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KATAA UNYANYAPAA - REFUSE THE STIGMA.

*The long walk to inclusion of people with disabilities in
Kenya, with a particular emphasis on children's right
to education*

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KATAA UNYANYAPAA - REFUSE THE STIGMA. THE LONG WALK TO INCLUSION OF PEOPLE WITH DISABILITIES IN KENYA, WITH A PARTICULAR EMPHASIS ON CHILDREN'S RIGHT TO EDUCATION

INTRODUCTION

This work is based on my personal experience and started during one of my trips to Kenya when I came across the campaign developed by World Friends and CISP about the conditions of the mothers with children with disabilities in the slums of Nairobi¹. Children with disabilities in the slums are the last of the last. Disability not only compromises their development, but marginalizes the families where they live and often divides them. The diagnosis of mentally or physically impaired children is likely to be a traumatic experience for their families. Having a child with disability tends to influence the lives, emotions and behavior of family members. Most parents have expectations to raise a normal child, and hold hopes and expectations for planning the future of the child. In contrast, parents whose child has some impairment, may experience dramatic changes in their social life, plans, work life and their financial status.

It is under these premises that I started to work on this thesis that aims to bring to light the condition of people with disabilities in Kenya. The reason for my dissertation and how it was developed is to give voice to the “voiceless”, to denounce a situation that I saw with my own eyes and that is almost impossible to forget.

The work is divided into five chapters. Chapter 1 offers an historical overview of the country, providing data regarding the population and the socio-economic situation in Kenya. I also mention the traditional beliefs because they may influence how a person with disability or his/her family is treated. In fact, a lot of people in Kenya believe that disability can be caused by curse and that, for example, laughing at people with disabilities could cause an individual to have a child with a disability himself or herself.

¹See for example, the “No one excluded” campaign <http://www.world-friends.it/it/lotta-alla-disabilita/> World friends and CISP also produced a documentary called “Refuse the stigma”.

This chapter contains a short description of the political history of the country and birth of first associations dealing with disabilities, in order to contextualize the themes discussed later on and to shed light on the future government plans to be implemented across the country. Furthermore, I describe the critical areas that I visited and that are more significant for my analysis: some Nairobi's slums and the rural area of Nyahururu. Charter 2 focuses on different ways of defining what disability is and the prejudice and discrimination resulting therefrom. I submit that the use of appropriate language is important to the process of building respectful relationships, and the choice of terminology can reflect the way in which disability is perceived. I also analyze other concepts strictly related to disability in the Kenyan context, such as poverty and stigma and how they influence each other. Finally, I illustrate the different models approaching of disability, starting from the “medical model” where the person is viewed as weak and needy and the society is not seen as having any underlying responsibility to accommodate people with disabilities; passing through the “social model” that sees disability as created by the impact of environmental factors (or societal barriers); to finish with right-based approaches which tend to regard the social exclusion of people with disabilities as a denial of their basic rights. Chapter 3 offers a legal framework on the rights of people with disabilities from both national and international perspectives. I also make a short analysis of the report on implementation of the Convention on the Rights of Persons with Disabilities submitted by the Kenyan government in 2011. In particular, the chapter focuses on the notions of legal capacity and independent living and on how stigma associated to mental disabilities results in affected people being denied a wide variety of economic, social, cultural, civil and political rights. Chapter 4 is centered to children's right to education and in particular to access to education for children with disabilities or special needs. The original definition of the right to education - as agreed by the international community - is contained in Article 26 of the Universal Declaration of Human Rights of 1948. From here, I analyze the legislative development process of the right to education, in national and international instruments. The chapter also provides an overview of the Kenyan education system and the role of special education. Actually, I thought it was important to make a distinction between special, integrated and inclusive education and how teachers and parents perceive them.

Chapter 5 is a case study based on some interviews I made between April and May 2015. The interviews were made thanks to the following associations and NGOs working on the field: World Friends, DeafAid and Saint Martin-CSA. Twenty five interviews were conducted with family members of people with disabilities to further understand the challenges disabled persons face both in a rural and urban environment: namely in Kibera, Mathare, Korogocho, Babadogo (slums of Nairobi) and Nyahururu. These interviews provided firsthand accounts of problems and challenges faced by people with disabilities and their caretakers. Unfortunately, I did not have the chance to interview any father. Twenty six interviews were conducted with volunteers, staff members and community members in the mentioned areas to understand the community's perception of disability. The community interviews also provided evidence of the social and cultural stigmas regarding disabled people that have developed over the years. Investigating these stigmas helped to further understand the cultural and social discrimination against individuals with disabilities. Finally, I interviewed also ten teachers from different schools, but I did not have the chance to meet them and see the schools.

Since when I visited Kenya and grew aware of the situation I started to reflect on the fact that the rights of persons with disabilities, and especially children, were violated every day and that a country like Kenya (that considers itself a democracy) had still a long way to go to achieve basic standards of equality and human rights. Kenya has one of the best democratic and inclusive constitutions in Africa. However, discrimination, deprivation and segregation are still widespread.

It has to be said that the government has enacted sweeping legislation to empower people with disabilities through education, access to health care, shelter and employment. Many people with disabilities in Kenya have eventually occupied prominent positions in many fields, but in my opinion, this is only a "façade inclusion". The Constitution of Kenya approved in 2010 recognizes in Article 54 that persons with disabilities are entitled to be treated with dignity and respect and not to be referred to in a manner that is demeaning, to access educational institutions and facilities for persons with disabilities, to have reasonable access to all places, public transport and information, to use sign language, Braille or other appropriate means of

communication and to access materials and devices to overcome constraints arising from the person's disability. Nevertheless, in most urban areas, people with disabilities live in informal settings characterized by poor living conditions, indigence and illiteracy (KNSD, 2008). Poverty and disability are inextricably linked; these combined factors limit access to education, employment, and lead to economic, social, cultural and political exclusion.

The Kenyan national education system is characterized by inadequate availability of those structures and facilities that can respond to the myriad challenges faced by learners with special needs. Talking with some mothers (most of whom were not willing to open up) I realized that a lot needs to be done. One of them said: "Integrating children with disabilities is a great challenge. People are not ready to come out of their comfort zone. They don't realize that they [children with disabilities] can be good in school. Some teachers shut their eyes and don't want anything to do with them."

I met many parents of children with disabilities who struggle in vain to find appropriate schooling for them, in the end forced either to educate them at home or leave them there while they go out to work.

In theory, children with disabilities in Kenya have two choices when it comes to education. They can attend an integrated school which should enable them to study alongside able-bodied children. On the other hand, for children with more severe disabilities, there are schools for students with special needs which cater for their particular conditions. Parents get extra grants to enable them to pay for tuition. However, there are no schools for students with special needs near the main slums, and head teachers of supposedly integrated schools often argue that their institutions lack adequate facilities to accommodate children with special needs.

Under the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, governments around the world, including Kenya, have taken upon themselves the responsibility of ensuring that all children, irrespective of ability or disability, enjoy their rights without discrimination of any kind. These two Conventions bear witness to a growing global movement dedicated to the inclusion of children with disabilities in community life. Concern for inclusion is rooted in the recognition that all children are full members of society: that each child is a unique individual who is

entitled to be respected and consulted, who has skills and aspirations worth nurturing and needs that demand fulfillment whose contributions are to be valued and encouraged. Inclusion (and not only integration) requires society to make physical infrastructure, information and the means of communication accessible so all can use them, to eliminate discrimination so none is forced to suffer it and to provide protection, support and services so every child with a disability is able to enjoy her or his rights as do others. Children with disabilities are disproportionately denied their rights to education, and this undermines their ability to enjoy the full rights of citizenship find gainful employment and take up valued roles in society' (UNICEF, 2013: 2-3). The 2010 Constitution of Kenya makes primary education free to all, yet no study undertaken to describe the situation of children with disabilities in terms of their rights to education, confirms the assumption that they are enjoying the same rights as their counterparts with no disability.

Still, the greatest barriers to inclusion are caused by society not by medical impairment: social stigma and negative parental attitudes to disability which may arise out of religious and cultural beliefs play a crucial role. History shows that ignorance, neglect, superstition and fear are social factors that have exacerbated isolation of persons with disabilities. The desire to avoid whatever is associated with evil has affected people's attitudes towards persons with disabilities simply because disability is associated with evil. Most of these negative attitudes are mere misconceptions that stem from lack of proper understanding of disabilities and how they affect functioning. Getting a disabled child is often seen as the result of wrongdoing by the parents, while some may also think the impairment as the result of a curse or witchcraft. Some people also believe that disability is contagious, for example that marrying a relative of a person with disability or imitating or laughing at someone with a disability can cause disability. Poverty and gender discrimination are the main contributors to the negative attitudes towards children with disabilities and in many cases aggravate the situation. The main causes of disabilities in East Africa are related to preventable diseases (like malaria) and to malnourishment and these mainly affect poor families. In most of these families, the scarce resources are allocated to able bodied siblings because they are seen as better performing. Little remains for school fees, transport and other needs of children with

disabilities. Also, within many families, boys are provided for more than girls. This places daughters with disabilities in the most vulnerable situation.

The Kenya National Commission on Human Rights' report of 2007 on the Rights to education for children with disabilities, assessed the extent to which children with disabilities were accessing the right to education in both rural and urban area. This study however, does not analyze the extent to which children with disabilities enjoy their rights to education in the slums. The exact situation of children with disabilities has not been systematically researched. This lack of information, accurate data and discussion has violated their inherent right to education and threatens the educational goals set by Vision 2030. For this reason, my thesis seeks to examine the situation of people with disabilities in Kenya in general and in vulnerable areas of the country in particular. Not only the slums are penalized but the difficulties significantly increase if we move to the rural areas too. Here, poor access to basic services also exists for “normal people”, not to mention those with disabilities, especially physical impairments. In particular, during my researches, I have come to know the Saint Martin a religious grassroots organization based in Nyahururu, that has a Community Programme for persons with disabilities. What struck me was its philosophy: people with disabilities and normal people can and should live together. In fact, in Effatha and Betania, people with intellectual disabilities live together with people who come to assist. The family-like environments are supported by the local community of volunteers. In 2014, 400 volunteers were active in the field assisting beneficiaries and reaching out to other people in the community; 39 community volunteers and 19 Community Rehabilitation Workers were given training sessions on various technical aspects to enhance their work with the beneficiaries. 1005 children with disabilities worked with the programme during the year. 264 new children with disabilities were identified and enlisted for programme support. Out of these, 162 were screened and rehabilitation plans developed to assist them. These are just few numbers that describe the dedication and efficiency of the Saint Martin, of its volunteers and, by extension, of the whole community. The experience of Saint Martin can be taken as an example of community involvement in the daily commitment to the inclusion of people with disabilities.

CHAPTER 1 GENERAL OVERVIEW OF KENYAN HISTORY, POLITICS AND ECONOMY

1.1 Overview of the country

1. Map of Kenya

The Republic of Kenya is a country in Eastern Africa, with an extension of 582,646 sq. km and a population of approximately 41.61 million people. It has an estimated growth rate of 3%. Over 60% of the population, 23,346,328, live in rural areas (KNBS, 2011).

Kenya is divided into 47 counties that are headed by governors who were elected in the first general election under the new constitution in March 2013.

With 42 ethnic groups, 30 languages, and 100 dialects, Kenya is characterized by ethnic heterogeneity. The largest ethnic groups are Kikuyu, Luo, Luhya, Kamba and Kelenjin. There are other minorities like Indians, Europeans and Arabs. The official language is Kiswahili and English. The main religions are Protestantism, Catholicism, Islam and “traditional beliefs”. Religion and traditional beliefs may considerably influence attitudes towards persons with disabilities, in particular to have a child with disabilities.

2. Socio-economic situation

Although it is one of the most economically successful countries in Africa, since 1990 there have been many problems like economic stagnation, problems due to the implementation of economic reforms, chronic corruption and since the election 2007 political problems like strikes, riots, and civil commotions.

The main sectors driving the economy are agriculture and forestry, tourism, wholesale and retail trade, transportation and financial intermediation. Kenya’s economy recovered from a period of stagnation in the 1990s and has expanded steadily since 2002 (KIHBS, 2005). Nevertheless, over half of Kenyans, including 9 million children,

live below the poverty line. The rural population is disproportionately worse off, with over 47 % below the food poverty line and a food poverty gap of 16 % (UNICEF, 2005) While Kenya has a growing entrepreneurial middle class, faster growth and poverty reduction is hampered by corruption and by reliance upon several primary goods whose prices have remained low. Inadequate infrastructure threatens Kenya's long-term position as the largest East African economy, although the Kenyatta administration has prioritized infrastructure development. In fact, Nairobi has contracted with a Chinese company to begin construction of a new standard gauge railway, but the project allegedly has been beset by corruption and fraud.

The affluent middle class are seen to benefit from the gains while the poorest deciles of the population do not. In monetary terms, this makes the Kenyan society a highly unequal one. This shows that the economic growth of the past years has not yet translated into inclusive development in Kenya.

According to the World Bank, “Persons with disabilities on average as a group experience worse socioeconomic outcomes than persons without disabilities, such as less education, worse health outcomes, less employment, and higher poverty rates.” (World Bank, 2012). As will be explained in the following chapter of this thesis, researchers have demonstrated that these reduced outcomes may be attributed to a multitude of institutional barriers and other factors. Furthermore, the prevalence of disabilities in impoverished populations has been predicted to follow a cyclical pattern by which those who live in poverty are more likely to acquire a disability and those who have a disability are more likely to become impoverished.

Despite major achievements in the health sector, Kenya still faces many challenges. The life expectancy estimate has dropped to approximately 55 years in 2009 – five years below 1990 levels. The infant mortality rate is high at approximately 44 deaths per 1,000 children in 2012.²

The major plague remains AIDS/HIV,³ being Africa South of the Sahara termed as the

² The WHO Health-Related Millennium Development Goals Report of 2011 estimated that only 42% of births were attended by a skilled health professional.

³ The UNAIDS in 2004 reported that the prevalence rate in Kenya stands at 6.3%. It is also estimated that 2.4 million children are orphans and half of them through HIV and AIDS.

most affected region. The Kenya AIDS Indicator Survey reported that 21.4% lived in households that received at least one type of free external support to help care for the children, while the majority (76.6%) of these children's households has received no support. According to the WHO, 2005 malaria is a major public health problem in Kenya, with malaria burden and transmission patterns varying across the country. The areas near Lake Victoria and at the coast - among the chosen areas for this field work - are particularly exposed.

Similarly, access to health care is one of the major problems for people with disabilities. The inaccessibility for those living in poverty has a substantial impact on the rate of disability within this population. Individuals living in poverty face higher health risks and are often unable to obtain proper treatment, leading them to be significantly more likely to acquire a disability within their lifetime. Financial barriers are not the only obstacles those living in poverty are confronted with. Research (Peter, Garg et al., 2008: 165) shows that matters of geographic inaccessibility, availability, and cultural limitations all provide substantial impediments to the acquisition of proper care for the populations of developing countries. Sex-specific ailments are particularly harmful for women living in poverty. The World Health Organization estimates that each year 20 million women acquire disabilities due to complications during pregnancy and childbirth that could be significantly mitigated with proper pre-natal, childbirth, and post-natal medical care (DFID, 2000: 3).

3. Traditional beliefs

In East Africa, traditional beliefs about the causes of disability continue to be prevalent. This is an important factor to consider because beliefs about the causes of disability may influence how a person or family is treated. S. G. Harknett classifies beliefs about the causes of disability in three categories: traditional animism includes beliefs that disabilities are punishments for bad deeds or the result of witchcraft exercised by other people; Christian fatalism beliefs revolve around notions that disability results as an act of God's will; medical determinist beliefs accept the explanations of modern medicine as to the cause of disabilities (Harknett, 1996:18-24). It is not uncommon for

individuals to use multiple categories of beliefs about cause, perhaps in an effort to neutralize negative beliefs about disability, such as suggesting a medical explanation in addition to traditional animism (Ingstad, 1995: 246-264).

Beliefs about causes of disability were often described as expressed in proverbs, folktales, oral tradition, and from interviews with traditional healers. Mbah-Ndam explained that disabilities are “regarded as punishment from the gods or bad omens, and hence [people with disabilities] are rejected or abandoned.” (Mbah-Ndam, 1998: 251).

There are also descriptions of taboos that, when broken, are thought to cause a disability. For example, the Nandi of Kenya considers wrong to kill animals without good reason during a wife’s pregnancy. Having sexual intercourse during pregnancy is also a taboo, and breaking this too can cause the child to have a disability (Ogechi, Ruto, 2002: 63-82).

Laughing at people with disabilities could cause an individual to have a child with a disability himself or herself, cause an accident to befall you, or cause future generations in your family to be cursed. A study from Kenya reported that family members and health care personnel believed that seizures were caused by several factors including birth trauma, abuse, witchcraft or spirits, and contact with certain animals (El Sharkawy et al., 2006: 201-212). Although it may seem absurd in Western culture, misdeeds of family members can also cause a disability. Family members can do something wrong and the family can be punished for the act with a child with disability. Beliefs are changing and fewer East Africans are described as believing that witchcraft, curses or retribution from God(s) are the sole cause of disability. Medical explanations are more widely accepted. The influences of Christianity and Westernized education and medicine have altered traditional belief. Nevertheless, these beliefs emanate from years of oral tradition and beliefs emanating from traditional religions continue to be described as part of the culture.

1.2 Political history of Kenya

1. Political history and birth of first associations dealing with disabilities

Without dwelling on the history of colonial period and the struggle for independence, it

is interesting go into the recent political history of the country to better understand its current complexity⁴.

It is to consider that European and Arab presence, in particular in Mombasa, dates to the Early Modern period but the European exploration and exploitation began only in the 19th century. As it is well known, Kenya has been a British colony for several years⁵.

