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"Nothing About Us Without Us"; Empowerment, Disability and Community Development in Kenya

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The more students work at storing the deposits entrusted to them, the less they develop the critical consciousness which would result from their intervention in the world as transformers of that world.
-Paulo Freire

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Abstract

The World Bank describes disability as "a hidden face of African poverty" (White and Killick 2001:xv). The purpose of this study is to explore the meaning of disability in Africa and, most specifically, in Kenya. First, it will look at the cyclical connections between poverty and disability and argue that social programs addressing disabilities must be incorporated into development efforts. Next, it will discuss the importance of programs which empower people with disabilities. And finally, it will assert that people with disabilities themselves must have a significant voice in the development of these programs that are meant to support and empower them. This study is based mainly on library and internet research, and it incorporates the work of several social theorists. The most relevant theorist to this particular study is Paulo Freire, in his *Pedagogy of the Oppressed.* This study also incorporates two personal interviews. The goal of this research is to discuss issues of urgency in today's global society in hopes that this theoretical reflection may lead to practical and applicable insights.

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Introduction

During the five weeks I spent working at an orphanage in Kenya last summer, I was overwhelmed by the intensity and multitude of needs that I encountered. I felt extremely "spread thin," realizing that although my resources and ability to help could make an impact in the lives of certain individuals, they would not even make a dent in the bottomless pit of problems facing the Kenyan people, or the rest of Africa for that matter. There is a place for charity, but I began to think a lot about more long term and sustainable giving. How could I help in a way that would last longer? How could I help in a way that, instead of creating dependence, would allow local people to better support themselves in the future? These questions are at the root of my study.

I also attempted to bring together macro-level issues with micro-level issues, as I believe that both are important to address. I am interested in the role of social work in addressing the needs of individuals and communities at a local level, and particularly as it relates to people with disabilities. I am also interested in international development and issues arising from the needs of developing countries. While in some sense, these two topics pull the mind in very different directions, one focusing on the local and the other focusing on the global, I also believe they are deeply interconnected. It is important to address surface-level problems as well as the deeper causes. Part of my goal in doing this research is to process questions I have about the meaning of development, the most beneficial approach to development, and the connections between two of my passions; social work with people with disabilities, and international development.

I have chosen a title for this paper which I believe embodies the essence of this research. “Nothing about us without us” is a slogan that has emerged out of the global disability rights movement. It has been used in as diverse places as an international disability rights conference in Eastern Europe and a disability rights group in South Africa (Charlton 1998). As will become clear later on, responses to disabilities must happen in dialogue with people who have disabilities. We should not attempt to discuss and address the needs of these individuals except in cooperation with them. This is one of the main focuses of this paper, and thus the slogan made an appropriate title.

It should be noted that the issues and questions that I address in this research, particularly related to poverty and development, are infinitely larger than the confines of this paper. For that matter, they are infinitely larger than any individual or organization could hope to exhaust. But this is not an excuse for apathy. Rather, it is a plea for humility. We cannot ignore the complex web of issues that makes poverty so difficult to address, and we must be careful to avoid simple solutions that will really not offer any long-term change. And so, I write this paper with an understanding of the limits of my knowledge. I also write it, however, with an understanding of the urgency of the issues I explore, and with hopes to offer important theoretical insights that might be of practical use.

Above all else, I hope that this urgency will come across. Africa is a place of resilience and life, but also a place of disparity and extreme need. This continent is increasingly burdened with a growing HIV/AIDS crisis, disease, poverty and more. According to the World Bank, "Africa is falling behind on all fronts, leading to an Africanization of global poverty" (White and Killick 2001:xxv). It is critically important to combine theoretical reflection with action in an attempt to respond to this situation.

In exploring these issues, though, we have to remember both the multidimensionality and humanity of poverty (White and Killick 2001:xiii). We cannot forget that there is no single explanation or solution that can exhaust the discussion. We also have to remember the humanity behind the issues, and it is my hope throughout this entire paper that my research will not be just abstract concepts, but rather a discussion grounded in compassion for real people.

Definitions

Since this research centers on disabilities, it is important to have a clear understanding of the meaning of this word. *The Social Work Dictionary* defines disability as "Temporary or permanent reduction in function; the inability to perform some activities that most others can perform, usually as a result of a physical or mental condition or infirmity" (Barker 2003).

This is the technical definition of disability, and yet societal reaction plays as big a role in defining the meaning of a particular disability as does the actual physical impairment. I will discuss this concept later on in my research, but it is important to be aware that there are many layers that combine to explain this term.

What is development? In this paper, I discuss the importance of disability social services to community development. Therefore, it is important to define community development, which is a vague, yet complex term. First, it is important to note that when I refer to community development, I am *not* implying that Kenya is different from the West and that we therefore need to help them become more like us. Certainly there are cultural differences, and this does not make either culture right or wrong. Instead, I am stating that Kenya faces extreme poverty, disease, and related issues and that it is important to respond to these issues. Economic development, therefore, is important in order to help people to become "better off." I discuss development in terms of the importance of increasing quality of life, allowing people to have more choices and opportunities, and providing for basic needs. This must be done in a culturally sensitive way, recognizing the expressed needs of the local people.

