Disability Education Programming for Caregivers in Uganda

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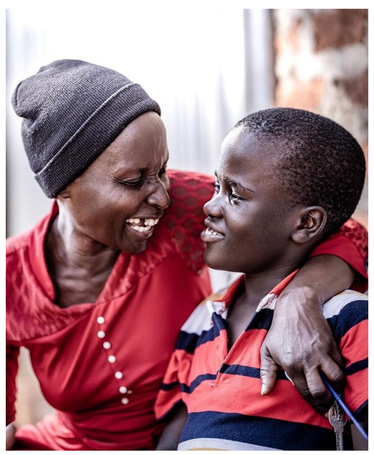
BACKGROUND

Although Uganda has made progress in recent years towards increasing their national commitment to disability rights and increasing disability inclusion in legislation and policy, there continues to be a large implementation gap due to negative cultural attitudes towards disabilities, poor funding, and inadequate/inaccessible education and training programs (Abimanyi-Ochom & Mannan, 2014; Riche & Anyimuzala, 2014). Although Uganda has made substantial progress, the microsystem level (including family systems) continues to require intervention and programming to increase inclusion and quality of life for children with disabilities.

Many caregivers of children with disability living in Uganda are unaware or uneducated about what caused their child's disability, how to accommodate their child's disability in their every-day life, and their child's potential for inclusion and independence in life. For Ugandan caregivers, the correlation of stress levels and their child's functional outcomes is directly effected by the caregiver's access to support services, including education about their child's disability (Bannink, Idro & van Hove, 2016).

Ekisa Ministries is a non-profit organization in Uganda that strives to fill this gap through providing services for children with disabilities and their families. This program development aims to provide Ekisa's community care program families with access to sustainable disability education services in order to increase their ability and confidence to properly care for their child to positively affect their family's overall quality of life.



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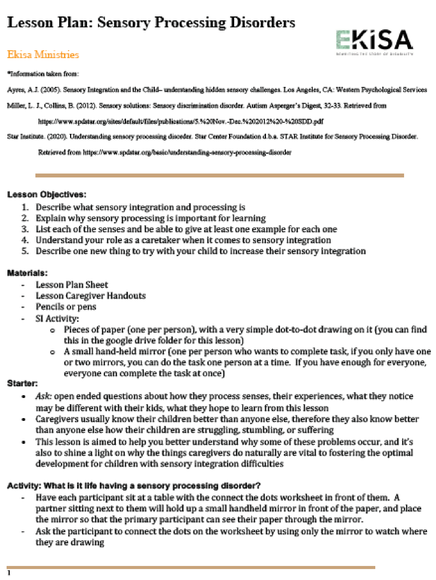
FOCUSED QUESTION

Does a sustainable model of implementing caregiver education regarding prevalent disabilities in children living in Uganda increase understanding of disability and increase familial quality of life?

PROGRAM DETAILS

Ekisa Ministries currently has four "Community Core Groups" consisting of parents of children with disabilities living south-eastern Uganda that receive services through Ekisa. Every month, each of these "core groups" meets together along with Ekisa staff members to receive services through Ekisa, including social work services, social support through community engagement, certain therapy services, and more.

A lesson plan was developed for Ekisa social work staff members to implement during core group sessions (that occur approximately once a month) to increase caregiver's knowledge of disability, specifically sensory processing disorders and cortical visual impairments (which are of high prevalence for children with disabilities served by Ekisa). These educational programs will be easily replicated by all social work staff members at Ekisa, and will be able to be re-utilized for additional caregivers that would benefit from the trainings.