During the history of Kenya there have been concentrated efforts to help the people with disabilities since the mid- 1900s. In 1946, The Salvation Army Church established a program to rehabilitate men blinded during the Second World War II as the first program to provide organized care to people with disabilities (Grut, Ingstad, 2007: 11). This program later developed into the Kenya's first school of blind, providing education to blind children from the entire nation. Other missionary groups from all over the nation followed suit developing different institutions of learning for children with various disabilities such visual, hearing, and physical. As more schools for individuals with disabilities began to emerge, the colonial government began to support these schools by providing teachers and financial grants. Eventually the government took control of these special intuitions that the British missionaries established. In 1959, the Kenya Union for the Blind (KUB) was found as the first organized disability organization in Kenya. KUB was formed to promote and advocate for services for the blind. Actually it was very useful, as it severed as the model for other disability organizations to follow like the Kenya Society of the Physically Handicapped (KSPH) and The Kenya National Association of the Deaf (KNAD), which were established in 1986 and 1987 respectively. These groups became much more powerful when they joined together along with other community based groups to form The United Disabled Persons of Kenya (UDPK) in 1989. With the UDPK working as a collective body, it used its new platform to promote and raise awareness to identify the needs and services for people with disabilities. The United Disabled Persons of Kenya are not in operation

⁴ For more information on history of Kenya see: Branch Daniel, "Defeating Mau Mau, Creating Kenya: Counterinsurgency, Civil War, and Decolonization." Cambridge, U.K.: Cambridge University Press, 2009; Kawaja Peter and Southall Roger, "Uncertain Democracy: The electorate crisis of 2008", Routledge, Oxon, 2010; Kagwanja, Peter "Kiraitu Murungi: An Odyssey in Kenyan Politics", East African Education Publishers, Nairobi, 2012.

⁵ The colonial history of Kenya dates from the establishment of a German protectorate over the Sultan of Zanzibar in 1885, followed by the arrival of the Imperial British East Africa Company in 1888. From 1920 it is known as Kenya Colony.

today but a host of new groups have been formed to carry out UDPK's duties.⁶ Most recently, in 2004, the National Council for Persons with Disabilities (NCPWD) was created.⁷

As mentioned previously, the colonial government provided teachers and financial grants for schools and institutions for the persons with disabilities in the mid twentieth century. But in the early 1960s, the British Government was tumbled by Jomo Kenyatta and the Mau Mau Movement. On December 12th, 1963, Kenya became an independent country and a Republic. During the composition of the Kenya's Independence Constitution, creating laws and policies for the persons with disabilities was not a priority on the list. In fact, the term disability or any disability related words was not mentioned one time. Protection against discrimination on the basis of a disability was not even considered.

Since the announcement of the contested presidential election results on 30th December 2007 giving a second term to Mwai Kibaki, Kenya has been in its worst political crisis since independence. Over 1,000 people have died and 300,000 have been displaced in violence with a serious ethnic character. (Africa Report, 2008)

Economic and political inequalities were some of the major causes of the 2007 post-election violence in Kenya. Belonging to the superior and government-favored ethnic tribes gives one an edge over the less privileged tribes in accessing the political and economic resources of the country. It was generally perceived that Kikuyu and Central Province had been enjoying more of the economic and political resources of Kenya before and after independence at the expense of other regions or tribes. The attempt to correct the economic and political imbalances in these arrangements between Kikuyu and the Kalenjin and Luo resulted in violence.

But little is known about what happened to the people with disabilities during that time, because the media did not give much attention to them and only few articles were

⁶ Some of these organizations include Kenya Society for the Blind (KSB), the Association for the Physically Disabled of Kenya (APDK), the Kenya Society for the Mentally Handicapped (KSMH), the Kenya Society for Deaf Children (KSDC)

⁷ □ Its creation follows the enactment of The Persons with Disabilities Act Bill of 2003. The Council is a semi-autonomous government agency (SAGA) whose parent Ministry is the Ministry of Gender, Children and Social Development.

posted on the internet. Relief agencies built up camps where internally displaced people (IDP) could receive humanitarian assistance like food, water, shelter, and security but one group was unable to get access to the aid, namely people with disabilities.

The Organization Leonard Cheshire Disability (LCD) and Phitalis Were Masakhwe⁸ visited various displaced persons camps and they realized that the situation for people with disabilities was very difficult. Many people with disabilities had to abandon their wheelchairs and crutches in the flight from their homes and were carried to camps by friends and relatives. They suffered more than their able bodied counterparts because many of them were unable to access basic needs support as food, water, clothes and bedding. In a situation where everybody is scrambling for food and clothing especially the persons with disabilities are often not strong enough to queue and to find a way through the crowds to get support. Beside the violence, the elections have failed to send people with disabilities to parliament benches which means that millions of Kenyans remain unrepresented. Therefore, nobody can argue at the political level for their rights. Although they were involved within political parties in pre- election campaigns they were not successful.

The stigma of disability affected people with disabilities during their daily lives and also during political campaigns. Furthermore Masakhwe emphasized that many constituents believed that people with disabilities could not make successful politicians. Another problem was that political parties failed to nominate people with disabilities in Parliament. Above all the media, NGOs, and development partners also played a role and failed to encourage the presence of people with disabilities in politics.

In the 2010, the Republic of Kenya's government went through massive changes when a new constitution was ratified by Parliament. Under the new constitution, 47 new counties were established as local government replacing the old system of 8 provinces, which were further broken down into districts (149 in total). The fundamental changes of the new constitution were to reduce the powers of the central government (Executive and Legislative branches) and strengthen the powers of the local

⁸ Masakhwe, a Kenyan sociologist, wrote an article in collaboration with the organization Leonard Cheshire Disability (LCD) about "Post- election violence and disabled people in Kenya; issues for reflection and action" (2008) which it is useful to explain the situation of people with disabilities during that time.

government.

Even though there has been significant progress for persons with disabilities with the creation of the Persons with Disability Act, National Council for Persons with Disabilities, and special rights granted under 2010 Constitution, persons with disabilities in Kenya are still a heavily marginalized community. The Kenya government has done a great job in creating laws and policies for persons with disabilities; however, they have not done a sufficient job at implementing these laws and policies into practice. As it will be shown by my research, throughout the nation, individual with disabilities lack health and rehabilitation services, education and employment opportunities, and are highly discriminated against by society, especially in rural communities where resources are scarce.

2. Vision 2030

In 2007, the Kenyan government unveiled Vision 2030, an economic development programme that aims to put the country in the same level as the Asian Economic Tigers by the year 2030. The Economic Pillar of Vision 2030 seeks to improve the prosperity of all regions of the country and all Kenyans by achieving a 10% Gross Domestic Product (GDP) growth rate by 2017. Within the Medium Term Plan 2013-2017, six priority sectors⁹ that make up the larger part of Kenya's GDP (57%) and provide for nearly half of the country's total formal employment were targeted.

Through this strategy, Kenya aims to build a just and cohesive society with social equity in a clean and secure environment. It, therefore, presents comprehensive social interventions aimed at improving the quality of life of all Kenyans. This strategy makes special provisions for persons with various disabilities and previously marginalized communities.

The economic, social and political pillars of Kenya Vision 2030¹⁰ are anchored on macroeconomic stability; continuity in governance reforms, enhanced equity and wealth

⁹ Tourism, increasing value in agriculture, a better and more inclusive wholesale and retail trade sector, manufacturing for the regional market, BPO (Business Process Outsourcing), financial services, oil and gas.

¹⁰ Education and training, health, environment, housing and urbanization, gender, children and social

creation opportunities for the poor. In particular they provide improved representation of people with disabilities in decision making process and the implementation of disability fund.

3. Beyond-2015 MDGs

At the beginning of the new millennium, world leaders gathered at the United Nations to shape a broad vision to fight poverty in its many dimensions. That vision, which was translated into eight Millennium Development Goals (MDGs), has remained the overarching development framework for the world for the past 15 years.¹¹

In terms of the perceived MDG successes, Kenya has performed well in combating HIV/AIDS and other diseases (MDG 6), in part thanks to intense donor funding geared towards these issues. Especially the US-led PEPFAR initiative has geared significant funds towards the attainment of MDG 6 in Kenya.¹²

Kenya is also on-track to achieving MDG 2 on education. This is attributed to a great extent to the introduction of free primary education during Kibaki's first presidency in 2003. Also in the recent years it has received the highest proportion of government's funding allocations to the MDGs.

Kenya is not very likely to achieve MDG 3 on gender equality even if some progress has been made there. Gender parity in primary education has been high during this decade and even in recent years it has somewhat increased. The public sector appointments of women have somewhat increased, possibly assisted by the new Constitution of 2010, which guarantees a representation of at least two thirds of either gender in all public sector appointments. Still the last elections (2013) were not very

development, youth and sports.

¹¹ <http://www.un.org/millenniumgoals/> As it is well known the eight MDGs are: eradicate extreme poverty and hunger, achieve universal primary education, promote gender equality and empower women, reduce child mortality, improve maternal health, combat HIV/AIDS, malaria and other diseases, ensure environmental sustainability, develop a global partnership for development.

¹² The United States is the largest bilateral donor to Kenya, and more than half of the U.S. aid comprises of PEPFAR, the President's Emergency Plan for AIDS Relief, which is channelled through the U.S. State Department. The U.S. aid figures have increased more than five-fold: from USD 119 million in 2003 to more than USD 700 million in 2011.

encouraging in terms of women's representation as only 19% of parliamentarians are currently women. (UNDP, 2013)

Much of the assessment of Kenya's MDG progress, however, depends on what one means with this word. For example, despite success in MDG 2, there are many concerns still remaining in the education sector. The concerns over MDG 2 relate to regional disparities and the low quality of education. While primary school enrolment has increased, there has been a dramatic fall in the quality of education. In Kenya, schools have become overloaded, with a perennial deficit of teachers (in 2013 standing at a deficit of around 80,000 compared to 60,000 in 2008), and the private schools that have mushroomed to meet the shortfall have received mixed ratings. Further, secondary schools are suffering from a high (and increasing) number of dropouts. Similarly, despite success in MDG 6, many challenges in improving the health sector still remain, as indicated by the problems with maternal health. The current challenges in the health and education sectors also speak for paying more attention to the quality of the services, not simply to the quantitative targets.

Maternal health and maternity services (MDG 5) are in precarious condition. According to WHO (2012), the main causes of maternal mortality include hemorrhage, infection, high blood pressure, unsafe abortion, and obstructed labor. Other research has pointed to the importance of women's health and nutrition prior to pregnancy. (Magadi et al., 2001) Furthermore, in Kenya, cultural practices like early childhood marriage have also been shown to influence the likelihood of maternal mortality. The disparity due to different social conditions, provision of obstetric care, health-related behavior, nutritional or health status, or a combination of these factors might add to the list of many variables that influence the likelihood of meeting this MDG. Specifically in Kenya, the causes of maternal mortality have been associated with maternal age, antenatal clinic attendance and educational attainment.

In Kenya, as elsewhere, the greatest challenges in assessing MDG progress have been with MDG 7 (to ensure environmental sustainability) and MDG 8 (global partnerships). The success of MDG 7 is often viewed from the narrow perspective of environmental health and sanitation as opposed to the broader concept of ecological integrity. It can be also seen as the disparities between rural and urban areas, for example in access to clean

drinking water. Kenya has one of the lowest access rates to clean water sources in the whole world. Concerted actions are needed and some have already been taken especially in addressing the water supply situation in the urban slums. MDG 8 reporting has been equated with mobile technology as a measure of its success, this is hardly indicative of global partnerships.

It is noted that MDG do not specifically address disability concerns, but the rights of persons with disabilities is a transversal theme to all MDGs, so deliberate efforts will need to be made to integrate disability issues in its MDG implementation programmes.

Disability is a development issue and there is need to acknowledge the rights of persons with disabilities to development and the need to address factors that push them into absolute poverty. Disability and poverty are often intertwined. The Ministry of Planning and National Development's MDG Progress Report for Kenya 2003, indicates that the level of poverty in Kenya now stands at 56% against a target of 21.7% by the year 2015. The majority of persons with disabilities live in extreme poverty. Therefore, there is a need to develop strategies to empower persons with disabilities, reduce their poverty levels, and make them self-reliant and able to participate in national development.

A series of post-2015 consultations were organized in Kenya, mainly by the government and NGOs. While the consultations have pointed to the importance of new concerns – e.g. employment, youth, energy, security and conflict and agriculture – in general, there seems to be a preference also in Kenya for the continuation of the MDGs in a modified and improved form, as “MDG+”.

The Kenya National post-2015 consultation report emphasized five themes that are also some of the issues that can be found in the Vision 2030.¹³

The strategies need to include development of disability sensitive programmers at the national and local levels. Additionally it would require participation of non-state actors in this endeavor.

¹³ □ These areas include: agriculture and food security; employment and enterprise; health; universal education and gender; environment.

1.3 Context

1. Nairobi

Nairobi can be described as the capital of East Africa. It was founded by the British Empire around 1899. A reason for this was that the railway authorities thought that the central location could be of value for the rural economies and a railway could also help to build a successful trade relationship between Kenya and Uganda. For this reason, the colonial authorities chose not to establish an industrial centre in Nairobi and the city was also thought to mainly be a residential place for non-Africans. However, in order to create the city they needed African construction and service workers and they therefore allowed male African migrants to stay temporarily in the city. To restrict non-workers coming into the city the colonial government decided to implement pass laws and the 1922 Vagrancy Act, which made it easier to demolish “unauthorized huts”, and unemployed Africans were removed by force from the city. (De Smedt, 2009: 203-204) The African inhabitants that were working in Nairobi had to stay in designated areas (so called “Native reserves”) at the edges of Nairobi and these were in many cases separated according to ethnic groups. This was done as a part of a strategy to try and separate Africans, who were thought to have diseases, from healthy Europeans, and, also as an attempt to control all the migrants. However, the attempt to control migration flows to Nairobi was harder than expected and during the 1930s many rural inhabitants decide to try to improve their lives in the city but with lacking resources many of the rural migrants settle down in slums, and particularly in East Africa’s biggest slum, Kibera: (SIDA, 2010: 1) Kibera is located in the south of the city and it is home to up to a million people, many of whom live in abject poverty.

Nairobi provides a good illustration of the rapid rate of urbanization: in 1948 Nairobi’s population was 120,000 people but this has rapidly grown to reach 3 million residents in 1999¹⁴. However, officially slums were not recognized. Maps of urban centers almost

¹⁴ □ “Census Data”. 1999 Government of Kenya. Despite reservations on the accuracy of the census data there is nevertheless a steady increase in the overall population with an average rate of growth of over 5 per cent. It’s

universally show slums as unoccupied land. By the turn of the century the Government of Kenya had adopted a more accommodative view of informal settlements. A moratorium on slum demolition issued in 1996 was seemingly affected after 2000 and the number of slum demolition and evictions decreased. This is because the campaigns of civil society and communities and international pressure made it increasingly difficult to continue to ignore the slum issue as a major national challenge. In fact, over decades the city has functioned as the region's financial and communication centre and many international nongovernmental organizations (NGOs) have their headquarters located in Nairobi.

This turning point is the adoption of instruments like the Poverty Reduction Strategy Paper and the formation of the Nairobi Informal Settlements Coordination Committee. Nairobi's vast slums¹⁵ and informal settlements are, like all communities, places where people live, work, eat, sleep and raise their children. But the residents of informal settlements must cope with inadequate housing, little access to water, sanitation and other basic services, and the ever-present threat of forced eviction. Nairobi's slums are the consequence of both explicit government policy and decades of official indifference. In particular, informal settlements were excluded from city authority planning and budgeting processes, which meant in effect that public policy often treated these areas as if they did not exist. (Amnesty International Kenya, 2009: 6) By the government's own admission, however, these initiatives "tended to exclude target groups from the planning process" and were subject to corruption in allocating housing and other shortcomings (GoK, 2005) Most residents of Nairobi's settlements do not have access to public water supplies, which are available to other residents of the city. The longstanding view that informal settlements were illegal meant that local authorities were not held responsible for providing access to water and other essential services (UNDP, 2006: 14). Nor has privatization meant that settlement residents receive water at rates that are affordable or even comparable to the prices paid in wealthier

generally felt that the population is now well over 4 million.

¹⁵ The term informal settlement is often used in preference to that of slum, but in this thesis the terms are synonymous. I use the UN-HABITAT definition, which defines a slum as a contiguous settlement where inhabitants have inadequate housing and basic services, is often not recognized nor addressed by public authorities as an integral or equal part of the city, and where residents living under the same roof lack one or more of the following: access to safe water; access to sanitation; secure tenure; durability of housing and sufficient living area.

communities.

The Kenyan Public Health Act and its subsidiary rules set out detailed standards for housing and sanitation¹⁶. Local authorities are expected to supervise the enforcement of the law. However, as the Nairobi City Council Planning Department itself acknowledged to Amnesty International, these laws have never been enforced in relation to Nairobi's slums and settlements because "these areas are not and have not historically been integrated into the city's urban plans"¹⁷.

The government has established few schools and health care centres in settlements, so residents are forced to rely on private facilities, where they exist. In theory, residents may access the government hospitals and health units in Nairobi that are close to the slums and settlements, including the nearby Kenyatta National Hospital, the country's main public health institution. However, most residents indicated that the cost of care at these hospitals and institutions is often beyond their means. (many people in the slums do not have ID.)

In November 2000, in recognition of the continuing growth of slums and informal settlements, the government and UN-HABITAT agreed to start KENSUP. The programme aims to "improve the livelihoods of at least 5.3 million slum dwellers in Kenya by the year 2020.

The largest slums of Nairobi today are: Kibera that emerged in 1912 when a group of former soldiers from the Nubian community, who had served in the British army, were granted temporary rights to settle on a small area of densely forested land. Over time the government authorized other people to settle there. Today, up to 1 million people live on about 550 acres of Kibera land, most of it owned by the government¹⁸;

Mathare that was established in about 1963 on government land. The total population is

¹⁶ Chapter 242 of the Laws of Kenya, which regulates public health and sanitation and grants authority to local authorities to monitor compliance in relation to sanitation.

¹⁷ □As reported in Amnesty International Kenya: The unseen majority Nairobi's two million slum-dwellers, June 2009: Amnesty International interview with the Nairobi City Council, Planning Department on March, 6 2009. During this interview, Amnesty International delegates were informed that the council was also hampered by lack of adequate resources – human and fiscal – as well as corruption, competence and the lack of autonomy in making decisions.