Introduction to Kenya

Before discussing disabilities in Kenya, a brief introduction to the more recent history and culture of Kenya will prove to be useful. Kenya is in East Africa, bordered by Sudan, Ethiopia, Somalia, Tanzania and Uganda, and with a portion of its border on the Indian Ocean. Kenya is a mixture of more than 42 ethnic groups, including the famous Maasai, who spread across Kenya and Tanzania. There are also many Kenyans of Asian descent, Europeans living there because of the former colonization by Britain, and representatives from other regions (Sobania 2003). Clearly, Kenya's population includes a high amount of ethnic diversity.

For many years, Kenya was under the rule of the British. This colonization began in 1885 and continued until 1963. In 1944, the Kenyan African Union (KAU) began pushing for independence. Future president Jomo Kenyatta joined the KAU in 1947 and in 1952 was put in jail on charges of leading the Mau Mau rebellion, a campaign which aggressively fought for independence and objected to white settlers in Kenya. Kenyatta later was released from jail and led the Kenya African National Union (KANU), a group pushing toward African rule. On December 12, 1963, Kenya became independent and Kenyatta became the Prime Minister. A year later, Kenya became a republic by popular vote, and Kenyatta became the first president of the newly independent country. Since that time, Kenya has had two additional presidents. Daniel arap Moi, formerly vice president under Kenyatta, was president from 1979 until 2001. In 2002, Mwai Kibaki beat Uhuru Kenyatta, son of the first president, to become Kenya's third and current president (Sobania 2003).

Karl Marx describes a two-class capitalist system of capitalists or bourgeoisie, and proletariat. In this system, the bourgeoisie have all the power and use it to exploit the proletariat (Ritzer 2003). Kenya is a country of extreme "haves" and "have-nots." In the Kenyan context, they are referred to as "Wabenzi" and "Wananchi." Wabenzi are the Mercedes-Benz drivers, or the upper classes. Wananchi, by contrast, are the lower and middle working classes, the unemployed, and the underemployed (Sobania 2003).

While we can learn about general attitudes towards disabilities in Kenya, we also must be careful not to rely entirely on generalizations, as most likely people with disabilities "are viewed very differently from person to person and community to community, as in any place" (Pickens 2006). This variation, of course, is present in any society.

Hypotheses

These hypotheses focus on developing African countries, and most specifically on Kenya, although they also have broader implications and are applicable outside of this context.

1. There is a cyclical connection between poverty and disabilities, and therefore, it is essential to address the needs of people with disabilities as an integral part of community development.
2. Social programs for people with disabilities must focus on the empowerment of these individuals.
3. People with disabilities and their families, as well as the local communities, must play a key role in the development of these social services.

Methodology

This project is largely theoretical. I have done extensive library and Internet research. Through this research, I have studied international development, the nature of disabilities, models for responding to disabilities, the history and culture of Kenya, social conditions and disabilities specifically in Kenya, African poverty in general, and more. Clearly, each of these topics is far too broad to cover in any kind of depth, and particularly when they are combined. Therefore, there were certain topics for which I simply tried to gain a broad basic understanding through which to set the context. These included issues such as international development and African poverty. I cannot claim, of course, to exhaust these issues, but it is important to address them because of the foundation that they create. There were other topics, then, that I tried to cover in more depth. These were issues relevant specifically to disabilities in Kenya. Again, while slightly more specific, my topic is still very broad. I chose to study a fairly large topic in less depth, rather than to narrow the scope of my research and go more in depth. I made this decision because of my desire to make connections between large issues such as poverty and disabilities, and to gain a greater understanding of what it means to live with a disability in a country such as Kenya. In order to do so, it was helpful to draw from a large range of information.

Part of this research focuses on the work of certain social theorists who I found relevant to my topic. These theorists include Charles Horton Cooley, Erving Goffmann, Howard Becker, and Paulo Freire. The most useful of these is Paulo Freire, and his work in *Pedagogy of the Oppressed.*

A second part of this project is based on personal interviews. I chose this method because I recognized the importance of the insights of individuals with relevant experience. These were in-person interviews, which I audio taped, with the permission of the interviewees, and later transcribed. I conducted two interviews, in which I consulted with three people. In the first interview, I spoke with Dr. George Pickens, a professor of Global Ministries at Messiah College. Dr. Pickens lived in the Ivory Coast for 7 years, and then in Kenya for another 7 years. In Kenya, he lived in Nairobi, in Gumo, an area on the edge of the Kibera slums. He taught at Daystar University and at a theological college, and he worked at an inner city church. I chose to interview Dr. Pickens because of his experience living in Kenya, which provided important cultural insights.

Additionally, while he did not work directly in disability services, he had certain related observations which, because they were specific to Kenya, were useful to my study.

