

# Understanding Disability in Sudan

By

Leon Nyerere

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Thesis committee:

Dr. Deborah Stienstra (Academic supervisor), Department of Disability Studies University of Manitoba

Dr. Jennifer Mactavish, Department of Disability Studies, Department of Disability Studies University of Manitoba

Dr. Eliakim M. Sibanda, Department of History, University of Winnipeg

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## Abstract

Sudan has been at war for decades. As such, many research areas in Sudan have not been investigated. Disability is one of these areas. Although the little literature available indicates that Sudanese have negative attitudes towards disabled people, there is still lack of rich literature on how persons with disabilities are perceived in Sudan. The objective of this exploratory research is to start the process of understanding how people with disabilities in Sudan are perceived by engaging persons with disabilities in identifying barriers hindering them from participating in society and measures they think should be taken in order to overcome the identified barriers. Using a qualitative research design, four adults living with physical disabilities were interviewed. The data obtained was analyzed using a Key Theme Analysis Method. The findings from this study suggest that people with disabilities face many barriers that prevent them from participating in their society. These barriers include: negative stereotypes, unemployment, low economic status, sense of hopelessness, corruption and race and religious factors. I hope findings of this research paper adds to the existing body of literature and reminds disability activists and their allies worldwide the importance of collective efforts to fight against exclusion of disabled people in their respective societies.

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## Dedication

I dedicate this research project to the four research participants who volunteered to share with me their painful stories: Edreena Lusuncio Wani, Juma Scobis Kabo Andaragu, Dominic Fabio Ojok, and Lucia Kpoakan. Because of your stories, the world will get to understand what it is like to be a disabled person living in Sudan.

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# Chapter One

## Introduction

In Sudan, disabled people are the most excluded and isolated segment of the Sudanese population (Scottish Catholic International Aid Fund, 2008). This research project investigates some of the major barriers to inclusion of internally displaced South Sudanese with disabilities in the Sudanese society from their own perspective and some measures they think are required to address these barriers. This exploratory research project was guided by two research questions:

1. What are the most significant barriers to inclusion of internally displaced South Sudanese with disabilities into the larger Sudanese society from their own perspective?
2. What are some measures they think are required to address these barriers?

Based on both economic and humanitarian reasons, it is imperative that barriers to inclusion of disabled people in Sudan are identified and removed. For example, Omer (1990) suggested that, as a developing country, Sudan cannot afford to exclude the huge population of the disabled from participating in economic development. He said any development planning strategies that relegate the development of the capacity of disabled people to a low priority can only be economically counterproductive in the long run. While it is important to remove impediments to inclusion of persons with disabilities because of their vital role in economic development, people with disabilities shouldn't be valued just for their economic contributions. As argued by Yazbeck, McVilly and Parmenter (2004), the primary reason governments around the world should promote inclusion of disabled people in society where disabled persons are able and allowed to be



themselves among others is not because of their economic importance but because disabled people are human beings and they have rights just like everyone else.

When I started working on this research project, Sudan was still one country. But on July 9, 2011, the country split in two: The Republic of Sudan and Republic of South Sudan. This study is relevant to both countries in spite of the split. While the research was conducted in the North, the targeted population was the internally displaced South Sudanese living in Hajyusif area in Khartoum. Due to the protracted civil wars, a large population of Southern Sudanese migrated and settled in the periphery of the nation's capital. This population was predominantly Christian and those who practiced African religion. Initially, my intention was to investigate barriers to inclusion of all Sudanese with disabilities. However when I visited Sudan in 2009, I learnt that animosity and mistrust existed between black and "Arab" Sudanese. Ethnic Africans from Darfur, Nuba Mountains and South Sudan were often seen as the enemy of the State by the "Arab" dominated government. Therefore asking "Arabs" to participate in the research was not only difficult but could have also put my life at risk. The Sudanese government (the republic of Sudan) was suspicious of those who lived in the West. The level of suspicion increased when one was non-Muslim and non-"Arab" like myself. Carrying research in "Arab" dominated areas could have easily gotten me arbitrarily arrested. The police in The Republic Sudan at the time were known for their use of excessive force on detainees, which occasionally had resulted to death. For my own safety, at that point, I found it wise not to include Sudanese "Arabs" as part of my targeted population.

I chose to conduct my field research in Hajyusif because, first, as I have already mentioned in the literature, a big percentage of Southern Sudanese lived in that area and

my family lived there as well. I did not have to worry about accommodation and navigating the area. My family existence in the area also lessened suspicion about my presence.

When I was working on the introduction part of this paper, I thought it would be important to include Sudan's pre and postcolonial history to assist readers who have little or no knowledge of Sudan to get a better understanding of country.

### **Sudan's pre-colonial and post-colonial history**

Francis Deng (2006), a prominent scholar who has written extensively on Sudanese conflicts, described the Republic of Sudan, prior to its up in 2011, as "a theater of proliferating conflicts" (p. 157). The causes of Sudanese civil wars ranged from power imbalance between the core and periphery of the country to "an imbalance that both reflected and perpetuated culturally entrenched ethno-religious discrimination against non-Arabs and non-Muslims" (Neff 2008, p. 25). Since it gained independence in 1956, Sudan has had two major civil wars. To understand Sudanese conflicts, one must understand not only racial and religious make up of the country but also how British colonial administration governed it.

Sudan was seen by the outside world as simply an Arab-African country, but Sudan's diversities are unusually complex (Wolfers 1981). By landmass, Sudan was the largest country in Africa, but its geographical location was a matter of contention. Depending on who you ask, Sudan was described either as a Middle Eastern/Arab country or as a part of sub-Sahara Africa/Black Africa. Deng (2006) wrote that people who have been in control of the country define themselves as Arabs and also Muslims,

and identify more with the Middle East than with Black Africa. The northern part of Sudan is made up of ethnic Africans (Blacks), who are the majority, and Sudanese Arabs who are the minority but as Deng said, they have been in control of the country since it gained its independence in 1956. Most of the ethnic Africans in the north have been converted into Islam.

Historically, Jalata (2005) wrote, the northern part of the region, which is now the modern Sudanese state, was once the famous indigenous kingdom of Nubia (black Africans). According to Jalata, Nubians, who were predominantly Christians, had trade connections with the Arabs before the emergence of Islam. However, he says, when the Nubian civilization declined and the kingdom became weak, the number of Muslim Arab immigrants increased in Nubia. According to Jalata, a signed treaty with Arabs who colonized Egypt in AD 640 led to the peaceful migration of more Arabs into Nubia, who gradually colonized the kingdom. Most Nubians, Jalata wrote, remained Christians until 15th or 16th century when the Arabs in Sudan began to convert Nubians and other local ethnic groups into Islam. Jalata wrote that before Sudan was colonized jointly by British and Egyptian consortium, the Sudanese Arabs had a movement known as the Madia. Madism, according to Jalata, “was both a religious and a political movement which aimed at a return to the Orthodox Islamic constitution in government, culture and religion” (p. 91). While ethnic Africans and Arabs populate northern Sudan, the southern part of Sudan is made up of mainly Black Africans who are predominantly Christians and those who practice African religions.

The territory that is now the Sudan prior to its division in 2011 was ruled by British Egyptian consortium from 1899 to 1956 (Wolfers 1981). Sharkey (2008) said, when

British and Egyptian forces overthrew the Madist State and established the Anglo-Egyptian consortium, Northern Sudanese society was highly stratified. He said Sudanese Arabs occupied the top of the social pyramid while black Africans were found in the bottom of the pyramid. According to Sharkey, the British colonial authorities preserved and respected those local status hierarchies and reinforced them through education policies. They did so, Sharkey wrote, by favouring high status 'Arab' males for the academic educations that would lead to administrative jobs, mean while, they guided those of African descent into army careers and manual jobs.

In regards to the northern and southern regions, the British colonial administration ruled them as two distinct entities, with the north advancing politically and economically, while the south remained isolated and undeveloped (Sharkey 2008, Deng 2006). For example, Jalata (2005) said that "there were only five university graduates and one secondary school in the South when Sudan gained its independence in 1956" (p. 92). The British encouraged Christian missionary activity in the south, while forbidding this in the Islamized north (Wolfers 1981). While Arabic was used in the north Sudan as language of instruction, English was used in the south for the same purpose (Wolfers 1981 and Sharkey 2008). Wolfers said the British deliberate policy of administering the north and the south as two separate entities, made the process of achieving national unity difficult if not impossible.

When the British was forced to leave Sudan by anti-colonial forces, the ill prepared southerners and other Black Africans in the North, came under the control of the northern "Arab" elite (Deng 2006 and Sharkey 2008). The northern "Arab" elite, Deng and Sharkey argue, began to implement policies of Arabization and Islamization

forcefully in the South with an objective of harmonizing the South with the North, culturally, religiously, linguistically and ethnically. One of the first things that the successful post-colonial government did was to replace English as the language of instruction in the South with Arabic (Sharkey 2008). According to Arabization and Islamization policies, if a non-Arab became a Muslim, and acquired a Muslim name and culture, he became an Arab (Sharkey 2008). Sharkey argues that “for the Northern Sudan Arab government which constituted the de facto central government, there has been an obsession since independence with the political need to project the Sudan to the outside world as a homogeneous Arab nation; a nation with one language (Arabic), one religion (Islam), one culture (Arab-Muslim culture), and most importantly, one race (Arab)” (p. 26).

The forceful policies of Arabization and Islamization in the South were met with rebellion by the Southerners. The first civil war, which pitted the North against the South, erupted in 1955, only eight months before the country attained its independence on the 1st of January 1956 from British and Egyptian consortium. The conflict was stopped in 1972 by a peace agreement that granted the South a regional autonomy, and it was resumed ten years later in 1983, when the government unilaterally abrogated that agreement. The second civil war, which began in 1983, came to an end after more than two decades through a Comprehensive Peace Agreement (CPA) signed on January 9, 2005. Both civil wars, the first and the second, were fought mainly in the South hence these wars affected the South more than the North. The two civil wars between the Southern Sudanese and the central government had been generally perceived as Northerners versus Southerners, Arabs versus Blacks, and Muslims versus Christians.

But the on-going conflict in Western Sudan (Darfur), the discontentment of people from regions of Eastern Sudan and Nuba Mountains with the central government, have brought to the surface one of the root causes of conflicts in Sudan: an unequal distribution of resources and power. The Christians and those who follow African religion in the south and the non-Arab groups in the north are largely marginalized. These groups, as it has already been discussed in the literature, are not given equal opportunities in comparison to those who claim Arab pedigree. It is alleged “the vast majority of government positions in Khartoum, from cabinet ministers to their drivers and all the bureaucracy in between, were held by members of three Arab tribes which represented only 5.4 percent of the population” (Sharkey 2008, p. 42). This goes to show how the majority of Sudanese have been left out in power sharing. Sudanese history is long and complex but I hope this brief history of Sudan’s pre and post-colonial era is helpful for those who have no previous knowledge of Sudanese society.

This thesis is divided into six chapters. The first chapter is the introduction. Chapter two is on the theoretical/conceptualization frameworks that guided me through the course of writing this paper: International theories of African states and the social model of Disability Studies. The third chapter is the literature review. The literature review consists of five sub-sections. The first subsection discusses how disability is understood in the Western World and in Sub-Saharan Africa. The second subsection, which is quite different from the first one, describes Sudanese socioeconomic and political nature and how they have affected lives of disabled people. It also discusses the lack of commitment by the government towards this group. The third subsection discusses how barriers to inclusion of persons with disabilities are understood and

addressed by the government and the non-governmental organizations (NGOs). The fourth subsection discusses the future of people with disabilities in Sudan. While the medical model is still the dominant paradigm in defining and solving problems facing disabled people, in this subsection, it is shown that there are signs that disability activists have begun to challenge the way they are unnecessarily excluded from accessing the same opportunities available to the non-disabled population. Lastly, in the fifth subsection, gaps in the literature are identified, followed by recommendations.

In chapter four, I discuss methodology and methods used to investigate barriers facing disabled people in Sudan. I also discuss recruitment of research participants as well as data analysis method that I used to organize and analyzed my data. I used a qualitative research design to inquire issues facing this population. For the method, I chose in-depth interviewing approach to solicit information from research participants.

Chapter five is about data presentation. This chapter is divided into four major sections: data presentation, measures to address barriers identified, areas for further research and summary of the research findings. The data presentation is divided into two subsections. In the first subsection, stories of the research participants are presented according to emerging themes. In the second subsection, the themes that were identified are further analyzed and the findings are presented. The second section discusses measures to address barriers. The third section discusses areas for further research. In the fourth section, a summary of research findings is presented.

Lastly, in Chapter six, I conclude the paper by sharing my view about future of persons with disabilities in Sudan. The argument I present in this chapter is that while disabled people will continue to face enormous challenges, injustices that they will

continue to encounter will not go unchallenged as it was in the past because people with disabilities in both Sudans are becoming increasingly aware of their right.



## Chapter Two

### Theoretical/conceptual frameworks

Having been born and raised in Sudan, I have had the privilege of seeing firsthand how people with disabilities are treated. A handicapped person in Sudan is often laughed at openly even in the presence of the person. Children often run after a handicapped person, mimicking how the person walks. People with psychiatric disabilities are often referred to as crazy. For a long time, I thought the lives of people with disabilities are full of sadness, and perhaps they do live a life of sadness considering the inhumane treatment they get from the non-disabled population. I never thought persons with disabilities have aspirations just like everyone else. My negative perception of persons with disabilities changed after I formed a bond with a handicapped Kenyan student in a high school. My experience with him as a close friend changed the way I view persons with impairments. It was from that point that I began to think that impairment does not necessarily disable a person. He prompted me to ask rhetorical questions such as why are disabled people presumed to be worthless? Why do some people have to be labeled as disabled while others are not?

This research project investigates some of the major barriers to inclusion of internally displaced South Sudanese from their own perspective and some measures they think are required to address these barriers. Two conceptual frameworks guided this exploratory research project: (i) international development theories of African states and (ii) the social model of disability. The first conceptualization framework will help those that are not familiar with Sudan to understand why it has been marred with conflicts and poverty since it gained independence from Britain. This conceptual framework will also

assist in understanding the link between a weak/fragile state and barriers to inclusion of disabled people. I use the second conceptual framework (the social model of disability) to assist me in uncovering barriers to inclusion of persons with disabilities in Sudan. I will also use criticisms of the social model to enrich understanding of both internal and external barriers to inclusion of persons with disabilities. Although the social model and its criticisms were developed mainly by Western scholars with Western society in their minds, they are relevant for understanding why persons with disabilities in Africa are living in the margins of their own societies given that lives of people in Africa are increasingly shaped by the Western economic and political systems. This however does not imply that there are no cultural, economic and political differences between these two regions. Also it does not imply that there is no need for Africans to develop their own culturally appropriate disability model. I will deal with each conceptual framework separately.

A critical race theory could also be useful in understanding Sudanese conflicts and marginalization of certain groups of citizens. Critical race theory is concerned with studying and transforming the relationship among race, racism and power between the dominant Whites and people of colour (Delgado and Stefancic 2001). But I have not used it as one of the conceptual frameworks because the issue of race in Sudan is very complex in that those who refer themselves as Arabs are interracial (between Arabs and black Africans). They are darker in skin complexion; in fact, some of them are even darker than some Black Africans (Deng 2006 and Wolfers 1981). As Sudanese Arabs travel abroad, their identity as “Arab” is challenged. Writing about Sudan’s Arab identity crisis, Al-Baqir al-Afif Mukhtar (Sharkey 2008) said, Sudanese who are half Arabs think

of themselves as Arabs, whereas the Arabs think otherwise. When Sudanese Arabs travel to the Western world they are categorized with 'Blacks' and in Middle East they are not considered as Arabs but 'abid', an Arab word that means slave (Sharkey 2008 Wolfers 1981).

Perhaps the reason Sudanese Arabs do not want to identify themselves as Blacks even though the outside world see them that way is because of the negative connotation attached to being black in the Arab world. Sharkey (2008) argues that when the British and Egyptian forces began to colonize Sudan in 1898, there was no such thing as a self-identified 'Sudanese Arab' among Muslim elites in Sudan. At that time, he argues, to be Arab was to be Muslim, to be Arab was to be free, and, ideally, it was to claim an Arab pedigree. The term Arab, Sharkey argued, connoted high status. By contrast, Sharkey wrote, a deeply entrenched slave trade had bestowed servile connotations on the adjective Sudanese, which was derived from the Arabic term sud, meaning 'black people. He says that in the view of high-status Muslims who regarded themselves as Arabs, being Sudanese meant being black, and being black, in turn, meant having low social status. Sharkey says, the British colonial authorities preserved and respected these local status hierarchies and reinforced them through education policies.

This negative perception of Black Sudanese continues to the present day. In his own words, Deng (2006) wrote, in Sudan, "the normative framework provided that a person who was a Muslim, Arabic-speaking, culturally Arabized, and could claim Arab descent was elevated to a position of respect and dignity, while in sharp contrast, a non-Muslim black African was deemed inferior, a heathen, and a legitimate target of enslavement" (Deng 2006, p. 156). The Sudanese government run by the Arab Sudanese

treats non-Arabs and Arabs as though they have different entitlements (Sharkey 2008). Quoting Amir Idris, a Sudanese born Assistant Professor of African Studies at Fordham University, Sharkey stated that those who are considered Arabs by the racialized state are treated as citizens while those who are perceived as non-Arabs are treated as subjects. Some scholars have even attributed the decades of civil wars in Sudan including the ongoing conflicts in Western Darfur to racist attitudes of Sudanese Arabs toward Black Africans (Sharkey 2008 and Jalata 2005).

Race and racism does exist in Sudan but it is difficult to single out racism as a culprit of injustices committed against non-Arab Sudanese because, first, Sharkey said, there is a lack of study of racism in Sudan. Sharkey argued that the issue of racism in Sudan has been so sensitive a topic that it has been largely ignored. He said those accused of being racist tend to deny it while those who claim to have experienced racism testify to its relevance in day-to-day life. Second, Sharkey argued, in Sudan, issues of language, culture, religion and race are so closely interlinked as to be inseparable.

Due to the lack of study of racism and the nature of its complexity, I have decided to exclude it as a conceptual framework. In addition, there is no literature that links race and racism and barriers to inclusion of persons with disabilities. Because of its inadequacy, I have decided to examine Sudanese political and social crisis in a broader theoretical/conceptual framework that addresses African economic and political performances and the impact it has on the disabled population. In this conceptualization framework, I discuss some of the theories that have been put forward to explain the lack of African States' economic and political progress. I then discuss how some of these African States' economic and political conditions have deteriorated so much that they

have been classified as fragile and failed states. In this conceptual framework, I make the connection between fragile or failed states and barriers to inclusion of persons with disabilities.

## International theories of African States

This conceptual framework does not only give background information about Sudan and the conflicts that have overshadowed it since its independence, but it also helps in understanding how these conflicts have erected more barriers to individuals with disabilities. In International Development discourse, most of African states are referred to as weak states because of their inability to achieve economic growth compared to other regions of the world. A number of theories have been advanced to explain African states' economic underperformance. One of the explanations that have been given is that most of African states lack institutional quality and capacity to design and implement policies, make credible commitments, run an efficient bureaucracy and provide constraints to opportunistic behavior (Englebert 2000 and Martinussen 1997). Englebert (2000) said that there are two competing groups of scholars that have attempted to explain Africa's lack of institutional quality and capacity. One of these groups argues that Africa's stagnation, poor governance and weak state capacity is as a result of its low level of civic culture and social capital. The other group, however, argues that most African states lack institution quality and capacity because of their ethnic diversity. According to this group, "ethnic diversity has led to social polarization and entrenched interest group in Africa and has thereby increased the likelihood of selecting socially sub-optimal policies as ethnic representatives in government fail to internalize the entire social costs of the rent creating

policies they adopt” (Englebert 2000, p. 9).