Lesson Plan: Sensory Processing Disorders

Ekisa Ministries

*Information taken from:

Ayres, A.J. (2005). Sensory Integration and the Child- understanding hidden sensory challenges. Los Angeles, CA: Western Psychological Services

Miller, L. J., Collins, B. (2012). Sensory solutions: Sensory discrimination disorder. Autism Asperger's Digest, 32-33. Retrieved from https://www.spdstar.org/sites/default/files/publications/S.%20Nov.-Dec.%202012%20-%20SDD.pdf

Star Institute. (2020). Understanding sensory processing disorder. Star Center Foundation d.b.a. STAR Institute for Sensory Processing Disorder. Retrieved from https://www.spdstar.org/basic/understanding-sensory-processing-disorder

Lesson Objectives:

1. Describe what sensory integration and processing is
2. Explain why sensory processing is important for learning
3. List each of the senses and be able to give at least one example for each one
4. Understand your role as a caretaker when it comes to sensory integration
5. Describe one new thing to try with your child to increase their sensory integration

Materials:

- Lesson Plan Sheet
- Lesson Caregiver Handouts
- Pencils or pens
- SI Activity:
  - Pieces of paper (one per person), with a very simple dot-to-dot drawing on it (you can find this in the google drive folder for this lesson)
  - A small hand-held mirror (one per person who wants to complete task, if you only have one or two mirrors, you can do the task one person at a time. If you have enough for everyone, everyone can complete the task at once)

Starter:

- *Ask:* open ended questions about how they process senses, their experiences, what they notice may be different with their kids, what they hope to learn from this lesson
- Caregivers usually know their children better than anyone else, therefore they also know better than anyone else how their children are struggling, stumbling, or suffering
- This lesson is aimed to help you better understand why some of these problems occur, and it's also to shine a light on *why* the things caregivers do naturally are vital to fostering the optimal development for children with sensory integration difficulties

Activity: What is it life having a sensory processing disorder?

- Have each participant sit at a table with the connect the dots worksheet in front of them. A partner sitting next to them will hold up a small handheld mirror in front of the paper, and place the mirror so that the primary participant can see their paper through the mirror.
- Ask the participant to connect the dots on the worksheet by using only the mirror to watch where they are drawing

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METHODS

To achieve the goals of this program, the methods below were implemented. These methods were chosen based off of evidence supporting that in-person dissemination was more effective than on-line educational trainings for caregivers in Uganda (Hartley et al., 2005), and Ekisa staff member subjective opinions reporting that social group trainings have increased effectiveness (Personal Communication, 2020). The following methods were implemented:

1. Interviewed staff, volunteers, and caregivers of children with disabilities in Uganda to identify current conceptions of disability and subjects to integrate in to caregiver educational programming
2. Identified the best practices and effectiveness of educational formatting and dissemination methods for caregivers of children with disabilities through a critically appraised topic paper
3. Collaborated with Ekisa staff members on formatting of educational programming and lesson plan hand outs
4. Presented education program to staff members, and received feedback to evaluate effectiveness of educational program development

RESULTS

This educational programming will be implemented in future community core group sessions, and lead by Ekisa staff social workers, who were trained to disseminate the material.

Subjective feedback was received by Ekisa staff members who are familiar with educating family members, and feedback indicated a strong probability of effectiveness of this program.

Limitations include limited flexibility of time schedule for implementation and evaluation of program, and lack of quantitative evaluation of effectiveness of this program.

BOTTOM LINE FOR OT

Skilled occupational therapy intervention and caregiver education is needed to improve the quality of life for children with disabilities and their families, and ultimately play a role in reducing stigma of disability in both local and international communities.

Occupational therapists are equipped with unique skills and abilities that make them essential in disability advocacy, and occupational therapists can affect positive change in individuals, families, and communities through sustainable education programming, community empowerment, and fostering familial structures.

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Bannink, F., Idro, R., & van Hove, G. (2016). Parental stress and support of parents of children with spina bifda in Uganda. *African Journal of Disability*, 5(1), 1–10

Hartley, S. O. V. P., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: care, health and development*, *31*(2), 167-180.

Riche, N., Anyimuzala, J., (2014). Research Study on Children with Disabilities Living in Uganda: Situational Analysis on the Rights of Children with Disabilities in Uganda. Retrieved from http://fenu.or.ug/wpcontent/uploads/2013/02/UnicefUganda_CwDs Study_SituationalAnalysisFinalReport_2014.pdf