

CULTURAL CONTEXTUALIZATION OF DISABILITY IN UGANDA: NEW  
APPROACHES TO COMMUNITY-BASED REHABILITATION

BY

KEVIN S. HUTCHINSON

A thesis submitted in partial fulfillment

of the requirements for the

Degree of Masters of Social Sciences

In International Care and Community Development

NORTHWEST UNIVERSITY

Kirkland, WA

April 4th, 2013

**Table of Contents**

Abstract.....4

Foreword.....5

Introduction.....7

Introduction to Disability in Uganda.....9

Introduction to Community-Based Rehabilitation.....11

Disability in the Ugandan Culture.....14

    Traditional Beliefs of Impairments.....15

    Religion in Uganda and the Role of the Church.....19

    Education in Uganda.....25

    Conclusion.....27

Recommendations.....28

    Conscientization.....28

    Cultural Dimensions and Education.....30

    Participatory Methods.....33

        PWD Participation.....34

        Partnerships among Community Development Organizations.....37

        Community Members.....39

        Education.....42

        Religion.....45

Conclusion.....47

References.....51

Appendix .....57

### **List of Acronyms Used**

CBR- Community-Based Rehabilitation

CBROs- Community-Based Rehabilitation Organization

CD- Community Development

CDOs- Community Development Organizations

CC- Chili Children

CWDs- Children with Disabilities

DPO's- Disabled People Organizations

LMICs- Lower and Middle-Income Countries

PHC- Primary Healthcare

PWDs- People with Disabilities

SOH- Spring of Hope

WHO- World Health Organization

### Abstract

The author outlined a method that aimed to improve the lives of people with disabilities in developing nations. The model, community based rehabilitation, is the popular standard in providing care to people with disabilities in rural areas of developing nations. The author of this thesis argued that the community based rehabilitation model has traditionally been focused too much on the individual rather than the community surrounding the individual. Children with disabilities have often been stigmatized and rejected in many rural communities in developing nations. This author used a case study that showed different aspects of the Ugandan society that perpetuate these stigmatizations and rejections of children with disabilities. To overcome these stigmatizations in the Ugandan culture, the author responded by recommending ways to change these negative perceptions. The recommendations start with community based rehabilitation workers knowing the intricacies of the culture they are working in and, secondly, advancing participatory methods within each community. Specific examples to how to implement these methods are outlined as well as real-world examples and stories from the field.

*Key Words:* Disability, Uganda, Rehabilitation, Contextualization, Culture, stigma, impairment.

## Foreword

“Why God, oh why?” she screamed in her local tongue – Lugandan. Her eyes pursed, trying to hold the tears back. Her grandson, Joseph, lay still on the cold cement floor of their clay and sand hut. I put my forefingers on his long, cold, and damp throat. There were no beats. No words were said between her mother and me, but she could see from my face the fate of her grandchild. Joseph was still- he was dead. He was only 20 years old; with an estimated weigh at around 50 lbs. the last time our organization came to see him about two weeks before his death.

I had never met Joseph before that day. While on the boda-bike (small motorcycle) travelling back to the clinic, Barbara asked me if I would like to go see him and I hesitantly said yes. Her question, now in my mind, was asked by God. I heard about Joseph from a co-worker one week before. She told me how Joseph had suffered from malaria for several weeks and was so sick he was unable to eat any solid food. He had endured malaria once before in his short life as an infant. The malaria had attacked his nervous system and the effects of this sickness left Joseph suffering from cerebral palsy during his adolescent years. Stories like his were all too common in the Kangulumira district of Eastern Uganda.

I placed my hand on the shoulder of Joseph’s grandmother and I prayed with her. Barbara, looking as if nothing had happened, gestured me to step back on the boda-bike. I could not believe she showed no emotions during this intense moment. I realized that Barbara had seen this setting many times before. This situation was not new to her—a

person dying from malnutrition in a remote area of Uganda. This situation was the norm for her and other families in Kangulmira.

As the wind blew through my hair, my dusty eyelids tried to hold the tears back. Children screamed, "*Mzungu!*"- a Lugandan word for a Caucasian person- as I clung to the driver. For the past three weeks, I would smile and wave to the happy children. Today I sunk my head into the back of the driver as tears flew to the red earth. "Why doesn't she care? Why didn't we stay longer?" I asked those questions to myself, and I still do to this day.

Three days later, Joseph was buried. His mother was not there at the time of his death because she was in Kampala trying to find work so she could pay for Joseph's many medical needs. She was not there to help her child, to give him food to survive, or to console her mother after the death of her grandson. Joseph's situation deteriorated without the care of his mother and the lack of care from the rest of the community. This situation is not new in rural Uganda. It has happened for generations. It is ingrained in their culture.

## Introduction

This was just one of many difficult encounters I had while volunteering for Shin the Kangulumira Sub-County in Uganda. There are many reasons why Joseph was in said situation. Most of the factors attributing to Joseph's condition, and ultimately his death, were a result of the cultural disposition of impairment. Joseph lived in a rural community where medical and rehabilitation services are almost non-existent. Joseph's mother had given up on him, and didn't see any hope for his rehabilitation so she left him in the care of her mother. He was kept indoors- where he had little chance to sit up, move around, or keep his muscles from tightening- because his grandmother was ashamed of having a disabled child in her home. Moreover, the family's chronic poverty led Joseph to live in a state of malnutrition and without proper medicine. Joseph's impairment was, in the medical sense, the "cause" of his death. However, the culture in which he lived in promoted the degradation of his condition, which, ultimately, led to his death.

When a person with impairment becomes alienated, discriminated against, or handicapped by their environment in a particular society, that person can then be described as "disabled." Therefore, when I speak of people with disabilities (PWDs) in this paper, I am referring to people with any impairment that may lead to the individual being discriminated against, stigmatized, or systematically excluded from their society. This paper will guide the reader to understand how a specific community in the Ugandan culture defines disability and the way culture shapes how people treat, react, provide services to, and act towards people with impairments. I have also made recommendations to the Community-Based Rehabilitation (CBR) field on how to provide culturally competent services for PWDs in developing nations. I contend that it is imperative that

CBR workers in Uganda, and the rest of the developing world, to understand the socio-cultural contextualization of disability in order to provide effective, sustainable, and holistic services to Children with Disabilities (CWDs) and their families.

A person's impairment does not make that person "disabled" necessarily. The contextualization of impairment in a society in which the disabled person lives will shape how that person is treated. Culture, the great enabler and generally a positive term, can also be disabling. If there is anything people do naturally, it is that they live culturally, in groups, with goals, rules, expectations, abstractions, and untold complexities. Culture shapes all that we know and gives all the tools with which to learn (McDermott & Verenne, 1995). Culture can also be destructive, divide people into groups, and disseminate inequalities. Social repercussions to impairments are culture-sensitive and culture-bound. Many cultures contextualize people who have impairments differently, and so, many individuals are disabled in different ways.

This paper will help the reader to understand the cultural complexities surrounding children with disabilities in Uganda. People in Uganda, and other developing nations in Africa, understand disability through social interaction and participation in informal and formal institutions. I concentrate on CWDs because my fieldwork was with children. Education, religion, and traditional beliefs are just some of the social platforms that help make meaning of disability. To change perceptions of CWDs in the Ugandan society and others in the developing world, community development workers must use participatory methods to include CWDs in all aspects of society.



Community-based rehabilitation (CBR) is a method developed by the WHO to utilize community resources to better the lives of CWDs. The CBR method, although, tends to focus too much on the individual and not the society surrounding the CWD. I will later recommend ways CBR can change its vision in order to reduce stigma surrounding the CWD.

### **Introduction to Disability in Uganda**

PWDs, irrespective of where they live, are statistically more likely to be unemployed, illiterate, to have less formal education, and have less access to advanced support networks and social capital than their able-bodied counterparts (Yeo, 2005). This is no different in Uganda where anywhere from 4% (just less than one million people) to 7.1% (2.1 million people) of the total population is considered to have a disability (Ministry of Finance, Planning and Economic Development, & Uganda Participatory Poverty Assessment Process, Kampala, 2008). These statistics are very vague because each culture, subculture, community, and family will perceive the term “disability” in a different way. Statistics cannot be trusted because many perceive a disabling condition in different ways: a sickness, impairment, a curse, etc. Kisanji (1998) described the issue of disability statistics, “The currently available statistics on the prevalence of impairments in different parts of the world is guesswork because perception of impairments is culture-bound, and culture-sensitive assessment instruments are yet to be developed” ( p.2).

CWDs have faced stigma and rejection in Uganda for centuries. My research and professional experience has shown me that people in many developing nations who have various chronic illnesses and impairments are often stigmatized—that is, marked as

different by others and socially devalued because of this difference (Shuttleworth & Kasnitz, 2004). Goffman (1963) defined *stigma* as a discrediting attribute, an undesired difference from social expectations (p.4). The social model of disability- which the World Health Organization (WHO) is moving towards- draws a distinction between impairment and disability. Impairment refers to physical and/or psychological abnormalities of the body or brain while the term disability refers to the manner in which society alienates or discriminates those with impairments (Lang & Murangira, 2011b, p.166). This definition of disability will be the working definition throughout the paper. Impairment is a human characteristic; it knows no bounds in terms of location, type of condition, age, social or economic status (Kisanji, 1998, p.3).