Another attempt to explain why most African states have remained economically stagnant is that most African leaders, who inherited artificial polities from colonialism, turned to neo-patrimonial strategies to foster their power and prevent the dislodgment of their peasant societies (Englebert 2000). Englebert argues that these neo-patrimonial policies, which are fundamentally redistributive in nature, use the resources of the state to attain their political and essentially private aims of power maximization. The outcome is that the capacity of the state is weakened and policies that foster economic growth are avoided (Englebert p. 9).

These theories are in many ways applicable to Sudan. As a nation-state, Sudan was created by and inherited artificial polities from colonialism akin to most African nation-states (Sharkey 2008, Wolfers 1981 and Jalata 2005). Sudan is also ethnically, racially and religiously heterogeneous (Deng 2006 and Wolfers 1981). Ethnic and religious diversity in Sudan is one of the reasons the country has been in conflicts even before it gained its independence from the Anglo-Egyptian consortium. As I have discussed earlier, the “Arab” dominated government in the North has been preoccupied since the inception of the modern Sudanese state to project it to the outside world as a homogeneous Arab nation (Sharkey 2008). The Sudanese government’s persistence to project Sudan as an Arab nation, has been resisted by non-Arab Sudanese, especially by Southerners who practice mainly African spiritual believe systems and Christianity (Deng 2006, Wolfers 1981). The Sudanese government’s economic and political policies tend to benefit one racial group more than other. For example, Idris (Sharkey 2008) says that “Arab” dominated regimes in the North have treated non-Arabs and Arabs as though they

have different entitlements. He says those who are considered Arabs by the racialized state are treated as citizens while those who are perceived as non-Arabs are treated as subjects (Sharkey 2008). The government's political ambition to project Sudan as a nation with one race, one religion and one culture and at the same time favoring one group (Arabs) over the others has created resentments among Black Africans (Sharkey 2008). This is partly the reason why Sudan has been in conflict for decades.

Due to the perpetual conflicts, Sudan is described as a failing state among other nations such as Somalia, Zimbabwe, Afghanistan, Pakistan, East Timor, and Liberia described as failed/fragile states (Loeb 2009). According to the crisis state research centre (CSRC) definition, a fragile state is:

a state that is susceptible to internal and external shocks and domestic and international conflicts. "In a fragile state, institutional arrangements embody and perhaps preserve the conditions of crisis: in economic terms, this could be institutions (importantly, property rights) that reinforce stagnation or low growth rates, or embody extreme inequality (in wealth, in access to land, in access to the means to make a living); in social terms institutions may embody extreme inequality or lack of access altogether to health or education; in political terms, institutions may entrench exclusionary coalitions in power (in ethnic, religious, or perhaps regional terms), or extreme factionalism or significantly fragmented security organisations". While CCI defines a failed state "as a condition of "state collapse" – eg, a state that can no longer perform its basic security, and development functions and that has no effective control over its territory and borders. A failed state is one that can no longer reproduce the conditions for its own existence (CSRC 2006).

Loeb argues that fragile/failed states makes inclusion of persons with disabilities even harder as the non-disabled population becomes intolerant of the disabled citizen due to deterioration of economic conditions. For example, in Zimbabwe, Loeb says, as the economic situation deteriorates, people are becoming less and less tolerant toward those deemed to be burden on their families. Economic deterioration in Zimbabwe, Loeb says has resulted into a widespread abuse and neglect of children with disabilities (2009).

According to Loeb (2009), “the livelihood of people with disabilities is dependent on an open and accessible socio-political environment, free of physical, attitudinal and legislative barriers” (p. 27). As a fragile state, overshadowed by years of conflicts, Sudan is far from providing the conditions delineated by Loeb.

Before moving on to the next conceptual framework, here is a summary of the first conceptual framework. Most of African states including Sudan are unable to make policies that encourage economic growth. There are two theories that have been advanced to explain the reasons as to why most of African states experience economic underdevelopment. According to the first theory, most African states lack institutional quality and capacity to design and implement policies, make credible commitments, run an efficient bureaucracy and provide constraints to opportunistic behavior. The second theory states that the reason for African states’ economic underachievement is because most African leaders, who inherited artificial polities from colonialism, turned to neo-patrimonial strategies to foster their power and prevent the dislodgment of their peasant societies. One of the consequences of economic underdevelopment to people with disabilities, particularly in the case of Sudan, is that non-disabled population has become more intolerant to those living with disabilities.

While this conceptual framework is helpful in uncovering barriers to inclusion of people with disabilities as a result of conflicts, the next conceptual framework (social model) will not only help me in uncovering barriers to inclusion of persons with disabilities in Sudan but also in explicating why disabled people are excluded in society in the first place. As I have already mentioned in the literature earlier, I will also use criticisms of the social model to



enrich understanding of both internal and external barriers to inclusion of persons with disabilities.

### The social model of disability

It is almost impossible to engage in disability discourse without making reference to the medical model. In spite of the strong criticisms that have been leveled against the medical model, it continues to be used in one way or another to define and measure disability. The medical model, which approaches disability issues from functional limitation perspective, is based on the sick theory advanced by Parsons (Donoghue, 2003). According to the theory, Donoghue says, “the sick are exempt from the obligations and responsibilities that most members of society are expected to hold. Their state is generally considered to be undesirable and, for that reason, they are expected to seek professional assistance to bring relief to their situation” (p. 200). For many years, Donoghue says, the medical model was regarded as the authority on disability research. However, Donoghue says the medical model came under harsh criticism in 1960s and 70s, partially due to its conceptualization of disability primarily as illness.

Following publication of “the fundamental principles of disability” by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 in the United Kingdom, the social model of disability emerged (Oliver 2004). According to UPIAS (Oliver 2004), it is the society that disables impaired people. Disability, it argues, is something put on top of impaired people by the way they are unnecessarily isolated and excluded from participating fully in society (Oliver 2004). The social model differentiates between disability and impairment. It defines impairment as lacking part or all of limbs, or having

a defective limb, organism or mechanism of the body and it defines disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have impairments and thus excludes them from the mainstream of social activities (Shakespeare and Watson 2002). From a social model perspective, then, the solution to the exclusion of people with impairment in society is to remove disabling environments and cultures.

Although the social model of disability has made it easy for people to understand what exactly that is excluding them from participating fully in society, Nick Watson (2004) says, exposure of the social model to comprehensive debate and academic scrutiny has placed it under strain. First, there are those who criticize the social model for overly relying on Marxist theory to explain why people with impairments are excluded in society. Both Vic Finkelstein and Mike Oliver blame capitalism for exclusion of persons with disabilities (Barnes and Mercer 2004). According to these important figures, Finkelstein and Oliver, and other social model writers, the industrial capitalists demanded that those who do not own the means of production have to sell their labour in the service of a fast moving and exchanging industrial labour process. Those who were unable to trade their labour on these terms faced exclusion from society (Thomas 2004). By creating these conditions, Russell (2001) suggests, the industrial capitalism created a class of disabled people who did not meet the ideal working body requirement, hence their labour power was effectively ignored. Consequently, disabled persons came to be perceived as a social problem, and have to be segregated from mainstream life and into a variety of institutions including workhouses, asylums, prisons, colonies, and special schools (Thomas 2004, Russell 2001).

In his 1980 monograph, Finkelstein (1980) said, prior to the industrial revolution, people with impairments were active, asserted their rights and were seen as responsible for their actions. However, according to Finkelstein, this positive attitude towards persons with impairments changed when the modern capitalism emerged. Disabled people, he says, began to be seen as passive and in need of help. Going by the Marxist theory, in order to overthrow disablement, disabled people must find ways to engage in the class struggle (Armer 2004). Armer (2004) argues that the Marxist theory, when taken to its Marxist conclusion, runs contrary to the fundamental principle of the social model because the Marxian Utopia, he argues, is fundamentally an able-bodied construction. Thomas (2004) says that although there is potential in finding disability theory from Marxist historical materialisms, this theory is still incomplete and need further development. Thomas argues that

the historical analysis itself requires verification in terms of empirical evidence. For example, what did people with impairments 'do' in pre-capitalist and pre-industrial communities, what were their social roles and status? What proportion of people with impairments was institutionalized once industrial capitalism had taken hold? What were their social, the particular experiences of girls and women with impairments, and how did this differ from the male experience? What difference did other markers of ascribed social identity (age, "race", sexuality and class) and of impairment type make to disabled people's social positioning? (p. 36).

These questions, she suggests, need to be answered in order for the Marxist historical materialism to be applied in explaining exclusion of persons with disabilities from society. Armer challenges the notion that disabled people are excluded from participation in the industrial labour force because they are viewed as costly. This kind of argument Armer argues:

is a rather outmoded argument that is no longer sustainable. It ignores the pace of technological innovation, and particularly the effects of IT/ICT. Given the reported change in contemporary western society from an economy based on manufacturing to one based the supply of information, there is no inherent economic, or 'market', bias against the employment of people with impairments

per se. It is potentially more cost-efficient to provide a home PC and telephone line than expensive inner-city office space; meanwhile, the use of IT can help negate many alleged effects of physical or sensory impairment in relation to employment. On a lower level of technology, the increasing development of power tools and aids has progressively reduced the physical demands of much economic activity. In many cases people with various impairments are able to compete in the labour market on equal terms: that they are often not allowed to do so suggests to me that factors other than market economics are in play (Armer 2004, p. 50).

Second, the social model of disability is criticized for representing only a part of a much complex multi-layered experiences of people with disabilities (Watson 2004). In fact, Watson argues that by regarding the environment as the main disabling factor, the social model is as potentially damaging as the medical model, which approaches restrictions that have kept disabled people from participating fully in the society only from a functional perspective. Shakespeare and Watson (2002) argue that by denying that impairment is not one of the disabling factors, “impairment is completely bracketed, just as sexual difference was the taboo subject for the women’s movement in the early 1970s” (p. 11). According to Shakespeare and Watson (2002), by rejecting the causal role of the body in explaining oppression, disabled radicals have followed their feminist precursors in denying difference entirely. They also added that achieving a barrier-free environment cannot solve all problems disabled people are experiencing. For example, they argue that removing environmental obstacles for someone with a certain kind of impairment may well generate impediments for someone else with a different impairment. It is impossible, they argue, to remove all obstacles to people with impairment, because some of them are inextricable aspects of impairment, not created by the environment.

The criticism that the social model dismisses impairment as a disabling factor has been addressed by Oliver in his article “The social model in action: if I had a hammer”.

As a model, Oliver says, the social model does not dismiss impairment as a factor in disabling people with disabilities nor does it object to the role of medical model in improving lives of disabled persons (Oliver 2004). Even some of the strong critics of the social model such as Tom Shakespeare and Nicholas Watson (2002), who have suggested that the model is outdated and should be abandoned, have also said that the social model is not that rigid as many disability activists make it look. But they seem to suggest that the voices of the radical social model followers are stronger than the moderate ones. It is these radical applications of the social model that Shakespeare and Watson and perhaps many other critics are against.

Third, the social model is criticized for focusing on the public experiences of oppression such as social barriers, at the expenses of the more personal experiences of oppression which operate at the emotional level (Reeve 2004). Reeve argues that the psycho-emotional dimensions of disability also play big role in exclusion of persons with disabilities. Reeve says that the stares that disabled people get and the feeling of pity and hostility toward them once they step into the public domain, have psycho-emotional impact in disabled persons, which Reeve says become a barrier that restrict people with disabilities from leaving their homes. Personally, Reeve says, it is the psycho-emotional dimensions of disability that restricts her from stepping into the public more than the physical structure.

Lastly, Shakespeare (2004) criticizes the social model for glossing over culture, which he says is one of the major barriers to inclusion of persons with disabilities. He argues that people with impairments are disabled, not just by material discrimination, but also by prejudice. Prejudice, Shakespeare argues, is not just interpersonal but is also

embedded in cultural representation, in language and in socialization. In his article, “Cultural Representations of disabled people,”(Shakespeare 2004) Shakespeare explains that throughout history, people with disabilities have been objectified. According to Shakespeare, it has been assumed that disabled people are passive, akin to animals, objects rather than subjects. He says an example of this objectification is evident in the way that contemporary societies provide for disabled people by mean of charities, which fill the gap left by the unwillingness of statutory bodies to meet their obligations to disabled citizens. Charities, he argues, operate by presenting extremely demeaning images of disabled people in order to provoke pity and sympathy in non-disabled people, who are then motivated to make donations. Shakespeare argues that pity is not only an expression of superiority but it can also be the obverse of hatred and aggression. Shakespeare also argues that the media representation of disabled people depoliticizes struggles of disabled people by always taking an individualized perspective, focusing on disability as personal tragedy. According to Shakespeare, the portrayal of disabled people in the media as patients, criminals and non-human, form the foundation on which the attitudes toward, assumptions about and expectations of disabled people are based. The USA disability rights based movement also points to prejudice and stereotype as major factors in constructing disability and the barriers that have prevented the disabled population from participating fully in society (Donoghue 2003).

These are some of the main points about the social model of disability as discussed in this conceptual framework. The social model of disability approaches problems of exclusion of persons with disabilities from social and political standpoint as opposed to the medical model that addresses exclusion of persons with disabilities mainly

as illness or as a result of functional limitations. The social model is criticized for: overly relying on Marxist theory to explain why people with impairments are excluded in society; representing only a part of a much complex multi-layered experiences of people with disabilities; focusing on the public experiences of oppression such as social barriers, at the expenses of the more personal experiences of oppression which operate at the emotional level; and for glossing over culture, which is one of the major barriers to inclusion of persons with disabilities.

About the role of impairment in disabling people with disabilities, the social model does not deny that impairment is a disabling factor in preventing a disabled person from participating fully in a society nor does it object to the contribution of the medical model in improving lives of individuals living with disabilities.

The social model as a conceptual framework used in this study helps in understanding the general theoretical questions; why are people with disabilities excluded in their respective societies and what are some of the ways that barriers to inclusion of disabled people can be removed? While the social model helps in understanding the general theoretical questions, the first theoretical framework: ‘African states’, helps in understanding how Sudanese socio-economic and political conditions have contributed in erecting more barriers to inclusion of people with disabilities.

Having discussed the two conceptual frameworks, and before moving to the literature review section, I would like to clarify major terminologies that I have used throughout this research study: disability, people with disabilities, disabled people, and people with impairments.

## Note of terminology

### Disability

Like most terms in social sciences, disability has no one particular definition because “there is no objective concept of disability; hence, disability is a subjective, socially derived concept” (Brown 2001, p. 155). Differences in conceptualization of disability by the medical and social models of disability prove the point. While the medical model defines disability as a problem of biological functioning at the individual level caused by a disease or health condition, the social model defines disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have impairments (Lutz and Bowers 2005 and Shakespeare and Watson 2002). Recognizing the need for a more integrated approach, Lutz and Bowers (2005, p. 1039) say, the World Health Organization (WHO) developed a more comprehensive approach to disability: the International Classification of Functioning, Disability, and Health (ICF). The ICF integrates both medical and social model perspectives, recognizes disability as “a complex phenomenon that both a problem, of functioning and impairment, at the individual level and as a complex and primarily a social phenomenon” (Lutz and Bowers 2005, p. 1039). But Lutz and Bowers say critiques of the ICF suggest that the ICF conceptualization of disability remains rooted in the philosophical underpinnings of the medical model and structural functionalism and, thus, carries with it assumptions that do not adequately address the complexity of the subjective experience of disability.

While countries in the West, for example, Canada, the United States and Britain are broadening their definition of disability, which was once defined exclusively from a



medical stand point, to include environmental factors, in most African countries studies on disability still presuppose a medical and individual definition of disability instead of the one based on an interaction between person and their environment as suggested by the ICF (Stienstra 2004). Stienstra observed that although the definition of disability varies in each African country, all of these different definitions are based on a list of impairments. In Sudan, a disabled person is defined as “a person who is permanently unable due to physical or motional or visual or hearing defect to perform action done by healthy persons of their age” (Gladnet collection, Sudan country profile 2004, p. 5). This definition is clearly guided by the medical model.

In this paper, I have used people with disabilities, disabled people/persons and people with impairments interchangeably to refer to people who have been marginalized by society because their bodily and cognitive functional limitations deviate from the norm. These differences are caused, in most part, by environmental barriers and lack of support. With the terminologies clarified, I now move on to the third chapter: the literature review.

## Chapter Three

### Literature Review

#### Overview of disability in the world and in Africa

According to the United Nations Enable fact sheets on persons with disabilities, 650 million, about 10 per cent or of the world's population live with disabilities, making this population the largest minority group in the world (UN enable). And, according to the World Health Organization (WHO) Regional Office for Africa, 10 percent, about 35 million, of Africans live with disabilities (WHO regional office for Africa). This percentage is considered by WHO as a conservative estimate. Masakhwe (2004), a disabled activist and a writer says, with malnutrition, accidents, crime, diseases and all manner of violent conflicts prevalent on this continent, Africa risks yet another dubious distinction of being the place with the fastest growing number of persons with disabilities in the world.

Although people with disabilities are the biggest minority group in the world, their human rights continue to be denied and are kept on the fringes of society in all parts of the world (UN General Assembly, 2006). This prompted the United Nations General Assembly to adopt the Convention on the Rights of Persons with Disabilities in 2006. According to the UN General Assembly report, despite the fact that the pre-existing human rights conventions provide considerable potential to promote and protect the rights of persons with disabilities, this potential was not being realized. The objective of the newly adopted Convention is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UN General Assembly 2006).

Although the Convention on the Rights of Persons with Disabilities does not create new rights, it does set out the legal obligations on States to promote and protect the rights of disabled people. As of 2010, 145 countries have signed the convention, 89 have signed the optional protocol, 88 have ratified the convention, and 54 have ratified the protocol (UN enable). Sudan is not only one of the signatories to the convention but is also one of the countries that have ratified both the convention and the protocol. While the adoption of the Convention on the Rights of Persons with Disabilities by these countries is a positive sign that they are ready to make commitment to improving lives of people with disabilities, the Convention's impact on lives of this marginalized population still remains to be seen.

In developed nations such as Canada and the United States of America, barriers to inclusion of persons with disabilities are attributed by some scholars and disability movement activists to prejudice and stereotype (Furrie 2006 and Donoghue 2003). Javad Hassan (1991) says that developed regions such as North America and Western Europe, and countries such as Australia and Japan are reversing the negative stereotypes of disabled people through equalization of opportunities in education and employment and through the provision of social security. In these nations, he says, accessibility is improving and negative phrases like "a twisted mind in a twisted body" are rarely used. But, in developing countries, such as Pakistan, Hassan (1991) argues, the situation is much different. He says mass poverty affects disabled people the most, making them the poorest of the poor. Hassan (1991, p. 4) writes, "inadequate education and employment opportunities, "internalized oppression" (a kind of psychological warfare), stereotypes borrowed from medieval English literature, the charity model and the lack of a cohesive

movement and a united voice, have collectively ensured disabled people stay at the "bottom of the barrel".