¹⁸ □An Inventory of the Slums in Nairobi (unpublished report), Pamoja Trust, 2009, citing "Inventory of Nairobi slums", Matrix Consultants, 1998 p.102. The government's slum upgrading strategy puts the estimated Kibera population at "500,000 residing on 225 hectares of land".

unknown. It too is divided into villages. Part of the settlement is on government-owned public land but most is on land owned by private companies and individuals; Korogocho is an informal settlement started in the early 1980s. Over half of the land is government/public land and the rest is privately owned. It is estimated that over 120,000 people stay in about seven villages of Korogocho. Although the average size of rooms is similar to other settlements, the houses in Korogocho are of a more permanent nature with walls of building blocks and iron sheet roofing. The majority of residents are tenants; Mukuru Kwa Njenga is home to an estimated 75,000 people and lies 10km south-east of Nairobi's city centre. The settlement began in 1958 when farm laborers lived there on land that was then owned by white settlers. It subsequently attracted the urban poor who built makeshift homes. Today, it covers about 80 acres of government-owned land allocated on 99-year leases to private owners.

The material useful to the drafting of this thesis¹⁹ was collected in all above mentioned slums and in the small slum of Kayole, located in Embakasi, which is considered part of Nairobi's Eastlands area.

2. Rural areas

As mentioned, Kenya is often considered as one of the most developed countries in East Africa, but this view is not necessarily based on living standards in the rural parts of the country. In 2011, International Fund for Agricultural Development (IFAD) published a report concerning development issues in rural Kenya. Nearly 79 per cent of Kenya's population lives in rural areas where they rely on agriculture for most of the income. Around half of the country's 40 million people are poor or unable to meet their daily nutritional requirements. The majority of the poor people live in rural areas. However, it is important to point out that some conditions have improved since the early 1980s, but even if that is the case the poverty rate has remained steady at about 48 per cent. When

¹⁹ □ It includes interviews to the mothers of children with disabilities, to the social workers of the CBOs and to the operators and professionals of the NGOs working in the field.

reading about Kenya's development Nairobi is usually in focus. Nairobi can today be seen as a city that is heading in the right direction when it comes to economic development. Unfortunately, this might not be the case for the country's rural areas. The rural economy depends mainly on smallholder subsistence agriculture, which is producing around 75 per cent of the country's total agricultural output. Western Kenya is good for agriculture and the sector provides the most jobs in the area. However, because of fertile soil the population density in good farming areas is more than six times the country's average of 55 people per km². The high population density makes it harder for the average farmer to invest and they therefore have to farm on limited areas of land (IFAD, 2011: 1-2)

Generally, women are suffering more than men in rural areas and there can be many reasons for why this is the case. In her book Anne Mary Njeri Mungai confirms the issues that were given by the female informants. Girls living in rural areas tend to drop out of school because of various reasons related to gender structures. The author highlights the clashes between the roles of women and traditional values on one side, and the school culture and expectations on the other. She argues that many of the traditional values still have a major impact on young girls in Kenya today and many girls are brought up to become wives, mothers, and cultivators. (Njeri Mungai, 2002)

As discussed, in order to combat the challenges of disability, the Kenyan government has created several laws and policies to address disability concerns like the Persons with Disabilities Act of 2003 and the National Disability Act of 2006. Despite these initiatives, only a small percentage of people with disabilities have received the services offered by the Kenya government and other organizations. Rural area communities in particular, have suffered greatly from this unequal distribution of services for individuals with disabilities. Members in these communities often face more problems accessing medical services, education, and employment compared to their urban counterpart. In addition, the poor economic state of a rural environment compounds the challenges for persons with disabilities. This is a major reason why many persons with disabilities in those areas live in extreme poverty. Therefore, there is an essential need to empower these communities so they could obtain a better quality of life. In particular my research covers the communities of Nyauhuru area, in Laikipia County, where

(without dwelling on the peculiarities) the same problems of other rural areas can be identified.

Another issue that affects people with disabilities in a rural environment is the social, culture and economic discrimination. Here, there are common misconceptions that a person with a disability is cursed and is a disgrace to his or her family. In fact, they are often seen as a burden for their family. As a result of this, many are neglected, mistreated, isolated, or hidden from the public's eye. In extreme cases, persons with disabilities are even abused and exploited by family members in exchange for food or money. The social and cultural stigmas associated with disabilities also create economic barriers for individuals with disabilities. It is very hard for a person with disabilities to work in rural environments because most of the work done is agriculture based, which requires abled bodies.

Ignorance of their constitutional rights, privileges and protections is another problem that people with disability in a rural environment face. Many persons with disabilities are unaware of the national laws and policies that have been created in the last decade. This fact is evident because only a small group of persons with disabilities have been exercising their rights and usually the majority of them come from urban areas where more health and educational services are readily accessible. One major reason why persons with disabilities in the rural areas are ignorant of their rights is because they often lack education. With little to no education, it is very difficult for a person with disability able to decipher the legal language. Another reason why persons with disability in these areas are unaware of their rights is due to the insufficient effort by the Kenyan government or non-governmental organizations to raise disability awareness in rural areas. In order for the disability laws and policies to be implemented, citizens in rural areas have to be knowledgeable of these laws and the government should be working at the grassroots levels to achieve this.

CHAPTER 2 DEFINING DISABILITY

2.0 Introduction

People with disabilities may look or behave differently from other people. Although using an oversimplification, it can be said that everyone looks different, most cultures have a model of ‘normal’ appearance and behavior, reinforced through images in art and the media, and this can create unease when interacting with people who are different from this ‘normal’ model. In some societies, it is normal to use physical or descriptive labels to refer to people (‘the big one’, ‘ginger-hair boy’). When applied to people with impairments, this labeling tends to create a sense that the person is totally defined by the impairment – that nothing else about her is important. Since most common terms for impairments are rude or derogatory, it also tends to reinforce negative attitudes towards people with disabilities. Probably more importantly, these people – because of their condition - are excluded from education and employment in many societies. As a result, they tend to have lower than average levels of income, and may not be able to contribute financially to the household or community. So, this means that they are not seen as productive or valuable members of the community, but as a burden, or even as worthless. These attitudes are often reinforced in societies where there are relatively large numbers of people with disabilities making a living by begging. Beliefs and attitudes like this create a sense of shame about impairment and people with disabilities. Parents and other caregivers are often very fearful for their children or their loved ones with disability.²⁰ They are afraid that the person will have an accident or be abused by other people. Mothers of children with hearing impairment and children with learning difficulties often feel that other people do not know how to interact with their children, and will not treat them properly. However, this parental fear contributes greatly to the future exclusion and segregation of people with disabilities. As a result of a desire to protect them, many children, and adults with learning difficulties or mental health problems, are kept inside the household at all times. If it is not possible to keep a child

²⁰ These examples are the result of my interviews to parents and caregivers met in Nairobi and Nyahururu.

with disability under constant supervision, or if he/she has grown too big to manage, he/she may be tied up to stop her from wandering off or hurting himself/herself. Parents often want their children to attend a special school or institution, as they believe that they will receive specialist education and care, and be protected from the ill treatment or abuse they fear in the community. However restricting the freedom of people with disability, whether they are kept at home or in an institution, is a denial of their most basic rights. It deprives them of social contact and stimulation. This can severely limit the cognitive development of babies and infants, especially if they have hearing impairments or learning difficulties, with the result that they never learn to communicate, respond to other people or care for themselves. This leads to further isolation and exclusion, and increases the pressure on primary caregivers such as mothers and siblings. In institutional settings, this lack of social contact and stimulus leads to people with disability becoming even more dependent, until they are unable to function outside – they become institutionalized. Shut away in the household or in special institutions, people with disabilities are often invisible outside their immediate family. This can contribute to further segregation, as parents and family members do not see any active people with disability within their community, so they continue to believe that their relatives would not be able to function outside. As far as my experience in Kenya is concerned, in general, people do not decide deliberately to discriminate, they just do not think of including people with disabilities. On the other hand, institutions do not provide awareness on this issue and often church is the first place where people with disabilities are excluded and stigmatized. Because they are ignored or rejected, they are not able to participate in society. This makes them less visible, so other people continue to ignore them, and reinforces the idea that they cannot make a contribution: the vicious circle is thus triggered.

The starting point of this chapter is an overview of disability literature and an introduction of some useful conceptual frameworks to fully understand the complex conceptualizations linked to the issue of disability.

2.1 Definition of disability and related concepts

1. Disability and impairment

Defining disability is a complex and controversial issue: what disability is and who may or may not be a person with disability are fairly contested matters. This may be so because unlike other social distinctions (such as gender, age or color), disability has no singularly overarching trait which is obvious in all people who either are placed or claim belonging under that tag.

For several years disability had been seen as merely physical or medical impairment leaving aside all the collateral obstacles that this condition entails. According to the World Health Organization's Classification of 1980, disability is a term which, in relation to an individual, describes a functional limitation (for performing tasks, skills and behavior) which he or she may have arising from physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature. The above definition is founded on the "medical" model of disability. (WHO, 1980)

A new version of the International Classification of Impairments, Disabilities and Handicaps is now being drafted to embrace improvements in the field. One of the major developments is the more specific recognition of the social construction of the third dimension of disability. It is being proposed that this third dimension be renamed "participation", and that its definition recognize the critical role played by environmental or contextual factors in restricting full participation.

More recently, another definition has been given by WHO: "Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An *impairment* is a problem in body function or structure; an *activity limitation* is a difficulty encountered by an individual in executing a task or action; while a *participation restriction* is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives." (WHO, 2014)

Disability is also often categorized according to different types of impairment. A person with a hearing impairment, for example, is thought to have a different type of disability to someone with an intellectual impairment. However, Oliver already in the '90s rejects the categorization of people with disabilities in terms of medical impairment, arguing that “all disabled people experience disability as social restriction, whether those restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general population to use sign language, the lack of reading material in Braille or hostile public attitudes to people with non-visible disabilities” (Oliver, 1990: xiv). It follows from Oliver’s argument that it makes more sense to categorize the various types of impairment that a person with disability may have, rather than the disability itself. There is some evidence of legacy between the type (or types) of impairment(s) that a disabled person has and the levels of discrimination and barriers that they have to face. For example, the World Disability Report affirms that “people who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those with physical or sensory impairments” (WHO & World Bank, 2011: 8).

Besides impairment type, people with disabilities can be differentiated by a multiplicity of social factors, each of which may be a basis for additional marginalization. The UNCRPD recognizes this, pointing out that people with disabilities may be “subject to multiple or aggravated forms of discrimination on the basis of race, color, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status” (UNCRDP, 2006: preamble) The Convention pays particular attention to gender discrimination, recognizing that women and girls with disabilities are subject to multiple discrimination (UNCRDP, 2006: art.6).

The impacts of various impairment types can also vary due to local factors, such as the “environment (urban/rural), type of society (developed/less developed) and cultural and societal norms” (World Bank, 2007: 31). For example, rural environments may be far more disabling, for those with physical impairments, than urban environments. In Africa, and also in the case of Kenya, a lack of physical infrastructure in rural areas, such as pavements, may create more difficulties in moving around than in urban areas. Additionally, as resulting from my experience, rural livelihood strategies in Kenya are

often very reliant on hard physical labor, making it harder for those with physical impairments to make productive contributions.

In terms of economic empowerment, the characteristics of the local economy may place those with certain types of impairment at a greater disadvantage than those with other types. According to the World Bank, those with intellectual impairments may face greater barriers to economic empowerment in societies where jobs require high levels of literacy and IT skills, than in societies where manual skills are more in demand. This argument is rejected by Ryan and Thomas, however, who point out that technological advances have simplified many types of work, as “many complex and skilled operations have been broken down into short repetitive sequences”. (Ryan, Thomas, 1987: 25) This may be true for developed countries, but it is not the same for developing countries. Certainly the technological progress has reached African countries in large scale, and also Kenya is benefiting from it, but the level of technologization especially in agriculture is very low, particularly in rural areas.

Another aspect is that the experience of disability may also depend on specific circumstances surrounding the disability. In terms of economic empowerment, for example, individuals acquiring impairments later in life may have already had the opportunity to acquire skills and work experience, and therefore have an advantage over those who have impairments from an early age.

2. People with albinism

Little information is available on the situation of persons with albinism in Kenya. There are no accurate estimates of the number of people living with the condition and little systematic research has been undertaken to identify the full range of obstacles and disadvantages which they face. However, it is clear that people with albinism face severe disadvantages, arising in part because of prejudice and superstition and in part as a result of failure to make reasonable accommodation for their particular health and social needs. In common with other countries in the region – notably neighboring Tanzania, as well as Burundi and the Democratic Republic of the Congo – albinism is the subject of significant superstition in Kenya, which in some cases has led to violence

against those with the condition. Some people believe that the body parts of persons with albinism have special powers to confer prosperity or good health, while others believe that albinism is a curse which can be “cured”. Isaac Mwaura, a spokesman for the Albinism Society of Kenya (ASK) describes a wide range of contradictory superstitions held by Kenyans about albinism: “In some cases, superstition or stigma has led to violence against those with the condition. A 2009 news report on attitudes towards albinism in Kenya cites as typical the case of two brothers, John Brown Shamallah and his brother Collins Maikuva, whose parents were told by other villagers in their area that they should be placed in boiling water “so that they would become like other normal children.”

In recent years, the government has begun to take steps to address the situation of persons with albinism. In August 2009, Mr. Eugene Wamalwa, an MP from the Party of National Unity, tabled a petition calling on the government to take steps to protect people with albinism. The petition called for amendments to the Persons with Disabilities Act or the introduction of a new law to cater to the specific needs of persons with albinism, a specific category for albinism in the national census and a waiver of the duty charged on sunscreen for people with albinism²¹. In August 2010, ASK pressed the government over its failure to address these issues and the government announced that it did plan to conduct a special census and that the National Council for Persons with Disabilities was in the process of drawing up amendments to the Persons with Disabilities Act to include albinism.²²

Myths and superstitions fuel the abduction, trafficking and killing of people with albinism in many parts of Africa. Body parts of people with albinism are believed by some to possess magical powers capable of bringing luck and riches if used in witchcraft rituals. Some even believe that the witchcraft ritual is more powerful if the victim screams during the amputation, so body parts are often cut from live victims, especially children, according to a 2013 report from the U.N.’s Office of the High Commissioner for Human Rights. A complete set of albino body parts – including all

²¹ “MP Presents Petition for Albino Law”, The Daily Nation, 6 August 2009

²² “Govt to Conduct Census for Kenyans with Albinism”, The Daily Nation, 31 August 2010.

four limbs, genitals, ears, tongue and nose – fetches the equivalent of \$75,000, according to a 2009 report by the International Federation of Red Cross and Red Crescent Societies. That estimate is based on information provided by police in Dar es Salaam, Tanzania. In 2015, ASK was still working on a strategic plan to review the normative framework on albinism.

3. The language of exclusion

Disability terminology can be a sensitive issue, as well as a theoretically significant one. The use of appropriate language is vital to the process of building positive and respectful relationships, and the choice of terminology can reflect the way in which disability is perceived. In particular, it is important to avoid labeling people by their impairments (for example, ‘the blind’ when referring to people with a visual impairment) or devaluing expressions, such as ‘invalids’, which reinforce notions of people with disabilities as helpless objects of pity.

Different terms have been used for people with disabilities in different times and places. The changing fashions have caused terms to rise or fall in popularity. As mentioned, at this time, disability and impairment are commonly used. Handicap has been depreciated as a result of false folk etymology²³ that says it is a reference to begging. It is actually derived from an old game, Hand-i-cap, in which two players trade possessions and a third, neutral person judges the difference of value between the possessions²⁴. The concept of a neutral person evening up the odds was extended to handicap racing in the mid-18th century. In handicap racing, horses carry different weights based on the umpire's estimation of what would make them run equally. The use of the term to describe a person with a disability—by extension from handicap racing, a person carrying a heavier burden than normal—appeared in the early 20th century.

²³ From *American Heritage Dictionary of the English Language*. Houghton Mifflin. 2001: The word “handicap” did not originate as a metathetic corruption of “cap in hand” in reference to disabled beggars. The word originally referred to the game hand-i-cap, in which forfeits were placed in a cap.

²⁴ Definition of handicap in *Oxford Dictionaries (British & World English)*.

In English there is a kind of linguistic prescription known as people-first language²⁵. It aims to prevent perceived and subconscious dehumanization when talking of people with disabilities and it is sometimes referred to as a type of disability etiquette. The American Psychological Association style guide states that, when identifying a person with impairment, the person's name or pronoun should come first, and descriptions of the impairment/disability should be used so that the impairment is identified, but is not modifying the person²⁶. Improper examples are "an obsessive-compulsive man, or woman" or "a mentally ill person"; more acceptable terminology includes "a man or woman with Down syndrome" or "a man who has schizophrenia". It also states that a person's adaptive equipment should be described functionally as something that assists a person, not as something that limits a person, for example, "a woman who uses a wheelchair" rather than "a woman in/confined to a wheelchair."

The World Bank recognizes that different expressions are considered appropriate in different languages and cultures, and recommends asking individuals with disabilities for their own preferences. However, it does approve the term "people (or persons) with disabilities", in order to emphasize the person first and the disability second. While this term appears to have been accepted on the international stage (it is adopted by the UNCRPD), it does appear to conflict with the opinions of many of proponents of the social model. In fact in UK, the term "disabled people" is generally preferred to "people with disabilities". It is argued, under the social model, that while someone's impairment (for example, having a spinal cord injury) is an individual property, "disability" is something created by external societal factors such as a lack of wheelchair access to the workplace. This distinction between the individual property of impairment and the social property of disability is central to the social model. The term "disabled people" as a political construction is also widely used by international organizations of disabled people, such as Disabled People International (DPI).

²⁵ It first appears in 1988 as recommended by advocacy group in the United States. The usage has been widely adopted by speech-language pathologists and researchers, with 'person who stutters' replacing 'stutterer'.

²⁶ It is codified in the style guide of the American Psychological Association (APA), titled the *Publication Manual of the American Psychological Association*. The APA states that the guidelines were developed to assist reading comprehension in the social and behavioral sciences, for clarity of communication, and for "word choice that best reduces bias in language"

Another term that is well connected and has strong implications with “disability” and “exclusion” is the word stigma. Stigma among the communities is not an insignificant matter. The term “stigma” was introduced by the sociologist Goffman in 1963 and describes an attribute of a person, which is denigrating. The main point is the negative definition of the attribute. Stigma affects prejudices and attitudes and exists in all societies. The appreciation is based on the utilization of stigma terminologies like cripple, moron, etc. The consequences of stigmatizations are fear, insecurity, and isolation from social life. The main point of Goffman is how an individual deals with the situation. Furthermore a stigma is an attribute of a person that is deeply discrediting to social identity. How soon a stigma discredits one’s very personhood depends upon its visibility. He identifies three types of stigma: the first is “abominations of the body”, it is to say the physical deformities that are visible and make a person with disability immediately discredited, versus those “blemishes of individual character” and “tribal stigmas”²⁷ that are less easy to perceive. (Goffman, 1963: 3,4-13,14).