Even though Uganda has been one of the leaders in Africa for enacting legislature protecting the rights of PWD's, there has been a significant "implementation gap" as no regulations or methods to implement legislature have been enacted (Lang & Murangira, 2009a). The African Decade of Disabled Persons jump-started the disability movement in Uganda. In fact, the Ugandan Parliament has five PWDs representing the country. Many laws in the past 20 years have been passed that protect and promote, in principle, the rights of PWDs, including health, education, and voter rights. However, even with these new laws, the lack of legal implementation and the prevalence of traditional cultural beliefs transforming attitudes about PWDs have left PWDs stigmatized and living on the margins of the Ugandan society.

### **Introduction to Community Based Rehabilitation**

Most scholars agree that PWDs, no matter how they are perceived, are among the most vulnerable and most underserved populations on the planet, and for people living in developing nations, poverty breeds disability and vice versa (Lang & Murangira, 2009a; Shuttleworth & Kasnitz, 2004; World Bank, 2009). Those who are already disabled have lower living standards through adverse impacts on education, employment, income, and increased spending on disability-related expenditures. Poverty may also increase the prevalence of disability through poor health and its determinants (World Health Organization & The World Bank & WHO, 2011). In the past decades, Primary Health Care (PHC) was the model being used in developing nations before CBR came to fruition. The PHC method separated PWDs from society, and focused on institutionalization and individual healthcare. PWDs were separated from mainstream society in healthcare, education and other social services. In order to improve on the PHC method and to combat social stigma, poverty, and lack of access for PWDs to social services, Community Based Rehabilitation (CBR) was introduced by the World Health Organization (WHO) in 1978. Lang (2011) described the reason behind the WHO's reasoning to switch to a CBR method:

The original impetus for the emergence of CBR derived from the recognition that, given the social and economic profiles and demographic projections found in many countries throughout Asia, Africa and Latin America, traditional patterns of disability service provision were deficient and inadequate in meeting the needs of disabled people. (p. 167)

CBR was first initiated by the WHO to improve access to rehabilitation services for PWDs in low-income and middle-income nations by making optimum use of community members and community resources to better the lives of PWDs (Khasnabis, & Motsch, 2010, p.11). CBR organizations (CBROs) implement these objectives this by helping PWDs to be included in community healthcare initiatives, inclusion in community education programs, helping to create income generating activities, and advocacy to local governments to provide necessary social programs to PWDs. The rural environment in lower and middle-income countries (LMICs) tends to lack necessary resources and infrastructures that support PWDs. PHC workers noticed this gap in service and began to develop the CBR strategy to help families in the rural setting. The model calls CBR professionals to draw on existing organizations and infrastructures, recruit local supervisors, involve the community in important decisions, connect CBR with the locations' own development goals, and take responsibility for the inclusion of this underserved population (Lang, 2011).

CBR is now the popular method in treading PWDs in developing nations. Lang (2011) described in his work, *Community-Based Rehabilitation and health professional practice: Developmental disabilities and challenges in the global North and South*, that among scholars who study the social and cultural effects of disabilities, many have been digressional regarding the concepts of “care”, “rehabilitation”, and “health”, because by their very nature, the provision of such services dehumanizes the nature of disability and impairment (p. 166). From its origins, the CBR implementation has been very individual and impairment-focused because it was based from a medical model (Ndaziboneye, Nyathi & Mzoma, 2006; Sally Hartley, personal communication, February 11, 2013).

Thus, more careful detail needs to be aimed at stakeholder participation in order to steer away from this individualistic approach, which does not encourage the participation of PWDs in community activities. Instead, I argue that CBR workers must focus their attention on the community members and their culture just as much as the disabled individual in order for true rehabilitation to take place.

The WHO lists five key components of CBR: health, education, livelihood, social and empowerment. The WHO, along with most other organizations, tends to look at each of these categories at the individual level and not within the culture in which the program is taking place. CBR workers tend to advocate for PWDs to be included in each of these areas, but many do not concentrate on changing these institutions' perceptions.

The culture surrounding the disabled person will tell the worker whether the society will view the person in a positive or negative light. Normalizing judgment has become a typical cognitive style, classifying "people in terms of their relationship to a social norm" (Douard, 1995, p. 154). As Canguilhem (1989) observes, "norms, whether in some implicit or explicit form, refer the real to values, express discriminations of qualities in conformity with the polar opposition of a positive and a negative" (p. 240). If the CBR worker focuses on the individual while ignoring the community or the "other," the social norms will still exist and the PWD remains stigmatized and rejected in their respected society. As I will discuss later, the participatory approach is one that will have the most impact on the contextualization of disability in a culture.

In the Ugandan context, CBR workers, especially those coming from the Global North or Western nations, must first understand the way Ugandan society contextualizes

the term “disability” within their culture. The next section describes the many ways the Ugandan culture perceives, treats, discriminates against, and/or integrates PWDs in their lives and communities. The information described next comes from my extensive literary review of disability in Uganda as well as my fieldwork in 2012 with the CBRO, SOH, in the Kangulumira Sub-County, near Jinja, in southeastern Uganda.

### **Disability in the Ugandan Culture**

As I have shown previously, CWDs in Uganda lack proper access to crucial social services at the same time stigmatization and rejection remains the largest hurdle for many CWDs to overcome in Uganda and other LMICs. Many children and adults face stigma and are rejected, abused, and discriminated against because of local traditional values and perceptions of CWDs. For example, in Uganda, CWDs face stigma because many rural villagers still use derogative terms that reinforce conditions of stigmatization and exclusion, and often lead to rejection and conditions of vulnerability to poverty (Ministry of Finance, Planning and Economic Development, & Uganda Participatory Poverty Assessment Process, Kampala, 2008).

The local term for a person with a disability in the Kangulumira Sub-County is “obulemu” and the term for a disabled child is “omwana aliko obulemu.” In a personal interview (August 22, 2012), Juliana Nyawacho introduced me to some of the derogatory terms used by Ugandans in the Kangulumira Sub-County. Many terms, such as “obulemu” and “ekirema” for PDWs and “omwana aliko” for CWDs, strips the person of their humanity by reducing them to an object—an item whose very identity is centered on

the disability. These belittling terms are just some of the obvious cultural signs of stigmatization. Other cultural phenomena such as traditional beliefs, education, and religion have more subtle ways to discriminate and stigmatize CWDs.

### **Traditional Beliefs of Impairments**

Perceptions of the cause of disability also alienate CWDs in the Ugandan society and can cause other physical and psychological problems. In Uganda, perceptions of causes of disability in some rural communities are attributed to being "God's will". Some believe that a disability is something which man has no control over because it is an act of God, especially when the cause is not completely apparent as in an accident or from a violent act (MFPED, 2008). In a study conducted in Uganda (Ministry of Finance, Planning and Economic Development, & Uganda Participatory Poverty Assessment Process, Kampala, 2008), the researchers described local religious and traditional beliefs subjecting PWDs to stigma and isolation:

In some communities cultural constructions and witchcrafts were linked to causes of disabilities. There is still strong perception in almost all the rural sites visited that if the “spirit” demands are not adhered to they can lead to children in some families being blind, physically disabled, epileptic or with mental retardation, cerebral palsy, hydrocephalus, hunchback. Witchcraft can also cause disabilities especially mental health problems, some physical deformities and impotence.

(p.16)

When working alongside SOH, I gleaned from community members and CBR workers that many CWDs and their families visit “witch doctors” or traditional healers before

seeking the help of trained medical professionals. The reasons are twofold: first, traditional healers are much more abundant than medical clinics in rural areas such as Kangulumira. Visiting the traditional healer is much more convenient and less time-consuming than travelling sometimes up to six hours to a clinic by foot or taxi. Secondly, traditional beliefs regarding disability equate a disability to a curse by a family member, ancestor, or spirit. Also, some traditional beliefs view disabilities as caused by a sin that a parent made in the present or past life and therefore they visit the traditional healers because they are experts in the spirit realm. A report by the Uganda Ministry of Finance, Planning, and Economic Development on Disability and Poverty (2008) described the cultural beliefs of disability and traditional healing:

[Chronic] disability which could not be explained was attributed to evil spirits, curses on people, their families or communities for misdeeds in the past or, on other occasions, feuding parties be they individuals or families accusing one another of bewitching the other. As a result, it was found that parents with strong cultural beliefs refuse to take their children for proper medical treatment in preference of traditional healers. (p.18)

I experienced these phenomena quite regularly when I was participating in my fieldwork with SOH. On one occasion, a girl, who I will call “Sarah” and was believed to be between fourteen and seventeen years old, came into the SOH clinic complaining that she had been seeing visions. The girl, whom I found out suffered from epilepsy, described to me that she can no longer go to church due to her visions and because she was afraid of what her family members may have done to her. She described to me that her parents believed that her uncle had cursed her with this impairment. Her parents and the rest of



her family believe she is bewitched and they no longer treat her with any respect or dignity.