Like in most parts of the world, attitudes toward disabled population in most African societies are negative (Stienstra 2004). For example, in Senegal, many children with disabilities do not go to school because societal attitudes encourage parents to hide their disabled children. It is a common belief among Senegalese, particularly, the villagers that a disabled child brings shame and bad luck to a family (Raising the voices 2002). In Southern Africa, people with disabilities are regarded as a damaged population (Power, 2001). In Ethiopia where the majority of the poor rely on small mobile shops to make ends meet, permits to run such small shops are denied to persons with disabilities (Raising the voices 2002).

Although negative attitudes toward people with disabilities in Africa are similar to their counterparts in the West, the status of most African countries as fragile or weak states make the challenges disabled Africans face more difficult to overcome and sometimes incomparable to their counterparts in the developed countries. Loeb (2009), who is one of the handful researchers that have dedicated themselves to probing issues affecting lives of disabled population in Southern Africa, says, "many of Africa's citizens may count themselves among the ranks of the poor, and in any given situation, people with disabilities will be located on the lowest rungs of the ladder" (p.26). While disabled people in developed countries may have social security to fall onto in the case of unemployment (although the current social security system in the West is not satisfactory), in Africa, social security for persons with disabilities is non-existent. While in most developed countries disability activists are pushing for narrowing the

employment gap between disabled and non-disabled, in sub-Saharan Africa, persons with disabilities are still grappling with the question of where they will get their next meal, and unemployment is high regardless of whether one is disabled or not (Loeb 2009 and Masakhwe 2004).

According to Loeb (2009), countries that have been delineated as fragile states not only raise new challenges to persons with disabilities, they also make the already negative attitudes against people with disabilities worse. For example, he says, competition over limited resources could mean that people with disabilities are served last or not at all. In Zimbabwe, Loeb says, as the economic situation deteriorates, people become less and less tolerant toward those deemed to be burden on their families. Economic deterioration in Zimbabwe, Loeb says, has resulted in widespread abuse and neglect of children with disabilities (2009). According to Loeb (2009), “the livelihood of people with disabilities is dependent on an open and accessible socio-political environment, free of physical, attitudinal and legislative barriers” (p. 27). Given the long history of conflicts in Sudan, the Sudanese state is far from providing the conditions Loeb has described. In the following subsections, I will discuss Sudanese socio-economic and political condition and its impact on lives of the disabled population. I will then move on to discuss how disability is understood in Sudan, the barriers that disabled people face, how the government and the international NGOs are addressing these barriers and the future of persons with disabilities in Sudan.

## Sudanese socioeconomic and political condition and disabled people

As a fragile state, Sudan has been overshadowed by conflicts for decades. These have often been along racial, religious and ethnicity lines. According to Sudan Health report compiled by the World Bank, (Decaillet, Mullen and Guen (2003), Sudan is unable to provide basic services to its citizens. The few available resources, the report stated, only benefit handful of elites in the centre of the country. According to the report, NGOs are often left to fill in the gaps left by the government.

Many years of civil wars plus bad government policies have had enormous impact on Sudan's health care provisions. According to the Sudan Health Report (Decaillet, Mullen and Guen 2003), physicians are concentrated mainly in Khartoum and other states that are in the centre. For example, In Khartoum, there are 35 physicians per 100,000 population, while in Darfur and other states that are far from the centre, there are only 1 or 2 physicians. Government's health spending, according to the report, is highly skewed towards the ruling class. Health care provisions for the most marginalized groups such as the internally displaced persons (IDPs) in Khartoum are mainly offered by international NGOs.

The condition of health services in South Sudan is even worse. According to the Sudan Health Report, South Sudan region, which is further away from the centre, has the least health care services. As per the report, South Sudan has only 17 hospitals and 94 health centers to serve a population of about 6 to 8 million (Decaillet, Mullen and Guen 2003). According to the report, only 60% of South Sudan population is within reach of basic health services. Most of the health services are offered by international NGOs and UN agencies, focusing on meeting basic needs through humanitarian programs (Decaillet,

Mullen and Guen 2003). Currently, there are almost no mental health services in South Sudan with one or two localized exceptions such as the activities provided by NGOs (Roberts, Damundu, Lomoro and Sondorp 2009).

Although Sudanese revenue has increased as a result of the recent oil exploration, Sudan's expenditure on health services remains one of the lowest in the world (Decaillet, Mullen and Guen 2003). In 2005, the World Health Organization warned that unless funds for humanitarian interventions are secured immediately, millions of people throughout Sudan would not have access to health services. According to the World Health Organization, the current lack of funding coupled with growing insecurity in areas such as Darfur will reduce access to safe water and healthcare services resulting in a possible significant increase in cases of malaria, meningitis, diarrhea diseases, acute respiratory infections and measles (Medilinks 2006).

The impact of the Sudanese prolonged civil wars, which have triggered wide spread poverty, and absence of social amenities is more profound on the most vulnerable groups such as people with disabilities (Odomo 2009). According to the 2000 Multiple Indicator Cluster Survey (MICS) conducted by the World Bank, disability prevalent in Sudan is caused "mainly by longer-term sequelae of infectious diseases, maternal morbidity and the effects of war and displacement" (Decaillet, Mullen and Guen 2003).

The disabled population is the most neglected segment in Sudan. Disabled people are excluded and isolated not only by society but also by mainstream services and development programs (Scottish Catholic International Aid Fund, 2008). Omer (1990) said, probably the most striking feature of the problem of disability in Sudan is the complete absence of solid data on the problem. Since its independence, Sudan has not

included questions regarding people with disabilities in the national census until 1993. As per the 1993 census result, about 1.6 percent of the Sudanese population is disabled, with some variations among the Northern States (Gladnet collection, Sudan country profile 2004). According to the Sudan country profile compiled by the International Labour Office (ILO) (Gladnet collection, Sudan country profile 2004), which I have used extensively in this literature review, states that it is generally agreed that these figures do not give an accurate picture of the actual disability prevalence rate, which is believed to be higher. Sudan has been in civil wars for decades and it is widely known that wars produce many people with disabilities (Oliver 2004). Based on this logic, then, the 1993 census pertaining to persons with disabilities doesn't reflect Sudan's reality. The recent census conducted in 2008, which almost covered all parts of the country also included questions about people with disabilities. The census included 3 questions about disabled people. These questions were only included after disabled people's organizations lobbied the population census bureau to include them (Action on disability and development 2009). The census results particularly pertaining to persons with disabilities have not been released yet, which means that the problem raised two decades ago by Omer (1990) remains i.e. there is still absence of solid data on disability in Sudan.

The government of Sudan lacks a firm commitment to protecting, providing adequate programs and services, and lacks of effort in removing environmental barriers that hinder people with disabilities from participating in society (Gladnet collection, Sudan country profile 2004). Article 11 of the 1998 Constitution of the Republic of Sudan lays down general principles of justice and social solidarity, including specific mention of people with disabilities:

The Republic of Sudan shall guard justice and prompt social solidarity to



establish a basic structure of society that provides the highest standard of living for every citizen and fairly distributes the national income, curtailing excesses and preventing the exploitation of the vulnerable, elderly and handicapped (Gladnet collection, Sudan country profile 2004, p. 6).

Sudan has also enacted two specific instruments in favour of disabled persons: the Act on Welfare and Rehabilitation of Disabled Persons in 1984 and a law concerning the Privilege of War Disabled in 1998 (Gladnet collection, Sudan country profile 2004). The 1984 act also provides for the setting up a National Council to establish general policy for the welfare of disabled people and oversee regional councils in Sudan. The Act makes provision for measures to promote employment for disabled persons. In 1992, the government passed a General Education Act which aims at providing equal opportunity in education for people with disabilities (Gladnet collection, Sudan country profile 2004). Recently, according to the Gladnet profile, the Government of Sudan has put forward resolutions for the exemption of disabled persons from all study fees; conducting of a comprehensive survey of all persons with disabilities in Sudan in collaboration with the Islamic World Council on Disability and Rehabilitation; establishment of a city called Alamal in Khartoum, which will be equipped by the most advanced instruments for the care and rehabilitation of disabled persons; and a review of current disability rules in Sudan.

The enactment of laws and resolutions aimed at improving the lives of persons with disabilities has been welcomed by international organizations such as ILO but without translating these resolutions and the enacted laws from paper to action, they are of little help to disabled people. To date, “the General Secretariat of the National Council for Welfare and Rehabilitation of disabled persons provided for in the Act on Welfare

and Rehabilitation 1984 has not yet been established. The Regional Councils have not been established either as provided for in law” (Gladnet collection, Sudan country profile 2004). This clearly shows that the government lacks commitment to issues relating to persons with disabilities. The government’s lack of commitment to people with disabilities reflects the general societal attitudes toward this population. In Sudan, disability is still a taboo. Like in Senegal, parents of disabled children in Sudan often hide their children away for the fear of what society might think of them (Jane-anne 2009). Such negative perception of persons with disabilities creates barrier to inclusion of these group. Widespread poverty, which is partly attributed to the decades of civil wars in Sudan, has somehow made Sudanese society intolerant to disabled people. Osman Abdelrahim, a Country Director for Action on Disability and Development (ADD) says that the consequence of Sudanese unsteady economy has in many ways worsened the situation of disabled people. He says, in many ways, people with disabilities are denied access to basic services such as education, health, water, information and communication as a result of depressing social attitudes and government policies of service provision (ADD Sudan program 2009).

From a vantage point of one man who is a disability activist, and as reported by Geoffrey (1998), a writer for a human rights newsletter, once an individual acquires impairment, he/she is no longer regarded as resourceful. He said disabled people who were employed before they became disabled did not only lose their jobs but they were thrown out of their families. The activist says that parents have resorted not to pay school fees for their disabled children because it is seen as a waste of resources (Geoffrey 1998).

Another major barrier to inclusion of persons with disabilities in the Sudanese

society is the issue of accessibility to the public arena and lack of assistive devices to help disabled people in their daily lives. Most disabled people in Sudan are too poor to afford bus fare and, even if they can, buses are inaccessible to wheelchair users. This is how one disabled activist put it: “far from Khartoum center, buses are available, but very crowded, without any special facilities for the disabled” (Hardister 2007). Hardister also says that some groups of persons with disabilities such as blind people and deaf people do not have access to technical devices.

### Addressing barriers to inclusion

In Sudan, there are very few programs and services targeting people with disabilities as most of the international NGOs do not include this part of Sudanese demographic into their development agenda (ADD Sudan program 2009 and SCIAF Sudan Evangelical Mission, 2008). For example, currently, there are only two Cheshire Services in Sudan that provide both residential care and outreach/community based rehabilitation programs (Gladnet collection, Sudan country profile 2004). This is reminiscent of Yeo and Moore’s (2003) analysis that there is widespread exclusion of disabled people from international development organizations and research. Although it would be beneficial for disabled people when their needs are included in international NGOs agenda, Yeo and Moore (2003) cautioned against dependency on NGOs to meet the needs of disabled people. First, NGOs, Yeo and Moore say, NGOs have relatively small and insecure funding. Second, their provision is unsystematic and discretionary. Third, they say, international NGOs are minimally regulated.

With pressure and assistance of NGOs and International Labour Organization

(ILO), which is funded by government of Ireland, the government of Sudan has taken some steps in addressing some of the barriers that restrict persons with disabilities from taking part in their respective communities. According to the Sudan country profile report (Gladnet collection, Sudan country profile 2004), the government has established a community based rehabilitation program (CBR) for persons with physical disabilities. The purpose of the CBR program is to develop effective measures for the rehabilitation of people with disabilities, to achieve the goal of full participation and equality, and to make full use of local potential in the area of vocational rehabilitation in terms of training and employment. The report also stated that the Government of Sudan has established a production plant for people with disabilities with the assistance of the Islamic Rehabilitation Agency and United Nations Development Program (UNDP). The objective of the production plant is to provide employment for qualified disabled persons in a number of trades.

According to report, in spite of these signs of progress by the government to rehabilitate people with disabilities and help them to enter into the labour force, the government still lacks a firm policy commitment toward people with disabilities. Without such commitment, the report stated, there will be no meaningful improvement in training and employment of persons with disabilities. But even if the government is committed to vocational rehabilitation for disabled people so they could enter the labour force, the approach it is taking is individualistic in nature and focuses only on impairment; an approach the social model criticizes. For example, a problem of unemployment cannot be solved without addressing other environmental disabling factors such as transportation and negative attitudes toward disabled people (Oliver 2004). Secondly, as Yeo and

Moore (2003) say, by focusing mainly on impairment prevention and rehabilitation while ignoring problems that have prevented people with disabilities from participating fully in their respective societies, could easily imply that persons with disabilities exemplify failure, who need to be pitied and who are less worthy of full participation in their respective societies.

Thirdly, without changing negative attitudes of people towards disability, the government's intention of improving the lives of people through vocational rehabilitation program will not be successful. Tervo and Palmer (2004) pointed out that a successful rehabilitation is limited by negative attitudes that lead to or support negative expectations. In a country where people with disabilities are openly insulted in the streets, lack of a firm policy commitment on the part of government toward disabled people only reinforces the attitudes that people with disabilities are of no worth.

While the medical approach to addressing health issues facing people with disabilities, if applied in a respectful manner is helpful, barriers faced by disabled people in their daily lives shouldn't be reduced just to their bodies. A medical clinic in Khartoum is now offering genetic counseling for families that have had a child with Down syndrome (Ellaithi et. el 2008). Although the doctors say they are fully aware of some of the controversies about genetic counseling in its universal application, they claim that it is important to provide information for families about the possibility of having another child with the same disability (Ellaithi et. el 2008). They claim that the first group of families that they suspected of carrying Down syndrome genes were offered and accepted genetic counseling (Ellaithi et. el 2008). But what they didn't mention was whether the families that they offered and accepted genetic counseling could realistically make informed

decisions. They didn't mention the role of their power as medical experts in influencing decision of those who accepted genetic screening.

Some of the NGOs serving people with disabilities might have good intentions of improving lives of disabled people in Sudan but their actions display demeaning attitudes toward people with disabilities. For example, a statement made by Neglected tropical disease (NTD), one of the non-profit organizations operating in Sudan proves the point:

We wish to thank all the individuals and organizations that have contributed to the control of NTDs in Southern Sudan over recent decades. Without their dedication, many lives would have been lost and many people would not have been cured from disabilities (Rumunou et. al 2009).

This statement was made with a lot of carelessness and lack of sensitivity to people with disabilities. The authors equate disability in general to diseases. If someone lacks a limb, would the person be referred to as suffering from a disease? Such a statement demonstrates how negatively the NTD views people with disabilities. Secondly, the NTD assumes that everyone with disabilities would want to be cured of their disabilities, which has been proven not to be true, at least in the West. For example, a study conducted by a team of researchers investigated the assumption that disabled people want improvements in their functional abilities, or complete cures. Contrary to this assumption, the study found out that many and especially those who have had lengthy experience with a permanent disability, no longer search for a cure for the disability (Hahn and Belt 2004). In fact, these authors argue that disability, and even functional impairment, is neither a disease nor a bodily attribute that can be removed by medical intervention. Some of the disabled people who participated in the study, Hahn and Belt say, complain that doctors tend to ignore immediate health problems in order to concentrate on what may be perceived as another pointless attempt to find a cure for their

impairments. Although the medical model still has a role to play in improving health conditions of persons with disabilities, challenges facing people with disabilities, from jobs to education, from attitudes to medical needs cannot be alleviated “simply by putting money into addressing the highest identified disease or condition, but requires creating and sharing knowledge, facilitating participation among those most affected, and developing inclusive and response strategies together with those most affected” (Stienstra 2004, p. 8).

The next subsection discusses the future of people with disabilities in Sudan. While the medical model is still the dominant paradigm in defining and solving problems facing disabled people, in this subsection, it will be shown that there are signs that disability activists have begun to challenge the way they are unnecessarily excluded from accessing the same opportunities available to the non-disabled population.

#### Future of persons with disabilities in Sudan

As in most developing countries, in Sudan, people with disabilities live in their respective communities and are taken care of by their own family members (Omer 1990). However, there is a growing concern that this kind of arrangement might no longer be sustainable. In his article, “A third world perspective: with special reference to the Sudan” (Omer 1990), Omer says that so far the families of the disabled people have obeyed the very strong social, religious and moral pressures to continue looking after their disabled members, but he says there is a limit to this. This is an old article but I have used it because of the lack of recent data on this particular subject area in Sudan. According to Omer, the increasing complexities of modern life and the weakening of the

social fabrics introduced with progressive urbanization and economic pressure are slowly but steadily undermining this traditional commitment and it may not be too far in the future that huge numbers of disabled people will have nobody to look after them. Omer (1990) urges the community to start looking for ways and means whereby this magnificent family effort is sustained and augmented.

However, the good news is that there are already signs that Sudanese have begun to shift their understanding of disability from one that is based exclusively on the medical model to the one that is based on the social model of disabilities. For example, one government official from South Sudan government was quoted by a reporter, saying: “from the social aspect, people with disabilities are disadvantaged not only by their impairment but also as a result of the limitations imposed on them by attitudes of people as well as social, cultural, economic and environmental barriers that prevent their full participation in society” (Odomo 2009). This rare statement by this government official acknowledges that barriers to inclusion of people with disabilities are caused by many other factors than impairments.

Another positive sign is that people with disabilities are organizing themselves and advocating on their own behalf. Recently, while celebrating the UN Convention on the Rights of Persons with Disabilities, the disabled community in the town of Juba voiced their discontent with how they are treated. They complained that they are restricted from getting access to physical environment, transportation, information and communication, technological systems and facilities openly provided to the public (Stephen 2009). They also demanded their inclusion in key administrative systems starting from the lowest government level to the highest authority (Stephen 2009). Some



local reporters and bloggers have also begun to take interest in issues relating to the disabled population. For example, in 2006 there was anger in the bloggersphere pertaining to an allegation that all disabled teachers were getting fired. Disability activists condemned the move and asked the minister of education to stop discrimination against disabled teachers. Although this allegation was denied by the responsible minister, it is a positive sign that the voices of disabled activists and their allies are getting heard (Kuek 2006).

### Gaps in literature

The research project I intend to undertake investigates some of the major barriers to inclusion of internally displaced South Sudanese with disabilities in society from their own perspective and some measures they think are vital to address these barriers. From the literature, disability is understood in Sudan mainly as a health problem. Such perception of disability affects how challenges to inclusion of persons with disabilities are addressed. There are three barriers that have been identified in the literature, each of which plays a role in the exclusion of persons with disabilities: negative attitudes, environmental limitations and lack of assistive devices. Although there is a lack of rich literature, the little literature available indicates that Sudanese have negative attitudes toward disabled people, as is also common in the rest of the world. There is also a lack of consideration for persons with disabilities in the way public modes of transportation are designed. For instance, buses are designed in such a way that they are not accessible to some disabled groups, wheelchair users, for example. Blind people and deaf people do not have access to assistive devices they need for their day to day activities.

From the literature review, the government of Sudan approaches barriers to inclusion of persons with disabilities in the labour market and schools purely from an individualistic perspective. For example, the government's response to barriers preventing disabled people from participating in the labour force is to provide them with vocational training, which is only a part of the complex issues preventing the disabled population from securing employment. It is also apparent in the literature that modern life characterized by the Western economic system is altering the way families take care of their loved ones with disabilities.