During my researches I found out that many parents reported feeling shame and guilt about their children with disabilities. Some families even built a shed in their banana or maize plantation to keep the children out of sight and ensure that nobody knew of their existence. Some impairments attract extra stigma, such as leprosy and mental ill health. This is often related to fear or to differences in appearance. For example, people with mental health problems may behave in unexpected and frightening ways, as well as people with certain kinds of learning difficulty. For many centuries, leprosy was falsely believed to be highly contagious, and in addition it can often cause facial disfigurement. Similarly, people with albinism (lack of skin pigment) experience profound stigma in many African countries because they look so different from other people.

As far as my experience is concerned, in rural areas and slums, formalities are left to politicians or to international organizations. I believe that the people in those environments unknowingly support the vision of the social model, focusing on the

²⁷ Goffman defines “blemishes of individual character” perceived as weak will, domineering of unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior.” Tribal stigma of race, nation and religion, that “equally contaminate all members of a family”

social construction of disability. The people I talked to did not give much importance to the issue of language. Many, even among the operators, had never even heard of people-first language. They recognize discrimination, but not focused on language or better on terminology. The blind people I interviewed during my visit at Kenya Society for the Blind did address themselves as “blind”, not “people with visual impairment”. Some of them were grateful about the fact that in the Western countries we refer to them as people before considering the disability, but they recognize the futility of a politically correct language if at the same time their rights are not respected with equal accuracy and dedication.

4. Disability and liminality

Another theoretical framework to analyze the situation of people with disabilities is offered by the anthropological study of rituals because it can be used to explain a liminal state of the disabled,” caught and fixed in a passage through life that has left them socially ambivalent and ill- defined, condemned to a kind of seclusion no less real than that of the initiate in the puberty rites of many primitive societies.” (Murphy et al., 1988: 235)

People with disabilities have similar characteristics as other marginalized groups. They are outsiders and have been taken separated for a long time. Their loss of communicative functions as well as mobility and other barriers, can lead to isolation from mainstream society. There are a lot of people in twilight zones of social indefiniteness or in other words in a state of “liminality”. According to Murphy et al., Arnold van Gennep in his classic work, *The Rites of Passage*²⁸, defined three stages in life crisis: separation, merger or transition, and reincorporation. Through these steps an individual enters in the initiation process and creates a new identity through the process of separation to reincorporate in a new social role. He argued that people in a liminal condition are without clear status and they live therefore “between” without firm identity or role definition. Due to this non status the interaction with them becomes

²⁸ Original published in 1909.

unpredictable and problematic and they are seen as socially dangerous people. (Murphy et al., 1988: 23)

Disability is an in-between state because the person is neither sick nor well. It is expected that the patient will get better (due to rehabilitation, hospitals, or special schools) and he/she is then welcomed back to his/her roles. However, the person with disability experiences no such transition because he/she does not fit in a defined social role. Rather the social distance between them and the society is not narrowing but it is getting bigger leading to physical isolation and non-communication. Societal attitudes and prejudices strengthen the individual's decision to remain at home and his/her liminal condition becomes a permanent status. (Murphy et al., 1988: 238) This concept applies perfectly to the situation of people with disabilities in Kenya. They live in a society that still refuses their condition and parents hide their children in a room in the house or even lock them while going to work or worst when they have guests and do not want to show the "Divine Punishment".

According to Murphy et al., another characteristic of liminality is what Turner calls the invisibility of the initiates. For example wheelchair users are aware that they are noticed by everyone in public places and acknowledged by nobody. However they become invisible due to the fact that they are easily ignored. Especially children with disabilities are brought in special schools, separated from their families and social life of their community. Moreover for those who become disabled later they are separated in rehabilitation institutions and hospitals. They become invisible like the multitude of invisible poor all over the country. The ritual interpretation may help to understand that disability is partly socially constructed allowing us to see it "as culturally and historically malleable, rather than as rooted in and fixated by biology, as in the medical model." (Murphy et al., 1988: 241)

2.2 Disability and poverty

1. Poverty: a multidimensional concept

Understanding poverty requires a focus on peoples' living conditions in a

comprehensive way. The concept of poverty as well as the concept of living conditions is complex and multi-dimensional. The understanding of living conditions has developed from a relatively narrow economic and material definition to a concern with human capabilities and how individuals utilize their capabilities. An individual's level of living is defined not so much by his or her economic possessions, as by the ability to exercise choice and to affect the course of his or her life (Loeb and Eide, 2004). In other words poverty arises when the individual is deprived of the opportunity to lead a healthy life, he/she does not enjoy a decent standard of living, is not able to participate in social and political life and/or lacks respect and self-respect. When individuals with different levels of functioning encounter barriers to health services, education, employment, public services, and infrastructure, they are disabled. That is, "disabled" in the sense that they are not given the ability to participate in economic activities and lift themselves from poverty. Disability is thus to be understood as an interaction between human functioning and an environment which does not account for different levels of functioning. In other words, people with physical or mental limitations are often disabled not so much because of their functioning level, but because they do not have access to education, labor markets, and public services.

Given the World Bank and the World Health Organization estimates about 15% of the world's population consists of people with disabilities and disability prevalence is higher for developing countries. One-fifth of the estimated global total, or between 110 million and 190 million people, experience significant disabilities (WHO & The World Bank, 2011).

The linkage between poverty and disability, in particular in developing countries is bi-directional: on the one hand poverty causes disability through malnutrition, poor health care and dangerous living conditions; on the other hand disability causes poverty by preventing their full participation in the economic and social life of their communities.

The global focus on poverty highlighted by the Millennium Development Goals (MDGs) is of particular concern to persons with disabilities. A growing body of research now shows that the most pressing issue faced by millions of persons with disabilities worldwide is not their disability but rather poverty. (World Bank, 2004) Much of this poverty is the direct and indirect result of exclusion and marginalization of

persons with disabilities due to stigma and prejudice about disability. This stigma and prejudice, in turn, is often the result of a lack of knowledge of and awareness about people with disability which exists at all levels starting from the family to the community to decision makers at the highest levels, and includes all those who simply have not understood that persons with disabilities need the same opportunities and rights available to all other members of society.

2. Development and poverty

The economic empowerment of people with disabilities is vital to the achievement of global development targets, such as the MDGs, as most international development agencies now acknowledge. The need to address poverty issues, particularly in developing countries, provides a compelling rationale for promoting the economic empowerment of persons with disabilities. It can also be argued, however, that increasing the productivity of this large chunk of society can only be beneficial to the economies of developing countries as a whole. Enabling one person with disability to make a contribution to the production of goods and services not only increases the net economic benefit of that individual to society, but may also release family members from at least some of their caring responsibilities, thus enabling them to engage in productive activities themselves.

Amartya Sen in his book “Poverty and Famines” (1981) emphasizes that some discussions lead to the opinion that the prevalence of poverty in the country is not only a form of the suffering of the poor but a relative luxuriousness of the nation as a whole. Sen highlights the coupling of disadvantages between the income deprivation of a person and his ability to convert that income into functioning. A perfect example is a person who has disability and his ability to income is reduced and in addition he would need more income to achieve the same functioning as an able bodied person. Thus he concluded the real poverty lays in terms of capability deprivation rather the reduction of income.

Sen concentrates his focus on the general ideas of the conception of poverty. He starts off by investigating the Biological Approach. Here, he quotes Rowntree, who in his

study had defined ‘primary poverty’ in respect of families whose total earnings were insufficient to obtain the minimum necessities for the maintenance of merely physical efficiency. It is an unsaid truth of life that starvation is the most telling aspect of poverty. However Sen underlines that this approach of poverty has several gaps in its implementation inherently because there are significant variations related to the physical features, climatic conditions and work habits in different parts of the world. Taking for example, the Americans and Europeans have been growing in stature as their diets have continued to improve over time hence there is a difficulty in drawing a line somewhere as there is a bit of difficulty in determining the ‘minimum nutritional requirement’ as there is an inherent arbitrariness between various groups and regions.

Though it is easy to solve the problem of ‘minimum nutritional requirement’ which is not a very high cost basket of essential food requirements, however the difficulty lies in the people’s food habits. For example in Kenya people are used to eat *ugali*, *sukumawiki*²⁹ and *nyama choma* (grilled meat). Even if *ugali*, which we can compare to Italian “polenta”, is not very rich in nutritional value, Kenyans don't spend a day without it. The arrogance of many NGOs and other international organizations to bring “Western food” and to eradicate eating habits of the poor find great barriers and obstacles.

Another issue is that the minimum requirements of non food items are not easy to determine. Now, this problem can generally be tackled by assuming that a specified proportion of the total income will be spent on food and consequently with this assumption the minimum food cost can be used to derive the minimum income requirements; but here again the proportion spent on food varies with the variation in the relative prices and availability of goods and services. So malnutrition captures only one of the aspects of the idea of poverty.

Furthermore, Sen in his book, *Development as Freedom* (1999) emphasizes on poverty as capability deprivation in underlining the theory of poverty. He contemplates that poverty must be seen as the deprivation of basic capabilities rather than merely taking into consideration the income aspect which forms a standard measurement as to whether

²⁹ Sukuma wiki, a Swahili phrase, which literally means "to push the week," is a simple dish made with greens similar to kale or collards that can also be made with cassava leaves, sweet potato leaves, or pumpkin leaves.

the person is poor or not. Income may be the most prominent means for a good life without deprivation, but it is not the only influence on the lives we can lead. If the paramount interest is in the lives that people can lead—the freedom they have to lead minimally decent lives—then it cannot but be a mistake to concentrate exclusively on one or another of the means to such freedom. More attention should be put to impoverished lives, and not just at depleted wallets.

The idea of seeing poverty in terms of poor living is not new. Indeed, the Aristotelian account of the richness of human life was explicitly linked to the necessity to “first ascertain the function of man,” followed by exploring “life in the sense of activity.” In this Aristotelian perspective, an impoverished life is one without the freedom to undertake important activities that a person has reason to choose³⁰.

Adam Smith also felt impelled to define “necessaries” in terms of their effects on the freedom to live non-impoverished lives, such as “the ability to appear in public without shame”. (Smith, 1776: 479) This is a good example of a capability deprivation that takes the form of social exclusion. This relates to the importance of taking part in the life of the community, and ultimately to the Aristotelian understanding that the individual lives an inescapably “social” life.

Furthermore, being excluded from social relations can lead to other deprivations as well, thereby further limiting our living opportunities. For example, being excluded from the opportunity to be employed or to receive credit may lead to economic impoverishment that may, in turn, lead to other deprivations (such as undernourishment or homelessness). Social exclusion can, thus, be constitutively a part of capability deprivation as well as instrumentally a cause of diverse capability failures.

3. Vicious circle of poverty

The vicious circle of poverty is often explained by a diagram that shows how disability and poverty cause and reinforce each other. (Table 1) Disability leads to poverty,

³⁰ Aristotle, *Nicomachean Ethics*, Book I, section 7; in the translation of D. Ross (1980), p. 12-14. Martha Nussbaum (1988) has illuminatingly analyzed the reach and relevance of the Aristotelian approach.

through such factors as social exclusion, denial of rights and lack of opportunities for economic, social and human development. Conversely, poverty creates vulnerability and ill-health - through such factors as poor nutrition and sanitation, lack of access to vaccination programmes and dangerous working and living conditions - which in turn cause disability. (DFID, 2000: 4)

The vicious circle concept has been criticized by Rebecca Yeo, (2005) who points out that disability and poverty have much in common, and that the DFID diagram, due to its emphasis on the two-way causal link, obscures the common factors that characterize both disability and poverty in general. She argues that processes of social exclusion, which apply to people with disabilities, such as limited access to education, employment and basic health services, are very similar to those that apply to poor people in general. This view is echoed by Philippa Thomas, who states that “disabled people share the general profile of the non-disabled poor” (Thomas, 2005: 4)

Yeo suggests that, given this common ground between disability and poverty, the relationship between the two would be better represented by another diagram (Yeo, 2005: 21). This diagram (Table 2) shows how processes of marginalization, isolation and deprivation, as well as lack of access to most aspects of community life, are common to both the poor with or without disabilities, although there are also characteristics that are specific to each of these groups. For example, the poor with disabilities might face additional exclusion, such as lack of physical access to public buildings, due to the nature of their particular impairments, while, conversely, the poor without disability may face additional disadvantage, as they would not benefit from positive discrimination measures targeted at those who have disability, such as employment quotas. When the relationship between disability and poverty is understood in this way, the implication, as Yeo clearly explains, is that any initiatives designed to reduce poverty, in general, are also likely to benefit people with disabilities who are poor. She concludes that disability activists should consider making alliances with other more general campaigns to reduce poverty (Ibid.).

From my point of view, these conceptualizations of the relationship between poverty and disability actually complement each other, rather than representing opposing views, because they simply highlight different aspects of a complex relationship. Yeo’s Venn

diagram highlights the commonalities between poverty and disability, emphasizing on the the social factors which reinforce both and providing a basis for disability activists to align themselves with anti-poverty campaigners. The vicious circle concept, illustrated by the DFID diagram, focuses more on the impact of impairment, but it also highlights the chains of causality, which helps to explain why the overlap between poverty and disability that Yeo observes is so large and deep-rooted. Given the above considerations, Sen's observations and arguments tend to reinforce both of these positions. Taken together, these concepts deepen our understanding of the relationship between disability and poverty, each adding weight to the justification for promoting the economic empowerment of people with disabilities.

2.3 Different models of disability

1. From individual to social models

Traditionally, disability has been understood in terms of the 'individual model of disability', which tend to perceive "the problems that disabled people experience as being a direct consequence of their impairment". (Oliver and Sapey, 2006: 22) These problems may be caused by functional limitations or psychological losses, but either way they are located firmly within the individual, and "assumed to arise from disability". (Oliver, 1996: 32) For example, a spinal injury, which causes paralysis, may disable an individual by preventing her from walking, which in turn may limit her ability to travel or to find employment. If the individual also incurs psychological losses, such as depression or loss of confidence, as a result of the injury, then this creates further disability.

The medical model is "rooted in an emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual". (Brisenden, 1986: 20) This perspective tends to imply that medical intervention and rehabilitation, in order to restore 'normal functioning', are the only means of enabling people with disabilities to cope with life in mainstream society. Under this model it is

easy for people with disabilities to be viewed as weak and defective, needy and dependent (since they are assumed to require the aid of medical professionals), and generally incapable of getting good jobs, living on their own or participating fully in society. So, the society is not seen as having any underlying responsibility to accommodate people with disabilities; these people must instead adapt themselves to existing circumstances, usually with help from medical professionals who provide treatment and rehabilitation.

The categorization of medical model³¹ is rejected by Oliver, who argues that “there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalization is one significant component” (Oliver, 1996: 31). For Oliver, the individual model of disability covers a wide range of issues, including medicalization, psychological and charitable perspectives. These are all underpinned by personal tragedy theory, which perceives disability as “some terrible chance event which occurs at random to unfortunate individuals” (Ibid.) This way of thinking has been reflected in the perception that persons with disabilities are unable to make a useful contribution to society and should, therefore, be separated into special institutions “for their own good and to stop them being a burden on others”. (Barnes, Mercer, 2003: 3) This approach was prevalent through much of the twentieth century, and applied through various religious, educational and charitable institutions, as well as through medical and psychological interventions. However, as O’Reilly (2007) observes, segregated institutions are still very much in existence, particularly in developing countries. Despite the criticisms, the individual model continues to exert a powerful influence, as evidenced by the continued existence of segregated services and the widespread prevalence of charitable attitudes towards disability and people with disabilities around the world today.

Increasing dissatisfaction, often expressed by people with disabilities themselves, with individual model perspectives, has led to the rise of the ‘social model of disability’. The model has its origins within the UK disability movement of the 1970s, when a group of people with disabilities, including several that had been involved in protests against

³¹ Medical model or individual model can be used as synonyms

institutional practices at the Le Court Cheshire Home, came together to form the Union of the Physically Impaired Against Segregation (UPIAS) (Barnes and Mercer, 1997). The Union provides an early example of an organization of people with disabilities, which created a platform for them to voice their concerns and opinions, rather than having them represented by others.

UPIAS was among the first to see disability in terms of social oppression: this understanding of disability is encapsulated in the Union's "Fundamental Principles of Disability": "Thus we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, 1976: 14). The growing feeling, among people with disabilities themselves, that social oppression and discrimination was the root cause of their disability, was then articulated in academic terms by Mike Oliver as the 'social model of disability', a new paradigm which would locate disability firmly within society, rather than within the individual with disability. Oliver attributed the ideas behind the social model to the original distinction between impairment and disability drawn in the 1976 UPIAS document, and called for "a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations on certain groups and categories of people" (Oliver, 1983: 23)

The social model sees disability, therefore, as created by the impact of environmental factors (or societal barriers) on a person with an impairment. The clear implication is that society itself should adapt to the needs of people with disabilities, rather than the other way around. This provides the basis for the argument that societal barriers need to be removed, in order to reduce and eliminate disability.

Oliver takes the analysis a stage further in 'The Politics of Disablement', which provides a materialistic account, explaining how the individualistic ideology of capitalist society has shaped attitudes towards people with disabilities and created much of the social oppression which persons with disabilities experience. He also argues that the structure of capitalist economies has tended to exclude people with disabilities, as

industrial societies have developed and production has been increasingly organized around factory work and individual, waged labor. As a result, he concludes, “disabled people came to be regarded as a social and educational problem and more and more were segregated in institutions of all kinds” (Oliver, 1990: 28).

2. The “religious model”

The so called “religious model” views disability as the punishment inflicted upon an individual or family by an external force. It can be due to an offence committed by the person with disability, someone in the family or community group. Sometimes the presence of “evil spirits” is used to explain strange behaviors, especially in conditions such as schizophrenia. Acts of exorcism or sacrifice may be performed to expel or placate the negative influence, or even worse.

