

# Changing Cultural Perception on Disability through Empowerment of Families and Local Leaders

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## Abstract

Advocacy workshops tailored to influential community groups results in sustainable and beneficial changes for children and youth impacted by disabilities in Kilifi County Kenya. From June 2015 through April 2017 Kupenda conducted 23 workshops with 603 participants. They included tailored workshops for pastors, traditional healers, government leaders, and families impacted by disabilities. Based on surveys, 73% of participants believed in spiritual causes of disabilities. After participating in our workshops 67% of those with superstitious beliefs, claimed to believe in the biological causes of disabilities presented to them. In addition to changing belief systems, 73% of workshop participants provided evidence of action on behalf of families impacted by disabilities in their communities. Our work with these community groups provides evidence that change in belief systems and awareness about disability issues within the local population leads to support and inclusion of families impacted by disabilities.

## Background

Kupenda for the Children, a U.S. based nonprofit organization, and its Kenyan partner organization, Kuhenza for the Children's Foundation, are improving the lives of thousands of children with disabilities in Kilifi County, Kenya and select regions of Tanzania. Our work to improve social and cultural views related to disability leads to proper implementation of disability legislation and actions that help children with disabilities access the education, health care and social inclusion they need to reach their greatest potential. This success is the result of Kupenda and Kuhenza's work to strategically educate and empower spiritual leaders, as well as families impacted by disability and other stakeholders.

According to World Health Organization (WHO), there are one 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>

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, too many people view children with disabilities as not fully human and believe they have been cursed by witchcraft or God. These

beliefs often cause mistreatment of children with disabilities like hiding, neglecting, abandoning or abusing them. Some of these children are even murdered at birth.<sup>4</sup>

In most developing nations, local leaders have a significant impact on community norms, beliefs and behavior related to children with disabilities. In regions where these leaders believe disabilities result from curses or are a punishment from God, children with disabilities are often excluded from social life and left without proper medical and educational services. Presenting leaders with information about the true causes and effective treatments for disabilities helps to reduce these negative beliefs and harmful treatment strategies and increase acceptance and support for children with disabilities.<sup>5</sup> In sub-Saharan Africa, community leaders with the greatest influence over community belief systems tend to be pastors and traditional healers due to their prevalence, proximity to rural populations, and widely trusted services, counsel and support. Government representatives' beliefs and actions regarding disabilities are also important to influence as they have access to the most resources of any of our target groups. This is in addition to having the ability to create and implement legislation beneficial to people with disabilities. Based on discussions with a variety of disability rights organizations in the U.S., it was discovered that most exist because of the advocacy of individuals with disabilities and/or their families. However, many of the families in Kilifi county do not have access to proper resources or care regarding disabilities. The distinctive roles of the four groups who participated in advocacy workshops led by Kuhenza and Kupenda, are important to understand for maximum success.

## Church Leaders

Many church members and leaders believe disabilities have spiritual causes, due to their interpretation of the Bible and the widespread prevalence of traditional beliefs.<sup>6</sup> They believe causes may include behavior such as incest, infidelity, or demon possession. In Kenya, Kupenda's baseline surveys indicate the majority of Kupenda's pastor beneficiaries believe children with disabilities have been cursed and must be healed. Those who remain unhealed are often accused of having a lack of faith, causing them and their families to be further stigmatized and excluded from the church. In some cases, pastors who have been "unable" to heal a disability have also been seen as lacking connection to God and lost members of their congregation as a result. Because more than 80% of Kenyans practice Christianity, these beliefs have a significant influence over the views held by most of the population.<sup>7</sup> Fortunately, when Christian leaders understand biblical texts regarding inclusion of people with disabilities in the church, along with biological causes and effective treatments for disability, they often develop positive beliefs regarding people with disabilities. As they share the new knowledge and attitudes with their communities and congregations, more children with disabilities are welcomed into the church and provided with care, support and inclusion.<sup>8</sup>

## Traditional Healers

Interviews with Kupenda's beneficiaries and research from Kenya Medical Research Institute (KEMRI) indicate a high prevalence of harmful traditional beliefs and witchcraft practices on the Kilifi Coast of Kenya. Although some traditional healers provide appropriate care for children with disabilities, many others conduct harmful "healing" practices and share inaccurate information that encourages discrimination, neglect, abuse or even murder of these children. Many of these leaders also encourage families to pursue spiritual remedies instead of medical care, leading to increased morbidity and mortality among children with disabilities. For example,

families in our programs have reported that traditional healers burn the heads of children with hydrocephalus with hot sticks and cut the tongues of children with speech impediments or no speech at all. Often these traditional belief systems are combined with practices from other religions, such as Christianity and Islam. Because many Kenyans live in remote regions or are too impoverished to pay transportation costs, access to health facilities is often a major barrier to effective care. As a result, most families who have a child with a disability will first consult traditional healers in their community for diagnosis and care. Educating traditional healers about disability can help to sustain and expand their helpful practices while reducing harmful treatments and improving health care referrals.