In the second interview, I spoke with both Francoise Pedeau and Matt Walsh. Francoise is a French woman who has served in Mahadaga, Burkina Faso for 20 years. During that time, she developed and still runs a handicap center called Handicapes en Avant, which is dedicated to creating a higher quality of life for people with disabilities. Burkina Faso is a French-speaking country in West Africa. While the information I obtained from Francoise is not specific to Kenya, she has a deep understanding of, and commitment to, the value of disability social services. Kenya and Burkina Faso are both developing African countries that struggle with many similar issues. Their distinctions should not be underestimated, but Francoise's insights can provide information extremely relevant to the Kenyan context. Matt Walsh, with whom I also spoke in this second interview, is the director of Dokimoi Ergitai (DE). The purpose of DE is to use the gifts of Engineering majors in particular, as well as students from other disciplines, to create appropriate technology. They develop equipment that that is useful and sustainable within developing countries.

Findings, Conclusions, and Theoretical Analysis

Hypothesis One

My first hypothesis is that there is a cyclical connection between poverty and disabilities, and therefore, that it is essential to address the needs of people with disabilities as an integral part of community development. In other words, I suspected that poverty increases the chances of having a disability and/or worsens the impact of that disability, and that the presence of a disability has the same impact on poverty. While I will draw from global analyses of development in order to support this argument, I will focus the discussion on conditions particular to Kenya.

The Department for International Development is an organization within the British government that focuses on responding to poverty and promoting development. This organization supports this first hypothesis. According to the DFID, "Poor people with disabilities are caught in a vicious cycle of poverty and disability, each being both a cause and a consequence of the other" (DFID 2000:1). The DFID asserts that it is essential to address the needs of people with disabilities, because without doing so, they say it will be nearly impossible to solve world poverty. "Eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account." (DFID 2000:1) Disability is essential to development and should be an integral part of efforts to achieve international development goals.

The overlap between poverty and disabilities is an initial indicator that there may be a connection. About 5% of the world population has a disability, and over 75% of these people are from developing countries, according to the World Bank (DFID 2000). The World Bank also estimates that 20% of the poorest people in the world have disabilities (KAR 2005). "More often than not [people with disabilities] are among the poorest of the poor" (DFID 2000:1). Therefore, the presence of a disability is more likely to coincide not only with poverty, but with poverty at its extreme.

Poverty as a precursor to disability

One reason for this overlap is that poverty and disabilities both leave people more vulnerable and with a lack of opportunity. There is ample evidence to suggest that poverty increases a person's chances of having a disability. This relates to the lack of access afforded to the poor.

> Disabled people are largely invisible, are ignored and excluded from mainstream development. Disability cuts across all societies and groups. The poorest and most marginalized are at the greatest risk of disability. Within the poorest and most marginalized, disabled women, disabled ethnic minorities, disabled members of scheduled castes and tribes etc. will be the most excluded. DFID cannot be said to be working effectively to reduce poverty and tackle social exclusion unless it makes specific efforts to address disability issues (KAR 2005: 9).

There are several causes of disability, and many disabilities are preventable. "As many as 50% of disabilities are preventable and directly linked to poverty" (DFID 2000:3). Malnutrition, for example, is a common cause of disability (DFID 2000).In this way, the effects of poverty can result in disability. Furthermore, when an individual has little or no access to health care, what would have been a minor illness or injury can become much more serious, leaving that person permanently disabled (White and Killick 2001). If an individual in a war-torn country receives a gun-shot wound in the leg, for example, the amount of wealth and access to health care which they have will have a large impact on the long-term outcome of that injury. If they can afford and access proper health care, there will most likely not be any long term ramifications of the wound. If they are not able to get this health care, however, the wound may become infected and result in the loss of a limb. Therefore, people living in poverty are more vulnerable to disability. Poverty also makes living with a disability more difficult because it limits the access that a person can have to support. “It is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services” (DFID 2000:2). One of the largest difficulties of poverty is that it reduces the access that individuals and families have to the very supports and services which they need the most, such as rehabilitative services, for people with disabilities. This reduces their opportunities to learn appropriate ways to cope with the disabilities and to still be integral members of society.

Disability as a precursor to poverty

There is also much evidence pointing to the fact that having a disability often increases one’s chances of living in poverty, and that it makes this poverty more severe. “Disabled people are typically among the very poorest, they experience poverty more intensely and have fewer opportunities to escape poverty than non-disabled people” (KAR 2005:9). Part of the reason that disability so often coincides with poverty is that having a disability, like poverty, increases economic strain and limits opportunity. It makes it much more difficult for a person to achieve education or find employment (DFID 2000). A very small percentage of children with disabilities in developing countries receive education. Literacy rates are also extremely low for people with disabilities (DFID 2000). If and individual cannot read, is not educated, and has no job, he or she will not have the tools necessary to escape poverty. Disabilities quickly take away opportunities from individuals and makes it much more difficult for them to navigate society. The World Bank describes disability as “a hidden face of African poverty” (White and Killick 2001:xv).