The foregoing traditional and contemporary Biblical and theological views on disability have a bearing on the way in which society responds to the presence of persons with disabilities in Kenya, and in particular how they impinge on their rights. Kenyan society continues to use antiquated religious beliefs to explain the presence of those people. The consequences of the interpretation of disability to denote sin, disobedience, ignorance, and unbelief have contributed to some Christians adopting a discriminatory attitude toward persons with disabilities. The origin of disability in Biblical interpretation is still found in the thinking of Christians today. The linking of disability to the "perfect body image" that is found in the Bible has caused people with disabilities to be viewed and treated negatively. Society evaluates the depth of religious belief based on bodily perfection. It is assumed that if one is "right" with the Lord, there is no excuse for having physical flaws (Whenam, 1981). The result is that people make a direct connection between physical perfection and spiritual righteousness, so many persons with disabilities are discouraged from looking for a religious home and feel neglected by the church. This image of a lesser and sinful being is reinforced by the way preachers bombard these people with healing messages. Because of the notion that disability is connected to sin, persons with disabilities in Kenya are often a target of healing

ministries in churches. Pressure is often placed upon them to accept miraculous healing. If healing does not take place, it is confirmed that they indeed are sinners.

If traditional Biblical and theological perspectives on disability give the impression that disability is a tragedy and a punishment or curse from God for sin, in recent years there have been theological discussions on disability that are liberal and empowering to persons with disabilities and, while also grounded in Biblical texts, work in opposition to traditional theological interpretations of the Bible. These include images of God, such as the one proposed by Eiesland, in which God is portrayed as having a disability. According to Eiesland, this disabled God is part of the "hidden history" of Christianity. She makes a connection between the image of God as Disabled and the resurrection story, in which Jesus appears to his followers and reveals his injured hands and feet (Lk. 24: 36-39). The image of God includes pierced hands, feet, and side. She highlights the resurrected Christ's revelation of his wounds to his followers. In presenting his impaired hands and feet to his disciples, the resurrected saviour calls his disciples to recognize in the marks of impairment their connection with God and their own salvation. The risen body of Jesus as "impaired" is taken as a further sign of God-Jesus embodying disability in his resurrected body and suggests that "disability indicates not a flawed humanity but a full humanity" (Eiesland, 1994: 207). The Disabled God values embodiment in all its diversity and provides a profound example of inclusion, love, and acceptance.

The contemporary church continues to raise questions about persons with disabilities seeking to enter the ministry. Suggesting that certain physical disabilities are a disqualification for the ministry, Lev. 21:16-23 has been used to warrant barring these persons from ecclesiastical visibility and authority. According to Govig (1982: 95), "this text is a barrier to the ordination of people with physical impairments. It is applied literally to forbid PWD from preaching." A study conducted on the ordination of persons with disabilities in the Presbyterian Church of East Africa in Kenya shows that the church harbors some reservations in the ordination of persons with disabilities. It is believed that disability may hinder one's performance as a minister (Mwangi, 2007). The church has a great influence on people in Kenya, so it should work to facilitate the integration of disability issues into the whole spectrum of the life of the church and society while at the same time giving attention to those special and unique areas

necessary to equalization of opportunities. One of these areas includes advocacy in disability human rights concerns. This means working with the churches towards participation and inclusiveness of persons with disabilities in the spiritual, social, and development life for the general improvement of services for persons with disabilities. The church must become an advocate for and with them and push more for the inclusion of people with disability in society and in international organizations agenda.

3. ICF model

The social model provides a powerful alternative to traditional approaches based on the individual model, reflected in the current tendency of many development institutions and bodies, as well as governments, to advocate for the inclusion, empowerment and participation of people with disabilities.

But even by looking at the social model, it is important for the constitutional and legal framework to reflect the International Classification of Functioning, Disability and Health (ICF) model developed by the World Health Organization (WHO, 2001). According to the WHO model, the ICF is a classification of health and health related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual's functioning and disability occurs in a context, the ICF also includes a list of environmental factors. The ICF focuses on the negative aspects of the interaction (measured as impairments affecting the body; activity limitations affecting an individual's actions or behavior or participation restrictions affecting a person's experience of life) between an individual (with a health condition) and that individual's contextual (personal and environmental) factors. In this case, to understand disability it is necessary to focus not only on the individual but also on the family and/or the social group within which the individual co-exists, and how the individual, the family and the society function and cope within their particular social and cultural setting.

Debates over the interpretation and application of the British social model have also touched on the context of developing countries. The social model provides the basis of a

political strategy, aimed at changing the structures of society and removing societal barriers, and many disability organizations and NGOs around the world have committed themselves to achieving these objectives. However, there are some doubts as to whether these political objectives truly reflect the priorities of people with disabilities themselves, particularly those living in poverty. Grech questions the wisdom of moving the focus away from impairment and functional limitations, in countries where “poor livelihoods (and ultimately survival) are often dependent on hard physical labor (e.g. agriculture), making a healthy body an imperative”. (Grech, 2009: 776) He suggests that a focus on medical or rehabilitative solutions, aimed at enabling people with disabilities to cope better with those impairments themselves, may reflect their immediate priorities more closely than strategies designed to bring about societal change in the longer term. The rights-based perspective provides an ideological basis for challenging the disabling role of society, because those who adopt this perspective tend to regard the social exclusion of people with disabilities as a denial of basic rights. Miles, for example, argues that “inclusion, advocacy and empowerment are key components of a rights-based approach to disability and development”. (Miles, 1999: 7) This represents a major shift in thinking from the individual model perspective, in which people with disabilities are required to adapt to the norms of a society that is not designed to include them, to an approach which values and thinks of people with disabilities as citizens with equal rights. These principles appear to have been embraced by donors and policy-makers throughout the world. The UNCRPD, for example, strongly emphasizes the rights-based perspective, declaring that “the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty”. (UNCRPD, 2006: preamble (m))

4. Rights-based approaches on disability

While this rights-based discourse, as illustrated above, appears to have gained increasing acceptance within the international development community, there is some

doubt as to how such rhetoric relates, in practice, to the everyday lives of those for whom the promotion of rights and empowerment may seem like irrelevant concepts. Mikkelsen (2005), for example, observes that many development organizations claim to have adopted the rights-based approach, without actually having developed their methodologies and capacities in order to fully operationalize such an approach.

One risk of adopting the rights-based perspective is that excessive focus on lobbying for improved rights may shift attention away from the more pressing needs of people with disabilities, particularly those living in extreme poverty. This dilemma, over whether the promotion of political freedom undermines the need to address poverty issues, was considered and rejected by Sen. He argued that the promotion of rights can actually raise awareness and understanding of economic need (i.e. poverty) and that “the intensity of economic needs adds to – rather than subtracts from – the urgency of political freedoms”. (Sen, 1999: 148). Others claim that the dilemma is real, because the process of actually fighting for political freedoms, or rights, can divert resources from service provision. Coleridge acknowledges this danger, pointing out that “reducing an NGO’s activities to advocacy for inclusion may mean that disabled people receive no services at all”. (Coleridge, 2007: 121). It seems vital, therefore, that disability organizations consider the possible trade-offs, at least in the short-term, between advocacy and service provision.

One solution to the perceived inadequacies of mainstreaming disability is the twin-track approach, as proposed by Department for International Development: on one hand addressing inequalities between disabled and non-disabled persons in all strategic areas of our work, on the other hand supporting specific initiatives to enhance the empowerment of people with disabilities. These two actions together may lead to equality of rights and opportunities for persons with disabilities. There appears to be a general consensus in the literature that this kind of approach represents the best hope of achieving meaningful social inclusion for people with disabilities.

The potential of local communities, including families of people with disabilities, to support and promote economic empowerment initiatives should not be underestimated, particularly in poorer countries, where community interdependence is often very strong. According to the International Disability and Development Consortium, “80% of

information, skills, resources that disabled persons need to enable them to fully participate and access their rights can be met within their local communities”. (IDDC, 2004: 4).

Community-based Rehabilitation (CBR) is an approach which has grown out of the debate between the so-called medical and social models of disability. Its supporters believe that it can meet the basic rehabilitation needs of four out of five people with a disability. CBR attempts to combine physical rehabilitation through medical care with empowerment and social inclusion through the participation of both the individual with a disability and the community in the process of rehabilitation.

CBR is often claimed to be the best approach to inclusion and social integration, and an effective means of making the best use of scarce resources. The WHO believes that it promotes and protects human rights while also creating equal opportunities and making the best use of scarce resources. The main objective of CBR is to empower people with disabilities to make best use of their abilities and access services, with the support of trained CBR workers who provide them with information and advocate for their inclusion, so that they can become “active contributors to the community and society”. (ILO, UNESCO & WHO, 2004: 2).

However, one of the biggest challenges facing any community-based disability programme is the need to overcome negative attitudes within communities.

2.4 Disability in the context of socio- economic structures in Kenya

The question arises of whether relations with institutions, organizations, and the media messages may affect the situations and the understanding of people with disabilities in a local context. Another fundamental question is how far being a person with disability is different in various cultural, social and economic contexts. If I compare cities in developed countries to those in developing countries, like Nairobi, I can easily come to the conclusion that they are fundamentally different in many ways.

They are not only different from the biomedical point of view but also from many other

perspectives. Social, cultural, economic, and physical conditions play at least as important role as the medically defined impairment in generating a disability or “handicap” for an individual. To achieve equalization in all these areas requires an understanding of the particular context in which a person with disability lives. Ingstad and White state that: “seeing disability in context implies understanding disability not (as it once did) in one particular isolated cultural setting, but in contexts in which modern ideas about rights for persons with disability coexist with possibilities, constraints, and beliefs imposed by the local physical, social, economic, and cultural setting.” (Ingstad and White, 2007: 250). The authors confirm that full participation and equality are far from being achieved given the contextual circumstances of poverty, armed conflicts and underdevelopment, especially in African countries and particularly in rural areas. Moreover, they invite to consider that it is not only important to examine what goals are attainable, but which are desirable and in accordance with which ideology.

1. Socio- economic and socio- cultural causes of disability

In developing countries disabilities and diseases are caused mainly by socio economic factors as well as by genetic causes and complications at birth. In my fieldwork, some of the families in rural areas have their own land and a (small) house but in Nairobi most live in slum areas. As mentioned, all the houses or shelters are made of iron sheets and just a few families can afford a foundation made of concrete. That is why most of the families live directly on the ground. Above all the houses and roofs are not fixed which means that there are holes and the rain comes inside. Some live in mud houses with grass roofs. Because of the rain season all the houses are very humid. In addition because of cooking inside the walls are sooty and fill the windowless room with smoke. Most of the family members sleep in the same room in which they cook. Just a few of the families I have visited had electricity, not to mention sanitation facilities which means no toilet or shower. In Kenya only 46% of population in urban areas and 41% in rural areas use adequate sanitation facilities (UNICEF, 2013). Moreover, 39% of the

people have no access to clean water source (17% in urban areas; 54% in rural areas). Other environmental factors such as pollution, toxic substances, or insecticides can lead to illnesses and diseases and as a consequence to disabilities like blindness, leukemia, and epilepsy.

There are several causes that are responsible for high infection rates in developing countries like Kenya: lack of access to clean drinking water, exposure to raw sewerage; exposure to insects and other disease factors, sewerage contamination of water used for activities of daily living; household crowding; lack of access to preventative or curative medical care; cooking pots and charcoal burners in, or near, sleeping quarters can cause communicable respiratory diseases, mostly in crowded housing situations; also skin infections and diseases, such as leprosy, can spread in crowded and unsanitary conditions.

The combination of infections and the belief system like witchcraft can lead to stigmatization of the family within the community. Moreover the nescience (caused e.g. by inaccessibility to health care) of the etiologies of common infectious processes can hinder public health endeavors, immunization and monitoring.

Disabilities like blindness and deafness are closely linked to poverty and furthermore a decrease in income. Although many diseases could be preventable, due to high costs of medication they are not treated in time. Social factors play an important role: factors like overcrowded houses, domestic rubbish management, and living close to animals lead to a spread of infections which vary with the socio- economic status in which people live. To prevent all this, accessibility to economic structures like information, education, employment etc. is fundamental. Because if people are barred from communication they are also barred from information. There is a high demand on e.g. brailing printed information, sign language interpreters, eye- catching simplified messages and computer technologies to make information accessible for people with disabilities. Particularly deaf people if they have never been trained in sign language. Kelvin Onchong'a³² even talked about children who never learn sign language and therefore cannot communicate with their parents and guardians. They are not even in a

³² Responsible for Research and Learning Officer, DeafAid Kenya, interviewed in April 2015.

position to communicate and tell what is wrong with them. “When it comes to computer technology you realize that people with disabilities have various communication barriers. If you think of a deaf student in class unless the instructor is writing on a blackboard or any kind of means then this student will never be able to be trained. Or think of a blind person in a regular class unless the computer is able to voice that person will never use or to be able to access computer technology.”

2. Consequences on health care access

Article 25 of the UNCRPD emphasizes that State Parties should take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health related rehabilitation. The State is further obliged to provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities for children and older persons. In addition to these, the State is required to provide health care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent and to prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. However, evidence from a report by KNCHR in 2014 indicated that persons with disabilities continue to experience difficulties when accessing health care services. They experience discrimination, stigma, lack of informed consent regarding the medical procedures to be performed on them, unfriendly infrastructure and high cost of sexual reproductive health services as key obstacles to persons with disabilities enjoying health care services (KNCHR, 2014: 23-25). Hospital fees are another obstacle that hinders many persons with disabilities from accessing medical services. To many of them the charges are too high as most are unemployed and live in rural areas pronged by poverty, struggling to even get transport to the hospital. As I pointed out in the previous chapters, access to health care is a major problem in Kenya and we must take into account how poverty limits the access to health care especially for poor people with disabilities.

Social and environmental factors related to the situations in which people with disabilities and their families live, influence the complex interactions between disability, poverty and health. Lack of money for transport is the first, visible cause of lack of access to medical care. But even if people manage to get to the hospital they are not guaranteed to see a doctor. Several families mentioned how they got appointments to see specialists and hardly managed to raise the money to go, only to be told when they got there that the doctor was not in and asked to come back several months later.

Here an example based on my interviews. K. is a 1 year and 8 month old girl who lives in Korogocho slum. Her mother is a single mother who does the housework and lives with her family. She has one brother and a sister. They live in an iron sheet house and the chickens are running around everywhere. The girl has physical and mental impairments because her brain was damaged during birth due too little oxygen. The right side of her body is paralyzed, she cannot talk, and does not take food well. The child needs a doctor for advice, medical care and physical therapy but the parent is not able to provide that because of their financial situation. This example illustrates how poverty influences access to health care.

Another example: ear ailment and disorder are unfortunately not regarded as real disease, and most people especially from slum and vulnerable areas, do not seek medical attention for said disorder. There are three main reasons for disregard of the severity of the ear ailments; ear ailments are hidden and medical expense related ear ailment is very high, and very few hospitals in Kenya have ENT departments. It may seem absurd but simple ear problem that could have been treated with the antibiotics is left to progress, leading to hearing loss and eventually deafness. The situation could further be complicated for children who come from the slum areas. In Africa, perception of hearing impairment goes beyond disability itself. Often causes of hearing impairment are associated with various cultural perceptions. In many cases, hearing impaired children are perceived as cursed, hence discriminated against. This means that no effort whatsoever, is made towards intervention and rehabilitation of the deaf child, and he becomes a burden to his family and society.

Families living in rural areas face more obstacles in their access to modern health care than those living in urban areas. In fact, the primary health care system is not

sufficiently developed in all parts of the country. As health care is institution based, people have to be able to come to the hospitals or medical clinics to get help. While the antenatal care seems to be in place, there seems to be very little or no follow up of the children that do not develop normally. This is left to the initiative of the parents and one may think that is pure luck if a representative of a foreign NGO or a DPO happens to come along to help them.

Due to the fact that most of the time hospitals cannot be reached by people with disability or are unaffordable, traditional medicine is often used to treat illnesses and conditions in Kenya, especially in rural environments. It is significant that about 50% of the individuals with disabilities that I interviewed stated that they have used traditional medicine as a form of treatment, and it provides the measure of how these practices are still in force especially in rural areas. They still believe that disabilities are caused by unnatural phenomenon (witchcraft and spirits) that can usually be healed by traditional healers. My informant stated that numerous individuals with disabilities come from other towns and villages to seek treatment. Individuals with disabilities are usually given herbs, which are boiled and then drunk. This treatment only cost 100 shillings. In some cases, special rituals are performed in which the traditional healer throws charms into a fire. The traditional healer claimed that their treatment is 100 % effective; however, this statistic cannot be proven.

3. Infrastructural disadvantages

To show to what extent people with disabilities suffer from infrastructural circumstances a survey of their challenges and problems in daily life can be useful. In general persons with disabilities in Kenya are challenged by poor infrastructure and the Kenyan national survey for persons with disabilities maintained that 93% in rural areas and 87% in urban areas found it a major problem to survive without assistive devices.

In general accessibility plays an important role to participate in various activities. Crowds, lighting and noises are the most significant surroundings that affect people with disabilities (14, 7% are affected on a daily basis and 3, 4% on weekly basis). Three

out of five of those who are affected find the immediate surroundings a major problem in their daily life (KNS, 2008: 10-12)

That is why many people with disabilities have no access to various activities in life. For example, to drive a wheelchair in Nairobi is nearly impossible. Almost all the people I interviewed argued that the infrastructure is unsuitable for the persons with disabilities, (not only for them) but also for old people and mothers with children. Furthermore people with disabilities have no access to buildings as e.g. shopping centers, sometimes not even a restaurant or a second floor of any building; it is just not possible to access with a wheelchair.

Public transport is not accessible either and most of the time it is overcrowded. A person I interviewed commented if a matatu driver (small buses) takes a wheelchair driver in his vehicle he has a very big heart. I saw it one time when I passed by in a bus. “And again if the bus is full you can’t get a seat and you know in our country transport is not well developed ... so it’s actually a challenge. The strongest are getting in, because some are not strong.” To me the most baffling thing is that everyone knows that people with disabilities cannot access, but no one makes a big deal, or better they are all resigned. One day I was talking to a guy who I met in a matatu and he said: “Well when you have the misfortune to live in a country like this, you have to fight every day and you know that doing it against the authorities is a lost cause. We all grow with the understanding that the difficulties are on the agenda and if you are born disadvantaged you will remain forever. Also moms made peace with it. I know that people with disabilities cannot move because they cannot take the matatu, and as you said it is an acceptable situation, but it will take decades before things change (if they will). What about Europe?” Then I realized that even in Italy we are far from a complete inclusion of persons with disabilities in the society and we live with the presumption to be able to teach something to other countries. But it is time for developing countries not to make the same mistakes that developed countries made and to learn from what does not work in Western societies.