## Government Leaders

Throughout the world, there is widespread discrimination against people with disabilities, poor implementation of policies designed to protect these individuals, and inadequate funding and legislation in support of people with disabilities. As with religious leaders, some government officials also believe that curses, witchcraft, incest and evil spirits cause disabilities. More often they exclude families with disabilities from needed services because they simply are unaware of their needs. Because these government officials have a strong influence over community beliefs, distribution of funding, and implementation of legislation, their education and activism is essential to meeting the needs of children with disabilities. In many cases, in sensitizing these leaders inspires them to uphold existing legislation and either develop or expand laws to include children with disabilities in addition to funding special needs facilities and programs. Furthermore, they often share their new knowledge and attitudes at public forums, thereby raising awareness, improving social norms, and inspiring activism from community groups and compassionate individuals.

## Families Impacted by Disabilities

Based on discussions with successful western disability service organizations, most were stated by families impacted by disabilities. However, if parents don't care about their child with a disability, or are shunned by their communities and in isolation because of the disability, they are often unable to act. It can be difficult to find these families because many are too ashamed to admit they have a child with a disability. In some cases, we have witnessed parents of a child with a disability excluding this child when asked to report their number of offspring. In other situation, we've seen families hiding the children with disabilities to protect them from harm and prevent them from being ridiculed. Fortunately, parents who are accurately informed about their child's disability and feel empowered to help them access education and care often become their most successful advocates. Support groups, counselling, financial support and services referrals can help families better support and care for children with disabilities. Many supported families also become advocates for their children's rights and counselors for other families impacted by disability.

## Methods

### Study Participants

Participants for this study were selected from the Kilifi County of Kenya, Kupenda's primary intervention site. The population of Kilifi County is approximately 1.2 million and WHO estimates

indicate there are 120,000 children and youth in Kilifi with life-altering disabilities.<sup>9,10</sup> The education office in Kilifi County reports that only 3,000 children with disabilities are in a school of any kind.

We collected results connected to attitude and action for four influential groups involved in our workshops. We also work with large scale public gatherings and other individuals but they are more difficult to track so for the purposes of this study we focused on the groups we were meeting with for the first time enabling us to gauge pre and post impact on belief and action.

The 603 participants in these targeted workshops included:

- 216 pastors who participated in 8 pastor workshops;
- 70 traditional healers (herbalists, soothsayers and traditional birth attendants) who participated in 3 traditional healer workshops;
- 124 local leaders who participated in 4 government workshops; and
- 193 parents and caregivers who participated in 8 family workshops.

## Training Materials and Delivery Strategy

In partnership with local leaders and organizations, Kupenda developed four types of workshops, each targeting one of the following community groups with tailored information about disability definitions, causes, and rights.

### Church Leaders Workshop

Participants: pastors, church leaders

Content: The purpose of this workshop is to educate and empower Christian leaders in relation to disability, within the framework of Christian theology. By drawing on participants' beliefs and experiences related to disability, the workshop also guides them through the process of developing a compassionate, inclusive response to disability, based on the bible, and tailored to their communities' unique needs.

- **Traditional Healers Workshop**

Participants: herbalists, soothsayers, traditional birth attendants

Content: This workshop is coordinated and led by Kuhenza staff, a traditional healer, and a medical professional. A facilitated discussion takes place about common traditional practices that can help children with disabilities and others that can be harmful. Participants learn how to make timely referrals to local health facilities for their patients with disabilities who require more acute care.

- **Government Leaders Workshop**

Participants: chiefs, members of parliament, county commissioners

Content: During this workshop, government leaders are encouraged to collaborate with one another to include children with special needs in funding decisions connected to education, health, and legislation. They are also encouraged to share accurate disability knowledge with their communities and encourage traditional healers and other local leaders to identify, support, and refer children with disabilities in their regions.