Although the literature review identified some of the barriers that prevent inclusion of disabled people in Sudan, there remain several gaps in literature concerning the disabled population, which implicitly show that the disabled population is considered of less importance than non-disabled population by the Sudanese society.

- The first obvious gap in literature is the lack of national statistics about disabled population. There is lack of national data on disability based on age, gender, region and type of disability.
- The second major gap in literature is the lack of information on how different ethnic groups in Sudan perceive and treat people with disabilities.
- Third, there is an absence of theoretical debate in the literature that explains why the public has negative attitudes toward disabled people.
- Fourth, there is no literature on how environmental factors affect disabled people in their daily lives.
- Fifth, the little research that has been done on issues relating to disabled people has been conducted only from the vantage point of the medical professionals,

international NGOs and charitable organizations. Voices of people with disabilities are absent. This is part of objectification of people with disabilities that Tom Shakespeare discussed in his article “cultural representation of disabled people” (2002).

In order to address some of the gaps identified in the literature, this project will conduct qualitative research guided by the social model. When conducting this research, people with disabilities have to be in the forefront in identifying challenges facing them and they have to be part of finding the best possible approaches they think should be taken to solving the identified challenges. Since people with disabilities are the ones directly affected by ableism, from my perspective, then, disabled people have to play a central role in this research project in terms of providing information. This will help not only in gaining in-depth understanding about barriers to inclusion of persons with disabilities in Sudan but it will also help in finding solution(s) to these barriers.

## Chapter Four

### Methodology

The purpose of this research project is to identify some of the major barriers to inclusion of internally displaced South Sudanese with disabilities in the Sudanese society from their own perspective and some measures they think are required to address these barriers. Research questions for this project are: what are the most significant barriers to inclusion of displaced South Sudanese with disabilities in the Sudanese society from their own perspective? What are some measures they think are required to address these barriers? I used a qualitative research design to gather data for this study. As I have pointed in the literature review, the little research that has been done on issues relating to disabilities have been conducted by medical professionals and international NGOs without involving disabled people. This research will address this gap by including people with disabilities as participants identifying the barriers and possible solutions.

### Method

#### In-depth interviews

In order to get an in-depth understanding of barriers to inclusion of persons with disabilities in Sudan and to find some of the solutions to these barriers, I decided to interview four internally displaced South Sudanese with disabilities living in Khartoum. To ensure that participants are fully aware of terms and conditions for taking part in the research, I decided to interview only people who have reached the age of consent; 18 years and above.

I decided to exclude people with intellectual disabilities from taking part in this

study because their interpretations of accounts of events might be difficult to understand, particularly to novice researcher like myself. I also exclude people that have mental illness because of many years of civil wars; many Sudanese and South Sudanese in particular have witnessed traumatic events. Including people with mental illness in the research project might trigger recurrence of traumatic episodes that might have caused their mental illness at the first place. Although I didn't anticipate people with physical disabilities to experience traumatic recurrence, which was the case when I was conducting the research, I made sure that there was some form of resources in case a research participant's traumatic event recurs that I could refer the person to. Prior to conducting the research, I asked the local people whether there were counseling services that one could go to in case one experiences trauma. As I expected, I was told that there were none. The locals told me that church was the only place they turn to when they have problems. They said to access counseling services, which are located far from where internally displaced people live, one has to be rich.

All of the interviews that I conducted were on one-on-one basis. I chose one-on-one interviewing because it allows for a greater flexibility when it comes to when and where to conduct an interview. This did increase the likelihood of those interested to take part in the research. To ensure that every participant was asked the same topic, I followed an interview guide (see appendix C) to obtain information from research participants.

## Recruitment

To recruit participants for this project, I developed a recruitment plan, which was approved by my thesis committee. The plan was that I would contact organization(s) that offer programs and services to persons with disabilities such as Action Disability and Development (ADD), Handicap International and others to help connect me with their service users. Once I connected with programs and service users, and once I interviewed one person, I would then use a snowball sampling to recruit research participants. Snowballing is a non-probability sampling technique used when members of a special group, for example persons with disabilities, are difficult to locate (Babbie 2007). I chose this method of recruitment because as Singal (2010) wrote, identifying disabled research participants in developing countries can be difficult because of the stigma attached to disability. Once I interviewed one person, I would ask him/her to recommend another person that I could contact.

However, when I started the recruitment process, I was unable to communicate with the organizations I had in mind. I wrote to these organizations but I didn't hear back from them. When I travelled to Khartoum, I asked about these organizations but I couldn't find anyone who recognized these organizations by their names. Perhaps these organizations are either closed or they are located in a different part of the city. Instead, my younger brother's friend referred me to a woman by the name Edreena Lusuncio Wani. Edreena turned out to be a program director for Able Rights Development

Organization (ARDO), an organization that represents and advocates for all South Sudanese living with disabilities in Khartoum. Edreena lives with disabilities. She uses a wheelchair to get around. When I asked if she could take part in the project, she did not hesitate to be interviewed. I made an appointment with her and conducted an interview with her. At the end of our interview, I asked her to refer me to people she thought would be willing to participate in the project. She gave me contacts of two of her co-workers: a male and a female. I approached each of them and they agreed to participate. The fourth participant is a good friend of my younger brother and he comes from the same ethnic group as I am. In addition, he lived about ten minutes walk from where my family lived.

Prior to conducting an interview with each of the four participants, I provided each of them with an informed consent form (See Appendix B) Because most of them acquired their education in Arabic and used Arabi-Juba in their daily lives rather than English, I read the consent form for each of them in English and then interpreted it in Arabi-Juba. Arabi-Juba is a nonstandard version of Arabic spoken mainly by Sudanese from the Southern part of the country. I ensured that they understood both the benefits and possible risks of participating in the research. All of the four participants gave their consent to identify them by their names and to publish their names in the final research paper. Throughout this paper, I will be identifying them by their first names<sup>1</sup>. Due to safety concerns, initially, I intended to identify participants by pseudonyms but I was

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<sup>1</sup> You might have noticed that I identify research participants by their first names instead of last names. This is because in Sudan and South Sudan in particular, people are identified by their first names rather than last names as practiced in the West perhaps other parts of the world.

asked by the Ethics Board to give research participants the option to be identified by their real names, which I did.

Now that I have described how I recruited my research participants, in this next section, using a key theme analysis approach, I describe stages that guided me in managing my data, analyzing it and presenting my research findings.

### Key Theme Analysis Method

As a novice researcher, I was overwhelmed by a number of data analysis methods used in a qualitative research design. Most of the qualitative data analysis methods are not clearly outlined. Initially, I chose hermeneutics method to analyze my data. But like most of the other data analysis methods, it requires a lot of time and is more complex than is needed for this project. When I was defending my thesis proposal, my thesis committee members advised that I use the Key Theme Analysis instead. I find the Key Theme Analysis method easier to grasp because of how clearly it has been outlined.

Before detailing how I went about analyzing my data, this is a brief summary of the processes involved in analyzing my qualitative data. Using Creswell's (2007) book, "Qualitative inquiry and research design: choosing among five approaches" as a guide, I commenced my data analysis by organizing my qualitative data using the Microsoft Word program. In the second step, I developed codes or categories to sort transcripts of my interviews into categories. In the third step, I identified emerging themes. In the last step, I made my own interpretations of the data and presented them as my research findings.



### Data management

The first step in qualitative data analysis, Creswell says, is data management. Going by his suggestion, after transcribing my data successfully, I began managing my data by saving transcripts of my interviews into documents using the Microsoft Word program. The transcribed interview from each research participant was saved as a document. Each of the documents or transcripts was marked by a 't and a number'. For example, 't1' means transcript 1, t2 means transcript 2, and so forth. In order to locate the saved transcripts easily, I put all of them under one folder.

One of the difficulties that I faced when transcribing the interviews was that all of the interviews but one were done in Arabi-Juba. Although I am competent in Arabi-Juba, it added more challenge when transcribing interviews from Arabi-Juba to English. I had to put extra effort to listen and translate what was said in Arabi-Juba and searched for words that best described what a participant said. The quotations I have used in this paper are my translation of the words of the participants.

### Getting sense of database

Following the organization of the data, Creswell says, researchers continue their qualitative data analysis by getting a sense of the whole database. To do this, I followed Creswell's (2007) suggestion by reading my interview transcripts in their entirety several times before breaking them down into parts. To facilitate my understanding of the whole database, as Creswell suggests, I wrote memos on the margins of each transcripts as I read them several times. These memos helped me in developing my codes and later

themes.

### Coding

As I began to make sense out of my interview transcripts, I started to develop codes or categories to sort my transcripts into categories. Going by Creswell's suggestion, I looked for code segments that enabled me to develop themes.

### Classifying themes

After coding my data, as Creswell suggests, I identify 15 themes. Through a process Creswell described as winnowing, I reduce the themes that identify into nine manageable sets of themes.

### Interpretation

After grouping codes into several themes and reducing many of the identified themes into a few manageable themes, I then moved on to the last stage of my data analysis, which is the interpretation of the data. Interpretation, Creswell says, entails making sense of the data, noting lessons learnt. From the major themes that I identified, as Creswell suggested, I formed larger meanings out of these themes and then present them as my research findings.

### Credibility issues

This section tackles some of the credibility issues that I didn't discuss adequately in other sections. I rely on Patton's (1999) work to reflect on issues relating to credibility of my research findings. Patton suggests that to address the issues of credibility in qualitative research, "evaluators/researchers have the obligation to be methodical in

reporting sufficient details of data collection and the process of analysis to permit others to judge the quality of the resulting product” (p. 1191). I have, in the methodology chapter, outlined the process of recruitment, method of interviews and steps involved in my data analysis. In this section, I explain my interactions with the research participants and ask to what extent did this affect my data gathering and subsequently my data analysis and research findings. Also in this section, I discuss, efforts I made to ensure I reported accurate views of the research participants.

I commence this section by reiterating my philosophical position, which Patton suggests, is an important part in addressing credibility issues in qualitative research. In chapter two, I explained in detail the theoretical frameworks that guided my thesis, with the social model of disability being the major paradigm. A paradigm as Patton says, is a worldview, which tells researchers what is important, legitimate and reasonable. Throughout my data gathering and analysis process, I relied on the social model to look for factors that are considered as barriers hindering persons with disabilities in societies. Therefore I would like my work to be judged within the conceptual frameworks that have influenced my thesis. I am aware that there are many other paradigms, if used to gather and analyze data pertaining to barriers to inclusion of person with disabilities in Sudanese society, would yield somewhat different results. I don't consider this as a challenge to my research findings but an opportunity to understand these other multiple realities, which will enhance our understanding of barriers facing this population.

The second area that I want to touch on, which is important as far as credibility of my work is concerned, was how my presence as a researcher affected an outcome of my research findings. Patton argues that there are four ways that a researcher can affect an

outcome of a research findings: “reactions of program participants and staff to the presence of the qualitative fieldworker; changes in the fieldworker during the course of the data collection or analysis; the predispositions, selective perceptions, and/or biases of the qualitative researcher; and researcher incompetence” (p. 1202). I will only address areas that are applicable to me as a graduate student.

When I was conducting the interviews, I kept my own journal, noting both the spoken and unspoken words. Although I don't have a straight answer on how I affected the research participants and vice versa, one thing I observed was how freely the participants talked to me. This was perhaps due to the fact that I shared a lot in common with my research participants. For example, I come from the same region as they are and we all defined ourselves as Black Africans. My research participants and I were also non-Muslims. Linguistically, we all spoke Arabi-Juba. But I also had differences with them. Unlike my participants who were born and raised in Sudan and lived for many years in Khartoum, I spent more than a half of my life out of the country.

Judging by their choices of words and body language, most of the participants disliked Sudanese Arabs/Muslims. I on the other hand viewed Sudanese Arabs in a brotherly way. I acknowledged that Sudanese Arabs have inflicted a lot of pain to those Sudanese who identify themselves as Black Africans; however, I believe they acted out of ignorance. While the shared similarities with research participants played to my advantage in that the participants spoke freely to me, it also became a challenge during the interviews. Most of the participants tended to divert from the topic at hand to general political issues. Most of the political discussions that they brought up were along “racial” and religious lines. The participants blamed the Arab dominated government and

Muslims for all of their problems. Their bias against Arabs/Muslims was so strong that some of the participants tended to downplay some of the progress that the government had made to improve living conditions of disabled people regardless of race or religion. While I tried through my feedback to demonstrate to them that I identified with their plight, I remained neutral by not directly opposing or supporting their views. When a participant said something that was opposed to what the majority of the participants said, I didn't try to challenge their views but instead accepted these kinds of views to strengthen my data.

I wasn't too sure whether I was changed in the process of conducting the interviews. Perhaps growing up in a different environment and the short duration of time I had with the participants protected me from being influenced. My research questions and interview guide, which were thoroughly checked by my academic advisor, also helped me stay neutral. To determine what issues raised by the participants earned their way into the final thematic groupings, I relied on the research questions in conjunction with my theoretical frameworks and interview guide. I used my theoretical frameworks as a guide to look for socially constructed barriers to inclusion of persons with disabilities in societies. In conjunction with the theoretical frameworks, I identified themes based on the questions that I asked and the number of times certain issues were found in each interview. However, as Patton suggests, I also incorporated views that were at odd with what the majority expressed. Incorporating such themes, Patton suggests, helps add creditability in qualitative research because they assist evaluators to look at phenomena under investigation from a different perspective.

A third approach Patton suggests that will enhance trustworthiness in qualitative research is through what he terms as triangulation through multiple analysis. Having two or more researchers independently analyze the same qualitative data set and then compare their findings, Patton says provides an important check on selective perception and blind interpretive bias. However, he says the most common approach to analytical triangulation is to have those who were studied review the findings. Considering that this is a thesis project and because of limited time, I used to the latter approach to enhance credibility of my research findings. To ensure that participants' views were represented accurately, at the end of each interview session, I would reiterate what a participant said back to him/her. This helped in clarifying misunderstanding on my part. The memos that I kept during the interviews helped in highlighting areas that I misunderstood and the participants corrected me on. Given the distances and difficulties with communications with participants once I left Sudan, this was the only way to ensure that I could member check to verify the statements. In addition, I will send the final thesis to each of the participants once it is completed.

To illustrate that my analysis of the data reflects the research participants' stories, I present participants' stories first and then my analysis of the data later. By juxtaposing participants' stories and the data that has been analyzed, the readers can go back and forth to see for themselves how my analysis developed. I also used extensive quotations from the participants in the first section in order for the readers to understand how the participants felt about these barrier/themes.

By reiterating my conceptual frameworks and reflecting on experiences I had during my fieldwork, I hope the readers will be able to judge my research findings as credible.

## Chapter Five

### Data presentation

In this chapter, I present the data I collected. I divided my data presentation into two subsections: participants' stories and data analysis. The first involves presentation of emerging themes from the stories of the participants. In the first subsection, I withheld my judgment. I tried as much as possible to present only what the participants actually said. Therefore I have used quotations extensively to show how participants felt about these themes. The objective of collecting data for this research project is to find out from persons with disabilities in Sudan the barriers to inclusion of persons with disabilities in Sudan and what from their own perspectives should be done to remove the identified barriers. Before delving into the discussions of various themes that I have identified, I would like to briefly introduce each of the four participants that I interviewed.

Most of the participants I interviewed, based on what they told me, are well educated. Edreena Lusuncio Wani is a University graduate and currently pursuing a master's degree in one of the local universities in Khartoum. However, like most South Sudanese who studied in the North, she completed her studies in Arabic. She had no knowledge of the English language. Edreena is the Program Director for the ARDO. Both of her legs have been weakened due to an illness when she was 16 years old. She relies on a wheelchair for mobility.

The second participant, Juma Scopus Kabo Ndaragu completed a high school diploma. Juma also acquired his secondary education in Arabic. After graduating from a high school, he was drafted into the Sudanese national army. Juma was released from the



national army after serving his mandatory time. He was self-employed when he acquired his impairment. On his way home from a market place, Juma was hit by a truck and broke his right leg. When I met Juma, he was using a wooden walking stick to support him when moving or standing. Juma was unemployed at the time of the interview. According to him, since he acquired his impairment four years ago, he has been unable to find a job.

The third interviewee, Dominic Fabio Ojok, just completed his Computer Science degree in networking. Dominic was the only participant who spoke English out of the four. Dominic became disabled at infancy. He was three months old when a medical error was made, by a nurse who was giving him an injection, and affected his left leg. Although his left leg is weaker than his right leg, he does not need an assistive device to help him walk or stand. Dominic was unemployed at the time of the interview. However, he was volunteering for Disabled Rights Organization and Development, teaching other persons with disabilities English and computer skills.

The fourth participant, Lucia Kpoakan, completed her university in Arabic just like the other two participants. She was not born with disabilities but acquired impairment when she was four years old. Lucia said she was playing with other children when she fell and dislocated her hip joint. She said she didn't report the incident until the following day. Without immediate medical help, she said the accident permanently affected her right leg. Although Lucia limps, she doesn't require an assistive device to help her walk. Lucia was also unemployed at the time of the interview. She said she was employed in the past but decided to quit her job so she could look after her little daughter at home. She was a single mother at the time of the interview.

During initial stages of my interviews with the participants, I observed that almost all of the participants referred to themselves and other people with physical disabilities as “Mwawag or Mwawagin”. Mwawag or Mwawagin (plural) is Arabic word which means injured person instead of disabled or people living with disabilities. According to them, people with physical impairments are not disabled. Their argument was that people with physical disabilities are cognitively at par with the non-disabled population. People who are disabled, according these participants, are those who are living with intellectual disabilities. The participants used the word “Mojnum”, which means “Crazy” to refer to persons with intellectual disabilities. Lucia said, “For me, injured persons should be judged on their ability to use their brain. A person who cannot think and solve cognitive problems is a person who should be referred to as disabled. Injured person shouldn’t be seen as disabled” (t1). Juma on the other hand said, “We are disabled but are we disabled in mind? No, what I know is that a “crazy person” (a person with intellectual disability) is disabled. But disabled people know everything because God has given them mind to do everything” (t2). Now that I have introduced the participants and clarified some of the terms the participants used, in this next section I present their stories.

### **Participants’ stories**

In this subsection, I present the themes that I identified. As I have already mentioned it in the literature, to determine what issues raised by the participants earned their way into the final thematic groupings, I relied on the research questions in conjunction with my theoretical frameworks and interview guide. I used my theoretical frameworks as a guide to look for socially constructed barriers to inclusion of persons

with disabilities in societies. In conjunction with the theoretical frameworks, I identified themes based on the questions that I asked and the number of times certain issues were found in each interview. However, as Patton (1999) suggests, I also incorporated views that were at odd with what the majority expressed. Initially, I identified fifteen themes from the transcripts. However, when I took a closer look, I discovered that only nine of the themes out of the fifteen were major themes or actually constituted themes. The nine themes that emerged are as follows: Negative stereotypes, unemployment, transportation problems, lack of assistive devices, low economic status, sense of hopelessness, race and religious factor, impact of conflicts on disabled people, and solutions. Each of the themes is discussed separately.