In other words access to public buildings and disability friendly infrastructure would be very important so that every person with a disability can move freely, can go to school or work if he/ she is in a wheelchair, because inaccessibility leads to exclusion from

employment because even if people with disabilities are qualified for a job it depends on the building if he/she is able to work there.

In a Kenyan study only 16 % of disabled respondents had worked for pay, amongst those residing rurally this fell to 9 % compared with 25 % in urban areas (Cobley, 2012: 371-384). Cobley contends this is due to a combination of lack of opportunities, availability of assistive devices, difficult terrain and inadequate infrastructure in rural areas, which generally make school and work attendance more difficult. Imrie refers to this as “apartheid by design”. (Imrie, 1996)

2.5 Conclusion

Cross-cultural differences in the interpretation of disability show that the lives of people with disabilities are made more difficult not so much by their specific impairment as by the way society interprets and reacts to disability. As we can see from my short analysis, the social model of disability identifies three major types of discrimination. Institutional discrimination exists, for example, where no legal or other provision is made to ensure that children with a disability can attend school. Environmental discrimination is where a person with a disability is unable to participate due to a physical barrier, such as inaccessible public transport or inappropriately designed buildings. Attitudinal discrimination is often expressed through fear and embarrassment on the part of a person when confronted with a person with a disability. Also, low expectations of people with disabilities are discriminatory and undermine the confidence and aspirations of people with disabilities themselves.

The various models of disability help to identify some of the many factors which cause and exacerbate disability. The individual model, which is underpinned by personal tragedy theory and locates disability within the individual, is now largely discredited and seen as disempowering. The social model, which has risen to prominence in its place, provides a powerful conceptual framework, which seriously challenges the narrow, impairment focus of the individual model, and provides an ideological basis for the international campaign for the empowerment and inclusion of disabled people, as

reflected in the language of the UNCRPD. However, literature debates have called into question the way that some interpretations of the social model have tended to downplay the impact of impairments, while others have questioned the transferability of the model to developing country contexts.

The individual and social models, rather than being seen as mutually exclusive alternative standpoints on disability, could be viewed as representing opposite ends on a spectrum of disability models. Particular disability service providers will have their own perceptions of disability, partly shaped by the context in which they operate, from which they can develop their own standpoint, which may lie at any point along the spectrum.

Regardless of the model taken into account, it should be noted that discrimination and marginalization of people with disabilities have their origins in many factors such as in socio- cultural ones, manifested in conventional attitudes and family values, and further in socio- economic conditions such as poverty and accessibility to various fields of life. Prejudices and discrimination are socially and culturally constructed and institutionalized and based on oppressive power relations. Therefore it is important to reconstruct these factors to analyze and understand the origins of discrimination which lead to inequality.

Good practice is most likely to be ensured through an integrated/inclusive approach, using best practice in both social and medical terms. The key to ensure the best use of scarce resources is to listen to people with disabilities and to take full account of their views in making decisions, as well as tackling negative attitudes in society as a whole.

CHAPTER 3 LAW FRAMEWORK ON RIGHTS FOR PERSONS WITH DISABILITIES

3.0 Introduction

The shift from a “caring” to a “rights-based” approach to matters of disability began in the 1970s. The 1971 General Assembly Resolution on Declaration on the Rights of Mentally Retarded Persons noted that such persons enjoyed the same rights as all other persons (Article 1). Other relevant declarations are the 1975 Declaration on the Rights of Disabled Persons and the World Programme of Action Concerning Disabled Persons (WPA) adopted by the General Assembly in 1982. This Program tackled prevention of disability and rehabilitation of persons with disabilities; but, significantly, this resolution also dealt with human rights by discoursing on the equalization of opportunities for persons with disabilities.

Persons with disabilities are human beings sharing human rights on an equal basis with, and to the same degree as, other human beings. In the words of the Vienna Declaration and Program of Action: “The place of persons with disabilities is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers [...] which exclude or restrict full participation in society.”³³

The Vienna Declaration further stresses that: “special attention needs to be paid to ensure non discrimination and equal enjoyment of all human rights and fundamental freedoms by disabled persons”. These special measures entail conscious and deliberate efforts and programmes aimed at identifying and removing those barriers that would otherwise impede effective realization and enjoyment of human rights by persons with disabilities.

Having ratified the UNCRPD Kenya has to comply with article 35 that requires States

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Para. 64 of the Vienna Declaration and Programme of Action adopted by the World Conference on Human Rights of 1993

Parties to submit to the expert Committee on the rights of persons with disabilities a report on the implementation of the UNCRPD within two years after the entry into force of the convention. Kenya's state report was due in 2010, but was completed in August 2011. The considerations of the Committee on the Rights of Persons with Disabilities had been very useful for the writing of this chapter and for further speculations.

Viewing disability from a human rights perspective involves an evolution in thinking and acting by States and all sectors of society so that persons with disabilities are no longer considered to be recipients of charity or objects of others' decisions but holders of rights. A rights-based approach seeks ways to respect, support and celebrate human diversity by creating the conditions that allow meaningful participation by a wide range of persons, including persons with disabilities. Protecting and promoting their rights is not only about providing disability-related services. It is about adopting measures to change attitudes and behaviors that stigmatize and marginalize persons with disabilities. It is also about putting in place the policies, laws and programs that remove barriers and guarantee the exercise of civil, cultural, economic, political and social rights by persons with disabilities.

3.1 The UNCRPD

1. The Convention's principles

This Convention places legal obligations on States to promote and protect the rights of persons with disabilities. The introduction, for the first time, of a legally-binding instrument to promote the universal inclusion of disabled people provided an opportunity for real progress to be made in actually putting into practice the recommendations that were made in previous agreements, such as the Standard Rules and WPA.

The UNCRPD has now been signed by 160 nations (UN Enable, 2015), which represents a broad global consensus. Only 88 of these countries, however, have also ratified the Optional Protocol. Ratification is an important step as it signifies acceptance of the Convention as a binding piece of international law.

Countries that have ratified, therefore, have a legally-binding commitment to facilitating the implementation of the Convention within their own boundaries. This implementation process, as stated in a report by Ban Ki-Moon “calls for the formulation of strategic options for policies, programmes and evaluation measures that promote the full and equal participation of persons with disabilities in society and development” (UN, 2009, Paragraph 7).

Article 2 talks about “Reasonable accommodation”: it means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. “Accommodation” is the adjustment of a rule, practice, condition or requirement to take into account the specific needs of an individual with disabilities, with the aim of enabling this person to participate fully and equally. In the workplace, accommodation can include acquiring or adapting software and keyboards for an employee with a visual impairment, training or allocating extra time to complete a task. In education, reasonable accommodation might require the provision of alternative ways to fill course requirements, tutorial assistance or assistive technology. Employers, educational institutions, service providers and others have a legal obligation to provide reasonable accommodation. In deciding whether a company or a school has taken all required measures to accommodate an employee or a pupil with a disability, the concept of “disproportionate or undue burden” is the key. To establish a lawful exemption from the duty to accommodate, the employer or school must prove that accommodating the needs of an individual would impose an undue or disproportionate burden on the organization considering factors such as health, safety or cost.

Article 3 of the Convention identifies a set of overarching and foundational principles such as: respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; equality of opportunity and accessibility. Individual autonomy means to be in charge of one’s own life and to have the freedom to make one’s own choices. Respect for the individual autonomy of persons with disabilities means that persons with disabilities have, on an equal basis with others,

reasonable life choices, are subject to minimum interference in their private life and can make their own decisions, with adequate support where required. The principle pervades the Convention and underpins many of the freedoms that it explicitly recognizes, such as the freedom from nonconsensual medical intervention and the requirement that health care should be provided on the basis of free and informed consent. From this perspective, for example, a person with mental disabilities should be offered a range of options for mental health care such as psychotherapy, counseling, peer support and psychiatric medication, and should have the freedom to make a meaningful choice based on personal preferences. Likewise, a landmine survivor with a physical impairment should be provided with devices that facilitate his or her personal mobility so that he or she can enjoy as much independence as possible. Discrimination on the basis of disability means any distinction, exclusion or restriction which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise by persons with disabilities, on an equal basis with others, of all human rights and fundamental freedoms, and includes the denial of reasonable accommodation. Discrimination occurs, for example, when a woman is not allowed to open a bank account on the grounds that her disability would not allow her to manage her money³⁴. The concepts of full and effective participation and inclusion and accessibility mean that society, both in its public and in its private dimensions, are organized to enable all people to take part fully. Being fully included in society means that persons with disabilities are recognized and valued as equal participants. Their needs are understood as integral to the social and economic order and not identified as “special”. Article 12 defines equal recognition before the law and requires eliminating disability as a ground for depriving someone of his or her legal capacity, while Article 14 identifies liberty and security of the person that means monitoring psychiatric and other institutions to ensure that no one is placed there on the basis of their disability, including mental and intellectual disabilities, unless with their free and informed consent. Articles 24, 25, 27 recognize the rights of education, health and work, while the right to

³⁴This example is taken from interviews conducted in Kenya as part of a project by DRPI, the African Union of the Blind, the Kenya Union of the Blind and the Centre for Disability Rights, Education and Advocacy to monitor the rights of persons with disabilities in that country. The interviews contributed to “State of disabled people’s rights in Kenya (2007): Report”, available at: www.yorku.ca/dрпи/Kenya.html

participate in public and political life, article 29, requires election monitoring to ensure that election materials are provided in accessible formats (such as written materials in Braille and television advertisements with sign-language interpretation) and that voting booths are accessible (for example, with ramp access). The right to participate cultural life demands, among other things, examining whether sign languages and deaf culture are explicitly recognized.

2. Monitoring system

The Convention includes both national and international monitoring mechanisms (OHCHR, 2010). At the national level, article 33 identifies three mechanisms that are relevant for the implementation and monitoring of the Convention. First, States have to designate one or more focal points within government for matters relating to implementation; second, States have to give due consideration to the establishment or designation of a coordination mechanism within government to facilitate actions across sectors and at different levels; and third, States have to establish or designate a framework that includes one or more independent mechanisms to promote, protect and monitor the Convention's implementation. At the international level, article 34 establishes the Committee on the Rights of Persons with Disabilities, a committee of independent experts with several functions. First, on the basis of periodic reports received from States and other interested parties such as national monitoring mechanisms and civil society organizations, the Committee engages in a constructive dialogue with States on the implementation of the Convention, and issues concluding observations and recommendations for follow-up action to improve and strengthen implementation. Second, the Committee holds days of general discussion, open to the public, during which it discusses issues of general interest arising from the Convention. Third, the Committee may issue authoritative statements, known as general comments, to clarify specific provisions in the Convention or specific issues arising in the implementation of the Convention. Fourth, the Optional Protocol gives the Committee authority to receive complaints, known as communications, from individuals alleging violations of any of the Convention's provisions by a State that has ratified the Optional

Protocol. The Committee may present its views after considering the complaint in the light of the comments from the State concerned. Fifth, the Optional Protocol also provides the Committee with an opportunity to undertake inquiries in States parties if it receives reliable information indicating grave or systematic violations of the Convention. Human rights monitors should be aware of these mechanisms and of their functions. Monitoring activities could: provide national monitoring mechanisms with information on the state of implementation of the Convention; provide information to the Committee for its constructive dialogue with States; identify potential breaches of the rights of individuals under the Convention which could form the basis of a communication to the Committee under the Optional Protocol if the State concerned has ratified it; identify reliable information on grave or systematic violations of the Convention which could be submitted to encourage the Committee to undertake an inquiry under the Optional Protocol if the State concerned has ratified it; follow up on recommendations of the national monitoring mechanisms and the Committee to strengthen implementation of the Convention.

In practice, the collection of information about the enjoyment by persons with disabilities of their rights typically starts with the identification of sources of information. Monitors should consider a variety of sources: Constitutions, legislation and regulations are primary sources of information. In addition, monitors could also consider other sources such as parliamentary inquiries or reports; State policies and programmes relating to the implementation of legislation as well as budgets; decisions of judicial and quasi-judicial bodies such as courts and national human rights institutions; media reports, studies and research from academia or other research centers and civil society organizations.

3. Utopian aspirations?

If human rights are universal and apply to everyone, then why is there a need for a convention to protect the rights of a particular group, in this case people with disabilities? The UNCRPD largely reaffirms, recognizes or guarantees existing rights that are already recognized in instruments such as the Universal Declaration of Human

Rights, The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. (Megret, 2008: 494-516). However, these rights instruments have largely failed people with disabilities.

Stating the seemingly obvious, the UNCRPD applies human rights that are specific to people with disabilities, and encompasses fundamental principles of respect for dignity, non-discrimination, participation and inclusion in society, respect for difference, equality of opportunity, and accessibility. Megret refers to rights targeted at certain groups as the “pluralisation of human rights”, which may seem at odds with the concept of universality and equal rights for all; an ideal which Megret suggests is “both helpful and insufficient” (Ibid.)

Whilst acknowledging the potential of a universalist approach (that is recognizing and expecting the diversity of humanity) and its influence on the UNCRPD, Kayess and French (2008) also consider how its ‘Utopian aspirations’ may be difficult to realize. In fact, because the ideological premise underpinning the notion of universalism is predominately an egalitarian concept originating and led by countries of the global North, it further reinforces the cultural hegemony of a rights based approach – an approach that is not always the normative reality across states. The UNCRPD is clearly premised on the social model. Paragraph (e) of the preamble recognizes that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations, 2013). People with disabilities are therefore not viewed as objects of charity but rather “as subjects of rights able to claim those rights as active members of society” (Kamga, 2013: 227). However, due to factors such as historical discrimination, not everyone is starting from the same position when claiming rights, and hence instead of merely proclaiming rights the UNCRPD guides states to how rights should be implemented (Megret, 2008). This is achieved through measures such as awareness raising, reform and adoption of domestic legislation (substantive equality measures), training, employment quotas and provision of services. These measures emphasize the duty of states to the individual, which in some societies rarely exists or is even pejorative. Kamga (2013) argues that the UNCRPD ignores the communal approach to human rights in Africa and the notion of ubuntu, which

Desmond Tutu described as meaning “a person is a person through other persons” (Tutu, 1999: 31). The individualism of rights emanating from industrialized societies does not always reflect community structures based on traditional practices such as agriculture.

On the other hand, Megret (2008) suggests that the UNRPD’s general principle of “full and effective participation and inclusion in society” and Article 16’s right to “freedom from exploitation, violence and abuse’ imply a social dimension that also, perhaps contentiously, makes a broader demand ‘not only to the state but also to society’. From an African perspective, Kamga (2013) further contends that it is the duty of all communities to supplement the role of the state. Whilst the anti-discrimination initiatives contained in the UNCRPD are essential in curtailing state discrimination against people with disabilities, the expectation of governments to create an enabling environment by enforcing individuals to discourage discriminatory practices are, according to Lang ‘virtually impossible’ (Lang, 2009: 281). While Kamga supports community supplementation of the role of the state, Lang advises caution against the “privileging of local knowledge that ignores broader structural oppression that exists in many local communities” (Ibid.). This is not to say that participatory methods to development do not work, but that they can be influenced by local power relations and hierarchies. A universal approach undoubtedly faces certain contextual problems, particularly in implementation, but wallowing in a stagnant pool of cultural relativism will not help people with disabilities realize their rights either.

3.2 Legal capacity and independent living

1. The concept of legal capacity

Stigma associated to mental disabilities results in people being denied a wide variety of economic, social, cultural, civil and political rights afforded to others. People with mental disabilities, in particular, are often assumed to lack capacity to take charge and make decisions concerning their own lives.

Legal capacity means the opportunity to have rights and the power to exercise those

rights. Both of these elements are integral to the concept of legal capacity because they establish the rights and responsibilities of persons with disabilities to make their own decisions (The European Group of National Human Rights Institutions, 2008). Practically, legal capacity is the law's recognition of the validity of a person's choices. It is what allows a person to act within the framework of the legal system. In other words, it makes a human being a subject of law. Legal capacity is something that most people take for granted, so that upon reaching the age of majority (in Kenya, 18 years of age) one will be able to make one's own decisions which will be respected, so it is the right to become a self-determining individual. This has not been so for persons with disabilities, who have tended to be treated as "objects" to be managed as opposed to rights holders with their own interests and desires.

As mentioned, legal capacity comprises of two parts: the first part includes the right to be a subject before the law; for example, to be somebody who can own property, have a job or start a family; the second part goes further and includes the power to dispose of one's property and claim one's rights before a court. The main difficulty with disability generally - and intellectual disability and psychosocial disability specifically - is the easy presumption that disability simply equates with a lack of capacity or judgment. In large part this assumption rests on stereotypes and exaggerates the effects of disability. That is, it fails to see the person behind the disability.

Legal capacity is important as a result of the fact that goes beyond decision-making to the core of what it means to be human. Without legal capacity, our freedom to make choices is greatly diminished, and it is a fact that life choices are part of who we are. Having all or most decisions made for a person teaches them dependence and helplessness which devalues their humanity. Without legal capacity, many, (if not all) rights become meaningless: for instance, the right to own property, the right to private life, the right to work, the right to political participation and the guarantee of free and informed consent with regard to the right to health. Another consideration is that the state should acknowledge that there is a gender aspect to the manner in which the right to legal capacity plays out in the Kenyan context. In fact, women with disabilities face compounded barriers in seeking to exercise their legal capacity on an equal basis with others. Article 6 of the UNCRPD recognizes that women and girls with disabilities are

subject to multiple discrimination, and mandates States Parties to take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

Legal capacity is also important because it has a huge impact on how other people view persons with disabilities: for instance, service providers, public officials and members of the community. If persons with disabilities are seen to be incapable of making any decisions about their own lives, stigma about disability is reinforced. As it has already been explained, stereotypes are a significant barrier to the inclusion and participation of persons with disabilities in society.