- **Families Impacted by Disability Workshop**

Participants: children with disabilities and their parents or caregivers

Content: Because these families impacted by disability are often isolated and rejected by their communities, we open this workshop by asking them to share what they've experienced as a parent of a child with a disability. Our facilitator then provides information about their children's disabilities and trains them on home based care and communication strategies to help them improve their child's quality of life. These meetings also help parents learn about possible funding sources to help their children access education and care. Parents are encouraged to come together to start parent support groups, learn sign language, and advocate for new or improved special needs facilities in their communities.

In addition to this customized content, each of our workshops include participatory presentations and discussions about disability and related legislation and belief systems (i.e., *the United Nation's Convention on the Rights of Persons with Disabilities*, national Persons with Disability Acts) to ensure participants understand the rights and mandates supporting and protecting people with disabilities in their regions.

Every workshop also included accurate information on the true causes and effective treatments for various disabilities. Our facilitators then divide participants into small groups to develop action plans to guide them in identifying, including, assisting and celebrating children with disabilities in their homes and communities.

## Data Collection

Between June of 2015 and April of 2017, Kupenda surveyed the 603 workshop participants before and after their workshops to evaluate the changes in their attitudes toward people with disabilities.

After the workshops, we tracked changes in the participants' skills and behavior through group representatives and beneficiaries of their efforts. Changes were measured by recording the number of participants who took one or more of the following actions:

- Identifying children with disabilities in their communities,
- Referring children with disabilities to the Kuhenza office for services and/or counseling,
- Referring children with disabilities to health facilities for medical care,
- Referring children with disabilities schools for application and enrollment,
- Paying tuition fees to enable children with disabilities to attend school,
- Sharing information about disability in their communities,
- Constructing facilities for children with special needs,
- Providing of assistance equipment to children with disabilities,
- Establishing support groups for families impacted by disability,
- Working with other government leaders to establish special education programs in their communities,
- Volunteering at special needs schools, and
- Providing food and/or supplies to children with disabilities.

# Results

**Table 1. Pre- and post-workshop changes in participants’ attitudes toward disability**

	No. of workshops	No. of participants	No. of participants with superstitious beliefs about disabilities pre-workshops	No. of participants with superstitious beliefs post-workshops	Percent change in beliefs
<b>Pastors</b>	8	216	173	43	75%
<b>Traditional healers</b>	3	70	70	35	50%
<b>Government representatives</b>	4	124	25	0	100%
<b>Families impacted by disability</b>	8	193	174	97	44%
<b>Total</b>	<b>23</b>	<b>603</b>	<b>441</b>	<b>175</b>	<b>67%</b>

Based on pre-workshop surveys, 73% of workshop participants believed in spiritual causes and treatments for disabilities when surveyed at the beginning of our meetings. After workshops 67% of all participants with these incorrect views, reported to no longer believe them. This data also reveals 100% (70 individuals) of traditional healers in our workshops believed there were spiritual causes and treatments for disabilities, making them the group with the highest superstitions. Only 20% of government representatives (25 individuals) indicated believing in mystical causes of disabilities, making them the group with the lowest number of misconceptions about disability.

**Table 2. Reach and Impact of Kupenda’s Disability Advocacy Workshops (June 2015 – April 2017)**

	No. of workshops	No. of participants	No. of participants with evidence of action	Estimated no. of people reached through participants' advocacy efforts	Estimated number of children with disabilities benefitting
<b>Pastors</b>	8	216	162	8,100	810
<b>Traditional healers</b>	3	70	28	5,600	560
<b>Government representatives</b>	4	124	56	22,320	2,232
<b>Families impacted by disability</b>	8	193	193	1,930	193
<b>Total</b>	<b>23</b>	<b>603</b>	<b>439</b>	<b>37,950</b>	<b>3,795</b>

Report data indicates that 73% of our participants (439 individuals) worked to improve the lives of children with disabilities in their communities and/or homes (table 2.). Based on our program demographics, county-level data, and the project’s follow-up reports, we estimate these actions resulted in improved disability knowledge and attitudes among 37,950 people in our participants’ spheres of influence and improved quality of life for 3,795 children.