### 1. Negative stereotypes

All of the four research participants interviewed said that the non-disabled population has negative attitudes towards them. They said people living with disabilities are perceived as useless, beggars and shameful to be around. Edreena said, “In Sudan, people with disabilities are seen as useless. Your parents may be supportive of you but other relatives and people around you would say, this is just an injured person; he or she is useless and will not be able to help us in anyway” (t1). Edreena also explained how disabled people are perceived as beggars. “When you are walking in the public, for example, people start to throw coins at you assuming that you are a beggar” (t1). Lucia, narrating how disabled people are viewed as beggars, said, “one day when I went to a government office to inquire about jobs, a government official told me that he had no

money to give me. He thought I was there to beg for money” (t4). Another participant, Juma, commenting on how disabled people are viewed as useless and shameful to be around said, “In Sudan, when they see you as injured person, people think that you are just pretending to be a human being but in reality, to them, you are not a human being. They think you are unable to do anything. If there is a program/activity going on, you will not be allowed to participate. They will prevent you from taking part even when you want to. If people are sitting, they will not allow you to go close to them. You have to sit far from where people are sitting. If there is an occasion in the family, they will not allow you to appear in front of people because your appearance is considered as a shame” (t2).

The negative perception that people with disabilities are a shame to be around has made many families hide their disabled family members. Lucia explained, “There are people living in their houses, their families do not allow them to leave the house. They are ashamed for people to see their disabled members. They also complain that injured people waste family resources. This is a human being! Why do you see him as an animal? Why do you oppress injured people like animals and deny them chance to go to school and work?” (t2). Dominic also made similar comments: “Because I have been living here in Khartoum for about 19 years, I don’t know more about south, but here in the north.....it is a shame to have someone who is disabled in the family. If the person is a woman, that will be even worse. It is even difficult for neighbors to know that someone in this house has disability. For children, some times they will allow them to come out

but someone will always monitor them. But this is better compared to how women with disabilities are treated” (t3).

Some of the participants said that these negative stereotypes are embedded in Sudanese culture and that these stereotypes affect the lives of disabled people in significant ways. Juma, explaining how negative social attitudes are entrenched in Sudanese culture, said, “In our Sudanese culture, this is something I want you to understand, people here hate injured people” (t2). Some of the participants said that although negative stereotypes towards persons with disabilities affect everyone in this group, children and women are the most affected.

Based on participants’ accounts, school-aged children with disabilities are often not sent to schools because their families believe they will not be able to support them in the future. Edreena, said, “disabled children are not treated equally with their non-disabled counterparts. Children with disabilities have to always behave themselves. If for example, a disabled child fights other children or his/her siblings, his/her parents would decide not to take the child to school, after all, taking disabled children to school is seen as waste of resources because they will not be able to help the family in the future” (t1). Dominic said, “Families prefer to give a non-disabled child a chance to go to school over a disabled child. This is because it takes a lot of effort to put a disabled child on a bus. For example, a child that uses a wheelchair, first, the child needs to be carried from the bed and put on a wheelchair. Second, the child has to be pushed to the bus stop and third; the child has to be transferred from the wheelchair to the bus. Parents would rather keep

disabled child at home as a guard or they will use the person to beg and collect money for the family” (t3).

The second group that is affected the most by the negative social attitudes towards disabled people in Sudan, according to some of the participants, are women. In Sudan, the participants said, disabled women are thought of as unmarriageable. In regards to oppression of disabled women when it comes to making meaningful relationships, Lucia said, “in South Sudanese culture in general, it is thought that a disabled woman shouldn’t get married because on the one hand a family of a disabled woman thinks that their disabled daughter will be mistreated by a family of a prospective husband, but on the other hand, men are discouraged from marrying a disabled woman, for it’s believed that a disabled woman will not be able to do house work such as fetching firewood, cooking, etc” (t4). While the intention of the parents of disabled young woman is to protect their daughter from abuses, men are discouraged from marrying disabled women for the fear that they would not be able to carry out duties of a housewife.

The second theme, which is also one of the most cited problems, is unemployment among persons with disabilities.

## 2. Unemployment

Everyone that I spoke to said that employment opportunities are denied to persons with disabilities in Sudan. The participants gave five different reasons for the lack of employment among the disabled population. They are as follows: negative stereotypes of

persons with disabilities, lack of education, inaccessibility of government offices, lack of information, transportation problems, and neglect of persons with disabilities by the government. By and large, Dominic said, it is difficult for disabled people to find jobs. This was how he said it, “the general problem is that it is difficult for any disabled person to get a job. The only time a disabled person may be given a job is when a disabled applicant demonstrates that he/she has high competency to do the job being advertised and the employer cannot find a non-disabled applicant with a similar qualification” (t3). According to Juma, disabled people are not given jobs because they are thought of as unable to work. He narrated his own struggle with searching for jobs. “The issue of unemployment is painful to me. Since I got the accident in 2007, which is 4 years by now, I still struggle to walk. I have been praying that God gives me the strength so I can get a job but I have never gotten an opportunity to work. When you go asking for work, they will say you are an injured person you are unable to work” (t2).

Edreena gave a number of reasons as to why the disabled population does not have equal employment opportunities as non-disabled population. First she said, in the government sector, many government jobs are located in buildings that are inaccessible to persons with disabilities. It is difficult for wheelchair users to go up the stairs in order to reach the government offices. Second, there are no vehicles to transport persons with disabilities to places of work. Government should designate special vehicles to transport disabled employees. Government should also try to make the use of the Internet to help people with disabilities to work from home. When they complete their work they can just

send their work via the email. But in Sudan such things are nonexistent. Instead, people with disabilities have to go and work with non-disabled employees in the same working environment” (t1).

Dominic also cited inaccessibility to the government offices as one of the reasons for inability of persons with disabilities to secure jobs. Dominic was the only person I interviewed who said, so far, he has not been treated differently because of his disability. But he acknowledged that other people living with disabilities are treated differently in Sudanese society. Although he limps when walking, he doesn't require an assistive device for support. But even for him, he said, taking stairs present a challenge. In his own words, he said, “When the building is very high, to go through these steps, even I myself have a problem with that. I can go to third and fifth floor but after that I have to take a rest” (t4).

Like Edreena, Lucia also gave a number of reasons for problems of unemployment among persons with disabilities. “It is difficult to find a job when you are injured. This is because many people with disabilities are not educated. Those who want to go to school do not have money to pay for school fees. The reason disabled people are under educated is because they are always hidden at homes. Second, many people with disabilities cannot move because they don't have money for bus fare. When you cannot afford bus fare, you cannot find information about jobs. Third, persons with disabilities are not given information about availability of resources. The government has forgotten



us. The government is supposed to go from house to house to check on disabled people” (t4).

Before moving on to the next theme, here are the barriers the participants said prevent them from obtaining jobs: negative social attitudes towards persons with disabilities, inaccessibility to government buildings, transportation problems, lack of education among persons with disabilities, lack of digital technology and the lack of interest by the government to reach to the disabled people hidden at homes by their loved ones. The third major barrier I will be discussing in the next section is the lack of assistive devices/assistive technologies.

### 3. Assistive devices

Related to the issue of employment, some of the participants I interviewed indicated that many disabled people in Sudan lack the assistive devices they need for their daily activities. They said some of the assistive devices such as motorized wheelchairs, scooters and walking sticks are too expensive for disabled consumers to afford. In addition to the affordability of the assistive devices, some of the participants cited corruption as another reason they are unable to acquire assistive devices. Edreena, talking about how expensive assistive devices are, said, “A wheelchair costs about 550.00 Sudanese pounds and a walking stick costs over 100.00 pounds. Disabled people cannot get this kind of money ” (t1).

Touching on the subject of corruption in relation to how it has made it difficult for

some disabled people to acquire the necessary assistive devices they need, Juma said, “There is a place where I can get a special pair of shoes. The shoes will make my walking a little better and less painful. When I go there to get the shoes, they always tell you, come tomorrow, come tomorrow. I have been going there many times and the story is the same, come tomorrow, come tomorrow. It is always said in the newspaper that the government is helping injured people, but who gets this assistance? They only give this assistance to their relatives. A poor person like me cannot get this government aid. For you to get this assistance, you have to know someone that controls the distribution of these things. The government does provide these devices but the problem is the distribution” (t2).

Edreena also said that corruption has made it difficult for some disabled people to obtain assistive devices that were meant to be free. This was how she explained it: “When government gives assistance to persons with disabilities, the assistance does not get to everyone. People who control distribution of these devices are corrupt. They only give them to their close relatives and friends and the majority of poor people do not have access to them” (t1).

To sum up this section, these are the key points some of the participants made pertaining to the acquisition of assistive devices. They said that many persons with disabilities lack the assistive devices they need for their daily activities. According to them many individuals in need of assistive devices cannot obtain them because many disabled people don’t have purchasing power. Second, they said, people responsible for

distributing free assistive devices are corrupt.

The fourth theme/barrier that emerged and which I have briefly touched on in the previous theme is transportation problems.

#### 4. Transportation

Some of the participants said that transportation problems are one of the barriers preventing them from getting to places they would like to go to. When asked whether persons with disabilities face transportation problems in Sudan, Dominic said transportation was not a problem for persons with disabilities because the Government issues them with bus-passes. But apparently, not everyone gets a free bus pass from the government. Lucia said, “Movement of injured people from one area to another is difficult. If you have a bus pass that is good but for some people who don’t have them, they have to pay fees. Here, injured people use the public transportation system just like everyone else” (t4).

Speaking about the difficulties persons with disabilities face when using public transportation system, Juma said, “I have difficulty using the public transportation because of congestion in the buses and the lack of consideration for persons with disabilities. Sometimes before I even sit down, the driver starts to drive, prompting conductors to hold me so I don't fall. For example, three days ago when I was taking the public transportation, the driver began to drive even before I sat down. I told the driver, why couldn't you wait until I sit down? These kinds of things pain me a lot. People tell

you to rent a special car because you have difficulties with your walking. But I will force myself and do the best I could to take the bus (t4).

There were two concerns that the participants raised regarding transportation problems. One of them is that there is no special mode of transportation designed and designated for persons with disabilities. Second, people with disabilities who don't have a bus pass have difficulties moving around. For those who may have bus pass but have difficulties taking public transportation, they don't have money to take alternative means of transportations such as taxi.

The fifth major barrier, low economic status, which I am about to discuss, is closely linked to the problem of unemployment. Through stories that some of the participants narrated, I have demonstrated in the following section that people with disabilities are not respected in their communities because they cannot earn money to support themselves and people around them. I have also demonstrated that having low purchasing power has hindered many people with disabilities from participating freely in their communities. For example, they cannot afford to move from one place to another because they don't have money to pay for bus fare. Second, their status has also made it impossible for some parents to send their children to school and has prevented adults who want to pursue education from doing so.

##### 5. Low economic status

Most of the participants mentioned implicitly and explicitly that their lower socioeconomic status is one of the reasons they are confined to their homes, they are not

respected in their communities and they are unable to send their children to schools. Speaking of the importance of money in relation to mobility problems and earning respect in the community, Juma said: “If you are staying with your family and they are working, your family will give you some money to rent a taxi to move from one area to another. But someone like me who has no money, my movement is difficult. I have to make calls asking people to get something for me from the market. For example, right now I don't have money, so, I spend most of my time at home. When I get money that is when I can rent a taxi to move around. There is no empathy for persons with disabilities. When you see a disabled person, try to help him take a bus. But here, everything is money. If you have money, you are a human being. If you are a disabled person but you have money, people will begin to like you. Money has become life” (t2).

The lack of economic power has also made it difficult for some families to send their disabled children to school and it has also prevented adults with disabilities who want to pursue further education. Lucia said, “Some of us have children but our children are not going to school because we don't have money for school fees. We have been left to rely on ourselves and yet we don't have money. Money is very important. Without money, there is no life”. Some disabled people don't have money to pay for school. Some of them also lack money for transportation (t4).

Obviously, the lack of purchasing power among persons with disabilities can be pinned on unemployment. It is through employment that one can earn money. However, the low socioeconomic status of these participants from the Southern part of the country

can also be seen as a product of years of systematic discrimination against them. I will elaborate on this in the analysis subsection. The next theme, the sense of hopelessness and anger, is also connected to the negative stereotypes and the lack of economic power.

#### 6. Sense of Hopelessness and anger

According to the research participants, some individuals with disabilities have developed a sense of worthlessness and anger because of the constant negative stereotypes directed at them. This is what Juma said about the anger and sense of hopelessness some disabled people have developed. “There are some places in Haj-Yusif, where illegal activities take place. These places are not safe. A person like me, I don't go to these places, but most disabled people go to these areas because they are angry. They want to go to these places because they don't care about their lives. They wish something bad to happen to them because they don't want to live” (t2). Dominic made similar comments as well. He said, “People with disabilities think differently. For example, I am disabled but I am all right. But some of disabled people don't value themselves. This is because they feel that they have been pushed out of their communities therefore they start to have negative thoughts. Some of them will decide to stab someone so he could die with someone” (t3). Dominic also added that some disabled students have been discouraged from going to school because of the way they are treated. “It is difficult to go to school when you are disabled. People laugh at you and insult you. Some disabled people have refused to attend school in spite of encouragement from their families. This is caused by the negative reactions they get from other students” (t3).

Explaining how some disabled people have developed a sense of worthlessness, Lucia said, “Some injured persons made themselves to think that since I am injured person, I am not a human being; I can’t work; may be I should become a beggar. He/she will be angry all the time because he/she thinks there is no future. Some of these injured people still think that way” (t4).

Having read these themes, one begins to see connection between these themes. For instance, negative stereotypes as a barrier lead to employment challenges and which in turn lead to the lack of purchasing power/low economic status. One of the ramifications of low purchasing power among persons with disabilities is their inability to buy assistive devices they need and afford alternative means of transportation.

In addition to the six barriers discussed, is the seventh theme, quite independent of the six, but identified as important by participants. Here, I discuss how race and religious factors have added additional challenges to persons with disabilities from South Sudan.

### 7. Race and Religious Factor

Race and religion were pointed out by three of the participants as factors that have made it difficult for them to access health services and aid provided by the government. Speaking out of his experience, Juma said, “According to my observation, I have not seen a southerner here in the north using an electrical wheelchair. I only see Arabs/northerner using them. When you go to the hospital, they read names; they will single you out by

your name. When they see your name, they will know that you are not a Muslim and therefore you must be a Christian. When they find out that you a Christian, they conclude that you are not a human being. When you are a Christian, South Sudanese and injured person, your situation is worse. If you are a southerner and a Muslim, at least they will give you some positive treatment. The government is not helping people with disabled people who are Christians. The government only helps Muslims. Injured Muslims get help from the Mosques. The government go to their homes and give them food supplies” (t2).

Lucia said that living in Northern Sudan, as a disabled Christian is difficult. She said it is tempting for disabled Christians to convert to Islam just to get out of the hardship they are facing. This is how she explained it: “Here, people don’t see an injured person from the South who is a Christian as a human being. Some Injured Christians from the South have changed their faith because they are too poor to afford food” (t4). Edreena also added this: “Life is difficult particularly when you are injured. You may end up converting to Islam so you can be accepted. When they see injured Christians, Muslims will tell you to change your faith so you can get help. It is tempting sometimes considering that once you become a Muslim, you will be given money that you have never seen in your life” (t1).

However, Dominic had a different take about being a disabled South Sudanese Christian in Khartoum. According to him, disabled South Sudanese Christians are not treated differently from their Northerners/Muslims counterparts. This is what he said; “I



have been living with Muslims all these years. What I have come to know is that Muslims also fear God just as Christians do. Anyone who has disability is respected regardless of his/her colour because they fear that if they do something wrong to you, God will judge them” (t3). Dominic’s different perspective on this subject raises a question. Are disabled people from the South who are Christians are all treated differently? The answer to this question would have come from South Sudanese Muslims but unfortunately I was unable to recruit one.

So far, I have discussed 7 themes that directly erect barriers to disabled population. This next theme, “the impact of conflicts on persons with disabilities” is quite different. It is different in that it is not a barrier in itself but a consequence of negative social attitudes towards persons with disabilities. This theme also highlights impacts of decades of civil wars in the lives of this group.

#### 8. Impact of conflicts on persons with disabilities

Towards the end of my interview with Dominic, I asked him what else he would want to add before we concluded the interview. His answer was that he was concerned about the welfare of disabled South Sudanese living in Khartoum. He said, now that Sudan was going to split into two countries in July 9<sup>th</sup>, South Sudanese have begun to move back to their homes in South Sudan. However, he said, those with disabilities don’t have resources for relocation. He said some families have moved back to the South but have left their loved ones with disabilities behind. This was how he said it: “I am looking

for someone to help me assist disabled southerners to go back to the south. I am actually one of the volunteers assigned to do this. I heard that some families have left their loved ones with disabilities behind so, they are stranded here in Khartoum” (t3).

I will elaborate more on the impact of conflicts on persons with disabilities in the second sub-section of the data presentation. I will highlight how the conceptual framework of international studies explains the root causes of conflicts in African and how these conflicts have impacted persons with disabilities. However, before moving on to analyzing each theme in detail, I would like to present the solutions that the research participants suggested.

## 9. Solutions

After asking research participants about the barriers they face, I also asked them to suggest solutions they thought should be implemented so that the barriers that they identified can be removed. One of the things that the participants unanimously suggested was the creation of awareness about persons with disabilities. According to the participants, the public should be educated about respecting disabled people. People should be informed that disabled people are capable of working. Second, some of the participants urged the government to implement international laws that protect the rights of disabled persons. Third, some of them urged the government to provide jobs to disabled people because being employed is empowering.

Edreena said the government should urge the general public to treat persons with disabilities equally. To do this, she suggested that the government should implement international laws that have real impact in the lives of disabled people. She also added that assistive devices should be distributed to all disabled persons regardless whether or not they are able to work. “When you are disabled, you want to be viewed as equal to everyone. Injured people should be included in all aspects of life in the society. Injured people should be given their rights. Government should follow and implement international laws regarding to injured people. The government is not implementing laws that protect the rights of injured people. Whenever the government implements some of these laws, it only implements parts of laws that are not very important to injured people. The government should create awareness about inclusion of injured people in the society. Injured people are still not seen as human beings” (t1).

Dominic also emphasized the need to create awareness. He said awareness should be done through mass media outlets such as radios, televisions and newspaper. According to him, the public needs to be informed that it is not a shame to have a family member who is disabled. In his own words Dominic said, “We need to reach the public through radio, televisions and newspaper. We need to tell the public that it is not a shame to have someone disabled in your family” (t3). Finally, Lucia said although people still have the old conception of persons with disabilities as unable to do anything, things are changing for the better. “In our families, we still have the old mentality that an injured human being is unable to do anything. He is not important; he can’t live among us. But now

people have begun to come to a realization that injured people are capable of working just as non-disabled people. This has been possible because of awareness. More awareness still needs to be done” (t4).

In a brief summary, according to the participants, awareness should be created in order to create positive images of persons with disabilities in their respective communities. Second, some of the participants urged the Sudanese government to implement important international laws that protect the rights of persons with disabilities. Lastly, some of them urged the government to provide persons with disabilities who are willing to participate in the labour market with opportunities.

Having presented the stories of the research participants, in the next sub-section, I analyze the impediments that hinder disabled people from participating fully in their society and some of the solutions they suggested.