Some reports from locals and media suggested that in communities where witchcraft and traditional beliefs exist, community members believe CWDs are a result of curses. In communities in northern and eastern Uganda, witchdoctors are sacrificing disabled people in ritual ceremonies (Ssegawa, 2012). Of the multiple families I interviewed while working alongside SOH, I discovered that people will go to the local traditional healer first whenever the cause of an ailment is not self-evident. Given the prevalent belief that disabilities are not the result of a medical ailment, *and* the fact that many are the result of unseen factors, the decision to visit the traditional healer is purely logical from the cultural standpoint of the Ugandans. However, this is not true for all disabilities. If the disability *can* be directly linked to a seen event, such as an accident, families are more likely to seek out modern medical help. When a family visits a witchdoctor, they would generally be asked for either a sum of money or a domestic animal (e.g. goat or sheep) to sacrifice (personal communication, Teresha Clark, July 13, 2012).

My many interviews with families in the Kangulumira community led me to understand that the traditional healers held much influence in the cultural contextualization of disability in the community. SOH had a negative attitude toward the traditional healers in the area and had no relationship with these so-called “witchdoctors.” CBROs that work in the same community with these healers need to understand why many community members go to these healers rather first than actual doctors. Thus, I

advocate that the organization would benefit to understand the reasons families are visiting the traditional healers so to better reach these families.

I interviewed a traditional healer (anonymous, personal communication, July 18<sup>th</sup>, 2012) and participated in a ritual ceremony after I had a firm grasp on this cultural dimension. First, I introduced myself as someone who was interested in learning more about traditional healing and its ties to disability. The ceremony was a very insightful, participatory method that helped me to understand better the viewpoint of the healer and of many families of CWDs. After a ceremony where the traditional healer channeled an ancestor or spirit, I interview him and learned more about his perceptions and about other traditional healers' perceptions of disability.

This particular healer generally saw anywhere from two to five disabled patients per day but sometimes, on the weekends, he could see as many as 100 in a single day. He said that all of his clients must pay prior to any ceremony, whether it is in the form of money or a domestic animal, such as a goat or chicken, to sacrifice. To begin the healing process, the healer goes into a trance after smoking tobacco where he asks a spirit to enter his body. This spirit will speak through the healer and will decide what form of payment needs to be offered. Also during this trance, the spirit will choose which type of treatment needs to be conducted. He maintained that it wasn't him who made the recommendations or diagnoses but it was that of the spirits who channeled his being.

I asked said traditional healer about his perceptions of epilepsy—one of the most common impairments among CWDs in the area. He described to me that there are two different kinds of epilepsy: one being caused by accidental brain damage, such as a fall or

a sickness at birth; and the other is in the form of an evil spirit entering the person's body. The healer said he could only treat the latter, while he refers patients who have the former to a hospital in Jinja or the capital, Kampala. Finally, I learned that the healers feel that the local church believes that their workings are satanic. He told me that many of the healers actually belong to various churches, mostly Catholic, in the area. Some, though, especially the charismatic sects, are not friendly or open to speaking with the healers at all.

This interview along with my extensive literature review showed to me a great divide in the way the traditional healers perceive disability compared to the way Western models of CBR define disability. Traditional healers shape the contextualization of disability in Uganda. Perceptions of disability being a result of a curse or evil spirits result in CWDs being socially de-valued and stigmatized because they are seen as a product of evil-doings. Traditional healing is not the only aspect of culture that leads to local contextualization of disability. Religious beliefs and the beliefs of church leaders also shape the way Ugandans perceive people with impairments.

### **Religion in Uganda and the Role of the Church.**

Many Ugandan Christian views on disability can be summed when we look at the Gospel of Luke, specifically Chapter five. In verses 18-26, a paralyzed man was brought before Jesus by a few men. Then, Jesus forgave the men (who brought the paralyzed man to Jesus) of their sins, and then he performed a miracle on the paralyzed man:

Jesus said, "Which is easier: to say, 'Your sins are forgiven,' or to say, 'Get up and walk'?" But I want you to know that the Son of Man has authority on earth to

forgive sins.” So he said to the paralyzed man, “I tell you, get up, take your mat and go home.” Immediately he stood up in front of them, took what he had been lying on and went home praising God. Everyone was amazed and gave praise to God. They were filled with awe and said, “We have seen remarkable things today.” (Luke Chapter 5:22-26)

This biblical account of a miracle being performed to make the disabled man “able” is an example of how Ugandans view Christianity with regard to a disability. Many Ugandans believe the only way religion and disability are connected is the chance that a miracle can cure a CWD. Many parents of CWDs say that if they knew the cause of the disability, then it is not a spiritual matter. For example, a mother of a child suffering from epilepsy caused by a burn that occurred during infancy in Kangulumira explained, “We know the cause of the disability so there is no reason to pray. If we did not know the reason, we would seek spiritual assistance” (anonymous, personal communication, July 11, 2012). Another mother with a CWD suffering from cerebral palsy also explained her view on religion and disability in an interview:

Well, SOH was able to tell us why Waswa has this disability (malaria) so we don’t really think it is a spiritual matter... I do not pray anymore... My husband died a couple years ago and I have lost faith in prayer or religion. I am more concerned with keeping my family fed and my farm running. I would like to see my other children succeed. (anonymous, personal communication, July 11, 2012)

Therefore, when a cause is not known, prayer is only used to ask God for healing and miracles to “cure” their child yet not to help the child become a part of the community.

When a miracle did not happen, then the parent generally lost faith in religion. The lack of faith that many parents described, the lack of support by the church to CWDs, and the non-inclusive environment of the church have led to CWDs being left out of religious activities and spiritual assistance.

The CIA World Factbook (2013) claimed that almost 84% of the Ugandan population is Christian, while 12% are Muslim. Christian influence runs deep in Uganda and, especially in rural areas, the Pentecostal Christian church has heavy influence on the local population. The local churches in Kangulumira have been very slow to respond to the disability movement and challenges disability puts on their communities. As a result, many churches lack the basic infrastructure commonly found in a society that is more culturally competent towards PWDs. Ramps, automatic and wide doorways and accessible isles and restrooms are some of the common infrastructural challenges faced by PWDs in Kangulumira.

The Christian churches in the Kangulumira area of Uganda have not recognized PWDs in the community as well as have not provided an inclusive environment where PWDs and their families can feel supported by the church. In a survey (see Appendix) I performed over several weeks in Kangulumira and its surrounding areas, I found that many families felt too disgraced and embarrassed to attend church. I surveyed 27 mothers of CWDs who were given care from SOH. Out of the 27 mothers interviewed, 20 claimed Christianity as their religion (two out of these families said their father was Muslim while their mother was Christian). From these 20 mothers, an overwhelming majority of 18 said they attend church regularly. Unfortunately, these numbers do not tell the whole story. Only five of these 18 mothers said they attend church with their disabled child, and only

three of them said they felt supported by the church (additionally, none of the seven Muslim mothers said they felt supported by their mosques). Reasons for the lack of support and attendance of the CWDs varied. My survey also revealed that travel limitations for the child was a prevalent reason for lack of attendance along with the child's behavior issues, shame, and absence of support from the father.

From said research, I am confident to make the following claim: the uncooperativeness and inaccessibility to Christian churches in Kangulumira enhances social stigma within the community. Scarcity of proper education regarding disabilities appears to be a challenging task for pastors and parents to overcome. Pastors in the Catholic and Protestant churches were unaware of the amount of CWDs in the community, and were also unacquainted of the issues of accessibility to their churches.

In an interview I had with the head of the Catholic churches in the Kangulumira, I came to understand better the reasons behind the church's struggle with regards to including/not including CWDs and their families. Pastor Patrick Mbula is the head pastor of over 50 churches in the county. Not until recently had Pastor Patrick realized the importance of providing proper support to PWDs in the community. SOH had recently introduced a pastors-training program before I arrived in Uganda. A volunteer provided some basic education on the theology of disability as well as medical and inclusive education on disability. Pastor Patrick described his, and the broader church's, thinking about disability before these trainings:

Before (she came), in our community, we generally... didn't know and we didn't consider the teaching of disability and human beings. Sometimes people hide

them and leave them unattended to and the church was doing the same. The church was believing in one single way ...if I pray he will be healed or the child would be healed and when he is not healed they would lose faith. We didn't know exactly the cause of disability. (personal communication, Patrick Mbula, July 18, 2012)

The Christian church in Kangulumira was unknowingly excluding CWDs from their church, and thus, adding to the stigmatization of CWDs in their community and enhancing the contextualization of disability in a negative light in their culture. When the institution that arguably has the most influence on how Ugandan's perceive the world around them excludes and discriminates against CWDs, this has led to the community as a whole to retain negative attitudes and stereotypes towards CWDs. Fortunately for the church leaders, SOH provided several pastors training on disability which, in turn, changed the pastors perceptions of CWDs is leading to the changing of the contextualization of disability within the community. Pastor Patrick described his, and many other pastors, evolution of their thinking and perception of CWDs:

Now when this lady came she gave us a new idea, we changed the trend from thinking that that was only demonic to that there could be a cause. Now that thinking there is a cause, what can the church do is be responsible for enlightening the community that disability is not a demon possession but you can have a source. We realized that maybe somebody can become disabled during the birth time, during the pregnancy, and we also realized that the way they are thinking is wrong, so we realized that that can be done. That is what she brought us from her meetings and workshops. So that is what we learned: One, we

realized that disability is not demonic and two, we realized that the church can also help and that they can take all types of medication and they can be OK.