Strain on families

One reason for the impact of disability on poverty is that disability puts a tremendous strain on families. Particularly in developing countries such as Kenya, families are critical support systems for individuals, but having a disability sometimes excludes individuals from this support. "Those excluded from the family support system will typically be among the poorest of the poor" (White and Killick 2001:xx). Without a family to rely on, many people are left without a safety net. In Kenya, the majority of support for people with disabilities comes from families, as well as some assistance from Non-Governmental Organizations (NGOs), churches, and mosques. There is a lack of health care support from Kenyan government (Pickens 2006). And so, because of this gap in national efforts, the support of the family is particularly crucial. In situations in which there is a breakdown within the family or when a family simply does not have the resources to care for an individual, people with disabilities generally have very few places to turn.

The societal and familial reactions to disabilities and poverty are important to consider because of their fundamental impact.

> The poverty trap is as much a social phenomenon as an economic one, in many cases more so. The poor can become outcasts, whose very poverty removes them from the social support systems that may have allowed them to recover their position (White and Killick 2001: xiii).

In responding to disabilities, then, it is essential that we be aware of the cultural context in which we are working. If we are attempting to respond to disabilities in Kenya, for example, we must learn about the familial and community values that define the meaning of disability within that society. If we do not understand the layers of culture that cause a person with a disability to be excluded and disempowered, then we will not be able to assist in improving the situation. And the best way in which to increase our understanding of this cultural context is to talk to local people. We cannot presume to have all the answers and expertise and therefore that we do not need to rely on others. Furthermore, people with firsthand experience can help us to understand the realities of poverty and disabilities beyond a theoretical analysis.

Cyclical relationship between poverty and disability

The impact of poverty on disability and disability on poverty is simultaneous. "Poverty is both a cause and consequence of disability. The links between disability and poverty are well known" (KAR 2005:5). And yet each of these conditions not only increases the likelihood of the other, but it increases the severity and harmful implications of the other. "Disabled people share the general profile of the non-disabled poor….However, for disabled people, their lives are typically so much harder because of their impairments" (KAR 2005:6). Both poverty and disability tend to lead to vulnerability and exclusion, which, as discussed, is one of the main reasons why suffering from one of these conditions makes individuals so much more prone to the other. "More often than not [people with disabilities] are among the poorest of the poor" (DFID 2000:1). It is also important to note that poverty is relative. Many people suffer from poverty in different cultural contexts, so that some of these people may actually seem fairly well off compared to the others, and "people can be said to be poor when they are unable to attain a level of well-being regarded by their society as meeting a reasonable minimum standard" (White and Killick 2001:10). The impact of poverty is real regardless of its relative severity as it has a large effect on quality of life, access to the benefits of society, and well-being. We should be particularly aware, however, of poverty at its extreme and its relationship with disabilities.

Importance of responding to disability

Why is it important to recognize this connection between poverty and disabilities? It is extremely critical because such a relationship suggests that disability services should and must be incorporated into development efforts. There have been many global efforts to respond to poverty, and yet none of these have been as effective as one might have hoped. While the efforts may have been well intentioned, good intentions are not enough when millions of lives are at stake. It is clear that we need to re-evaluate the previous development strategies. The World Bank affirms the importance of reconsidering our global approach:

> Are the International Development Targets for poverty reduction achievable? Previous international targets have come and gone, and much academic analysis suggests a similar fate awaits these new targets. The impossibility of achieving these goals is not, however, our message. Rather, it is that, if they are to be achieved, something different, something more, needs to be done than at present (White and Killick 2001:xxvi).

The cyclical connection between poverty and disabilities is often unrecognized and therefore not taken into account in discussions of community development. "Disabled people are typically actively and unwittingly excluded from development activities" (KAR 2005:6). This is extremely unfortunate, as failure to incorporate disability social services into development efforts is detrimental not only to people with disabilities, but to the entire society. Since disability greatly increases the likelihood of poverty, and because poverty causes increased detriment for people with disabilities, responses to global poverty and hunger will be incomplete, and likely ineffective, if they do not directly address the needs of people with disabilities. Such a large percentage of the poor in developing countries have disabilities, and they are so isolated from benefits of society such as education and health care, that these international development targets will most likely not be reached until this population is empowered and integrated into community (DFID 2000).

In addition to the importance of disability social services to development and simply the necessity of having compassion for issues relevant to this population, this discussion is critical because disabilities impact the entire community. We often think of disability as an individual problem, but in fact, it has a large impact on both the families of people with disabilities and the community at large.

> Disability does not just affect the individual, but impacts on the whole community. The cost of excluding people with disabilities from taking an active part in community life is high and has to be borne by society, particularly those who take on the burden of care....The UN estimates that 25% of the entire population is adversely affected in one way or another as a result of disabilities (DFID 2000:4).

With an understanding of the importance of disability social services and their relevance to community development, it is now critical to note that an effective approach is just as important as the initial presence of these services.