## Analysis

In this second sub-section of data presentation, I analyzed and interpreted the themes that emerged. While in the first sub-section I presented mainly what the research participants said on various issues, in this sub-section, I tried to make connections between the themes that emerged and with the literature review. After discussing these barriers, I end my analysis with a discussion of further areas for research and action. Throughout my analysis process, I have relied on the two conceptual frameworks: the

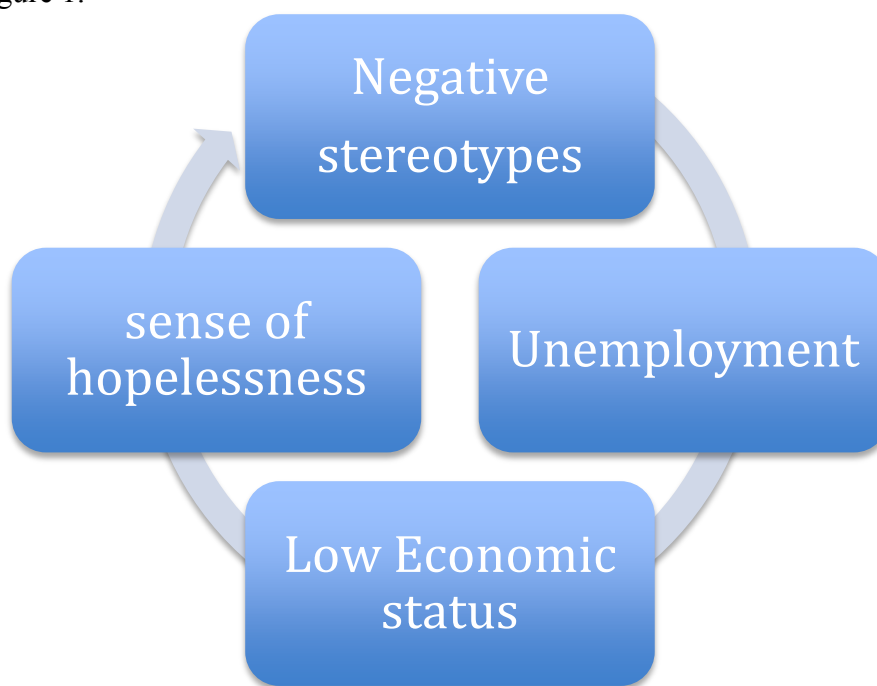
social model of disability and international theories that explicate socioeconomic failures in most African countries.

From the data that have been collected and presented in the first sub-section of data presentation, it is apparent that people with disabilities in Sudan face many barriers that have prevented them from participating freely in their society. The following were the barriers the research participants said hinder inclusion of persons with disabilities in Sudanese society: negative stereotypes, unemployment, lack of assistive devices, transportation problems, low economic status, sense of hopelessness, race and religious factors and impact of conflicts on disabled people. Some of the barriers that the research participants identified have also been identified in the literature review. Although there is a lack of rich literature, the little literature available indicates that Sudanese have negative attitudes toward disabled people, which have resulted in the denial of educational opportunities to disabled children, for example. (ADD Sudan program 2009, Jane-anne 2009 and Geoffrey 1998). It has also been identified in the literature reviewed that people with disabilities in Sudan lack access to assistive devices (Hardister 2007). The limited issues raised in the literature complement the themes identified by the research participants.

Most of the barriers that have been identified by the research participants are so intertwined as to be inseparable. All of these barriers, with exception of two, are connected to each other. It is impossible to treat each of them in isolation. For example, problems of unemployment are linked to negative stereotypes and the problems of

negative stereotypes are linked to low economic status and so forth. Because most of these barriers are all connected, they form what I refer to as a vicious circle of oppression. I have illustrated this by a use of a simple diagram as seen in figure one below.

Figure 1.



I have reduced themes such as the lack of assistive devices, transportation problems and inaccessibility to physical infrastructures into sub-themes. The reason for reducing some of the themes into sub-themes is because these themes were cited by some of the participants as the causes of these other major barriers (themes). For example, the lack of assistive devices and inaccessibility to the government buildings were cited as some of the reasons for unemployment among some of the disabled population.

Although none of these four themes or barriers can be pointed to as the most

significant barrier, I find it easier to start my analysis with the negative stereotypes. It is tempting to view negative stereotype as the main barrier because of how it has been cited by the participants as the cause of most of the problems that they face. While I agree that negative stereotypes of persons with disabilities are significant barriers, they are also fueled and perpetuated by these other three factors: Unemployment, low economic status, and sense of hopelessness. None of these barriers can be solved independently. As Oliver (2004) said, a problem of unemployment cannot be solved without addressing other environmental disabling factors such as transportation and negative attitudes toward disabled people. I will discuss each of the four barriers and illustrate how they are so interconnected that they form a vicious circle of oppression. To achieve this, I summarized each of the barriers and where appropriate, I used some of the quotations from the participants to highlight the significance of what the participants said. After demonstrating how each of the barriers are so intertwined, I will discuss how these other barriers, which are significant as well but can be solved independently, add to the fundamental problems the disabled population is already experiencing.

### Negative stereotypes

The participants I spoke to cited negative perceptions of persons with disabilities in Sudan as one of the major problems that they face. Generally, the participants said that disabled people are perceived as useless people who have no abilities to contribute financially to their families. Some of the participants said that disabled people are seen as an embarrassment. According to what the participants stated, some of the Sudanese hide

their family members with disabilities, particularly women, from the public. Women, the participants said, are disadvantaged when it comes to making meaningful relationships. According to some of the participants, disabled women are not marriageable because they are seen as incapable of performing household tasks.

Children, according to some of the participants, are the second group that is most affected by the negative social attitudes. Due to the negative social attitudes of persons with disabilities in Sudan, children with disabilities are not sent to school. Parents believe that even if they educate their disabled children, they will not be able to support them in the future. This theme also emerged in the literature review. Regarding the general negative social attitudes towards children in Sudan, a British woman who has been working in Sudan for years said that parents of disabled children in Sudan often hide their children away for the fear of what society might think of them (Jane-Anne 2009). Another Sudanese man, whose story was published online on Sudan Monitor website, said that parents have resorted to not pay school fees for their disabled children because it is seen as a waste of resources (Geoffrey 1998).

Two of the research participants implied that the negative stereotypes towards disabled people are rooted in Sudanese culture. This is best captured by Juma's statement: "In our Sudanese culture, this is something I want to make you understand. People here hate injured people" (t2). The other participant, Lucia, made reference to Sudanese culture when she was explaining the reasons disabled women are deemed unmarriageable. She said, "In South Sudan in general, it is thought that a disabled person



shouldn't get married because they might be mistreated in their partner's families. People don't want to marry a disabled woman, for they believe that she will not be able to do household tasks such as fetching firewood, cooking, etc" (t4). The first statement by Juma highlights the general dislike towards persons with disabilities. The second statement by Lucia specifies why women are not thought of as marriageable. From her statement, one would infer that disabled women in Sudan are thought of as unmarriageable not because they are disliked or hated but due to their perceived inability to carry out the roles associated with wives. However, discrimination against disabled women in this context can also result in dislike of this population for the wrong reasons. For example, some people might think that disabled women are unmarriageable because it is taboo to marry them.

Parents who decide not to send their disabled children to school may be influenced by economic problems. For example, Edreena said, "Disabled children are not treated equally with their non-disabled counterparts.....taking disabled children to school is seen as waste of resources because they will not be able to help the family in the future" (t1). This shows that the decision of parents not to send their disabled children to school is influenced in part by the lack of resources; particularly considering Sudanese economic underperformance caused largely by the decades of civil wars. Yeo and Moore (2003) suggest that when a country is going through economic hardship, it may be seen as economically irresponsible to give an equal share to a disabled child who is perceived as unlikely to be able to provide for the family in the future. Although the significance of

negative social attitudes towards disabled people cannot be disputed in preventing disabled school age children from attending schools, from what the participants said, the lack of resources seem to be the driving force behind families' decision not to send their disabled children to school.

The negative attitude as a barrier cited by the participants does not only prevent children with disabilities from being sent to schools but also hinders potential jobs seekers with disabilities from participating in the market economy. In the following section, I have summarized the factors that the participants gave as the reasons they are enabled to secure employment. I have also highlighted where negative stereotypes play a role in preventing disabled job seekers from access employment opportunities.

### Unemployment

Generally, unemployment is high in Sudan regardless of whether one lives with disabilities or not. There are no statistics available about unemployment rate among persons with disabilities in Sudan. However, from personal stories of these participants, job seekers living with disabilities are more disadvantaged compared to non-disabled job seekers. Unemployment among persons with disabilities is not an isolated barrier. The research participants I interviewed cited different reasons for their inability to get jobs. These are the reasons they gave: prejudice, inaccessibility to the government offices, lack of information and transportation problems. When one looks closely at each of the reasons for hindering disabled population from obtaining employment, one will discover that somehow the general negative social attitudes towards this group play a role. Some

of the participants blamed the lack of employment among disabled people on prejudice and negative stereotypes. One participant said that disabled people are denied jobs simply because they are disabled. This quotation from Juma best captures how disabled people are discriminated against when it comes to employment. “When you go asking for work, they will say you are injured person therefore you are unable to work” (t2). Another participant said, one time he went to one of the government offices to look for job and he was mistaken for a beggar (Dominic t3). Dominic said the only time they will give a job to a disabled person is when there is no qualified non-disabled person.

Second, some of the participants cited inaccessibility to the government offices as one of the impediments hindering disabled people from securing employment. Some of the participants said that most of the government offices are located in multiple storey buildings. To access these offices, the participants said, one has to take stairs. They said this makes it difficult for those who have problems with one or both limbs to drop their resumes or ask about availability of jobs. What this implies is that people who have problems with their limbs are indirectly discriminated from seeking jobs. Designing buildings without including ramps or elevators so those who have mobility difficulties can use indicates that Sudanese society has no consideration for individuals with disabilities. It is also an implicit indication that individuals with disabilities are not considered as productive citizens and that they don't have the rights to get access to the government buildings.

Third, the lack of information on employment opportunities was cited as one of the

barriers hindering persons with disabilities from getting jobs. In Sudan, mediums of communication are limited. The majority of Sudanese citizens do not have access to the Internet (Internet World Stats, 2011). Popular mediums of communications such as television, newspaper and radio usually carry mainly political messages and they are out of the reach of many Sudanese; the disabled and non-disabled alike. However, people with disabilities face unique challenges. First, they are poor, thus they cannot afford newspaper and televisions and even radios. Second, because of the stigma attached to persons with disabilities, families, as one of the participants said, tend to prevent their loved ones with disabilities from leaving home and freely interacting with others. Interacting with others is one way of finding information especially for the majority of persons with disabilities who are too poor to afford the available mediums of communication. This was what one of the participants said regarding to the confinement of disabled people in homes, “disabled people are confined to their houses and the government is not checking on them” (Juma t2). Here, negative social attitudes that have led to confinement of disabled people in their homes have also created barriers for this population in finding information about jobs.

Fourth, transportation problems, which are also closely linked to the lack of information, were cited as another reason preventing people with disabilities from finding jobs. When one has no access to mediums of communications such as the Internet, televisions and newspaper, for example, the ability to move from one area freely becomes the only alternative to find information. At times, public transportation in Khartoum can

be very difficult to use even for someone who doesn't need support. During rush hours, people literally use their muscles to secure seats in buses. Sometimes people organize themselves as a group to be able to board these buses. People with disabilities stand no chance to secure seats in these situations. In big cities in Canada such as Toronto, buses can be crowded but no one has to use force to get in and secure a seat. In the literature review, a woman in her own words said, "far from Khartoum center, buses are available, but very crowded, without any special facilities for the disabled" (Hardister 2007). I didn't fully comprehend this statement until I visited Khartoum and witnessed it myself.

Another transportation problem that individuals with disabilities face is that most of the bus drivers do not have empathy for persons with disabilities. Juma, one of the participants, said that bus drivers do not wait for him to sit. He said they tend to drive before making sure a person like him has sat down. Juma also added that he gets a lot of stares from fellow passengers making him feel uncomfortable. Juma said these stares sometimes make him feel like not taking public transportation. This concern about public stares has been raised by Reeve (2004). She argues that while the problems of physical barriers to inclusion of persons with disabilities should continue to be taken seriously, the psycho-emotional dimensions of disability as barriers to exclusion of persons with disabilities in society are equally important and should be taken seriously. Reeve says that the stares that disabled people get and the feeling of pity and hostility toward them once they step into the public domain have psycho-emotional impacts on disabled persons. This in turn becomes a barrier that restricts people with disabilities from leaving

their homes. Apart from overcrowding in the buses, the psycho-emotional dimensions of disability caused by stares as Juma was narrating, also contribute to confinement of persons with disabilities in their homes.

Lastly, some of disabled people cannot afford to pay for bus fare. This, according to one participant, makes it impossible for disabled people to find about job opportunities. Some of the participants said that although government does give free bus passes to disabled people, not all of them get these bus-passes.

I have demonstrated in this section that while factors such as inaccessibility to the government offices, lack of information and transportation problems, which hinder persons with disabilities from acquiring employment, are seen as independent problems, they developed as consequence of negative social attitudes towards persons with disabilities.

#### Low economic status

While negative social attitudes have led to difficulties in employment of persons with disabilities, unemployment among this population has led to their devaluation in their society. Unemployment among persons with disabilities translates to low purchasing power. Some of the participants said that because they don't have money, they do not have the option of seeking alternative means of transportation. Two of the participants said that money has become everything. They said that when one doesn't have money, no one wants to be around you and everything else becomes difficult. This is how Juma, one of the participants put it: "For someone like me who has no money, my movement is

difficult. I have to make calls asking people to get something for me from the market. For example, right now I don't have money, so, I spend most of my time at home. When I get money that is when I can rent a taxi to move a round. There is no empathy for persons with disabilities. When you see a disabled person, try to help him take a bus. But here, everything is money. If you have money, you are a human being. Everything is about money. If you are disabled and you have money, people will begin to like you. Money has become life" (t2). Here, Jumba expresses his frustration with the fact that he couldn't move and get things on his own because he has no money. His relative independence has been taken away from him.

The lack of economic power has also made it difficult for some disabled families to send their children to school and has prevented adults with disabilities who want to pursue education from doing so. Lucia said, "some of us are married and have children but our children are not going to school because we don't have money for school fees. We have been left to rely on ourselves and yet we don't have money. Money is very important. Without money, there is no life (t4)".

The lack of purchasing power attributed to the problem of unemployment among disabled people has also made it difficult, if not impossible, to purchase assistive devices that some disabled people need for their day-to-day activities. Some of the participants I interviewed said that they don't have the necessary assistive devices they need because they cannot afford them. They said assistive devices such as motorized wheelchairs, scooters and walking sticks are too expensive for disabled consumers to afford (Edreena

t1).

The low economic status of persons with disabilities goes beyond just unemployment. Like many other African countries, Sudanese economic and social policies, which I have discussed in the first conceptual framework (African States), are formulated in a way that they only benefit the minority Arab elites. The marginalized groups, for example, people from the Southern part of the country are assigned manual jobs that the Sudanese Arabs don't want to do (Jalata 2005). Persons with disabilities, who are unable to perform manual jobs and who come from one of the marginalized groups, are denied access to the national wealth. Therefore the lack economic power among persons with disabilities from South Sudan is as a result of decades of systemic economic discrimination rooted in Sudanese society. The lack of economic power combined with negative social attitudes that the disabled population is subjected to have made some of them develop a sense of hopelessness and anger.

#### Sense of Hopelessness and anger

Some of the participants said that because of the way disabled people are perceived negatively in their communities, some of them have developed anger and a sense of worthlessness. The mockery disabled students face at school has forced some of them to refuse to go to schools. This was what Juma said about the anger and sense of hopelessness some disabled people have developed. "There are some places in Haj-Yusif, where illegal activities take place. These places are not safe. A person like me, I don't go



to these places, but most disabled people go to these areas because they are so angry that they don't care about their lives anymore. They wish something bad to happen to them because they don't want to live" (t2). Lucia made similar comments. She said, "People with disabilities think differently. For example, I am disabled but I am all right. But some of disabled people don't value themselves. This is because, they feel that they have been pushed out of their communities therefore they start to have negative thoughts. Some of them will decide to stab someone so he could die with someone" (t4). Lucia also added that some disabled students have been discouraged from going to school because of the way they are treated. "It is difficult to go to school when you are disabled. People laugh at you and insult you. Some people with disabilities have refused to attend school in spite of encouragement from their families because of the negative reactions they get from other students" (t4). When disabled people are seen as angry all the time and displaying sense of hopelessness, non-disabled people develop and hold on to the negative stereotypes about disabled people.

I have described so far the first four major barriers to inclusion of persons with disabilities in Sudan. Based on what the research participants said, I have demonstrated how negative social attitudes towards disabled people have affected women, children and have resulted in erecting barriers that have prevented this population from obtaining employment and consequently relegating them to the lowest economic class. Unemployment, which has led to poverty among this population, has in turn made disabled people develop a sense of hopelessness. While negative stereotypes have a

profound negative impact on how persons with disabilities get jobs, the lack of employment among this population leading to low economic status and sense of worthlessness is in turn responsible for creating and perpetuating negative stereotypes that non-disabled people have towards individuals living with disabilities. When people are used to seeing disabled people as jobless, living in abject poverty, which in turn cause some of them to be aggressive, those without disabilities begin to think of persons with disabilities as not worthy of getting married, as in the case of women. These social realities of disabled people also make parents believe that sending their disabled children to school is not socioeconomically viable.

In addition to these four barriers that have formed vicious circle of oppression, two other factors, which are independent of the four and also of each other, make the already bad situation worse. These factors are: corruption, and race and religious factors.

### Corruption

Corruption exists everywhere in the world in different forms; however, in Africa and in Sudan in particular, the magnitude of corruption is enormous. Just to show how corruption affects lives of ordinary Sudanese, when I travelled to Khartoum in February 2011, a group of airport workers pretended that they were helping me with something that I could have done myself. They knew from my passport that I was coming from abroad therefore I must have money. They took control of my handbag and walked me through the custom checks. When I was cleared, they demanded I give them some money for their help, which I didn't need at the first place. I had no option but to give them some

money. I was told that in Sudan, no one could obtain any document from the government without paying some money to the government officials.

Corruption has touched everyone's life in Sudan including the most vulnerable ones. Some of the participants said that the government does give some help to persons with disabilities, however, they said, corruption has made it impossible for disabled people from South Sudan to secure some of this help. For example, Edreena said that when the government gives assistance to persons with disabilities, this assistance does not get to everyone. This is because, she said, people who control the distribution of these assistive devices are corrupt. She said people who control the distribution of these resources only give them to their close relatives and friends and the majority of poor disabled people do not have access to them (t1). The government's intention was to help disabled people get needed assistive devices for free, however, corruption is a barrier for disabled people. In addition to corruption as a unique barrier, race and religious factors have also presented a unique challenge to a certain group of persons with disabilities in Sudan.

#### Race and Religious Factor

Another barrier, which is unique to persons with disabilities from Southern Sudan, is the issue of race and religion. Most of the participants said their status as disabled, Christians and black, have made it difficult for them to access health services and aid provided by the government and other charitable organizations. Juma highlights

how race and religion have made it difficult for South Sudanese living with disabilities to obtain free assistive devices given by the government. “According to my observation, I have not seen a southerner here in the north going on an electrical wheelchair. I only see Arabs/northerner using them. When I go to hospital, they read names; they will single you out by your name. When they see your name, they will know that you are not a Muslim and therefore you must be a Christian. When they found out that you are a Christian, they conclude that you are not a human being. When you are a Christian, South Sudanese and disabled person, your situation is worse. If you are a southerner with disabilities but a Muslim, at least they will give you some positive treatment” (t2).

