

# Equipping Local Leaders to Advocate for Children with Disabilities



# **Overlooked and Underserved**

According to World Health Organization, there are over 1 billion people in the world (15% of the global population) who have a disability severe enough that it limits their participation in family, community and political life.<sup>1</sup> People with disabilities are often overlooked, even by community, religious and social justice organizations focused on supporting the marginalized. Lack of support means the great majority of people with disabilities live their lives without access to the health, education, employment or inclusion they rightfully deserve. Each year, such injustice leads to poor quality of life and early morbidity for millions of people with disabilities.<sup>2</sup>

# The Case for Kids

Among marginalized groups, children with disabilities remain the most excluded, discriminated against not only because of their disability but also because of lack of knowledge about its causes, implications and stigma.<sup>3</sup> In

many countries, the majority of people do not expect children with disabilities to be productive members of society and believe they have been cursed by witchcraft or God. These beliefs often cause families to mistreat children with disabilities by hiding, neglecting, abandoning or abusing them. Some of these children are even murdered.<sup>4</sup>

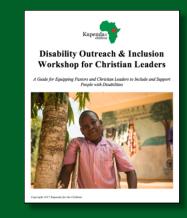
# **Targeted Sensitization**

In partnership with local leaders and organizations, Kupenda for the Children has developed a series of workshops, each targeting one of the following community groups with tailored information about disability definitions, causes, and rights.

- Government Leaders (i.e., chiefs, women's groups, members of parliament, county commissioners)
- Traditional Healers (i.e., herbalists, soothsayer, midwives)
- *Churches* (pastors, church leaders, congregations)
- Families Impacted by Disability (children with disabilities and their parents or caregivers)

Each workshop includes participatory presentations and discussions about disability and related legislation (i.e., the United Nation's Convention on the Rights of Persons with Disabilities, national Persons with Disability Acts) to ensure participants understand the legal rights and mandates supporting and protecting people with disabilities.

#### **Advocacy Training Guides**



Kupenda organizes advocacy trainings for pastors, parents, women's groups, government officials and traditional healers. Our training guides help workshop facilitators lead informative presentations and participatory discussions, which later inform participants' development of action plans, tailored to the disability cases and needs in their communities.



Hope for Zainabu



Six-year-old Zainabu has cerebral palsy, which has left her unable to walk or talk. For 2 years Kupenda has been conducting work-shops in Zainabu's community that inspire pastors, traditional healers, and government officials to change the stigma of disability and act on behalf of children with disabilities.

After our workshops, these leaders identified 76 children with disabilities in need of medical care or education. They brought these families together for Kupenda's Parent Workshop where they learned about the causes of disabilities and their legal rights. Although the families were motivated to send their children to school, we soon discovered that the appropriate schools were far away and too full.

Fortunately, the parents and leaders used what they'd learned in our workshops to fight for their children's right to specialized education. In just a few months, their group inspired the local government to donate 10 acres of land for a new school that will serve 140 children. The government also committed to paying the salaries of the school's teachers.

Zainabu and her mother are excited to think that they will soon have access to medical care, education and therapy services. Our occupational therapist has told them that these services will improve Zainabu's functioning and one day she may even be able to walk and communicate.

### **Knowledge to Action**

In addition to disability education, Kupenda's workshops challenge participants to develop action plans to guide them in identifying, including, assisting and celebrating children with disabilities in their communities. In the months following each workshop, Kupenda contacts participants to ensure and support action plan implementation and long term sustainability of inclusive practices.

# **Tailored Partners Models**

Kupenda's Disability Advocacy Training program is replicable and can be tailored for any community, nation or local leader group. We support partners who are interested in using this program by helping them 1) Identify and Recruit local leader participants, 2) Plan and Facilitate the training and 3) Follow-Up with Participants to ensure long term impact.

Training Implementation can be independent or collaborative, according to the following 3 models:

**Independent:** Kupenda sends partner the Participant Recruitment Steps, Facilitators Guide and Assessment Tools and provides the partner with remote implementation support. Partner reports workshop and follow up data back to Kupenda.

**Co-Facilitated:** Kupenda staff visits the partner and they plan and facilitate the workshop together. After the workshop, the partner reports follow up data back to Kupenda.

**Needs-Based:** Kupenda visits the partner and conducts a community needs assessment to determine the best implementation content and strategy. Kupenda and the partner then co-plan and co-facilitate the workshop and follow-up activities together.





#### **Evidence-based Program Outcomes**

Kupenda also supports its partners with tailored data collection tools that track improvements in the local leaders' Knowledge, Attitudes and Practices related to disability. We also provide tools and expertise to support partners interested in short or long-term impact evaluations.

# **Program Funding**

Kupenda assists partners in fundraising for program implementation and evaluation. We have earned government, foundation and philanthropic funds to support our disability advocacy programs in various nations around the world.

# Sustainable Impact

Kupenda's advocacy discussions and events have helped thousands of children with disabilities access the education, medical care, and legal rights they deserve. Children who are healthy and fully included in their communities also become a source of advocacy – they show others what is possible with appropriate support and adequate resources. Kupenda's advocacy model and tools can be implemented by government or private organizations and is easily adapted for any nation, language or culture.

For more information, visit http://kupenda.org or contact us at Kupenda@kupenda.org (978) 626-1625 P.O. Box 473, Hampton NH 03843

#### References

<sup>1</sup>World Health Organization (WHO). Disability and Health. Fact sheet. Reviewed November 2016. Accessed May, 24 2017:

http://www.who.int/mediacentre/factsheets/fs352/en/

### 23 Trained Leaders Reach more than 43,000 Residents with Disability Care and Sensitization



From 2017-8, Kupenda gathered reports from a sample of pastors and traditions healers who had participated in our disability advocacy workshops. These reports showed that, in just 8 months, these 23 spiritual leaders had:

- Given 264 public talks reaching 42,892 community members with messages of disability justice and inclusion
- Counseled 428 individuals impacted by disability (children and their family members)
- Referred 116 children with disabilities to medical facilities for care
- Referred 149 children with disabilities to special education or mainstream schools
- Invited 260 families impacted by disability to join church or support groups
- Invited 172 residents to join a community disability outreach group

Pastors also engaged in 731 conversations with individuals about disability justice and traditional healers had accompanied or referred 16 pregnant women to health facilities for care.

Each of Kupenda and Kuhenza's 1-day disability advocacy workshops are designed to train 25 spiritual leaders. As such, this data indicates the potential impact of a single workshop to substantially improve community sensitization about disability justice as well as care and referrals for children with disabilities and their families.

http://www.who.int/healthinfo/global burden disease/GBD report 2004update part3.pdf

<sup>&</sup>lt;sup>2</sup> WHO. Global Burden of Disease Report Part 3: Disease Incidence, Prevalence and Disability. 2004. Accessed May 24, 2017.

<sup>&</sup>lt;sup>3</sup> Global Partnership for Education. Children with Disabilities. 2017. Accessed May 24, 2017. http://www.globalpartnership.org/focus-areas/children-with-disabilities <sup>4</sup> Munyi, Chomba Wa. Past and Present Perceptions Towards Disability: A Historical Perspective. Kenyatta University, 2012. Accessed May 24, 2017. http://dsqsds.org/article/view/3197/3068