Hypothesis Two

My second hypothesis is that social programs for people with disabilities must focus on the empowerment of these individuals. First, I will clarify what I mean by "empowerment." *The Social Work Dictionary* explains this term as "the process of helping individuals, families, groups, and communities increase their personal, interpersonal, socioeconomic, and political strength and develop influence toward improving their circumstances" (Barker 2003). Essentially, then, empowerment is helping others to help themselves. It can lead to a higher quality of life without creating dependence. "Empowerment, participation and equal control become the means of overcoming a disability, rather than medical care alone" (DFID 2000:8). Empowerment, then, is an inseparable part of disability social services.

Redefining disability

Critical to the discussion of empowerment is a second look at the way in which we define disability. I previously gave a technical definition for the term, but it will now be useful to understand the term within its sociocultural context. First, I will make the distinction between impairment and disability:

> There is no universally agreed definition of disability. Historically disability was seen primarily as a medical condition, with the problem located within the individual. This medical or individual model was challenged by disability activists who reconceptualised disability as primarily a social phenomenon. This social model of disability draws a clear distinction between impairments and disability. Society disables people with impairments by its failure to recognize and accommodate difference and through the attitudinal, environmental and institutional barriers it erects towards people with impairments. Disability thus arises from a complex interaction between health conditions and the context in which they exist. Disability is a relative term with certain impairments becoming more or less disabling in different contexts (KAR 2005:1).

Therefore, while disability is generally considered to be an individual and physical or mental phenomenon, it will be appropriate to maintain a more holistic understanding of this term. Cross-cultural comparison shows that people with disabilities suffer more from societal reaction than from actual impairment (DFID 2000). This recently emerging 'social model' of disability, however "places the emphasis on promoting social change that empowers and incorporates the experiences of people with disabilities, asking society itself to adapt" (DFID 2000:8). It makes sense that society should change, rather than forcing the person with a disability into a mold, as societal reaction to a disability is as reflective of that particular society as it is of the actual disability (Hagner 2000). Society, therefore, must adjust to the needs of all its members, including those with disabilities (DFID 2000). It is essential that we maintain a holistic approach to responding to disabilities. "There is increasing recognition that the term disability does not simply express a medical condition but a complex system of social restrictions emanating from discrimination" (DFID 2000:8).

Howard Becker

A theory which is relevant to this study is Howard Becker's *labeling theory.* In his book, "Outsiders: studies on the sociology of deviance," Becker asserts that it is society which creates deviance. Society defines what it is that constitutes deviance, and based on this definition, certain members of the society are labeled as deviants and become outsiders (Becker:1963). According to labeling theory, then, people with disabilities are not inherently outsiders, but rather they are outsiders because society has chosen to label them as such. As is true of the previously discussed theories, Becker's labeling theory is important for those involved in creating disability social services to understand as they attempt to give these "labeled" individuals the chance to integrate more fully into society.

Charles Horton Cooley

Charles Horton Cooley's *Looking-glass self* theory provides useful insights into the limitations that stigma can create for people with disabilities. Cooley emphasizes the impact of the perceptions that other people have of us. He says that "We use others as mirrors to assess who we are and how we are doing" (Ritzer 2003:60). At times this "mirror" reflects an image similar to the way in which we see ourselves, and so reaffirms our self identity. Other times, it reflects an image that is different from the way in which we see ourselves and hope to be seen. In these situations, the mirror may cause us to change our self-perceptions. Thus, it is easy to see through the Looking-glass self theory that the perceptions which others have of us powerfully impact the way we view ourselves. For people with disabilities this means that the prevalence of stereotypes and prejudices that society holds about these individuals is likely to impact the way in which these individuals view themselves (Ritzer 2003). Cooley also discusses the *primary group* in relation to his looking-glass self theory. The primary group is the small, closely linked group of people with whom an individual has the most contact, such as family and close friends. The looking-glass self theory plays out the most through an individual's primary group, as this is one of the main places where a person is connected to the greater society. And so, the primary group of an individual with disabilities has a crucial role in the way in which that individual relates to the community (Ritzer 2003). Cooley's theories provide valuable insights into the impact of the perceptions of others. Part of the disempowerment of people with disabilities comes from social exclusion. Another part, however, comes from a type of self-fulfilling prophecy. People with disabilities learn from society that they cannot amount to much, and they then begin to internalize this belief.

Erving Goffmann

In *Stigma,* Erving Goffmann also describes the impact this stigma can have on the individuals who it alienates. Like Shutz, Goffmann says that we use categorization to simplify our dealings with new people (1963). There is a stigma attached to certain people and conditions, and yet Goffmann says that "Typically, we do not become aware that we have made these demands or aware of what they are until an active question arises as the whether or not they will be fulfilled" (1963:2). Goffmann's discussion of stigma is relevant to this study because people with disabilities are among those who are typically stigmatized in our society. Goffmann distinguishes between discredited stigma, in which the stigmatized quality in an individual is clearly visible, and discreditable stigma, which is not necessarily evident. (Ritzer 2003) Although not always, disabilities are often discredited stigma, in that they are clearly visible to outsiders. This means that it is hard to avoid the impact of stigmatization. Goffmann mentions the dehumanization of stigmatized people. Part of this dehumanization comes from the fact that stigma often spreads from stigmatized individuals to those close to them, and this sometimes makes people cautious about relating too closely to these individuals (Goffmann 1963). Goffmann's discussion of stigma is important in helping us to understand the major barrier that it creates for the goal of integrating people with disabilities into the community.