## **Pastors**

Among participants in this group, 75% of the pastors with incorrect beliefs about disability, reported changes in their beliefs and committed to sharing accurate information about disability causes with their congregations and communities after completing our workshop. Those who did not originally believe in superstitious causes or treatments were also motivated to make their churches more inclusive. As shown in the table 2, there is evidence that 75% of the pastors involved in our workshops (162 individuals) provided evidence of actions within 6 months, which included:

- Identifying children with disabilities in their communities in need of support,
- Referring children with disabilities to health facilities for medical care,
- Establishing support groups for families impacted by disability,
- Working with the government to start special need education programs in their communities,
- Sharing information about disabilities they learned in our workshops with their congregations
- Motivating church members to volunteer at special needs schools, and
- Providing food to families impacted by disabilities.

## **Traditional Healers**

Among our traditional healer participants, 50% (35 individuals) expressed interest in learning more about the medical causes and treatments of disabilities after completing our workshop and provided evidence of actions which included:

- Identifying children with disabilities in their communities in need of support,
- Referring children with disabilities to the Kuhenza office for services and/or counseling,
- Referring children with disabilities to health facilities for medical care, and
- Sharing information about disability in their communities.

## **Government Leaders**

After completing our workshop, all 124 of our government leader participants reported that they believed people with disabilities should be included in their work. Based on surveys at the beginning of workshops, only 20% believed disability was the result of curses but were aware that most people in their communities held superstitious beliefs about disabilities. At the end of the workshops none claimed to still believe in spiritual causes or treatments for disabilities. Although the majority did not have superstitious beliefs about disability most were unaware of the true biological causes and support services for them. Out of the 124 government representatives, 45% (56 individuals) provided evidence of actions, which included:

- Identifying children with disabilities in their communities,
- Referring children with disabilities to the Kuhenza office for services and/or counseling,
- Referring children with disabilities to health facilities for medical care,
- Referring children with disabilities schools for application and enrollment,
- Paying tuition fees to enable children with disabilities to attend school,
- Sharing information about disability in their communities,
- Constructing facilities at special schools,

- Working with other government leaders to establish special education programs in their communities,
- Giving disability-related talks during in their monthly public meetings and
- Reprimanding parents of children with disabilities for neglecting their rights

### **Families Impacted by Disability**

Although 10% of families surveyed did not believe in spiritual causes or treatments connected to disability, all 193 of the families involved in our parent workshops reported discrimination against their family member with a disability connected to the beliefs of others in their communities. Most families did not know about support services or have funds to pay for them. Approximately 80% of families reported that they had taken their children to traditional healers or their pastors for treatments. Even though only 44% reported an immediate change in superstitious beliefs after completing our workshop, all 193 of our family participants reported that they would take their children for educational or medical support services that Kuhenza staff recommended. All participants acted to apply what they had learned in our workshop as evidenced by:

- Forming parent support groups
- Starting income generating projects or savings accounts to help one another with their needs
- Coming to the Kuhenza office for further services and/or counseling,
- Taking their children to health facilities for medical care,
- Bringing their children to school,
- Applying for scholarships with the government or Kuhenza to cover their children's tuition fees
- Sharing information about disability in their communities, and
- Working with pastors, traditional healers, and government leaders to establish special education programs.

### **Discussion**

Communities on the coast of Kenya sustainably benefit children with disabilities when they are equipped with resources and have opportunities to collaborate with their peers. Although 67% of participants reported they changed their spiritual beliefs about disability to more accurate views, 73% were evidenced to act (table 1 and 2). This is due to the 27% of participants in our workshops who did not indicate they believed in superstitious causes of disability who were motivated to action through the facilitated discussions and distribution of information during the gatherings. Additionally, there were also some members who still believed in spiritual causes of disabilities but chose to act on behalf of children with disabilities anyway. Follow up research will be done to evaluate the positive results on the health and well-being of children with disabilities in the communities of the participants. However, the results of these targeted workshops indicate that a change in belief systems, regarding disabilities, motivates communities to do more for children with disabilities and their families including provision of health, education, and a inclusion in a loving community. Each targeted group played a unique role in reaching 37,950 people within their spheres of influence and they also work together to achieve long-lasting change.

## Church Leaders

Workshops tailored for pastors in Kenya, had an impressive effect on communities impacted by disabilities considering they had the second highest population reach out of the four target groups. These workshops were influential considering the dramatic shift in belief among pastors from most thinking curses and witchcraft are responsible for disability to the majority believing in true causes and treatments for people with disabilities. Most people claim to be Christian in our project area<sup>7</sup>. Therefore, the changes in Christian leadership influences their communities' beliefs especially when their pastors teach Christian responsibility to include and care for children with disabilities beyond healing rituals. This change in cultural attitude, results in beneficial actions of Christians on behalf of children with disabilities in their communities. Based on stories from individuals within the spheres of influence of these Christian leaders', further research is likely to reveal more benefits for this challenged population as the message spreads over time. Pastors involved in our workshops are often the first community leaders to work towards positive change for children with disabilities and to collaborate with traditional healers, government representatives, and families impacted by disabilities.