(personal communication, Patrick Mbula July 18, 2012)

After Pastor Patrick and many other pastors learned about disability, its causes, and ways to be inclusive, Patrick noticed a change in perception within the community. Pastors in the area constructed ramps, went out in the community to assess the needs of CWDs and their families, providing more support to parents, and teaching other community members about disability. Patrick described a major change of mindset for the members in the community:

Now, we have friends who are treating poverty and are constructing a house for them (parent of a CWD). Although it is physical, it is also spiritual. So we use the parents who are Christians and we use the church to reach out to the parents who have disable children. (personal communication, July 18, 2012)

Now, instead of community members ignoring the disabled children, and parents hiding said children, the church has made great strides in promoting the community to have an inclusive attitude toward CWDs. Only until recently have negative perceptions of CWDs started to change in this community. Many CWDs are still stigmatized in communities surrounding SOH, but the process is underway and may take some time to reach and alter all people in the community. These educational programs, promoted by SOH and other CBROs, have shown to be progressive to the perceptions of community members. Education initiatives are an important aspect of community-based rehabilitation that can help or hurt communities' perceptions of CWDs in Uganda



## **Education in Uganda**

In the most recent data on disability, The Uganda National Household Survey of 2005/06, found that out of the total population of 27.2 million, over two million people were living with disabilities in Uganda (Uganda Disability Scoping Study, 2009). Out of these two million people, the majority (over 31%) of the disabled are children (ages 0-17) (Lang, 2009a.). CWDs represent the largest group of disabled persons in Uganda. Most of these children do not receive effective educational resources, which is arguably the best way to combat social stigma.

CWDs in Uganda do not have proper access to inclusive education (IE) in Uganda. IE is defined by Friend, Bursick, & Hutchinson (1998) as the integration of most students with disabilities in general education classes. Mittler (2000) described that the trend in social policy is to advocate for IE in order to combat exclusionary and discriminatory practices. The Ugandan government has ratified the UN Convention on the Rights of Persons with Disabilities. Article 24 of this document endorses IE by saying, “with a view to realizing that this right without the discrimination and on basis of equal opportunity, State Parties shall ensure an inclusive education system at all levels and lifelong learning” (Lang & Murangira, 2009b, p. 21).

Though the Uganda government has sanctioned this article, as stated before, they are far behind in implementing many of their stated desires. One study showed that IE could not be implemented in an effective and sustainable way in Uganda given that their mainstream educational system is currently inefficient (Ministry of Finance, Planning and

Economic Development, & Uganda Participatory Poverty Assessment Process, Kampala, 2008, pp. 108-110). Inaccessibility to school buildings means that students in wheelchairs take significantly longer to reach classroom instruction. Narrow doors, steep steps, and the lack of special toilets discourage CWDs from going to school (MFPED, 2008, p.45). PWDs have also conveyed that the lack of different types of intelligence and learning support systems, to ensure that schools cater for learners' diverse needs, are also keeping CWDs from schooling.

In the communities where SOH works in Uganda, SOH provided to help include CWDs into schools. SOH was able to work with in the main community's primary school to integrate five CWDs (with various impairments) into the classroom. SOH worked with the "head of disability" in the school. While these children were attending school, unfortunately they did not have the proper tools to help them learn. The children who were deaf did not have teachers who knew sign language. Children who could not write were not able to take tests and were not given any alternatives. If a blind child were to attend school, no Braille was available.

In an interview with the school's "disability coordinator," I realized she was responsible for outreach and education in the community, helping teachers include the students in the classroom, accessibility issues in the school, finding each students place in the school, and planning activities for the disabled student (personal communication, anonymous, July 22<sup>nd</sup>, 2012). I realized that this person was also asked to teach classes and didn't have much time to complete these tasks because the lack of resources in the school. CWDs did not seem to overcome prejudice because they were not given the necessary tools to show that they can participate with able-bodied students in the school.

The opportunity for able-bodied children and CWDs to participate together in Uganda is limited. In a conversation with Teresha Clark, founder of SOH, (personal communication, Aug. 25, 2012) she noted stereotypes that CWDs cannot learn or are worthless are perpetuated by the fact that they are not given the opportunity to learn alongside their peers. Uganda lacks the necessary infrastructure and resources to implement IE in their schools. Without IE, all children in Uganda will not experience the proper atmosphere to break down barriers of attitude (Elekwe & Rodda, 2010, p. 119). Exclusionary practices will begin to be seen as the norm for able-bodied peers at an early age. Moreover, CWDs are not given the opportunity to develop crucial employment, social, and communication skills to help them be productive members of the community. The shortage of these skills denies CWDs opportunities for empowerment and prospects to change negative community perceptions.

### **Conclusion**

There are many social factors leading to the contextualization of disability in Uganda. From traditional beliefs to educational and religious practices, Ugandans define disability in terms of how these cultural foundations relate to impaired people. I have shown the many difficulties one CBRO had working in a context where CWDs were marginalized and stigmatized. CWDs are stigmatized in many impoverished nations around the developing world. What can CBROs do combat these cultural contextualizations of disability that stigmatize the disabled? The following section will guide the reader on different recommendations for CBROs dealing with these issues.

### **Recommendations**

Although the future of CWDs in Uganda and other developing nations may seem bleak, the field of CBR has made amazing strides in the past 34 years to improve living conditions for, arguably, the most vulnerable population in the world. CBR programs implemented by foreign agencies have not reached their full potential but they can do so by understanding their local community's culture better and by providing collective rehabilitation plans. Examples of the following recommendations are made specifically for CBROs in Uganda, but these themes can be used for other CBROs in developing nations which are led by foreign workers. These recommendations describe methods the organizations can use the CBR model in order to transform perceptions within developing nations and to change culture from disabling to enabling. I will spend the remainder of this work offering recommendations supported by many examples and statistics.

#### **Conscientization**

My first recommendation starts with all of the workers within the CBRO-staff and supervisors included. Intended or not, all outside community development workers will come with biases and an ethnocentric position of the culture they are entering. The first thing a CBRO must do is to self-reflect on their own biases and ill-defined cultural identities regarding CWDs and even the culture they are working in. As Korbin (1981) pointed out:

If we do not include a cultural perspective, we will be entangled in the ethnocentric position of considering our own cultural values and practices preferable, and indeed superior, to any other. At the same time, a stance of

extreme cultural relativism, in which all judgments of human treatment of children are suspended in the name of cultural sensitivity, would be counter-productive to promoting the well-being of the world's children. (p. 3)

Supervisors and staff, even when trying to work with the most vulnerable, will have an ethnocentric position that blinds them to some cultural dynamics in place in the community. A study on disability in Uganda found that most PWDs felt that institutions supporting PWDs are managed by those without disabilities, and who seem to lack a positive attitude toward them (MFPED, 2008, p. 39).

Social stigma will persist especially when CBR workers harbor these feelings. Therefore, I recommend that all CBROs first develop methods of self-reflection, or conscientization as Paulo Freire described in his famous work *Pedagogy of the Oppressed* (1970), where cultural sensitivity is priority.

Freire (1970) described a method in which individuals could develop critical understanding of their own social realities through reflection and identification of “generative themes.” This method starts with a dialogue in which the staff directs the discussion instead of an outside teacher. Small groups where respect is a top priority and the conversation is member-led and teacher-guided, will help to uncover each member's own biases of CWDs and the community in which they work. By doing so, workers will internalize their feelings and act in different ways when confronted with their own biases. An “institutional consistency” will begin to develop once all workers have uncovered their biases, and then are thus capable to respond in a culturally aware manner. A consistent reexamination is also necessary to help the most vulnerable, as Freire pointed

out, “those who authentically commit themselves to the people must re-examine themselves constantly” (Freire, 1970, p. 60).

### **Cultural Dimensions & Education**

Not only must a CBRO be aware of its own organizational biases, it must be aware of the dimensions of culture within the community it is working. Each society will have different cultural dynamics that can stigmatize or discriminate against a CWD. As stated before, an individual with impairment isn’t necessarily disabled, per se. It is when the social dynamics in each culture lead to conditions that hamper the individual’s development that a person is then “disabled.” Each CBRO must look at the cultural dynamics in play that leads to the disabling conditions.

Geert Hofstede, along with Gert Jan Hofstede, and Michael Minkov (2010), in his pioneering study on cultural dimension theory, provided key insights on how organizations can respond to different cultural dimensions of nations. In his study, Hofstede outlined five key dimensions of national culture: Power distance, individualism, masculinity, uncertainty avoidance, and long-term orientation (2010). In practical terms, a CBRO can study these dimensions for each culture they work in order to understand how the dynamics in play that lead to disablement or can help the worker provide culturally-sensitive programs that decrease social stigma.

For East Africa, Hofstede (2010) expressed a very low score for “individuality.” This means, in general, nations in East Africa live in collectivist societies which Hofstede (2010) defined as “societies in which people from birth onward are integrated into strong, cohesive in-groups, which throughout people’s lifetime continue to protect them in

exchange for unquestioning loyalty” (p. 92). A CBRO can look at this information and understand that family-bonds will be strong, thus CBR programs aimed at strengthening parents and family-member education and understanding of disability may help the CWD immediately. Societies where individualism is high, CBR workers may understand that family may not provide integral care to the CWD, so looking at strengthening ties in external institutions will be more beneficial.