Stigmatization of individuals with disabilities

Stigmatization and labeling are present in every society, to different degrees and with different victims. In order to understand the stigmatization and labeling in Kenya, it is important to be aware of cultural beliefs that impact the meaning of disability within their culture. For example, in traditional Kenyan culture, "people with disabilities were considered to be people that had a mysterious relationship with the spirit world. This could be good or it could be bad" (Pickens 2006). At times this could result in a person with a disability being honored with a position such a shaman because this connection to the spiritual world was perceived in a positive way. Often, however, people with disabilities were excluded from society, or totally outcast (Pickens 2006). Today's culture in Kenya has progressed from traditional culture, and yet it is still deeply rooted in this foundation. It is essential to recognize, therefore, that the stigmatization of people with disabilities is connected to deep seeded assumptions at the core of Kenyan culture. And this core, as is true in any culture, is extremely difficult to change.

Francoise cites a stigmatization of individuals with disabilities in Burkina Faso, as well, that is related to deeply rooted animism within the traditional culture. Children born with disabilities are often considered cursed, especially if they are female. She does say that this is changing, however, and that people with disabilities are beginning to be more highly valued. One element of the handicap center that Francoise stressed is that they try hard not to make it a "leper colony," in which people with disabilities are hidden away because they are not fit for society. Instead, individuals remain in their homes as much as possible, so that they can be present in the community, and yet at the same time they receive the services that they need (Pedeau 2006).

The progression of cultural values is a very gradual process, and it must be handled with care. As outsiders, we can make efforts to advocate for people with disabilities, but we also must treat their culture as sacred ground. Ultimately, it is best if efforts towards progress originate from within the local community, or are at least strongly rooted in this community. When we consider disability social services in Kenya, then, we must be very aware of this cultural background. We must remember, also, that there is diversity of opinion within Kenyan culture. According to Dr. Pickens,

> there are people who would see people with disabilities very similar to you and I, there would be people who would see them as being cursed by God and therefore God is doing something in their life where they need to be left alone because we don't want to get involved in whatever the spirit world is doing. Others would say that these people have a reason to expect others to help them. So I don't think there's any one way that they are viewed (2006).

So we must be careful not to over generalize and assume that there is one uniform view in Kenya towards disabilities, because their society is as diverse as our own.

Emile Durkheim

Another social theorist of particular importance to this discussion is Emile Durkheim and his theory on collective conscience. Collective conscience is "The ideas shared by members of a collectivity such as a group, a tribe, or a society" (Ritzer 2003:16). Durkheim differentiates between "mechanical solidarity" and "organic solidarity" as they relate to collective conscience. Mechanical solidarity describes smaller societies, in which the collective conscience is very strong and difficult to evade and deeply affects the ways people think and act. Organic solidarity, however, refers to larger societies in which the collective conscience is not as strong. It still impacts the ways in which people think and act, but it is easier to deter from and less deeply rooted in individuals (Ritzer 2003). An understanding of Durkheim's concept of collective conscience is useful as we seek to understand the meaning of disability in society. While collective conscience has more of an impact in a smaller community, it also has an impact within larger society, and in both cases affects the experiences of people with disabilities, often leading to stigmatization and exclusion. Dr. Pickens discusses the transition from traditional Kenyan culture to modern society. While the collective conscience in traditional culture had a strong impact on the way in which the community responded to disability, there is more diversity of opinion in today's culture in Kenya (Pickens). This does not eliminate the stigmatization faced by individuals with disabilities, but it does mean that there has been a gradual improvement, and that there is more of a possibility of incorporating views of empowerment.

Community Inclusion

The empowerment of people with disabilities requires an active response to the stigmatization and efforts to include people with disabilities more fully in society. People with disabilities are frequently excluded in all types of societies, so that the problem is not only in developing countries. The focus of this discussion, however, is on Kenya and other African countries. According to Dr. Pickens, there is an idea ingrained in many people in Kenya that individuals with disabilities will never amount to more than beggars on the street (2006). There is an idea that people with disabilities do not have much to offer and should therefore be excluded from the community. This societal reaction is harmful to the individual, the individual's family, and even the entire community. For example, in *Mental Retardation: A Life Cycle Approach,* authors Drew, Logan and Hardman state that there is a stigma associated with mental retardation that usually makes the event of finding out a child has this disability a crisis within the family (1984). This type of crisis is not exclusive, however, to families in which a member has mental retardation. The presence of any type of disability can place a huge burden on a family, and the more stigmatized disabilities are within a particular society, the greater this burden. Modern society, complex as it is, can be difficult enough to navigate for anyone, let alone a person with a disability that may hinder their participation. Unfortunately, society more often excludes and segregates this population than it takes the time to help them integrate and fully participate (Reischl 2000). Of interest to note is that people with disabilities in Uganda have attained the most representation politically of people with disabilities worldwide (DFID 2000). There is hope in East Africa.

