into and through adulthood. DD affect up to 20% of children worldwide. Caring for individuals with DD can be demanding, especially in lower- and middle-income countries (LAMIC) where greater caregiving burden is placed on families who often have limited knowledge about effective interventions, equating to a treatment gap of greater than 80 percent. Zambia is one of the poorest countries in the world, as evidenced by its designation as a lower-middle income economy (average annual per capita income of \$1,680) according to the World Bank. While the country's GDP has increased over the last decade, health services to individuals with DD have not kept pace. Barriers to care include limited financial resources, lack of specialists, scarce rehabilitation services, and the associated stigma of a disability. These barriers are particularly problematic in the rural areas of the country. The primary aims of this interdisciplinary CRIF project are (1) to systematically adapt an evidence-based caregiver skills training (CST) intervention developed by the World Health Organization (WHO) for children with DD and their caregivers for use in Zambia, Africa and (2) to gather data about its acceptability, feasibility, and social validity and the comparative utility of two different delivery formats of the intervention. In addition, we will gather preliminary data on child and caregiver outcomes. This project seeks to fill this gap by adapting the WHO CST into an accessible and feasible caregiver skills training program for the Zambian context so that caregivers in this area receive support to accelerate learning and development for children with DD during this critical developmental period.

Specific Aims (Goals):

1. To adapt, translate, and refine the WHO CST for caregivers in Zambia;
2. To evaluate the acceptability, feasibility, and social validity of the WHO CST in Zambia;
3. To examine preliminary evidence of the effects of the WHO CST on child and caregiver outcomes
4. To examine differences in acceptability, feasibility, and social validity of delivering the WHO CST in a group format and in an individual format.

SPECIFIC AIMS 1 and 2: ADAPTATION, TRANSLATION, AND REFINEMENT OF WHO CST

Design: The adaptation will include a formative study with basic qualitative methods to base adaptation of the program to the local context in the perspectives and experiences of community stakeholders that will be engaged with the program.

Participants: Four types of participants will be included in the proposed study including: (a) *Master Trainer*-responsible for training of group facilitators, (b) *Local Community Stakeholders*- individuals who play a significant role as decision makers or in the implementation of the program in the local context, including management personnel at the mission, (c) *Program Facilitators*- responsible for delivering the WHO CST program to caregivers, and (d) *Caregivers*- i.e., individuals who are likely to receive the WHO CST program

Measures: The primary data collection methods will be qualitative measures including: (a) key informant interviews with the master trainer and local community members, and (b) focus groups to elicit information on the acceptability, feasibility, and social validity for each format of the intervention (group and individual).

- *Key informant interviews.* Interviews will be conducted with the master trainer and local community members. A 90-minute semi-structured interview will be conducted prior to the program to inform the adaptation of the program to the needs of the local context.
- *Focus groups or individual interviews.* We will collect data from the stakeholders who participated in the adaptation process. The focus group will be used to elicit feedback on the adaptation process and the perceived feasibility and acceptability of delivering the WHO CST in the local context.

Data Analysis: The electronic voice recordings will be first transcribed in both the local language and English. Back translation of the transcripts will allow for an opportunity to check for accuracy. Transcripts will then be entered into a qualitative software program and coded using an open coding process where words or concepts that capture the data are linked to the text. Codes will be examined for consistency and redundancy via the constant comparative method. As such, themes will be developed by the researchers from examination and compilation of the codes produced via constant comparative analysis.

SPECIFIC AIMS 3 and 4: PILOT STUDY OF WHO CST IN ZAMBIA

Design: We will use mixed-methods to conduct the Pilot Study of the WHO CST in Zambia using formative qualitative measures and summative quantitative measures. We will use qualitative measures to collect data on the perspectives and experiences of the facilitators and caregivers who deliver or receive the WHO CST in the local context. We will also collect quantitative measures to capture the experiences and social validity of the caregivers who receive the intervention. The pre-post design includes two groups of caregivers who will receive different formats of the WHO CST (individual and group formats). Given the exploratory nature of the proposed project, we will examine each of the groups independently and explore differences in feasibility, acceptability, and social validity across formats.

Participants: The participants for the pilot study will include (a) two *program facilitators* – who will be responsible for delivering the WHO CST program to the caregivers, and (b) 10 *caregiver/child dyads* - who will participate and receive the WHO CST program.

Procedures and Measures: The primary data collection methods will include both qualitative and quantitative measures across multiple levels of respondents.

Data Analyses: Qualitative data collected during the pilot study will be analyzed using the methods described above for Specific Aims 1 and 2. Quantitative outcomes from the Pilot Study will be primarily descriptive and used to triangulate the findings of the qualitative measures. We will also conduct exploratory analyses to examine differences between the different methods of WHO CST format delivery (group and individual).

World Health Organization Caregiver Skills Training

The World Health Organization's *mhGAP Caregiver Skills Training Program for Families of Children with Developmental Disabilities* (WHO CST) is an evidence-informed early intervention program for caregivers of children with DD. The WHO CST has been fully developed in English and includes the following materials:

(a) Adaptation Guide, which is based on the scale up experiences of the WHO's Mental Health Global Action Programme; **(b) Materials for Facilitator Training**, which contains the procedures for training the local providers who will implement the program; **(c) Facilitator Guides for Training Sessions**, which focus on teaching caregivers strategies to engage their children in communication and play, promote child adaptive behaviors and learning, engage in positive caregiving strategies, and enhance caregiver well-being; **(d) Facilitator Guides for Coaching Sessions**, which provides caregivers with individualized coaching to help them identify how they can apply the strategies and techniques being taught during the training sessions in everyday routines and activities; and **(e) Participant Manual**, which will be provided to each caregiver and includes a visual display of the strategies and content being delivered in the training sessions. This intervention is designed to be **adaptable to local contexts** to provide caregivers of young children with DD with strategies to support their children's developmental and functional outcomes by training and coaching caregivers how to engage in daily activities with their children, how to support and increase positive child behaviors, and how to manage caregiver stress related to caring for a child with DD.