Discussions on legal capacity in Kenya reveal two elements. The first element has to do with the law, and largely addresses the aspect of legal capacity that entails the capacity to have rights, encompassing laws that forbid people with disabilities from having certain rights on account of their disability. Examples of the foregoing are laws that deny the vote to “persons of unsound mind” and laws that allow for guardianship for persons with disabilities. The second element of the way legal capacity plays out in Kenya has to do with the practice on the ground, and largely addresses the aspect of legal capacity that entails the capacity to exercise rights. As highlighted in the previous chapters, in Kenya the law is not the greatest barrier to the exercise of the right to legal capacity by persons with disabilities. Factors such as poverty and high rates of unemployment among persons with disabilities and the dependency that ensues as a result, a largely inaccessible environment, limited state support and services and unaddressed mental health care needs among other things negate the exercise of the right to legal capacity by persons with all types of disabilities. Hence, the problem of exercising legal capacity in Kenya is largely an informal rather than a formal one.

2. The concept of independent living

In my opinion, another concept closely related to legal capacity is that of independent living. Article 19 provides that persons with disabilities have the right to live independently in the community. Community living (also known as independent living), refers to persons with disabilities being able to live in their local communities as equal

citizens, with the support that they need to participate in every-day life. Independent living is about having the autonomy and independence to make decisions and having control over the choices and shape of one's life. In fact, the Article recognizes that persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement (a). Indeed, independent living has been regarded as a concept rather than an issue requiring specific legal definition. From this point of view, it is the philosophy underpinning the struggle by people with disabilities to achieve self determination, choice, autonomy, equal access, community inclusion and participation. Article 19 has been said to extend the traditional right of liberty. In the words of Kayess and French, Article 19 equates the right to liberty with the right of persons with disability to live in and be a part of the community (Kayess and French, 2008).

The issue of independent living is linked to all different aspects analyzed or mentioned so far. In fact, the right to live independently is further complicated by poor education (and poor self image and self-motivation that follow), which hinder market entry at a level genuinely commensurate with abilities. Furthermore, a lack of equally effective and accessible transport facilities hinders not merely labour market mobility but also ordinary social intercourse. Lack of access to the assistive devices needed to enable active and equal participation in life presents a particular problem for many of those with physical and sensory disabilities, which, in combination with direct discrimination against them, act as a barrier to independent living.

3. Legal capacity and independent living in international law

Kenya ratified the UNCRPD in 2008 and in 2010, the new Kenyan Constitution automatically incorporated ratified conventions, such as the UNCPRD, into Kenyan national law. Notably, Kenya did not make any reservations on Article 12 nor on Article 19, indicating the government's willingness to implement the provision in its entirety and undertaking an obligation on the government to secure this right in practice for people with disabilities in the country. These two articles essentially set out some of the

principles about how States need to shift away from substituted decision-making regimes. By “substituted decision-making” we include formal processes such as appointing guardians, estate manager, public trustee or courts’ direct management of people’s affairs and through informal norms that fail to respect the choices, will and preferences of adults with disabilities. Instead of substituted decision-making, States should adopt supported decision making, by which we mean respecting peoples autonomy and decisions, avoiding making decisions for people based on notions of a perceived “best interest”, and to provide people with access to support they may need to communicate their decisions or to have their will, preferences and choices understood and respected. The rights to legal capacity and independent living refer both to the recognition of the individual as rights holder, as well as an actor in law throughout “all aspects of life”.

Article 12 states among other things that States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law (1), and shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life (2). States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (3) and they shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law (4). The UNCRPD recognizes that some people need support in exercising their legal capacity and States must respect the agency of people with disabilities on an equal basis with others and must provide access to support for the exercise of that agency, it is to say that having a disability does not mean that the person requires assistance in all or every case.

Article 19 affirms that States Parties recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, prevent isolation or segregation from the community.

In any supported decision-making framework, primacy must be given to a person’s “will and preference” (Article 12(4)). This means that States must abolish substituted

decision-making based on someone's perceived best interests. This refers to the situation where a substitute decision-maker (who may be a government official, a local community leader, teacher, carer/family member, a friend or a member of the community) makes a determination based on what they believe is in the best interest of the individual, which may not be the same as the person's will and preferences. A support paradigm demands that the people around the individual work hard to communicate with the individual and to provide the support necessary for them to express their will and preferences and to act on these.

4. Legal capacity and independent living in Kenya

In Kenya the responsibility for caring for people with disabilities is often entirely on family members. As a result, these dealings are based on private and socially acceptable norms that have no direct reference to legal or human rights standards. It is unsurprising, therefore, that family members – often the caretakers/providers of basic necessities – believe they should make decisions for those they care for. Sometimes, decisions are made with good intentions and in other cases the family members do not know what to do. Since people have been socialized to believe and think that they know better than people with disabilities, they make decisions in total disregard to their opinions, views and feelings on the issue.

Kenya has a complex web of laws that address situations where individuals, because of a disability, are adjudged to have lost the capacity to make certain types of important decisions³⁵. This legal framework is based on a system of substitute decision-making, to occur in the best interests of the person who is deemed to lack legal capacity. Kenya has narrow guardianship laws that tend to target particular areas of decision making, for instance making it possible for one to lose legal capacity with regard to the management of property and financial affairs but retain legal capacity with regard to the decision to

³⁵ These laws include the Constitution of Kenya 2010, Mental Health Act (Cap 248), Age of Majority Act, Persons with Disabilities Act, No.14 of 2003, Civil Procedure Act (Cap 21), Criminal Procedure Act (Cap 75) Sale of Goods Act, Law of Succession Act, Traffic Act (Cap 403) Matrimonial Causes Act, Children's Act No.8, 2001, Penal Code, Sexual Offences Act, Evidence Act (Cap 80), and the Election Act. All laws quoted are available at Kenya Law Reports, 'Laws of Kenya' <http://www.kenyalaw.org/kenyalaw/klr_home/>

marry³⁶. None of the legal provisions touching on legal capacity in Kenya mention the central role of the persons' will and preferences in making decisions affecting their lives. Generally, the laws do not recognize the state obligation to provide access by persons with disabilities to the support they may require in exercising legal capacity as required under Article 12.

The spectrum of laws that touch on legal capacity in Kenya raise difficult issues. On the one hand, it may be asserted that these laws are a careful balance between the security and autonomy of persons with disabilities which, if properly implemented can promote their well-being. On the other hand, many persons with disabilities have long raised concerns about the assumptions that underlie both the substance and the implementation of laws ostensibly meant for their security and protection.

Concern has been raised that laws of this nature continue to view persons with disabilities as objects to be cared for, protected and managed by others as opposed to as full persons with equal rights, dignity and worth. For example, Section 3 of the Election Act, 2011 states that every adult citizen has the right to vote in accordance with Article 38 (3) of the Constitution. The Constitution grants every adult citizen the right to vote and participate in the electoral process. This right is subject to "reasonable restrictions", a phenomenon that is abstract and if unchecked, can be abused and stretched beyond its intended limits. Section 9 of the Act states that where a person has been adjudged or found to be of unsound mind, where the person is entitled to appeal the decision, the person shall not be disqualified from being registered until the expiration of thirty days after being so declared or until the appeal has been determined. Where a person, having duly applied to be registered as a voter, has not been so registered the person may lodge a claim to the registration officer and may appeal to the Principal Magistrates Court or further to the High Court. The Act disqualifies a person of unsound mind from being nominated as a Member of Parliament, county assembly, governor, speaker and other public offices. Section 36 outlines the criteria for allocation of special seats by political parties which include a requirement that the list shall include eight candidates four of whom shall be persons with disabilities.

³⁶ Section 107 of the Children's Act points to a situation in which a guardian is appointed in cases where a person is incapable of maintaining himself, or of managing his own affairs and his property on account of a disability.

Another example is the Matrimonial Causes Act (Cap 152). The fact that the ground of petition for divorce is premised on disability makes it a discriminatory ground and hence objectionable. Section 8(2) further elaborates on the circumstances and uses discriminatory and derogatory language that presents a person with disability as one that should be denied capacity to make an informed decision on life choices: “a person of unsound mind shall be deemed to be under care and treatment [...] of insane persons, lunatics or mental defectives, or is detained as a criminal lunatic under any law for the time being in force in Kenya.” The Act further makes the assumption that persons with disabilities do not have legal capacity and states that “every petition in a matrimonial cause shall be signed by the petitioner and in the case of an infant or a person of unsound mind it shall be signed by his next friend.” The Act like many other likens a person with disabilities to an infant or a child in terms of legal capacity and out rightly embraces the model of substituted decision making.

As will be explained below, in August 2010, Kenya adopted a Constitution that has been seen as progressive, and which specifically protects the rights of persons with disabilities. The UNCRPD is also part of the law of Kenya by dint of Article 2(6): Kenya having signed and ratified the Convention on the Rights of Persons with Disabilities in 2008, is constitutionally bound by its provisions. An imperative Article in ensuring that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life is Article 27. It states that “every person is equal before the law and has the right to equal protection and benefit of the law.” It further prohibits discrimination against a person on any ground including health status, age or disability. The state report identifies that Article 27 “guarantees equal treatment, including the right to equal opportunities in political, economic, cultural and social spheres”³⁷. With regard to the Constitution of Kenya and Article 12(5), the state report identifies that the Government of Kenya has put in place constitutional guarantees that ensure the equal right of persons with disabilities to own or inherit property. This, the State reports, is contained in Article 40 of the Constitution of Kenya which guarantees the rights of

³⁷Committee on the Rights of Persons with Disabilities, ‘Future Sessions; Consideration of Reports’ (National Report: Kenya’s Initial Report Submitted Under Article 35(1) of the United Nations Convention on the Rights of Persons with Disabilities - 31st August 2011)

every person, including persons with disabilities, to acquire and own property. The State, however, acknowledges that the issue of inheritance, especially for land, for persons with disabilities is still a major challenge as they are often disinherited of their property by their kin and guardians. According to Article 38 every adult citizen has the freedom to make political choices which include the right to be registered as a voter and be a candidate for public office without unreasonable restrictions. The Constitution however fails to interpret what “unreasonable restriction” means. Indeed sections 83(1)b, 99(2)e and 193(2)d of the Constitution are potentially in conflict with Kenya’s obligations under the UNCRPD to ensure that persons with disabilities are able to enjoy legal capacity on an equal basis with others. (UNCRPD, art.29)

Article 83(1)b limits Article 38 by providing that a person fulfill requirements for registration as a voter at elections or referenda if the person is not declared to be of unsound mind. Article 99(2) e disqualifies persons of ‘unsound mind’ from being elected a member of Parliament. Article 193(2) d disenables persons of ‘unsound mind’ from being elected a member of a county assembly. However, the Constitution is silent on the definition of ‘unsound mind’, and the term ‘unsound mind’ is not defined anywhere in the Laws of Kenya³⁸. (Equal Rights Trust and Kenya Human Rights Commission, 2012: 141)

In this regard, it is important to note that Kenya has also ratified the African Charter of Human and Peoples’ Rights which provides to every individual the right to equality before the law and equal protection of the law³⁹.

In early April 2014 Mental Disability Advocacy Center released “The Right to Legal Capacity in Kenya”. The report highlights the voices of people with mental disabilities themselves for the first time, shows that Kenya must take immediate action to ensure comprehensive recognition of the right to legal capacity of all people with disabilities in the country, and that the State must take a lead to tackle social prejudices which disadvantage the vast majority. In fact, one of the most significant findings of this report is the way in which ingrained social prejudices against people with mental disabilities

³⁸The court in *Republic v Chairperson Kilibwoni Disputes Tribunal & 2 others* (High Court at Eldoret 2009 e KLR Misc. Civ. Appli. 74 of 2009) stated that only a court of law can declare a person to be of ‘unsound mind’.

³⁹Article 3 of the African Charter of Human and Peoples’ Rights

leads to significant restrictions being placed on their independence and autonomy on a daily basis. Stereotypes of people with mental disabilities are reflected in a legislative framework which systematically denies them legal recognition in a wide variety of areas including education, employment, management of property and land and access to healthcare. The testimonies from people with intellectual disabilities and people with psycho-social (mental health) disabilities presented in this report provide a compelling case for the need for legal and social reform. Many of them, in their own words, describe the restrictions placed upon them on a daily basis, limiting their freedom to move, to associate with others, even to make decisions about marriage and founding a family. The effects of social isolation and discrimination are brought into even starker contrast in the testimonies of women with mental disabilities, many of whom reported experiencing gender-based violence, rape and even forced sterilization.

The report provides comprehensive recommendations to bring Kenya in line with international law, and specifically right to legal capacity guaranteed by Article 12 of the UNCRPD. For example, it recommends to introduce legislation and enabling regulations to guarantee the right to legal capacity in all areas of life for people with mental disabilities, including in accessing justice, healthcare and treatment decisions, the exercise of political and civil rights, family life and marriage, property and land law, and in the criminal justice system for both victims and perpetrators (Mental Disability Advocacy Center, 2014: 8).

In practice, the government of Kenya has given mixed signals with regard to people with disabilities exercising their legal capacity with regard to political rights, specifically, voting for people with intellectual disabilities and/or mental disability⁴⁰.

Advocacy by some non-governmental organizations including the Disability Caucus on the Implementation of the Constitution and the Kenya Association of the Intellectually

⁴⁰During the constitutional referendum campaign in 2010, the Interim Independent Electoral Commission (IIEC) Chief Executive Officer reportedly said that, “Voter registration and the act of voting means exercising discretion. Exercising discretion after considering all the relevant factors is a very intellectual exercise and perhaps if you are mentally impaired, you may not be able to exercise that capacity to use the vote”. About a month later, he is quoted as having said “There are about 3.6 million people with mental disabilities but what do you do with that number? ... How do you make the world realise that you are there? The only way to do that is to be a contributor in the major decision making process in your country ... let us make sure that at least a half of those with disabilities are registered”. Lawrence Mute, *Shattering the Glass Ceiling: Ensuring the Right to Vote for Persons with Intellectual Disabilities In Kenya* (2010) Thought and Practice: A Journal of the Philosophical Association of Kenya (PAK), p. 6

Handicapped prior to the August 2010 constitutional referendum resulted in the government registering and assisting some adults with intellectual disabilities in exercising their right to vote. The government for the first time allowed persons with intellectual disabilities to have their supporters assist them in casting the ballot. But the “laws” of the election campaign have long been known.

5. Formal guardianship

The first question posed to all the respondents is whether guardianship is common in Kenya. Unanimously, the answer is negative: “In this country we deal with matters outside the court, as much as possible. People generally don’t trust the law. I don’t know anyone – we have the extended family dealing with things. The guardianship law is not active”.

“We run support groups for persons with psychological disabilities in parts of the and there is no one I know who is under formal guardianship. I can assure you that formal guardianship is extremely rare in Kenya.”

“Most of the people with mental disabilities in the organizations are under what I would call informal guardianship. In our country, when you get a child with disability, you’re automatically the guardian. You don’t go to court, it’s natural, and naturally you become the guardian. With regard to the court process, amongst our members, no one is under formal guardianship.”⁴¹

Various explanations were given for the fact that the formal guardianship process is so rarely used in Kenya. First is that people find the formal justice system in Kenya inaccessible, particularly because it is deemed to be expensive. Secondly, people in Kenya tend to deal with things informally, as much as possible – across the board, not just with regard to issues regarding persons with disabilities. Thirdly, formal guardianship would probably be resorted to in instances where a person with a disability

⁴¹People from different organizations, such as World Friends, DeafAid, L’Arche Kenya interviewed between 06/03/2015 and 13/05/2015

came to property, and that is not too common given the widespread poverty in the country. A fourth reason could be because there is generally lack of awareness about guardianship.

Concretely, families are skeptical about allowing their family members with intellectual disabilities to make their own decisions. Families are worried about having to manage with the situation in case their family member with intellectual disability makes a bad decision. When support persons are not family members, families are concerned, for instance, about their family member with an intellectual disability being exploited financially. It may also be necessary to develop smaller measures of protection to ensure that families buy in to the idea of supported decision-making.

Some persons with disabilities do not have family to fall back on for support. Other persons with disabilities do have families, but are estranged from them: “There is tension between the person and the family. The family often does not understand. For a number of people at the support group, the biggest enemy is the family. They don’t understand, make negative comment, and so the last people the people with psychosocial disabilities want helping them, is the family. But here in Kenya, we don’t have alternatives. If we refuse the family, then there is the street.”

3.3 Other international instruments

1. Laying the foundations for UNCRPD

The enactment of the UNCRPD, in 2006, represents a major landmark for the worldwide disability movement, as it provides a legally-binding, internationally-agreed framework for promoting the economic and social participation of disabled people. In doing so, the Convention raises the profile of disability issues, such as the need to promote economic empowerment and to tackle poverty issues among disabled people.

In 1944, the ILO stated that “Disabled workers, whatever the origin of their disability, should be provided with full opportunities for rehabilitation, specialized vocational guidance, training and retraining, and employment on useful work”. (ILO, 1944: 1) Stimulated by the need for trained workers to replace those called to fight in World War

II, this signaled the beginning of rehabilitation and training programmes for disabled people in Europe. (O'Reilly, 2007) Since then, there have been a series of international agreements that have relevance to the issue of economic empowerment for disabled people⁴².

In the 1970s, two important UN declarations demonstrated growing international awareness of the importance of recognizing the human rights of people with disabilities. The first of these was the 1971 UN Declaration on the Rights of Mentally Retarded Persons, in which the economic rights of people with intellectual impairments and psychiatric issues were specifically addressed, perhaps for the first time in an international agreement. This wide-ranging declaration established that 'mentally retarded persons' should have the same rights as all other human beings, including the "right to perform productive work or to engage in any other meaningful occupation". (UN, 1971: point 3) The second one was the 1975 Declaration on the Rights of Disabled Persons, which promoted the political and civil rights (including rights to economic security and employment) of all people with disabilities. This declaration also stated the need to consult with DPOs "in all matters regarding the rights of disabled persons", (UN, 1975: point 12) which is an indication that the principle of actually involving people with disabilities themselves in the process of promoting and protecting disability rights was finally achieving international recognition.

Following the International Year of Disabled Persons in 1981, which was marked by various research projects, conferences and policy recommendations, the United Nations adopted the World Programme of Action Concerning Disabled Persons (WPA), in December 1982. This programme effectively restructured disability policy into three broad areas - prevention, rehabilitation and equalization of opportunities – and advocated long-term, multi-sectoral strategies that could be integrated into national policies.(UN, 1983) The UN General Assembly also stipulated that 1983- 1992 would be known as the UN Decade of Disabled Persons, in which member states would be encouraged to implement the WPA.