Hypothesis Three

My third hypothesis is that people with disabilities and their families, as well as the local communities, must play a key role in the development of these social services. The disability rights movement slogan which I previously mentioned insists on "Nothing about us without us," meaning that initiatives to support people with disabilities should be in collaboration with people with disabilities themselves. Logically, it certainly makes sense to include the people with the most inside knowledge. In a book by the same title as this slogan, David Werner applies this principle to disability rehabilitation services in communities of developing countries (1998). This principle is important for two reasons when we consider rehabilitation in the context of a developing country. First, we must recognize the insights of the people with disabilities and their families. Another level of application for this principle is that we must recognize the insights of local people, because of course they will have the deepest understanding of the cultural context and the usefulness of a particular strategy within that setting.

If we simply return to the definition of empowerment, which was essentially the process of helping others to help themselves, it is clear that this definition itself requires that people with disabilities and their families have an important role in the improvement of their own circumstances. Therefore, my second and third hypotheses are actually inextricably linked. And yet I will still discuss them separately so as to highlight the critical importance of both elements of this same issue.

Insights of individuals with disabilities

First, it is critical to rely upon the insights of people with disabilities themselves and their families. The most obvious reason for this is that giving voice to these people prevents some avoidable errors (Werner 1998). Who has more of an inside understanding of the needs of people with disabilities than those with firsthand knowledge? Society often disempowers this population and assumes that they are not able to contribute anything significant to the development of disability social services. And yet, intuitively, it only makes sense to take full advantage of their unique expertise. "Staying connected to families and people with disabilities, not just those who are fighters and agents of change but also those who struggle to survive every day, is essential" (Nisbet 2000:5). By drawing on the experiences of people with disabilities and their families, we can ensure that the social services that we develop together will go beyond theoretical ideas and be firmly grounded in the reality of these individual's lives.

People with disabilities have a lot to offer to the process of developing social services. It is therefore essential to take views of people with disabilities seriously in making decisions on what approaches to take (DFID 2000). Many people recognize the value of the opinions of people with disabilities for coming up with new innovations (Werner 1998). Unfortunately, not everyone shares this conviction. According to Werner,

> A lot of professionals are unwilling to include disabled persons as partners in designing solutions to their needs, and often disabled persons are reluctant to assume such responsibility. Nevertheless: Many major breakthroughs in rehabilitation technology have been designed and created by disabled people themselves (1998:5).

Many people working successfully with people with disabilities also have disabilities themselves (Werner 1998). And people with disabilities have made important contributions to the field of disability social services. A particularly noteworthy and widespread example is Braille, which was invented by a blind boy (Werner 1998).

Insights of local people

In a similar fashion, we must recognize the expertise of local people. Just as no one knows the needs of people with disabilities as well as those personally effected, it is also true that only local people really know the cultural context and values within which a disability service program will be implemented. "Disabled persons' needs differ, not only individually but also according to local customs, living conditions and environment" (Werner 1998:14). When working in a developing country, those wishing to support people with disabilities must be particularly conscious of the limits of their own knowledge of the local environment. If they fail to have this humility, they take a huge risk of being ineffective, or worse yet, of harming the very people who they are trying to support.

It is important to be aware of local social conditions, values, environmental factors, family structure, religious beliefs, and more. In an appropriate approach to service delivery, especially within a developing country, "Value is placed on indigenous knowledge and practices, the key being to 'unlock' existing expertise within communities to help them develop their own form of [rehabilitation]" (DFID 2000:9). Another reason that it is important to rely on the local people is that this contributes to the sustainability of a service delivery program. In other words, it ensures that the local community is not entirely dependent on an outsider in order to continue the services. It is important to not rely so much on leaders that, if they were to leave suddenly, programs would collapse (Nisbet 2000:7). This is particularly true of leaders who are not local to the community. A long-term goal of any disability service provider should be that it would become entirely self-sustaining and led by locals.

Dr. Pickens summarizes the importance of this type of response to disabilities that focuses on the expertise of the local people:

> I think that [societal change] starts at the grassroots. I think that's what needs to be happening. You start small. You start with local people. I don't think it works from the top-down. Although, I don't think we should neglect that, but it seems to me that you need to start with the local people (2006).

Francoise also recognizes the importance of relying on the local people and beginning at the grassroots. The handicap center has a staff of 17 people and 4 more in training, and all of these people are locals of Burkina Faso (Pedeau 2006). The staff also includes 5 people with disabilities, so that it is not only locals who are active in the development of the program, but also local people with disabilities. The center also sponsors a micro project, in which local people are given business loans, which they later pay back (Pedeau 2006). This builds up the local economy and makes it more sustainable, and yet even in the process itself, the local people are able to empower themselves and play a role in this development.