Some of the participants said the difficulties they face are so enormous that it is tempting to convert to Islam so one could get the help one needs. However, one participant disputed this claim. According to Dominic, disabled Christians from the South are not treated differently from their Northerners/Muslims counterparts. This was what Dominic said “I have been living with Muslims all these years and I have realized that people with disabilities are respected regardless of their colour or religion because Muslims fear that if they do something wrong to a disabled person, God will judge them” (t3). This obviously raises more questions. Are all disabled people from south Sudan treated differently because they are Christians and black or the experiences differ? If experiences differ, then, why do they differ? If I were to include people from Western Darfur as part of my targeted population, I wonder if the issue of religion would be brought up. Given that both groups involved in Darfur conflicts are predominately

Muslims, with one group describing itself as Sudanese Arabs and the other as Black Africans, my assumption is that race but not religion will be used as a marker as it is already being used by the black Africans to make their case to the international community.

In the case of the research that I conducted among south Sudanese, it would have helped if a South Sudanese who is a Muslim were interviewed. Unfortunately I could not find one. This is one of the limitations of this research, which I have discussed towards the end of this chapter. Before discussing some of the solutions that the research participants suggested, I would like to broaden the discussion about effects of conflicts on disabled people in Sudan. As I have already mentioned in the first part of the data presentation, only one person touched on this theme. In spite of this I find this theme worth including as part of research findings because of the significance of conflicts in the lives of Sudanese.

#### Effects of conflicts on disabled people

In her article “The Effect of Failed States on the Well-Being and Lives of People with Disabilities” (2009), Loeb stated that when there is a conflict, for example, a civil war, people with disabilities suffer the most because of the physical limitations that make it difficult for them to evacuate a conflict zone. In addition, she said that when there is an economic deterioration caused by conflicts, negative attitudes towards disabled people are exacerbated. South Sudanese with disabilities in Khartoum have experienced the on-

going conflicts in Sudan. This is even made worse when the country split in two on July 9, 2011 and those from the South were forced to relocate to their new country. A good number of Southern Sudanese are said to have relocated to the south already. However, those who couldn't afford transportation cost have not been able to relocate. Among those unable to relocate to the south due to financial strains are the individuals with disabilities. Dominic said many disabled people couldn't afford relocation cost to the South. He said some families have left to the South leaving their disabled loved ones behind (t3).

The decision of some families to leave their loved ones with disabilities behind is partly attributed to negative social attitudes towards this group. When a family makes a decision to leave their disabled members behind, it illustrates that disabled people are not valued equally with the rest of the family members, especially in times of transition and stress. It also shows the lack of economic power of persons with disabilities. Had people like Dominic and a few others with disabilities been employed, they, as a group, would be able to raise enough money to send considerable numbers of disabled people, who have been abandoned by their families, back to South Sudan.

Further discussions of the themes in conjunction with the conceptual/theoretical frameworks

I have relied on the two conceptual frameworks throughout the course of analyzing my data. Most of the barriers identified by the research participants are similar

in many ways to the social model explanation as to why people with impairments are not participating fully in their respectful societies. According to the social model, impairment does not disable people, instead it is the society that disables impaired people by the way they are unnecessarily isolated and excluded from participating fully in society (Oliver 2004). Barriers that societies erect to persons with disabilities, according to the social model, include but not limited to: prejudice and negative stereotypes; inaccessibility to public buildings; lack of assistive devices; unemployment; and psycho-dimensions of disability.

The stories of the four participants confirm the social model's claim that it is not the impairment that disable persons but barriers erected by the society. The participants I interviewed hardly attributed challenges they face directly to their impairments. None of them talked about the need for medical intervention in order to get them out of their predicaments. When the participants were explaining the reasons for their inability to secure jobs, none of them mentioned impairments as part of the reasons instead they said it was the attitudes of people towards their impairments that have made it difficult for them to get jobs.

Shakespeare (2004) who has contributed greatly in the social model discourse said that prejudice and negative stereotypes that disabled people face in the Western world are embedded in the Western cultures. Likewise, in Sudan, according to the participants that I interviewed, the negative perception of persons living with disability is embedded in the Sudanese cultures. The negative perception of individuals with

disabilities as not being resourceful and beggars, are some of the impediments preventing disabled individuals from participating fully in the Sudanese society. These negative perceptions of persons with disabilities, which are embedded in Sudanese culture as the participants have suggested, have prevented non-disabled population from having empathy towards disabled people. With the right supports, people with disabilities in Sudan can optimize their skills and be less reliant on others for their daily activities. For example, had Juma been given the pair of shoes that lessens the pain he feels when he walks, he wouldn't rely on others so much to get things that he needs from the market. He would go himself and get the things he needs. If ramps and elevators were installed in public buildings, wheelchair users and other people who have difficulties taking stairs would access employment opportunities and other vital information by themselves. If people don't hold onto negative stereotypes about persons with disabilities, children with disabilities would be given equal opportunities to attend schools with the non-disabled children. Job seekers with disabilities would be given equal opportunity in the job market. In short, it is the negative social attitudes but not impairments that have prevented many disabled people from taking part in all aspects of life in the Sudanese society.

While the social model helped me in comprehending and analyzing impediments disabled population face, the second conceptual framework: the international theories about African states, assisted me in understanding why Sudan is such an unfavorable place for individuals with disabilities. The international theories about African states, as I



have already discussed at length in the conceptual frameworks section, attempt to explicate possible reasons for African countries' failure to achieve both economic and political stability. According to these theories, the socioeconomic instability across many African countries is attributed to their leaders' irrational decision making, where socioeconomic policies are put into place to advance their economic and political interests. As a result, they argue, these irrational socioeconomic policies do not encourage economic growth, but lead to corruption and social unrest. Loeb suggested that the livelihood of individuals with disabilities is contingent on an open and accessible socio-political environment (2009 p. 27). When there is a conflict causing economic growth to plunge, people with disabilities suffer the most. This is because, according to Loeb, people develop more negative attitudes towards people living with disabilities and people with disabilities find it hard to escape when conflicts erupt.

Sudan has been in conflicts for decades since it gained its independence from the British government partially because of irrational decisions that its leaders made. Sudan is rich in many natural resources but its wealth is concentrated in hands of a few individuals. The disenfranchised majority took up arms against the state. The consequences of many years of conflicts are reflected on how many Sudanese are living in abject poverty. The negative perceptions of disabled people as not being resourceful is a reflection of the economic hardship that people in Sudan face as a result of years of conflicts. For instance, the decision of parents to deny their disabled children educational opportunities could be attributed to negative social attitudes caused by economic

hardship. If Sudan had inclusive socioeconomic policies, perhaps many families would have jobs and earned decent wages to support their disabled family members. Those in control of the distribution of assistive devices would not see a point of selling them or giving them only to their relatives. These are obviously hypothetical scenarios but the point I am trying to make here is that conflicts caused by poor socioeconomic policies, as the international theories on African states argue, are in one way or another responsible for some of the challenges that Sudanese living with disabilities face today.

In a brief summary, using examples, I have demonstrated how the two conceptual frameworks: the social model and international theories of African states helped me in forming themes from the interviews I had with the research participants. These conceptual frameworks also assisted me in analyzing these themes further. Having analyzed each theme one by one, I now turned to the discussion of some of areas that require further research actions.

### Measures to address barriers

This research study is guided by two research questions:

What are the most significant barriers to inclusion of internally displaced South Sudanese with disabilities into the larger Sudanese society from their own perspective? What are some measures they think are required to address these barriers?

While the first research question helped me in identifying the barriers that I have discussed above, the second part of the research question, which I will be discussing in

this section, assisted me in understanding solutions that the research participants suggested in order to overcome some of the barriers that they identified. Although this research project is not defined as an action research study, some of the solutions that the participants suggested demand government actions.

Some of the participants said that although people with disabilities continue to live on the margins of Sudanese society, they have noted some small positive government policy changes towards disabled people. For example, they said the government is now distributing assistive devices to disabled people and schools have been made more accessible to this population. This was what Domic said about some of the positive changes that disabled people have observed. “In the past, the government didn’t help people with disabilities. But as of 2010, I have seen our government give some bicycles and motorbikes for persons with disabilities. The government is also providing free education for disabled people. In the past, it was difficult for disabled people to go to schools” (t3). Some of the participants also mentioned the provision of free bus passes to this population as a sign of positive government policies towards disabled people.

Although not everyone has benefited from these positive changes due to factors such as religion, race and corruption, most of the participants acknowledged these new changes. However, all of the participants said that there remains a lot to be done in order to improve lives of disabled people significantly. They identified some gaps, which they suggested if the government addressed, would alleviate some of the challenges that individuals with disabilities continue to face. These are some of the gaps that they

identified: the government's lack of raising awareness about people with disabilities; lack of jobs; provision of adequate assistance for persons with disabilities such as bus passes and assistive devices; and lack of implementation of United Nations convention on the rights of persons with disabilities. When asked what ought to be done to address problems related to barriers to inclusion of person with disabilities in Sudan, the first suggestion each research participant gave was the need to create awareness about disabled people.

The participants said awareness is the key to creating positive images of individuals with disabilities. They said the public should be informed that people with disabilities are equal to everyone; they should not be treated as if they are not human beings. The awareness raising, they suggested, should be done through television, radios and newspaper. The second gap they identified was unemployment among persons with disabilities. They urge the government to provide jobs to disabled people because being employed, they said, is empowering. Third, some of them said, the government should provide free assistive devices to all persons with disabilities irrespective of their ability to participate in the labour market. Fourth, some of the participants urge the government to implement international laws that protect the rights of disabled persons. This was what Edreena said in regards to the lack of implementation of international laws by the government as far as people with disabilities are concerned. "The government is not implementing laws that protect the rights of injured people. Whenever the government

implements some of these laws, it only implements parts of laws that are not very important to injured people”.

When Edreena was talking about international laws concerning persons with disabilities, perhaps she was referring to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Sudan ratified this Convention in 2009, thus agreeing to implement it in Sudan and to be accountable for its implementation. The Convention contains provisions that countries including Sudan are called upon to adopt and implement in order for individuals with disabilities to enjoy all rights and privileges that everyone supposed to enjoy (UN General Assembly 2006). Three gaps identified by some of the research participants have also been mentioned in the UNCRPD. The Convention outlines ways through which state parties can combat some of the barriers disabled people continue to face in their societies. I will only discuss three provisions that are directly related to the three gaps that the participants identified: Creating awareness, provision of employment and assistive devices/technologies. I have made a brief summary of each of the three provisions.

### Raising awareness

According to the article 8 of the Convention, state parties, using appropriate measures, are urged to adopt immediately the provision in this article in order to combat harmful practices against this population by raising awareness and promoting positive perceptions and greater social awareness towards person with disabilities. Second, it

urges state parties to promote recognition of the skills, merits and abilities of person with disabilities, and their contributions to the workplace and the labour market. Third, the provision urges state parties to encourage all organs of media to portray person with disabilities in positive manners. Fourth, the provision also demands that state parties foster attitude of respect towards persons with disabilities in all school levels.

This provision complements some of the ideas that the participants put forward, for example, the use of media to raise awareness. The first report on the implementation of the UNCRPD in Sudan has not yet been submitted. But based on the stories of the participants, the government has not fully implemented this provision yet. Perhaps through advocacy, the government should be reminded of their obligations to this population as demanded by the UNCRPD. If the government implements this provision, negative social attitudes towards disabled people in Sudan would be changed significantly.

This next provision is about how state parties can ensure that their citizens with disabilities have equal opportunity to participate in the labour market.

### Work and employment

According to some of the participants, the lack of employment among persons with disabilities remains to be a challenge. The UNCRPD recognizes this problem and outlines ways to ensure that individuals with disabilities participate in the labor market on

equal foot. Below are some of the main issues that UNCRPD would like state parties to address:

Recognize the right of persons with disabilities to work, on an equal basis with others; Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, Enable persons with disabilities to have effective access to general technical and vocational guidance programs, placement services and vocational and continuing training; assistance in finding, obtaining, maintaining and returning to employment; Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business; Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

This provision on employment goes beyond just ensuring that the government prohibits discrimination against individuals with disabilities when seeking jobs. It also urges the government to promote vocational training opportunities to this group. In addition, the provision also urges governments to promote self-employment and development of cooperatives among disabled people. Encouraging disabled people to start their own business perhaps is one of the best ideas to ensuring that disabled people earn living, especially considering government of Sudan lack of capacity to create jobs to many of its citizens.

#### Habilitation and rehabilitation

While some of the research participants were mainly concerned about unavailability of assistive devices to persons with disabilities who need them, this provision is even broader in terms of ensuring that disabled people live relatively independent lives as much as possible. According to the provision under article 26:

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion

and participation in all aspects of life. 2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Providing necessary assistive devices to persons with disabilities is part of the action needed to ensure that disabled people achieve certain level of independence. But as this provision states, the government should also make sure that people with disabilities have access to health care, employment, education and other programs that are helpful in facilitating independent living among persons with disabilities.

In addition to these three provisions, the Convention also contains provisions on other barriers, which were identified by the research participants such as provisions on accessibility to physical infrastructures and specific provisions on women and children. If the government of Sudan implements some of these provisions and include them as part of its policies on disabled population, most of the barriers that people with disabilities face in Sudan would be reduced in a shorter period of time. This is because the Convention contains a broader approach to solving impediments that disabled people face in their communities. In a way, the Convention follows the social model of disability philosophy of how to overcome barriers that hinder individuals with disabilities from participating in their societies. The social model suggests that no one barrier to inclusion of persons with to society can be solved in isolation (Oliver 2004).

When one looks at the provisions that have been stipulated in the Convention, one would realize that it approaches barriers that people with disabilities face holistically. The Convention acknowledges that while extensive effort is necessary to raising awareness,



for example, through media and awareness training workshops, it is also imperative that these initiatives be followed by creating or amending the existent laws to protect the rights of disabled people so they can participate fully as citizens. It is through legislation, in my opinion, that rights of persons with disabilities can be effectively protected against many forms of discriminations, which ostracize this group from participating equally in the labour force, for example. The Convention also suggests alternative ways through which governments can help disabled people earn living. For instance, party states are urged to offer vocational trainings and encouraging disabled people to be self-employed. In addition to the barriers and gaps that some of the research participants identified and the further actions they would want the government to take, more research is still needed to comprehend issues affecting persons with disabilities in Sudan.

#### Further research areas

This explorative research study perhaps is the first of its kind to be conducted based on the social model philosophy in order to understand barriers to inclusion of persons with disabilities in Sudanese society from their own perspectives. While the study has managed to gather rich data from a small number of research participants, more research is still needed. This study was unable to explore all areas that require further investigations and this research project remains a Master's thesis rather than a large research project.

These are some of the areas that require further research in the future. First, more participants with disabilities need to be involved. Although the data gathered from the four participants was rich enough to inform us about some of the barriers disabled people face in Sudan, a larger number of participants could have produced even richer data. Second, only persons with physical disabilities were involved in this exploratory research. Perspectives and experiences of persons with intellectual disabilities and other groups are not included. People who have been labeled as disabled are very heterogeneous. Although the majority of disabled people may share some experiences, some challenges are not experienced across the board. For instance, challenges facing blind people may not be the same as challenges facing those labeled as intellectually disabled. Therefore further research is needed to investigate barriers that face these other groups.

Third, people who took part in this research were all Christians. Participation of South Sudanese Muslims would have given us a different perspective particularly in regards to how race and religion play in providing services to South Sudanese with disabilities in Khartoum. Future research whether conducted in North or South Sudan, should include participants of all faith: Christians, Muslims and those who practice African spirituality. The research should also involve people of different racial backgrounds.

Fourth, these research findings are only based on the accounts of disabled people. Perspectives of non-disabled people, who in this case are accused of discriminating

against disabled people, are largely excluded. Further research is required where non-disabled people are involved. Their perspectives are equally important in understanding and combating marginalization of persons with disabilities. Lastly, families of disabled people need to be involved in the future research. They will help us understand other issues that we might not get from both disabled and non-disabled people. I hope this Master's thesis would encourage researchers to pick interest in investigating these areas that require further study.

### Summary

Using a qualitative research design and an in-depth interviewing method, this study gathered qualitative data from four individuals living with physical disability or impairment. The four people are from South Sudan, the region that is now Republic of South Sudan. The data were analyzed using key theme analysis approach. Based on the questions asked, the research participants identified nine major barriers that hinder them as persons with disabilities from participating fully in their society. The participants also suggested a number of solutions to the barriers they identified. The nine barriers/themes that the participants identified are as follows: negative stereotypes, unemployment, lack of assistive devices, inaccessibility to public buildings, lower economic status, sense of hopelessness and anger, corruption, and race and religion.

I further narrowed the nine barriers down to six. I treated the first four major themes—negative stereotypes, unemployment, lower economic status, and sense of

hopelessness— as a group with close links. I call the circle that the first four themes form, a vicious circle of oppression. I reduced transportation problems and the lack of assistive devices into sub-themes because the participants described them as causes of these other major barriers. The other two themes/barriers—corruption and race and religious factors—exacerbate the four major barriers that disabled people are already facing.

By and large, the four research participants said, disabled people are perceived as useless people who have no abilities to contribute to their families. Some of the participants said disabled people are seen as an embarrassment. According to what the participants stated, some of the Sudanese hide their family members with disabilities, particularly women, from the public. Within the disabled population, women and children, the participants said, are the most disadvantaged. Disabled women are considered unmarriageable and disabled school aged children are not sent to school by their parents because they are not thought of as resourceful.

Unemployment among persons with disabilities is not an isolated barrier. The research participants I interviewed cite different reasons for their inability to get jobs. These were the reasons they gave: prejudice, inaccessibility to the government offices, lack of information and transportation problems. Some of the participants said that they are denied jobs not because they are not qualified but simply because of their disability status. While the negative social attitudes have led to difficulties in employment of persons with disabilities, unemployment among this population has led to their

devaluation in their society. Being unemployed means that disabled people do not have purchasing power. Some of the participants said that because they don't have money, they are unable to have the option of seeking alternative means of transportation such as taxi. Some of the participants said that because of the way disabled people are perceived negatively in their communities, some of them have developed sense of worthlessness and are angry all the time.

Some of the participants said that the government does give some help to persons with disabilities, however, they said, corruption has made it impossible for disabled people from South Sudan to secure some of these help. Another barrier, which is unique to persons with disabilities from Southern Sudan, is the issue of race and religion. Most of the participants said their status as disabled, Christians and black, has made it difficult for them to access health services and aid provided by the government and other charitable organizations.

The stories of the four participants confirm the social model claim that it is not the impairment that disabled persons with disabilities but barriers erected by the society. The participants I interviewed hardly attributed challenges they face directly to their impairments. For example, when the participants were explaining the reasons for their inability to secure jobs, none of them mentioned impairments as part of the reasons instead they said it was the attitudes of non-disabled people towards their impairments that have made it difficult for them to get jobs.

While the social model helped me in comprehending and analyzing impediments disabled population face, the second conceptual framework, the international theories about African states, assisted me in understanding why conflicts can create an unfavorable environment for individuals with disabilities. Decades of conflicts in Sudan as a result of irrational socioeconomic policies, as suggest by the international theories, have made conditions of persons with disabilities worse. Due to economic hardship, families have resorted to not sending their disabled children to schools and some of the families moving back to South Sudan have abandoned their loved ones with disabilities.