CBROs can also educate themselves on the dynamics of culture within a society by hiring and training members from the local community. Local staff will provide the best insight on how a community works, what dynamics are in play, and how families and participants may prefer care and respond to care. CBR workers who are not from the local community must spend time working and living within the community in order to better understand community dynamics. John Perkins (2007) described the need to live among the community to understand their needs, “[without] relocation, without living among the people, without actually becoming of the people, it is impossible to accurately identify the needs as the people perceive them” (p. 65).

SOH hired and trained local staff as physical therapists, occupational therapists and accountants. These local staff members were able to understand the family and community dynamics more than any outsider could, as they knew the customs and the language. Said staff was able to effectively counsel families and educate other community members about disability because community members had a build-in level of trust with these workers. SOH also recruited volunteers from the U.K. and the U.S. to provide services. However, non-local volunteers were not given proper education on Ugandan culture and were not educated on the complex reasons why CWDs were

socially stigmatized. Many of the volunteers came to SOH and experienced “culture shock” and were not able to provide the most culturally-sensitive, and ergo sustainable, services. Trust and rapport was not built up between volunteers and families because of language barriers, cultural differences, and time.

CBROs will be better served if local staff and volunteers are used within the given approach and demographic. This option is not always available because many developing nations lack the infrastructure to educate persons on disability. For example, many schools in Uganda lack staff trained on special education needs to help CWDs integrate into classrooms better (Ministry of Finance, Planning and Economic Development, & Uganda Participatory Poverty Assessment Process, Kampala, 2008, p. 40). CBROs may find it difficult to recruit educated local staff and may have to turn to overseas volunteers to fill this gap. If they do use overseas volunteers, CBROs need to provide the volunteers with proper education on local culture and disability-related information.

CBROs can also build trust with families with CWDs by employing PWDs. This can help to build trust with families, as they tend to prefer services that are managed by disabled people themselves. In Uganda, one development worker noted that, “For us, we believe ‘nothing for us without us,’ so we would rather have our own institutions managed and run by persons with disabilities and offering services to persons with disabilities” (Ministry of Finance, Planning and Economic Development, & Uganda Participatory Poverty Assessment Process, Kampala, 2008, p. 39). PWDs will know that the CBRO is not discriminatory themselves if it is managed by a PWD. This, again, will help build trust and provide another path were PWDs aren’t stigmatized in society.



Conscientization, Hofstede's (2010) cultural dimensions, hiring of local workers, and personal relocation will all help the CBRO successfully adapt to and understand crucial cultural dynamics at play. These methods need to be extensively employed before beginning programs. After cultural dynamics are better understood, CBR programs should then, and only then, proceed to provide care.

### **Participatory Methods**

Most CBR programs are focusing too much on the individual aspect of the person's impairment and not enough on why that impairment disables that person in that specific environment. A CBRO has the ability to improve the health of a CWD through physical and mental rehabilitation, but only other individuals within the community can provide an inclusive and stigma-free environment that enables CWDs to have productive and fulfilling lives in a community. CBR programs must focus less on individual rehabilitation and more on community rehabilitation as a part of community development. CBR programs can do this by informing themselves of the cultural dynamics of the groups they are working with by advocating that CWDs be included in all aspect of society. Organizations can do this by using different participatory methods with different stakeholders.

The next question a CBR program should ask before initiating any participatory projects is: "who are the stakeholders for this project?" Generally, in the given community, the stakeholders will be PWDs themselves, parents and family members of PWDs, community leaders and gatekeepers, CBR professionals and workers, other NGOs in the area, governmental organizations, and all other community members. A CBR

program should involve all of these stakeholders in their project in a participatory manner. It will be important to understand what we mean by “participation” before continuing.

The World Bank’s definition of participation involved stakeholders who “influence and share control over development initiatives, decisions and resources which affect them” (World Bank, 1994). Moreover, participation can be seen as both *transformative*- disseminating the voices of non-hegemonic voices will be the most powerful- and *instrumental*- traditional institutions are not working but can be improved by the involvement of the beneficiaries (Mohan, 2001, p. 2). The participatory method of CBR should involve both of these philosophies.

Traditional community development has been a “top-down” approach managed by powerful institutions, whereas at the grassroots level, which CBR can be considered, participation is managed by local stakeholders giving the community self-determination (Lang, 2011, pp. 167-168; Mohan, 2001, pp. 4-5). This type of participation is a key method in CBR so as to transform long-held beliefs. As stated before, the CBR method outlines how to use local community members and community resources to better the lives of PWDs (Khasnabis, & Motsch, 2010); but what should that look like? Each stakeholder has a variety of interests, different needs, and different challenges when it comes to participation. The most important participatory member is the PWD.

### **CWD Participation**

Some initiatives of CBR were, and still are, focused on the charity model, which isolates the individuals in their homes and limits empowerment and positive community

and social impact (Ndaziboneye et al., 2001). This method is economically unsustainable, unsuccessful in reducing social stigma, and unsuccessful in meeting the many different physical and social needs of CWDs. These programs, which are often run by outsiders, are seen as “belonging to the external provider rather than the community itself” (Ndaziboneye et al., 2001). The model creates dependency and doesn’t promote local investment or ownership from families of CWDs themselves. The United Nations Position on the Participation of PWDs and Their Organization stated in “Rule 3” that “PWDs and their families be actively involved in programme design for their own rehabilitation, right from the word go.” “Rule 18” stated that PWDs should be encouraged to participate in every initiative concerning them (United Nations, 1994).

Action on Disability and Development (ADD) in Uganda has a unique model that uses PWDs as CBR frontline workers. Chelshire Homes in Uganda provides formal employment to qualified PWDs and provides training to PWDs to build professional capacity for work. These examples gave PWDs themselves ownership of the programs and provided avenues so that others in the community could see the abilities of PWDs. PWDs became models for inspiring others to help and for other PWDs to become more active in the community (World Health Organization, 2003). These types of programs gave the DPO’s and the community the ability to sustain the project long after the external facilitator has left because the skills, attitudes, and philosophy will remain in the community (Nzabiboneye et al., 2001).

The sustainability of CBR programs will help to provide a path to transform culture because community members will begin to see the value of PWDs participation in society. The World Health Organization along with The Swedish Organizations of

Disabled Persons International Aid Organization (2002) described the importance of PWD participation in CBR in the following statement:

The most important thing is to bring changes in their (community members) attitudes towards persons with disabilities (PWD). We have to make them aware of the things that PWD can do to support themselves. We have to counsel them, giving examples of disabled people who are doing well in life.” (p. 29)

There may be some discrimination from community members when an organization uses PWDs as rehabilitation workers. Even attitudes of most professional rehabilitation workers toward the participation of PWDs is still negative (Ndaziboneye et al., 2001). These workers believe that PWDs should only be recipients of rehabilitation rather than providers of it. PWDs are in a minority group, which means they will have to overcome many barriers to this type of participation.

CBROs can further promote the participation of PWD in CBR by helping to form community-level organizations and help PWDs integrate into existing structures with non-disabled people. Organizing into groups or organizations will help PWDs to speak to decision makers, help CBROs to understand their specific needs, promote awareness, build-self-confidence, and fundraise. By integrating into existing structures such as women’s groups or youth groups, PWDs can become more involved in community decision making and provide a voice for PWDs needs in different areas. Forming community-level organizations and integration into existing organizations will help raise awareness and create inclusive alliances so to reduce stigma and discrimination.

A CBRO must also focus on the participation of the PWD within all the community. The next session will show that the sustainability of a CBRO can be in question when trying to provide too many services. A CBRO can combat this issue of sustainability by partnering with all community development programs in the area. Community Development (CD) programs promoting education, advocating for political participation, providing economic empowerment, providing healthcare initiatives, providing faith-based education, and all other CD projects can help PWDs in all of these areas. Including PWDs in these specific areas is the basis of CBR and, moreover, many of these CD programs are not actively involving PWDs in their projects for a myriad of reasons. CBR workers need to partner with these organizations to help include PWDs in all CD projects.

### **Partnerships among Community Development Organizations**

It has been noted that the most effective way to promote community involvement in CBR is to incorporate disability initiatives in the broader CD process (Boyce & Lysack, 2000, p. 11; Kandyomunda, Dube, Kangere, & Gebretensay, 2001, p. 138). Incorporating the CBR strategy into all community development approaches integrates disability in all facets of community life from childhood nutrition to education, from agriculture to family planning, and from income-generation to sanitation (Boyce & Lysack, 2000).

PWDs have historically been left out of traditional community development projects, which not only leads to more exclusion but marginalization in community decision making (Eskola, 2011). One reason for this is that many community

development workers may believe that they lack the resources, money, or education to provide effective services to this population so they leave them in the care of generally ill-funded and resource-lacking CBR programs. CBR has attempted to overcome the lack of involvement of other CDOs by making CBR a part of community development. A commonly accepted definition of CBR is now that it is a strategy within community development (Coleridge, 2001). CBR programs have aimed at providing holistic care, but without the partnership of other CDO's, CBR is unsustainable.

Another reason PWDs have been left out of traditional community development is because these people fall below the bottom-line in a bottom-up development process (Nganwa & Khasnabis, 2001, p.76). I have cited the many reasons that PWDs are among the poorest and most marginalized in the world. One startling fact is that PWDs make up 20% of the poorest of the poor in the world and only 5-10% of PWDs have access to health care and rehabilitation services (Nganwa & Khasnabis, 2001, p.77). Extreme poverty and living in remote areas are two of the major reasons PWDs are left out of traditional CD. How can CBR professionals expect to reduce social stigma and change community perceptions when the many programs set up to help the poorest and most marginalized are discriminatory to PWDs? CBROs must collaborate with CDOs to help them include PWDs and to provide collaborative alleys to development.