Community-based rehabilitation

One model of social service delivery that embodies these principles is Community-based Rehabilitation, or CBR, which strives to empower people with disabilities to play a key role in their own empowerment (DFID 2000). The handicap center in Burkina Faso, previously described, is a prime example of this type of service because of its reliance on local people and people with disabilities. In this holistic model of service delivery, service providers, people with disabilities and their families, and the community partner together to respond to the needs as they see them. "[Community-based Rehabilitation] attempts to combine physical rehabilitation through medical care with empowerment and social inclusion through the participation of both the individual with a disability and the community in the process of rehabilitation" (DFID 2000:9). This ensures that rehabilitation is as useful as possible. In many situations, assistive equipment can very useful for people with disabilities, but only if adapted to the individual and their specific needs. It is therefore essential to consult heavily with the individual in order to ensure that these aids are, in fact, as empowering as possible (Werner 1998). Additionally, the more say that an individual has in the services designed to empower them, the more autonomy and self-determination they will experience. "Advocates of CBR believe that it empowers individuals to take action to improve their own lives" (DFID 2000:9). There are CBR efforts all over the world, including in Kenya. David Werner cites a CBR program in Kenya as one of the "most innovative" that he has seen. It is located in Nairobi, in Matari Valley, a shanty town (Werner 1998). While there is much improvement still to be made in the way in which people with disabilities are viewed in Kenya and around the world, this program is evidence that there are also signs of progress.

Empowerment and Disempowerment

Furthermore, any efforts to empower people with disabilities are counterproductive if, in this process, they are stripped of power. Essential to empowerment is that people with disabilities must become integral and valued members of society. "People with disabilities have not always had the opportunity to participate fully and equally in the development and management of basic infrastructure services and shelter" (DFID 2000:13). The needs and desires of people with disabilities and their families are often not taken into account as much as necessary. And yet this is gradually changing. People with disabilities are taking an increasing role in society and in the development of services, and they are insisting on a voice (Werner 1998). Part of the importance of this voice is that there is a diversity of needs among people with disabilities (DFID 2000). While there are overarching models and ideologies for service delivery, these must always be applied to the present reality. This means that, in working with people with disabilities, services must be adapted to the needs of each individual.

For example, it is particularly important that any assistive devices are adapted specifically to the individual who will use them, rather than trying to force that individual into standardized equipment (Werner 1998). There is no better way in which to adapt to the needs of a person with a disability than by drawing on the insights of that person. "A rights-based approach to disability and development implies a right to self-representation. The rights of people with disabilities are best promoted by people with disabilities themselves" (DFID 2000:13). David Werner focuses heavily on the role of people with disabilities in service delivery. He views this service delivery very much as a collaborative effort.

> In this approach, the disabled person (and/or family members) often takes the lead, working as a partner and equal with service providers, technicians, or local craftspersons. With this sort of partnership approach, results tend to be more enabling than when assistive equipment is unilaterally prescribed or designed (1998:1).

This type of collaborative effort challenges a commonly held view of people with disabilities as passive receivers of services, and it is important to make this paradigm shift.

Paulo Freire

And finally, Paulo Freire provides a key theoretical foundation for this concept in his classic work, *Pedagogy of the Oppressed.* Freire discusses the "banking" model of education, and the relationship between teacher and student. The critiques that he makes are directly applicable to the relationship between disability service providers and people with disabilities and their families. In Freire's banking model of education, he critiques the typical method of schooling in which the active teacher "deposits" information into the passive students. In this model, he contrasts the teacher as a narrating subject to the students as listening objects (Freire 1993). In this comparison, it is clear that the banking model essentially takes away the humanity of the students.

> The teacher talks about reality as if it were motionless, static, compartmentalized, and predictable. Or else he expounds on a topic completely alien to the existential experience of the students. His task is to 'fill' the students with the contents of his narration-contents which are detached from reality, disconnected from the totality that engendered them and could give them significance (1993:71).

As Freire points out, the banking model fails to utilize and appreciate the lived experiences of the students. Now let me apply what I have already discussed of Freire's theory to the relationship between service providers and people with disabilities. Some people who aim to help people with disabilities fall into the unfortunate trap of a "banking model" of service delivery. Although they may have excellent intentions, they treat people with disabilities and their families as subjects or empty vessels who must receive their services. This model assumes the total ignorance of the students (Freire 72). And yet, according to David Werner, it is essential to focus on equality and partnership, not on 'providing services' (4). Freire affirms the importance of self-determination, and this is applicable whether in a classroom, in relation to people of a developing country, or in working with people with disabilities. "The more students work at storing the deposits entrusted to them, the less they develop the critical consciousness which would result from their intervention in the world as transformers of that world" (Freire 1993:73). We must strive for societies in which all people have the opportunity to be world-transformers.

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