According to the research findings of this study, persons with disabilities in Sudan are discriminated against in almost all aspects of life. These discriminations are mainly attributed to the negative social attitudes towards this group. These negative social attitudes seem to be embedded in Sudanese culture.

## Chapter Six

### Conclusion

According to the research findings, persons with disabilities in Sudan are discriminated against in almost all aspects of life. These discriminations are mainly attributed largely to the negative social attitudes towards this group. Some of the participants have suggested that these negative social attitudes are embedded in Sudanese Culture. It also seems that economic deterioration in the country has exacerbated the negative social attitudes that already exist towards people with disabilities. Judging from the current unstable economic and political trend in both Sudans, the negative social attitudes towards disabled people are not going to change for the better anytime soon. However, oppression of persons with disabilities is not going to continue unchallenged by disabled activists and their supporters as it was in the past.

When I was conducting the interviews, I sensed that disabled people in Sudan are becoming increasingly aware of their rights as human beings and as people living with disabilities. This is perhaps attributed to globalization. As globalization intensifies, people are travelling more frequently and as they do, they are also exchanging information. In the case of Sudan, the decades of civil wars have attracted many charitable and international organizations. Many who work for these organizations are from the west and some of them are sympathetic to the plight of disabled people. The Internet has also made it easier for a few who can afford it to obtain information on issues

of interest to disabled people. For Example, a participant like Edreena seemed to be aware of the United Nations Convention on the Rights of Disabled Persons. Her knowledge of the convention enabled her to know whether the government was fulfilling its obligations to disabled people or not. The more people with disabilities are opened up to the outside world, the more they will be vocal about the unfair treatment they receive in their society. People with disabilities have already begun to demand their rights. For example, as noted in the literature review, people with disabilities have reportedly demonstrated against the way they are restricted from getting access to physical environment, transportation, information and communication, technological systems and facilities openly provided to the public in South Sudan (Stephen 2009). This demonstration was unprecedented in the history of Sudan.

Perhaps the greatest lesson I learnt during the course of writing this research paper is the realization that people with disabilities have an opportunity to teach their non-disabled counterparts some political lessons. Sudan and Africa in general has no history of class formation. It is widely argued that the absence of class in most African countries is because of a strong “tribal” affiliation, which some of the international theorists have cited as one of the reasons many African countries haven’t been making rational policies. But from my vantage point, disabled people have the chance to escape this trap and form some sort of a class because they don’t benefit from “tribal” affiliation/identity politics. Most disabled people are considered as outcasts by their respective “tribes.” Therefore it is possible for them to come together and form a class or



at least a strong socio-political movement as suggested by Finkelstein and Oliver (2004) in order to influence public policies. With proper planning, such activism, including that already begun in South Sudan, can grow into a powerful group capable of influencing politicians' decision-making. Disabled people in Sudan have an opportunity to teach other citizens to fight for and defend their common interest instead of following leaders just because they consider them to be their kin.

Lastly, during the course of conducting the interviews, I was shocked to hear how similar stories of the participants were to other disabled peoples' experiences from other parts of the world. Some of the barriers that research participants identified in Sudan are analogous to some of the experiences that have been reported not only in Africa but also in the West and Asia. For example, negative social attitudes towards disabled people have been reported almost worldwide. I hope findings of this research paper adds to the existing body of literature and reminds disability activists and their allies worldwide the importance of collective efforts to fight against exclusion of disabled people in their respective societies.

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## Appendix A

### Ethics Protocol Submission Forms





UNIVERSITY  
OF MANITOBA

Fort Garry Campus Research Ethics Boards  
CTC Building, 208 - 194 Dafoe Road  
Winnipeg, MB R3T 2N2  
Phone: (204) 474-7122  
Fax: (204) 269-7173

Protocol # \_\_\_\_\_  
(Assigned by HES Admin.)

## FORT GARRY CAMPUS RESEARCH ETHICS BOARD PROTOCOL SUBMISSION FORM

Psychology/Sociology REB  Education/Nursing REB  Joint-Faculty REB

Check the appropriate REB for the Faculty or Department of the Principal Researcher. This form, attached research protocol, and all supporting documents, must be submitted in quadruplicate (original plus 3 copies), to the Office of Research Services, Human Ethics Coordinator, CTC Building, 208 - 194 Dafoe Road, 474-7122.

Principal Researcher(s): Leon Nyerere

Status of Principal Researcher(s): (please check): Faculty  Post-Doc  Student: Graduate  
X Undergraduate  WRHA Affiliate  Other   
Specify: \_\_\_\_\_

Address (to receive Approval Certificate): 128 Education building, University of  
Manitoba, Winnipeg, Manitoba, R3T 2N2

Phone: (204) 995-9347 Fax: (204) 987-2748 Email: [umnyerel@cc.umanitoba.ca](mailto:umnyerel@cc.umanitoba.ca)

Project Title: Understanding Disability in Sudan

Start date December 2010 Planned period of research (if less than one year):

Type of research (Please check):

<u>Faculty Research</u>	<u>Administrative Research</u>	<u>Student Research</u>
Self-funded <input type="checkbox"/> Sponsored <input type="checkbox"/>	Central <input type="checkbox"/>	Thesis <input checked="" type="checkbox"/> Class Project <input type="checkbox"/>
(Agency) _____	Unit-based <input type="checkbox"/>	Course Number: _____

Signature(s) of Principal Researcher(s):  
\_\_\_\_\_

For student research: This project is approved by department/thesis committee. The advisor has reviewed and approved the protocol.

Name of Thesis Advisor Dr. Deborah Stienstra Signature \_\_\_\_\_  
(Required if thesis research)

Name of Course Instructor: \_\_\_\_\_

Signature \_\_\_\_\_

(Required if class project)

Persons signing assure responsibility that all procedures performed under the protocol will be conducted by individuals responsibly entitled to do so, and that any deviation from the protocol will be submitted to the REB for its approval prior to implementation. Signature of the thesis advisor/course instructor indicates that student researchers have been instructed on the principles of ethics policy, on the importance of adherence to the ethical conduct of the research according to the submitted protocol (and of the necessity to report any deviations from the protocol to their advisor/instructor).

### **Ethics Protocol Submission Form (Basic Questions about the Project)**

The questions on this form are of a general nature, designed to collect pertinent information about potential problems of an ethical nature that could arise with the proposed research project. In addition to answering the questions below, the researcher is expected to append pages (and any other necessary documents) to a submission detailing the required information about the research protocol (see page 4).

1. Will the subjects in your study be **UNAWARE** that they are subjects? \_\_\_\_\_ Yes  No
2. Will information about the subjects be obtained from sources other than the subjects themselves? \_\_\_\_\_ Yes  No
3. Are you and/or members of your research team in a position of power vis-a-vis the subjects? If yes, clarify the position of power and how it will be addressed. \_\_\_\_\_ Yes  No
4. Is any inducement or coercion used to obtain the subject's participation? \_\_\_\_\_ Yes  No
5. Do subjects identify themselves by name directly, or by other means that allows you or anyone else to identify data with specific subjects? If yes, indicate how confidentiality will be maintained. What precautions are to be undertaken in storing data and in its eventual destruction/disposition.  Yes \_\_\_\_\_ No
6. If subjects are identifiable by name, do you intend to recruit them for future studies? If yes, indicate why this is necessary and how you plan to recruit these subjects for future studies. \_\_\_\_\_ Yes  No
7. Could dissemination of findings compromise

- confidentiality?  Yes  No
8. Does the study involve physical or emotional stress, or the subject's expectation thereof, such as might result from conditions in the study design?  Yes  No
9. Is there any threat to the personal safety of subjects?  Yes  No
10. Does the study involve subjects who are not legally or practically able to give their valid consent to participate (e.g., children, or persons with mental health problems and/or cognitive impairment)? If yes, indicate how informed consent will be obtained from subjects and those authorized to speak for subjects.  Yes  No
11. Is deception involved (i.e., will subjects be intentionally misled about the purpose of the study, their own performance, or other features of the study)?  Yes  No
12. Is there a possibility that abuse of children or persons in care might be discovered in the course of the study? If yes, current laws require that certain offenses against children and persons in care be reported to legal authorities. Indicate the provisions that have been made for complying with the law.  Yes  No
13. Does the study include the use of personal health information? The Manitoba Personal Health Information Act (PHIA) outlines responsibilities of researchers to ensure safeguards that will protect personal health information. If yes, indicate provisions that will be made to comply with this Act (see document for guidance - <http://www.gov.mb.ca/health/phial/index.html>).  Yes  No

**Provide additional details pertaining to any of the questions above for which you responded "yes."** Attach additional pages, if necessary.

In my judgment this project involves:  minimal risk  
 more than minimal risk

(Policy #1406 defines “minimal risk” as follows: “. . . that the risks of harm anticipated in

the proposed research are not greater nor more likely, considering probability and magnitude, than those ordinarily encountered in life, including those encountered during the performance of routine physical or psychological examinations or tests.”)

\_\_\_\_/\_\_\_\_/\_\_\_\_

dd mm yr

\_\_\_\_\_  
Signature of Principal Researcher

### Ethics Protocol Submission Form

Review your submission according to this:

#### Checklist

Principal Researcher: Leon Nyerere

<input type="checkbox"/>	Item from the Ethics Protocol Submission Form
X	All information requested on the first page completed in legible format (typed or printed).
X	Signatures of the principal researcher (and faculty advisor, or course instructor if student research).
X	Answers to all 13 questions on pages 2-3 of Ethics Protocol Submission form.
X	Detailed information requested on page 4 of the Ethics Protocol Submission Form in the numbered order and with the headings indicated.
X	Ethics Protocol Submission Form in quadruplicate (Original plus 3 copies ).
X	Research instruments: 4 copies of all instruments and other supplementary material to be given to subjects.
X	Copy of this checklist.

**NOTE: For ease of reviewing it would be much appreciated if you could number the pages of your submission (handwriting the numbers is quite acceptable).**

5. Research participants will be identified by their full names to the researcher and the supervisor. In the final research paper, participants will be identified using pseudonyms in order to protect their identities. Data will be accessible only to myself and the academic advisor. Once the thesis is finalized, the data including the tapes and computer files will be destroyed within six months of graduation.

8. Research participants will not be directly subjected to neither physical nor emotional stress. But because many Sudanese citizens have experienced decades of civil wars, there is possibility that during an interview, some of the research participants might experience emotional breakdown. In case this happens, I will terminate the interview session and refer the participant to counseling resources available in the area.

### **Summary of Project**

The research project I intend to undertake investigates some of the major barriers to inclusion of internally displaced South Sudanese with disabilities in society from their own perspective and some measures they think are needed to address these barriers. This research project will be guided by two questions: what are the most significant barriers to inclusion of displaced South Sudanese with disabilities into the larger Sudanese society from their own perspective? What are some measures they think are vital to address these barriers?

I hope this study will not only be able to identify barriers to inclusion of persons with

disabilities in Sudan and measures to address these barriers but also help in further studying of issues affecting disabled people.

I will use a qualitative research design with interview guide to gather my data.

### **Research Instruments**

Attached is interview guide (see appendix C) that I have constructed to help in answering the two research questions I have raised. All questions are open ended. The interview guide will be modified as the research progresses.

### **Study Subjects**

I plan to obtain the sample from three to five individuals with disabilities. In order to obtain rich data on barriers to inclusion of persons with disabilities, participants will consist of adult (i.e. over 18 years old), women and men from Hajyusif area in Khartoum.

### **Recruitment**

To recruit research participants for this research project, I intend to approach local organizations that offer programs and services to persons with disabilities such as Action disability and development (ADD), Handicap International and others to help connect me with their service users. Once I connect with programs and service users, who identify themselves as persons with disabilities, I will explain to them the purpose of my research project and ask if they will be interested in taking part in the project. I will also use the snowball sampling to recruit research participants. Snowballing is a nonprobability

sampling technique used when members of a special group are difficult to locate (Babbie 2007). Once I interview one person, I will ask him/her to recommend another persons that I could contact.

### **Informed Consent**

Attached is a consent form. It contains a brief description of the purpose of the research. The consent form also requires research participants to agree to take part in the research by putting their signatures on the form. For those who cannot read in English, they will ask someone to read it on their behalf.

### **Deception**

All research participants will be informed of the purpose of the research. Deception will not be used in order to elicit information from participants.

### **Feedback/Debriefing**

Due to the distance involved, I will provide copies of the transcripts to the research participants before completion of the research via email. The purpose of the feedback is to give opportunity for the research participants to determine the accuracy of the information obtained from them.

### **Risks and Benefits**

Research participants are not expected to be exposed to risks. But because many Sudanese citizens have experienced decades of civil wars, there is possibility that during

an interview, some of the research participants might experience emotional breakdown. In case this happens, I will terminate the interview session and refer the participant to counseling resources available in the area.

The benefits to participants are that they will learn about barriers their fellow participants experience through the final research paper. I will also volunteer to teach research participants basic computer skills for two weeks, three days a week.

### **Anonymity and Confidentiality**

Research participants will be identified by their full names to the thesis advisor and myself. However, the names of the participants will not be mentioned in the final report. In the final research paper, participants will be identified using pseudonyms in order to protect their identities. However, the participants will be asked whether they want to be identified by their names. Data will be accessible only to myself and the academic advisor. Once the thesis is finalized, the data will be destroyed within six months of graduation.

### **Compensation**

This is a voluntary project and no cost will be incurred by participants therefore no compensation will be given to them. Participants will be informed onset that their participation is voluntary. Only those willing to volunteer will be allowed to take part in the research. However, I will volunteer my time to teach basic computer skills to those who are interested using my own laptop for two weeks; three days a week.



Appendix B  
Consent form for research participants



UNIVERSITY  
OF MANITOBA

Fort Garry Campus Research Ethics Boards  
CTC Building, 208 - 194 Dafoe Road  
Winnipeg, MB R3T 2N2  
Phone: (204) 474-7122  
Fax: (204) 269-7173

Research Project Title: Understanding Disability in Sudan

Researcher(s): Leon Nyerere

Research Supervisor: Dr. Deborah Stienstra

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participant will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Before you can take part in this research project, please read and sign this consent form. After reading the consent form, we can proceed with the interview but if you don't want to proceed with the interview, you should understand that you would not be penalized for doing so. The purpose of the consent form is to make sure that as a research participant, you are at least 18 years of age and that you have full knowledge of the research so that you are not exposed to any risk that you don't want to take. The purpose of this research project is to investigate some of the major barriers to inclusion of internally displaced South Sudanese with disabilities in the Sudanese society from their own perspective and some measures they think are required to address these barriers.

The interview will be recorded using a cassette player to make sure that your views are well documented. But if you don't want your voice (interview) to be recorded, please check a box below to indicate that you don't want your voice to be recorded. All information obtained from you will be kept confidential. Only I, the primary researcher, and my academic advisor, Dr. Deborah Stienstra will have access to your recorded interview. After information obtained from you has been analyzed, the tape, which contains your recorded voice, will be destroyed after the thesis has been accepted by the University and your name will not be mentioned nor any other identifying characteristics in the research project paper. You will only be identified by pseudonyms. However, if you want to be identified by name and you want your name to appear in the final research paper, please put a check mark on a box below to indicate that you have given me the permission to identify you by name and to include your name in the final research paper.

Depending on how much information you want to give, the interview session will last between 30 – 60 minutes. Your participation is voluntary and you may withdraw from the study at any time without penalty by informing me of your intention. Also, you don't have an obligation to answer a question that makes you uncomfortable or for any other reason for that matter. You are free to end your participation at any time and doing so

will not impact your right as participant. You have three weeks after the time the interview was conducted to withdraw your data before it is included in the final research paper. If you would like to obtain a copy of the transcript and of the final research report after its completion, please check one of the boxes below. Also check one of the boxes to indicate which method of deliveries you prefer. Please print your name and sign below to indicate that you have agreed to take part in this project. If you are unable to print your name and sign this document, you have the option of asking someone literate in English to read and sign on your behalf.

### Risks and benefits

As a research participant, you are not expected to be exposed to risks. But there is a possibility of you breaking down emotionally as a result of taking part in this study, during the interviewing session or after. This kind of risk is anticipated because many Sudanese have experienced decades of civil wars, there is possibility that during an interview, you might experience emotional breakdown. In case this happens, the interview session will be terminated and you will be referred to available counseling resources so you could get some help. The benefits of taking part in this study is that you will learn about barriers other people with disabilities face through the final research paper.

I will also volunteer to teach research participants basic computer skills for two weeks, one hour a day, two days a week. I intend to have all lessons done at 10:00 am for those morning hours work best for them and 5:00 pm for those who prefer evening hours. But I will also try to be flexible if neither of the times works for you. I intend to have the lessons done on one-on-one but if you would like to have it in a group, which will depend on other participants willingness to participate in a group, please check boxes below to indicate that you are interested in learning basic computer skills and you want to have lessons in a group. You should know that having lessons in a group session would compromise your privacy.

- I do not want my voice/interview to be recorded
  
- I need a copy of the transcript
  
- I need a copy of the final research report
  
- I am interested in learning basic computer skills
  
- I want to have basic computer lesson in a group

The transcript or the final copy of the research report should be delivered to me by:

Mail

Email

If you have question(s) for me (researcher) or my advisor, feel free to contact us.

**Researcher:** Leon Nyerere  
Phone: +011-249-917-729-882 (Sudan), +1-204-510-6122 (Winnipeg, Manitoba)  
Email: [umnyerel@cc.umanitoba.ca](mailto:umnyerel@cc.umanitoba.ca)

**Advisor:** Deborah Stienstra  
Phone: +1-204-474-9971

In case you have a complaint of any kind related to this research project, contact:

Joint-Faculty Research Ethics Board (JFREB)  
CTC Building  
208-194 Defoe Road  
Winnipeg, Manitoba R3T 2N2  
Phone: +1-204-474-7122  
Fax: +1-204-269-7173  
Email: [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca)  
[www.umanitoba.ca/research](http://www.umanitoba.ca/research)

Name: \_\_\_\_\_ Ph: \_\_\_\_\_ Email: \_\_\_\_\_

Address \_\_\_\_\_

Participant's signature: \_\_\_\_\_ Date \_\_\_\_\_

Researcher's signature \_\_\_\_\_ Date \_\_\_\_\_

Translator's signature \_\_\_\_\_

## Appendix C

### Interview guide

## Interview guide

- 1 Tell me a little bit about yourself, your name, age, and occupation;
- 2 Were you born with disabilities or did you acquire it later in life?
- 3 If you acquired disability later in life, when and how did you acquire your disability?
  - What was life like for you before and after you acquired disability?
- 4 What do you think are the perceptions of people with disabilities by others in your area?
  - do they differ for women and men?
  - for children?
- 5 What do you think are the main barriers facing persons with disabilities?
  - are they different for women and men?
  - for children?
  - what are the barriers related to employment?
  - assistive devices?
  - public buildings and transportation?
- 6 What is the government doing to help disabled people?
- 7 What do you think should be done to enable disabled people to be accepted in society?
- 8 Do you think living in an area designated as for poor people present any additional barriers?
- 9 Do you think being black and disabled living in Arab/Muslim dominated city raises unique challenges?
- 10 Have you seen any changes in lives of disabled people? If there are changes, over what period of time?

11 Out of all issues we have talked about, what was the most significant issue for you?

12 Is there anything that you would like to add before we conclude the interview?