SOH did not partner with any other CDOs in the area and were, thus, unsustainable in their approach and unsuccessful in transforming stigma in all aspects of the community. SOH took it upon themselves to advocate for children to be included in education, they advocated to churches, helped to counsel families, provided OT and PT, and provided free medication. They were stretched to their financial limits because of

their willingness to do all of this by themselves and unwillingness to partner with any other local agencies. Moreover, they had volunteers pay to work for them, which was their biggest source of income. These volunteers, again, came unprepared, but SOH was willing to take them because of their unsustainable practices and apparent need of income.

SOH could have partnered with other CDOs in the area that had proven models and resources to help the organization. This would have lessened the burden on their resources and could have led to creative and collaborative programs. An example of a successful partnership can be seen in my experience with a CBRO in Eastern Uganda—Chili Children (CC). Instead of taking it upon themselves to train and teach local pastors in disability sensitivity, CC partnered with the local Anglican Church from its inception. Church leaders became aware of disability issues and were able to spread the knowledge to their other dioceses in the area. The Church was able to be effective in providing inclusive education and moral support to families with CWDs. The church used their resources, staff and volunteers to build an inclusive school and also to train teachers in their existing schools. This gave CC more time and resources to devote to other projects such as income generation.

### **Community Members**

The WHO made several recommendations to CBROs after the International Consultation to Review Community-Based Rehabilitation in May of 2003. The WHO recommended that CBROs become involved in community participation, that they have multi-sectorial collaboration, scaling up CBR programs, and other promoting of CBR

initiatives. Researchers and professionals have come to the conclusion that CBR will not work properly without the community and its citizens being aware of the abilities of PWDs and accepting them in all walks of life. How can a CBRO include community members in their initiatives effectively with the goal to transform their perceptions of a PWD from negative to positive?

Lang (2011) pointed out a common error of CBROs thinking when it comes to community participation. He stated:

CBR advocates have been criticized for an apparent assumption that local communities are benevolent, homogeneous, willing to get involved in meeting the needs of some of the marginalized members of their community and have adequate resources to do so. (p. 135)

Many community members believe that PWDs belong to the government, and so, they are the responsibility of the government (Rifkin & Kangere, 2001). Many families in rural areas of developing nations live in impoverished conditions and will focus on their immediate needs before getting involved in the lives of PWDs. The most appropriate way to initiate involvement of community members is to first locate the “gatekeepers” in the community and leaders of powerful institutions in the community.

Seiber (1992) described a gatekeeper as “persons who can help the researcher (or worker) learn the community culture and enter into effective working relationships with community members” (p. 128). The gatekeeper is a powerful person in the community and has the power to decide whether an outsider can be involved in the community. The gatekeeper and leaders of powerful institutions will be different in each context.



In Kangulumira, Uganda, a community gatekeeper and leader of a powerful institution was the head of the Catholic pastors of the county. Pastor Patrick acted as an important community member who could spread ideas and philosophies to other community member efficiently and effectively. Once SOH was able to gain Patrick's trust, they were able to educate him on the many definitions of disability, biblical theories of disability, barriers to social services faced by CWDs, and ways that the church can provide an inclusive atmosphere where CWDs could participate. By doing so, SOH advocated for CWDs to be included in church functions. This helped CWDs to participate alongside their able-bodied peers and promoted education of CWDs through church lessons, which helped reduce negative perceptions of CWDs in the community.

Changing perceptions is the first way to transform the culture into one that enables, but this should not be the end-game. Just because someone is "aware" that a CWD is not a product of a curse from an ancestor, that a CWD can in fact read and write, that a CWD can communicate and work, and that a CWD can have a fulfilling relationship, doesn't mean that the person will have the buy-in to spread their views to others or to change the way they will act. Only through participation can community members begin to accept and view CWDs as integral community members.

Different community members, such as a pastor in the case of SOH, can be asked to be participants in the CBR decision-making process. Other community leaders such as traditional healers in Africa, large landowners, business owners, healthcare workers, or principals and teachers all have the power to spread ideas and philosophies that can reduce stigma of PWDs effectively.

## **Education**

The International Disability and Development Consortium (1999) estimated that 98% of disabled children in developing countries are denied any formal education, which substantially lessening their chances to escape from poverty. CBR professionals have tried to combat this gap in service by introducing IE initiatives in the communities they are working in. Providing opportunities for children with and without disabilities to learn together in an inclusive environment is crucial to help non-disabled children to define CWDs in a positive light.

IE has been shown to be beneficial in improving access to education for CWDs and also positively affecting community attitudes towards disability (Kisanji, 1998). There certainly are difficulties in implementing IE in rural and impoverished areas, as explained. Inadequate teacher-to-student ratios, discipline problems, deficiency of both human and financial resources, high support needs, disability awareness, shortage of proper curriculum, absence of teacher coping mechanisms, and learning failure are just some of the challenges that IE faces (Ogot, McKenzie & Dube, 2008).

Much evidence would suggest that the IE approach has the capacity to change the cultural contextualization of disability in communities. Many of the negative stereotypes and social attitudes can be broken down when CWDs can learn alongside of their able-bodied peers, thus changing perceptions at a very important age (Lang, 2009b). The United Nations Educational, Scientific and Cultural Organization (2003) found that one problem limiting the successful participation of CWDs is that the curriculum that many national systems implement is too demanding and rigid so that teachers lack the

flexibility to tailor lessons for an inclusive environment. The curriculum might also be culturally insensitive, gender biased, or degrading (United Nations Education, Scientific and Cultural Organization, 2003).

How does a CBRO overcome these difficulties and successfully integrate CWDs into existing community schools? It was reported in Uganda that mobility was the biggest challenge keeping children from attending school (Ministry of Finance, Planning and Economic Development & Uganda Participatory Poverty Assessment Process, 2008, p. 45). Therefore, the first step is to make sure schools are accessible to CWDs and that the physical environment of the school is conducive for the participation of CWDs. CBR workers can help school staff to widen doorways, widen steps, build wheelchair ramps, and construct special toilets for CWDs.

The next step is to equip teachers with the proper tools and learning support systems to ensure pupils of all abilities are able to learn together and so teachers are able to cater to the diverse needs of their students (Elekwe & Rodda, 2010, p. 115; Ministry of Finance, Planning and Economic Development & Uganda Participatory Poverty Assessment Process, 2008, p. 45). CBR workers should provide schools with braille machines, easy-grip writing materials, larger desks, sitting pads for those who cannot use desks, and advocate to government entities for teacher training. Elekwe & Rodda (2010, p. 117) noted that inadequate training programs is another problem of achieving inclusion in developing nations. CBR workers need to advocate and challenge governments to develop new policies that restructure schools and equip teachers with the resources and knowledge to achieve IE. This will not happen overnight and CBR workers can help to improve the classroom in other ways in the meantime.

CBR workers can help teachers to develop culture-sensitive curriculums that will promote inclusion in all aspects of society and break down barriers in attitude at an early age. UNESCO made some recommendations of curriculum as follows:

The curriculum can facilitate the development of more inclusive settings when it leaves room for the centre of learning or the individual teacher to make adaptations so that it makes better sense in the local context and for the individual learner. (2003, p. 18)

Many CBROs have teacher-training programs that are strongly influenced by Western models (Elekwe & Rodda, 2010, p. 117). CBROs need to understand local culture and bring in materials that are relevant to the local culture. It makes little sense for an agricultural community to receive learning materials that were donated by Western nations that include examples of industry and large cities. Other materials and lessons that promote gender equality and encourage participation of CWDs in the community, which will help children to respect differences and help to break down attitudinal barriers at an early age.

The participation of CWDs in education is a crucial step is changing societal values and promoting an inclusive atmosphere. Children must be seen as active participants in the construction of societal values and are not just passive subjects of social structures (James & Prout, 1997, p. 8). In the PHC model, CWDs were either kept in their homes or sent off to special learning institutions specifically for CWDs. This process enhanced the stigma of these children and promoted negative attitudes towards

all PWDs in society. IE has proven to breakdown these attitudinal barriers at a highly influential age, and thus, will help to change social values towards PWDs.

### **Religion**

Many CBROs have the unique opportunity to provide information and education to religious establishments in the communities they work in. It was noted on pages 19-24 that many pastors and churches in the Kangulumira community in Uganda did not respond effectively to the needs to PWDs and their family members. Members in this community were influenced by many traditional beliefs of impairment and long-held beliefs in the Christian church that disability was a curse and that the only role of religion was to pray for healing. Many communities in the developing world, especially in Africa, will have these beliefs. CBROs must train and equip churches in these areas to respond and care for the needs of PWDs and their families.

I have already noted that many of the churches in the Kangulumira community were not physically accessible to PWDs. CBROs should first make these building accessible to PWDs by building wheelchair ramps, widen doorways and isles, build special toilets and seats, and supply Braille Bibles in the churches. The physical environment will be the easiest to make accessible. The spiritual environment will be a challenge and will take time to change. CBROs must bring pastor trainings to these churches as the first step to change long-held beliefs. SOH began pastor's trainings before my work there and community members as well as church members noticed differences in attitude because of this training.