## Traditional Healers

We have only strategically worked with traditional healers since 2015 whereas we have been utilizing and improving the methodology geared towards the other three groups since 2006. Therefore, the structure of these traditional healer meetings is likely to improve with time. Even though our workshop structure is still evolving, half of this group expressed a change in beliefs and practices and followed up with actions benefitting families impacted by disabilities (table 1, and 2). With 80% of people in these communities seeking healthcare from traditional healers these changes are influential on the people in the villages of traditional healers<sup>10</sup>. The high number of traditional healers expressing a change in belief towards disability reveals the effectiveness of our facilitated workshop though most have devoted their entire lives to practices based on false superstitions and have high rates of illiteracy. For some, they may not want to admit to changing beliefs about disability because it could impact their livelihood even if they are influenced by our workshops. Therefore, we are researching ways to connect them to income generating activities like commercial production of some of the herbal remedies they utilize that have been proven effective<sup>11</sup>. With only a few, distant, medical facilities available, traditional healers could become important first responders for sickness if they are properly trained<sup>12</sup>. With this in mind, follow-up meetings with traditional healers will also include basic first aid practices which will benefit the community and provide a possible source of income for traditional healers.

## Government Leaders

Although the majority of government leaders did not express belief in spiritual causes for disabilities, most admitted they had not supported their constituents with disabilities prior to workshops. Participants had the lowest percentage take actions after workshops compared to the other groups but they influenced more people because they are connected to government funding, legislation, and direct involvement with large community groups (table 1 and 2). They even have influence over traditional healers and can compel them to attend workshops tailored for them. The administrative challenges most government representatives face, impede their ability to immediately implement many changes motivated by our workshops. Even with these challenges, because of these workshops from 2015 to 2017, 17.8 million Kenya shillings (~\$186,000 USD) was provided by the government for hiring of staff, assistance equipment, and

construction of health and educational facilities for children with disabilities impacting more than 3,000 children in Kilifi County (table 2). Just one government official making positive changes regarding families with disabilities can impact between 400 to 10,000 people depending on the size of their district. Therefore, even if very few are motivated to do more for people with disabilities in their districts, large scale benefits may be achieved. As legislative hurdles are overcome and the message of inclusivity spreads throughout the regions, there is likely to be even more benefits for children with disabilities over time.

## Families Impacted by Disabilities

These workshops are often the result of pastor, traditional healer, and government meetings. The participants of the aforementioned workshops are asked to find families impacted by disability and bring them together during the Kuhenza gatherings they participate in. They then, work with Kuhenza to facilitate a family workshop. For example, in January 2017, children with disabilities were discovered through the traditional healers. They reported to the government chief who called them together, and a pastor hosted the Kuhenza family workshop in his church. Most families involved in Kuhenza workshops, have not had an opportunity to speak freely about their children or their challenges. The parents who attend, may have incorrect beliefs about the causes and treatments for disabilities, but they show up because they want to do what is best for their children. Therefore, 100% of those involved made efforts to improve the lives of their children when they are connected to the proper facilities and resources. The majority have been isolated from their communities and never encountered anyone in their situation. When they come together they find comfort in their shared experiences. Most continue to meet after the initial workshop which increases well-being for the families<sup>13</sup>. In addition to the emotional support they receive by coming together, some have started income generating projects and group savings accounts to support the health and nutritional needs of their children. These families end up being the strongest advocates for their children and encourage other parents by their example. Based on discussions with members of large western disability rights and service organizations, most began with a group of committed families impacted by disabilities. Therefore, in the years to come, it is expected that these families will bring about large-scale change for children with disabilities as a result of the family workshops in their regions.

## Conclusion

In just over 2 years, Kupenda's workshops improved community-based activism among pastors, traditional healers, government leaders and families impacted by disability in the Kilifi County of Kenya. Kupenda's disability advocacy workshops have equipped hundreds of local leaders and families to help 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 workshop can be implemented by government or private organizations and are easily adapted for any nation, language or culture. Equipping local communities creates sustainable change and increases benefits for children and youth with disabilities in Kenya and anywhere else in the world with similar belief systems.

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