The first step in helping pastors and other church staff to minister to PWDs is to help them to understand that *all* people are created in God's image (Genesis 1:27, 31; Psalm 139:13-16). No matter the ability or the weakness, God sees us all as his disciples. Jesus Christ told us that in weakness, His plan unfolds, "My grace is sufficient for you, for my power is made perfect in weakness" (2 Cor. 12:9). When churches understand the concept of God working intimately through human weakness, individuals affected with impairment should be seen as essential in the body of Christ (Thomson, 2011). CBR workers must help the local churches to understand this concept first. After all, isn't suffering normal in this world today? Suffering and disability should be seen as normal in this abnormal world but, with the resurrection of Jesus, these disabilities will become abnormal in His perfect world.

Secondly, churches must understand that Jesus worked intimately with PWDs, not just physically heal them, but also to spiritually and emotionally heal them. Jesus routinely ministered and revealed the Gospel to people with all types of disabilities. Twenty-three of Jesus's thirty five miracles involved PWDs (Thomson, 2011). He also cared for them, loved them, spoke with them, and lived among them. Churches need to understand that healing is not always available and that physical healing is temporary; spiritual healing is eternal. A church that claims to fully represent the body of Christ and leaves out spiritual assistance to PWDs is not really representing the body of Christ. Pastors can include PWDs in all church services and pastors can also provide much-needed counseling to families with PWDs. Churches can begin to minister *through* PWDs rather than minister *to* their needs. This means having PWDs active in the church-helping to pass out materials, welcoming members at the door, and anything else their

ability allows them. Church members will begin to see a new perspective and will see the power of God *through* the person and through weakness.

Churches may encounter many challenges when beginning to include PWDs in all parts of the church. Church members may feel senses of awkwardness, fear, ignorance, and rejection (Justice, 2011). These feeling can come from PWDs and from other church members. Just like in other social aspects, barriers and perceptions can only be broken down with time. Helping members to see the unique abilities we all have will, in time, lessen these fears and ignorance. Churches must let PWDs and their families know that there may be some resistance from other members and can help them by counseling and prayer. CBROs can help change the perceptions of PWDs through one of the most powerful institutions in a community- the church. These barriers and stigmas won't be broken-down overnight, but by promoting spiritual transformation, communities can begin to accept and include PWDs in all community functions and change the contextualization of disability in communities.

### **Conclusion**

Kissa is a 12 year old girl who lives in a small, rural village outside of Rukungiri, Uganda. Kissa was born a healthy girl but, as an infant, she contracted cerebral malaria. As an adolescent, she now suffers from cerebral palsy. CC recently came to Kissa's village to do a disability assessment. Her parents attended this assessment and were able to receive some services from CC.

CC has been in the area for over 10 years, and strives to provide culturally competent and holistic services to CWDs and their families. The first project CC did with

Kissa's parents was to teach them how to grow chilies in their garden (hence the name of the NGO). CC provided the seeds, the training, and the market to sell them to in the U.K. After the first growing season, Kissa's parents were able to make enough profit from selling chilies to buy her a new walking-assistant device.

CC also helped Kissa's parents to widen the doorways, build wider steps, and build a ramp to their front door. Kissa is now able to move about much easier and also able to gain muscles in her legs so that she may be able to walk someday. She no longer sits on the cold, dirty floor in the dark, but now sits outside in the sun and watches her siblings and parents work on their garden. CC also started to send occupational and physical therapists to her house to train her parents how to perform rehabilitation exercises. Kissa's movement and attitude have improved drastically, but her neighbors and other community members still avoid talking with Kissa's family, and her parents frequently get dirty looks from other community members.

CC began partnering with the Anglican Church of Rukungiri from the start of their organization. CC has teamed with the diocese, and recruited volunteers to help build an inclusive school near Kissa's village. In a year, Kissa will be able to learn along-side here able-bodied peers. The school will have ramps, wide doors, and teachers who are trained by CC and Church staff. She will learn how to read and write some words, and her peers will see/assist her progress. Her fellow learners will see her bright smile after she spells a word, begin to enjoy having her in class and view her as a child just like them.



CC and the Church are also working with the pastors in the area to teach them about the gospel of disability. The pastors will begin to understand that CWDs are not a result of a curse, but an important part of the body of Christ. Kissa's parents will feel more welcomed in the church and others in the community begin to notice Kissa being more active in the community. The pastors explain to the congregation about how Jesus cared for the lame and the weak and how all people are created in the image of God.

The community will slowly begin to accept Kissa and her family as important, contributing members of the community. Kissa may grow up and be able to walk, read and write, and may even become employed with the help of CC. However, this will not happen all at once. Kissa is not the only child who was helped by CC; many other boys and girls with different impairments were helped by CC and were given the chance to participate in the community.

Cultures take time to evolve and to respond to challenges. Also, cultures will take time to change and to develop different perceptions. The contextualization of disability in developing nations will not change overnight. This will be a long process, perhaps a generation or longer. CBR professionals will have to be patient and understand the complexities and shifting dynamics that they are working against. Only by concentrating on enhancing participation of stakeholders and being prepared for any cultural obstructions that may appear. Cultures change faster with new and altered policies and laws, to enforce a cultural shift to match modernity.

Having impairment does not mean the end to a quality life. The more elements of a society that are enabling will help the child to develop into an important participant in

society. The more a child can participate in community functions, the more perceptions of CWDs will begin to change. CBROs can help to change these perceptions by focusing less on individual rehabilitation and more on community rehabilitation. Methods described in my recommendations will promote community involvement. Only by being keenly aware of all cultural circumstances can CBROs respond effectively.

Changing the contextualization of disability in communities will enhance human rights for all people. CBR is an integral part of community development and should not be seen isolated in the community development process. PWDs should not be seen as passive victims of society, but they should be seen as active and contributing members of society. Including PWDs in the development process does not have to be expensive or resource intensive. CBR professionals can draw on existing community resources and knowledge to better the lives of PWDs and help to promote an enabling, compassionate, inclusive community. We are all disabled in certain ways. No matter what our ability is, the environment surrounding us can hinder our development. What we *all* can do is help that environment become enabling to everyone's needs.

### References

- Boyce, w., & Lysack, C. (2000). Community participation:Uncovering its meanings in CBR. In M. Thomas & M. J.Thomas (Eds.), *Selected readings in Community Based Rehabilitation: CBR in transition* ( Series 1, pp.42-58). Bangalore, India: Asia Pacific Disability Rehabilitation Journal.
- Canguilhem, G. (1989) *The Normal and the Pathological*. New York: Zone Books.
- Coleridge, P. (2001). *Disability, liberation and development*. London, UK: Oxfam.
- Douard, J. W. (1995) Disability and the persistence of the “normal.” In S.Toombs, D. Barnard and R. Carson (Eds.), *Chronic Illness: From Experience to Policy*. (pp. 154-175). Bloomington: Indiana University Press.
- Elekwe, C. J., & Rodda, M. (2010, November 10). The challenge of enhancing inclusive education in developing countries. *International Journal of Inclusive Education*, 6, 113-126. doi.org/10.1080/13603110110067190
- Eskola, T. (2011). Rural development through decent work. *International Labor Office*. Retrieved from: [http://www.ilo.org/wcmsp5/groups/public/---ed\\_emp/documents/publication/wcms\\_159006.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_159006.pdf)
- Freire, Paulo. *Pedagogy of the Oppressed*. New York: Herder and Herder.
- Friend, M., Bursuck, W., & Hutchinson, N. (1998). *Including exceptional students: A guide for classroom teachers*. Ontario, CA: Allyn & Bacon.
- Goffman E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs NJ: Prentice Hall.

Hofstede, G., Hofstede, G.J., and Minkov, M. (2010). *Cultures and Organizations: Software of the mind*. New York: McGraw Hill.

International Disability and Development Consortium (IDDC). (1999, October, 5). Seen and heard: Promoting the rights of disabled children globally. Seminar held in Brighton, UK. Retrieved from [http://www.iddcconsortium.net/joomla/images/IDDC/documents08/99iddc\\_rights\\_disabled](http://www.iddcconsortium.net/joomla/images/IDDC/documents08/99iddc_rights_disabled)

James, A., & Prout, A. (1997). *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. London, UK: Falmer Press.

Justice, M.A. (2011). Disabilities and the church. In Waters, L.J., & Zuck, R.B. (Eds.), *Why, oh God: Suffering and disability in the Bible and the Church* (pp. 55-68). Wheaton, IL: Crossroads.

Kandyomunda, B., Dube, S., Kangere, M., & Gebretensay, M. (2001). The Role of Local NGOs in Promoting Participation in CBR. In Hartley, S. (ed.), *CBR: A Participatory Strategy in Africa* (pp. 137-155), London: University College London.

Khasnabis, C. & Motsch, K.H. (Eds.). (2010). *Community-Based Rehabilitation: CBR guidelines*. Geneva, CH. The World Health Organization. Retrieved from: [http://apps.who.int/iris/bitstream/10665/44405/9/9789241548052\\_introductory\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/44405/9/9789241548052_introductory_eng.pdf)

Kisanji, J. (1998, May 21-24). Culture and disability: An' analysis of inclusive education based on African folklore. Paper prepared for the *International Journal of Disability Development and Education*. Presented at the International Expert Meeting and Symposium on Local Concepts and beliefs of Disability in Different Cultures, Bonn, Germany.

Korbin, J. E. (1983). Introduction. In Korbin, J.E. (Ed.), *Child Abuse and Neglect: Cross-Cultural Perspectives* (pp.1-12). Berkley, CA: University of California Press.

Lang, R. (2011). Community-based rehabilitation and health professional practice: developmental opportunities and challenges in the global North and South. *Disability and Rehabilitation*, 33, pp. 165-173. doi:10.3109/09638288.2010.487923

Lang, R., & Murangira A (2009a). A disability scoping study for DFID Uganda. Kampala, UG: DFID

Lang, R., & Murangira, A., (2009b). Barriers to the inclusion of disabled people in disability policy-making in Seven African countries. In J. Kampuvuori, & M. Scheinin. (eds.) *United Nations convention on the rights of persons with disabilities: multidisciplinary perspectives*. Helsinki, FN: Center for Human Rights of Persons with Disabilities in Finland.

Mcdermott, R., & Varenne, H. (1995). Culture as Disability. *Anthropology and Education Quarterly*, 26, 323-348. Retrieved from:  
<http://www.jstor.org.nu.idm.oclc.org/stable/3195676>

Ministry of Finance, Planning, and Economic Development & Uganda Participatory Poverty Assessment Process (UPPAP). (2008, October). *Disability and poverty in Uganda. Progress and challenges in PEAP implementation, 1997-2007 : National Report*. Kampala, UG.

Mittler, P. (2000). *Working toward inclusive education: Social contexts*. London, UK: Fulton.

Mohan, G. (2001). Participatory development. In: V. Desai, & R. Potter (Eds.), *The companion to development studies* (pp. 49-54). London, UK: Hodder.

- Nganwa, A.B., Khasnabis, C. (2001). CBR as part of community health development. In Hartley, S. (Ed.), *CBR as part of community development* (pp. 74-90). London, UK: University College London.
- Ndaziboneye, C., Nyathi, I., & Mzoma, F. (2006). CBR as Part of Social, Cultural and Political Development. In S. Hartley (ed.), *CBR as Part of Community Development*, (pp. 40-48), London: University College London.
- Ogot, O., McKenzie, J. & Dube, S., 2008, Inclusive education and community based rehabilitation. In S. Hartley, & J. Okune (Eds.). *CBR: Inclusive policy development and implementation* (pp. 160–189). Norwich, UK: University of East Anglia.
- Perkins, J. (2007). *Justice for all: A strategy for community development*. Ventura, CA: Regal Press.
- Rifkin, S.B., & Kangere, M. (2001). What is Participation?. In S. Hartley (Ed.) *A Participatory Strategy in Africa* (pp.37-49). London, UK: University College London Center for International Child Health.
- Seiber, J.E. (1992). *Planning ethically responsible research*. New York, NY: Sage.
- Shuttleworth, R. P. (2004). Stigma, community, ethnography: Joan Ablon's contribution to the anthropology of impairment-disability. *Medical Anthropology Quarterly*, 18, 139-161. doi: 10.1525/maq.2004.18.2.139
- Ssegawa, N. (2012, 5, January). Uganda witchdoctors change tricks, behead disabled. *Chimpreports*. Retrieved from: <http://www.chimpreports.com/index.php/news/4420-uganda-witchdoctors-change-tricks-behead-disabled.html>
- The Central Intelligence Agency (2013). *The world factbook*. Retrieved from: <https://www.cia.gov/library/publications/the-world-factbook/geos/ug.html>

- The World Bank. (2009). *Rural development and disability*. Retrieved from <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:20193958~menuPK:419407~pagePK:148956~piPK:216618~theSitePK:282699,00.html>
- The World Bank (1994) *The World Bank and participation* (fourth draft), World Bank, Washington, DC.
- The World Health Organization. (2012, June 12). Children with disability more vulnerable to violence. *The World Health Organization* Retrieved from <http://www.unmultimedia.org/radio/english/2012/07/children-with-disability-more-vulnerable-to-violence/>
- Thomson, D.R. (2011). The disability-ministry perspective. In Waters, L.J., & Zuck, R.B. (Eds.), *Why, oh God: Suffering and disability in the Bible and the Church* (pp. 23-38). Wheaton, IL: Crossroads.
- United Nations (1994). *The standard rules on equalisation of opportunities for disabled people*. Geneva, CH: UN.
- United Nations Education, Science, and Cultural Organization (2003). *Overcoming Exclusion Through Inclusive Education Practices*. (ED-2003/WS/63). Retrieved from <http://unesdoc.unesco.org/images/0013/001347/134785e.pdf>
- Werner, D. (1987). *Disabled village children*. Palo Alto, CA: The Hesperian
- WHO. (25-28, May 2003). *International consultation to review community based rehabilitation (CBR)* [Conference]. Helsinki, FI. Retrieved from [http://whqlibdoc.who.int/hq/2003/who\\_dar\\_03.2.pdf](http://whqlibdoc.who.int/hq/2003/who_dar_03.2.pdf)
- WHO Disability and Research. (27 June, 2002). Equal Opportunities for All: Promoting Community-Based Rehabilitation (CBR) among Urban Poor Populations. *The World*

*Health Organization*. Retrieved from:

[http://apps.who.int/iris/bitstream/10665/69045/1/WHO\\_DAR\\_02.1.pdf](http://apps.who.int/iris/bitstream/10665/69045/1/WHO_DAR_02.1.pdf)

WHO & SHIA. (2002). Community based rehabilitation as we have experienced it.. Voices of persons with disabilities in Ghana, Guyana, and Nepal. Geneva, Switzerland: World Health Organization. Retrieved from

<http://whqlibdoc.who.int/publications/9241590440.pdf>

World Health Organization, & The World Bank. (2011). *World report on disability*. [Report No. 62783]. Retrieved from [http://www-](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2011/06/23/000356161_20110623012348/Rendered/PDF/627830WP0World00PUBLIC00BOX361491B0.pdf)

[wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2011/06/23/000356161\\_20110623012348/Rendered/PDF/627830WP0World00PUBLIC00BOX361491B0.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2011/06/23/000356161_20110623012348/Rendered/PDF/627830WP0World00PUBLIC00BOX361491B0.pdf)

Yeo, R. (2005, September). Disability, poverty and the new development. *Disability Knowledge and Research*, Retrieved from <http://hpod.org/pdf/Developmentagenda.pdf>

### Appendix

Age	Name	M/F	Religion	Church?	With Child?	Support	Comments
3	Shamada	M	Muslim	No	No	No	Father has passed away and mother is



Age	Name	M/F	Religion	Church?	With Child?	Support	Comments
							concentrating on keeping other children fed
3	Sebuliba Wilson	M	Christian	Yes	No	No	Limitations with travel keep child from church
16	Susanna	F	Christian	Yes	No	No	Parents think other family members cursed her. She has visions at church
8	Joan Hafula	F	Catholic	Yes	No	No	Does not bring child to church because she cries too much
2 ½	Sako	M	Protestant	No	No	No	Father won't let her go to church. Ashamed
3 ½	Kenneth	M	Christian	Yes	Yes	No	None
7	Zainah	F	Protestant/ Muslim	Yes	No	Yes	Church members pray for her regularly
6	Satinah	F	Muslim	Yes	No	No	There is nowhere for the child to sit in the Mosque
2	Samuel	M	Protestant	Yes	Yes	No	Members pray for the child
8	Lavverce	F	Catholic	Yes	No	No	None
8	Lawerence	M	Catholic	Yes	No	No	Child cries too much in church
3 ½	Amina	F	Catholic/ Muslim	Yes	No	No	Father is Muslim and won't let child go to church or mosque

Age	Name	M/F	Religion	Church?	With Child?	Support	Comments
5	Christina	F	Catholic	Yes	No	No	None
20	Stella	F	Catholic	Yes	Yes	Yes	Members pray for her
23	Sieda Najuma	F	Muslim	Yes	No	No	Child has mental disabilities so she won't understand church
3	Samadu	F	Muslim	Yes	Yes	No	None
20	Zura	F	Muslim	Yes	No	No	Father passed away and mother won't take her to mosque
3	Jamira	F	Muslim	No	No	No	The mother is not at home so they have no ability to go to church
10	Fato Suman	M	Muslim	No	No	No	The child is not able to be taken to mosque because of transportation
13	Muklazi	M	Muslim/ Catholic	Yes	No	No	Transportation issues- too far to church
3	Brian	M	Protestant	Yes	Yes	Yes	Mother abandoned son so grandmother raising him. Takes him to church regularly but she is losing hope because she isn't seeing much improvement
18	Veronica	F	Catholic	Yes	Yes	No	The church is not welcoming to the child.
8	Sseruwala	M	Catholic	Yes	No	No	Has no wheelchair so she cannot transport child to

Age	Name	M/F	Religion	Church?	With Child?	Support	Comments
							church
1 ½	Buginza	M	Catholic	Yes	No	No	Mother is unable to transport child
1 ½	Junior	M	Catholic	No	No	No	Mother is a Muslim, child and father is Catholic so the separation in the family causes them not to go to church.
Results			7 Muslim/ 20 Christian	20 YES 7 NO	8 YES 19 NO	3 YES 24 NO	