The UN Decade of Disabled Persons culminated in the introduction of the 'UN

⁴²Perhaps the most famous of these agreements is the 1948 Universal Declaration of Human Rights, which was the first major global declaration on the basic rights to which all are entitled.

Standard Rules on the Equalization of Opportunities for Persons with Disabilities’, which was adopted in December 1993. This set of guidelines was designed to “ensure that girls, boys, women and men with disabilities, as members of societies, may exercise the same rights and obligations as others” (UN, 1993: para.15) The aim, essentially, was to eliminate all forms of disability discrimination.

The positive impact of this agreement was highlighted by the Special Rapporteur, in his 1998 statement to the UN on the implementation of the Standard Rules: on the other hand, he notes that disabled people were still discriminated against in many areas of life, and largely excluded from employment. Lindqvist’s explanation for this demonstrates a perception of disability that appears to be strongly influenced by the social model. He states that “the exclusion of disabled people from the open society has its roots in lack of knowledge and attitudinal barriers. It mainly leads to neglect of the needs of disabled people when designing and constructing environment, services and programs, available to nondisabled people” (Lindqvist, 1998)

The World Summit for Social Development, in March 1995, was attended by 117 Heads of States or Governments, making it the largest gathering of world leaders that had ever taken place (UN, 1995). The conference ended with the adoption of the Copenhagen Declaration on Social Development, which set out a range of social development objectives, to be achieved through sustainable policies that promoted human rights and the empowerment of vulnerable groups. The Copenhagen Declaration was accompanied by a ‘Programme of Action’, which has a clear disability dimension. For example, in order to increase employment opportunities for people with disabilities, the Programme calls for antidiscrimination laws, affirmative measures (such as support services and incentive schemes), workplace adjustments and “promoting public awareness within society regarding the impact of the negative stereotyping of persons with disabilities on their participation in the labor market” (UN, 1995: para.62(e)).

An even larger gathering of the UN took place five years later, resulting in the adoption, by all 189 member states, of the 2000 Millennium Declaration. This famous declaration set out a blueprint for a global partnership, aimed at ensuring that “globalization becomes a positive force for all the world’s people”. (UN, 2000: para.5) This global partnership would focus on promoting peace and reducing poverty, through achieving

the eight MDGs by 2015. The Declaration refers to various vulnerable social groups, including women, children and those with HIV/AIDs. Surprisingly, however, there is no specific mention of disability. The Secretary-General of the UN, Ban Ki-Moon, has acknowledged the error of ignoring disability in the wording of the Millennium Declaration, and its accompanying guidelines, pointing out that, “as a consequence, periodic reviews of the MDGs that are under way within the UN do not include reference to disability issues” (UN, 2009: 3) His report concludes that these omissions, together with the difficulties in obtaining sufficient data on the disability situation in developing countries, have made it very difficult to assess the impact of the MDGs on people with disabilities.

In 2001, following consultations with Governments, employers’ organizations and workers’ organizations at a tri-partite meeting of experts, the ILO produced a Code of Practice for Managing Disability in the Workplace. The Code gives guidance on the implementation of various measures covered in earlier international agreements and covers a wide range of employment related issues. These include recruitment processes, workplace accessibility and adjustments, provision of training opportunities, career development, communication and awareness-raising. While not a legally-binding instrument, the Code was intended as a good practice guide to employers throughout the world, to be used in the context of national conditions, in order to “enable workers with disabilities to contribute productively to the enterprise and to maintain valuable work expertise” (ILO, 2001:1) While aimed primarily at employers, the Code was also intended to assist public sector agencies (in forming the necessary policies for promoting disability employment rights), workers’ organizations (in representing the interests of disabled workers) and DPOs (in promoting employment opportunities for their members).

2. African regional human rights instruments

Existing African human rights provisions on disability are not in one treaty but are scattered in general human rights treaties and specific treaties for particular groups where disability intersects. From the general human rights perspective, the African

Charter is the primary African regional human rights instrument (African Charter on Human and Peoples' Rights, 1981). The Charter provides for universal human rights, and article 2 entitles every person to enjoy "the rights and freedoms recognized and guaranteed in the present Charter without distinction of any such kind such as race, ethnic group, color, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status." Though article 2 does not specifically mention disability, the inclusive nature of the text, by using the phrases "such as" and "other status," suggests a more objective rather than subjective standard that includes disability. To promote a substantive approach to equality for persons with disabilities, the Charter provides for the universal right to the best attainable physical and mental health and special protections tailored to the specific "physical or moral needs" of the elderly and disabled. Therefore, States are mandated to take positive steps to ensure persons with disabilities have the capacity to enjoy the rights guaranteed under the Charter. Article 66 of the Charter provides the legal basis for adopting protocols for fully realizing human rights⁴³.

Based on this provision, the African Union proposed the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa. The AU adopted this protocol in reaction to the inadequacies of its U.N. equivalent, the Convention on the Elimination of all Forms of Violation Against Women (CEDAW). Unlike CEDAW, the African Women's Protocol specifically provides for the rights of women with disabilities. Article 23(a) and (b) of the Protocol provides that state parties undertake to (a) "ensure the protection of women with disabilities and take specific measures commensurate with their physical, economic and social needs to facilitate their access to employment, professional and vocational training as well as their participation in decision-making"; [and] (b) "ensure the right of women with disabilities to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity". (UN, 1979)

The African Charter on the Rights and Welfare of the Child is another example of a regional treaty addressing the rights of persons with disabilities. Article 13 provides that

⁴³ "Special protocols or agreements may, if necessary, supplement the provisions of the present Charter."

parties must provide “special measures of protection” for children with disabilities. The article requires appropriate measures to ensure promotion of dignity, self-reliance, and full participation in the society for handicapped children. It also mandates accessibility in public places. Lastly, the African Youth Charter includes provisions for persons with disabilities. Article 24(1) of the Youth Charter provides that: “State Parties recognize the right of mentally and physically challenged youth to special care.” The provision seeks to ensure access to education, training, employment, sport, physical education and cultural and recreational activities and, just like the Charter on the Child, calls on state parties to improve accessibility.

Despite the provisions on disability, the African treaties discussed above adopt a rudimentary medical model approach to disability that singularly attributes disability to impairment without considering social and environmental factors. Using phrases such as “handicapped children” and “mentally and physically challenged youths” demonstrate this. (African Charter of the Child, arts. 13, 24) In this way, existing African regional instruments on disability fall short of international human rights standards as prescribed in the UNCRPD that adopt a more social, rights-based approach to disability.

Human rights institutions formed by treaties include: the African Commission, the Committee of Experts on the Rights and Welfare of the Child, and the African Court of Human Rights⁴⁴. All the above bodies have eleven members and, although they are financed by and ultimately report to the AU, they act independent of the AU⁴⁵. Indeed, as of January 2015, only twenty-seven countries out of fifty-four African states have ratified the Protocol establishing the African Court of Human and People’s Rights, only sixteen have ratified the Protocol on the Statute of the African Court of Justice and only five have ratified the Protocol on the Statute of the African Court of Justice and Human Rights (African Commission on Human and People’s Rights). Despite existing for over twenty-eight years and playing a comparatively large role in regional human rights, the

⁴⁴ African Charter on Human and People’s Rights, at art. 30 (establishing the African Commission on Human and People’s Rights); African Charter on the Child, at 306 (establishing the African Committee of Experts on the Rights and Welfare of the Child); Protocol to the African Charter on Human and People’s Rights on the Establishment of an African Court of Human and Peoples’ Rights art. 1, 6 AFR. Y.B. INT’L L. 419 (1998) (establishing the African Court of Human and People’s Rights).

⁴⁵ Protocol to the African Charter, Establishment, at 422 (setting the limit of the African Court of Human and People’s Rights at eleven judges); African Charter on Human and People’s Rights at art. 64.

African Commission only recently started to include disability in its agenda. In 2009, the African Commission established a working group for older persons that were later amended to include persons with disability (African Commission on Human and People's Rights, 2009). This development was a result of the Ministerial Conference's recommendation to develop a regional protocol for persons with disability and the elderly. (African Commission on Human & Peoples' Rights, 2003) This Working Group effectively developed the first draft of the regional disability protocol. Despite the draft not seeing the light of day, the working group is currently drafting another protocol.

The ineffectiveness of African treaty human rights organs has been compounded by persistent lack of institutional coordination, proliferation, limited financing, and human resource incapacities. A recent report described the general African human rights institutional framework as "a system lacking in coherence, composed of institutions with overlapping and sometimes conflicting mandates and functions." These institutions compete for limited AU resources and are often "underfunded and understaffed." (African Commission on Human & Peoples' Rights, 2014) The combination of these factors has worked to undermine the functioning and efficiency of the AU human rights institutional framework. In terms of disability, the fact that only one related case has been handled is a testament to the low awareness of existing institutions and their role in disability human rights⁴⁶. Also, the isolated drafting of the first disability protocol by the African Commission Working Group may illustrate the bridge between African human rights institutions, disabled people's organizations, civil society, States, and individuals, including disabled persons.

3.4 National legislative instruments

1. National current situation

On a national level, Kenya has put in place various legislative measures; the most important is the Persons with Disabilities Act (2003). The Act (PDA), which sets out the

⁴⁶Purhohit & Moore v. Gambia

rights of people with disabilities in all areas of life, is the main piece of legislation concerning disability in Kenya. The PDA represents a signal of intent, by the Kenyan Government, to promote the equal participation of people with disabilities in society, in line with the principles underlying preceding international agreements, such as the UN Standard Rules. Section 12 of the PDA, concerning employment rights, prohibits various forms of discrimination, from recruitment processes to working conditions and career development. Section 12 also contains some affirmative measures designed to promote disability employment, including tax benefits to employers for adapting their workplaces and for employing people with disabilities, tax exemptions for employees themselves, and a requirement that all public and private sector employers reserve five per cent of jobs for people with disabilities. These are the kind of “special positive measures” that were called for by ILO Convention No. 159.

The PDA has been criticized, in some quarters, for lack of clarity and legal inconsistencies, which have proved a hindrance to its implementation. AFUB, for example, criticize its planned phased implementation, with some sections excluded initially, which has caused “mental anguish” among disabled people that are unsure as to how to interpret the Act (AFUB, 2007: 38) Their report also claims that the use of phrases such as “to the maximum of its resources” relies too much on discretion, leaving the PDA unenforceable and open to abuse. (Ibid.: 39) Action Network for the Disabled (ANDY), a Kenyan youth disability organization, have also criticized the slow implementation process, which they attribute to “lack of information and limited political and social acceptance of the extent to which disabled people continue to be denied their rights”.

In 2004, in line with PDA provisions, the Government set up the National Council of Persons with Disabilities (NCPWDS) as a semi-autonomous Government Agency, with a membership drawn from key government ministries as well as representatives from DPOs and disability-focused NGOs. The aim of this Council was to facilitate the implementation of the PDA, by formulating policies and measures designed to promote the participation of people with disabilities in society. Among the objectives set out in the Council’s 2006-2009 Strategic Plan was a commitment to “promote and facilitate the mainstreaming of persons with disabilities in social and economic development

through financing viable income-generating projects” (NCPWDS, 2006: 16) This would be achieved, according to the Plan, by developing criteria for the identification of viable income generating projects at the grassroots level and setting aside financial resources to support these projects.

In 2006 The National Disability Policy was developed by the Department of Social Services under the Ministry of Gender, Sports, Culture and Social Services. The policy aims to guide the Ministry’s plans on how to address the needs and concerns of persons with disabilities. It recognizes that persons with disabilities are a distinct group whose needs, capabilities and aspirations require special attention. The policy, however, does not recognize the right to legal capacity as being fundamental to persons with disabilities attaining equality and inclusion. On the topic of protection and legal services, the policy correctly notes that persons with disabilities are usually assumed not to have legal rights and in some cases, their capacity to make decisions is hijacked often resulting in their exploitation, abuse or at the least misrepresentation of their interests. In view of this, the policy includes a statement to ensure that the Persons with Disabilities Act is harmonized with international instruments to which Kenya is signatory. It further provides that persons with disabilities should be sensitized on their rights.

The Employment Act of 2007 also needs to be mentioned. The Act prohibits discrimination on grounds of disability. Section 5(3) provides that no employer shall discriminate directly or indirectly, against an employee or prospective employee or harass an employee or prospective employee on among other grounds, disability. Sections 5 (1) and (2) of the Act imposes a duty on the Minister, labor officers, and Industrial Court to promote and guarantee equality of opportunity in employment. Section 46(g) provides that disability does not constitute a fair reason for dismissal or for the imposition of a disciplinary penalty on an employee. However, the Act can be interpreted as contributing to the economic marginalization of persons with disabilities by not treating the employment of persons with disabilities as a subject requiring special concern. It fails to recognize that that they face discrimination when they seek employment and that they have limited opportunities compared to those without disabilities. It has no provision to impose obligations on employers to employ persons

with disabilities leaving them consequently to the liberalized job market, which is heavily biased against them. Besides these provisions in the Act nothing much has been undertaken in Kenya to deal with employment of persons with disabilities.

The National Gender Equality Commission (NGEC) is a constitutional Commission established by an Act of Parliament in August 2011. NGEC is sister Commission to the Kenya National Commission on Human Rights and the Commission on Administrative Justice (CAJ), all entrenched in the Constitution of Kenya under Article 59 under the umbrella the Kenya National Human Rights and Equality Commission. The key objective of the NGEC is to promote gender equality and freedom from discrimination in accordance with Article 27 of the Constitution of Kenya. In so doing, the Commission acts as the principal organ of the State in ensuring compliance with all treaties and Conventions ratified by Kenya relating to issues of equality and freedom from discrimination and relating to special interest groups including minorities and marginalized persons, women, persons with disabilities, and children. The Commission therefore plays a vital role in monitoring implementation of rights of persons with disabilities.

The Persons with Disabilities Act of 2013 constitutes a further step in seeking fighting against discrimination. Its object is also to provide for the rights and rehabilitation of persons with disabilities and to achieve equalization of opportunities for them. Furthermore, in 2013, the government established the Ministry of Labour, Social Security and Services. Under the current Ministry, the Department of Social Services is charged with the mandate to protect, advocate for needs of persons with disabilities, facilitate and coordinate disability mainstreaming in national development planning and budgetary processes. The department, together with National Council for Persons with disabilities (NCPWD) runs the Cash Transfer Programme for persons with severe disabilities.

In June 2015 an Amendment Bill was presented by Senator Godliver Omondi, representing people with disabilities. Article 54(1) of the Constitution provides for various rights in relation to persons with disabilities. The Constitution further establishes two levels of government, the national government and the county governments. These two levels of government have an obligation to ensure that persons

with disabilities within their jurisdiction are protected and that the requirements of Article 54(1) of the Constitution are met. It is in this context that this Bill proposes to impose on each level of government to address the socioeconomic needs of persons with disabilities. The Bill proposes to establish, in every county, a committee for persons with disabilities which shall have representations from the county government and organizations that run programs for the benefit of persons with disabilities. The committee will be mandated to advise on and put in place measures to ensure the socio-economic development of persons with disabilities in the county. The Bill further proposes to review the membership of the National Council for Persons with Disabilities in order to make the workings of the Council more efficient and representative.

Recent news reports that the Senate's push for a referendum has suffered a setback after some Senators. The formation of a select committee to spearhead the processing of the Draft constitution of Kenya Amendment bill 2015 that would culminate into a referendum was one of the recommendations of the special committee on constitutional and regal review set by the senate in June 2015. But when the notice of motion to establish the committee was read, some Senators turned down the appointment to the committee on grounds that they were not consulted a move that may throw the House push for a referendum into disarray. Nominated Senator Naisula Lesuuda said members who served in the previous committee should not serve in the new one, while Senator Godliver Omondi said representatives of people with disability are being discriminated in the formation of such committees.

2. The 2010 Constitution

With the promulgation of the Constitution of Kenya in August 2010, Kenya made a progressive step by recognizing the Convention as part of the laws of Kenya under Article 2⁴⁷. The Constitution enhances the protection framework for the rights of persons with disability and secures significant gains for them: article 7 recognizes sign

⁴⁷ Article 2 (6) of the Constitution of Kenya 2010 provides that any treaty or Convention ratified by Kenya shall form part of the law of Kenya under the Constitution

language, Braille and other communication accessible to persons with disabilities as part of the official languages; article 20 (5) (b) obliges the court, in applying any rights under article 43 to be guided by the principle that “in the allocation of resources the state shall give priority to the widest possible enjoyment of the right or fundamental freedom having regard to prevailing circumstances including the vulnerability of particular groups or individuals”; article 21 of the Constitution confers a fundamental duty on the state and every state organ to observe, respect, protect, promote and fulfill the rights and fundamental freedoms in the Bill of Rights and address the needs of vulnerable groups within society including persons with disabilities; article 27(4) on non- discrimination prohibits direct or on indirect discrimination against any person on any ground including disability; article 28 promotes respect and protection for human dignity of every person; article 43 recognizes economic and social rights including; highest attainable standard of health, housing, sanitation, freedom from hunger, clean and safe water, social security, education and emergency treatment.

The Constitution of Kenya, 2010 and the PDA, 2003 have both defined “disability”. Indeed, Section 2 of the PDA says that “disability means a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation.” The Constitution of Kenya under Article 260 says that “disability includes any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have, a substantial or long term effect on an individual’s ability to carry out ordinary day-to-day activities.” It can be noted that the two definitions have a few similarities and differences. With regard to the types of disability, both have mentioned “physical, sensory, mental or other impairment”. However, the difference is that the PDA has “visual, hearing, learning or physical incapability” while the Constitution of Kenya includes “psychological”, “condition or illness” within the definition. The second set of similarities is that they both bring out the issue of impact or effect. The PDA refers to impact on “social, economic or environmental participation”, while the Constitution does not talk of this but refers to “substantial or long term effect on an individual’s ability to carry out ordinary day-to-day activities” which one can equate to participating in social,

economic and environment issues. But, making reference to ‘social, economic and environmental participation’ is misplaced because people with disabilities are limited by society and/or the environment and not that an individual is limited from participating in their environment. It is worth pointing out that the PDA has not specified who is impacted by the “participation”. Further, it is not clear whether it impacts the society or the people with disabilities. Another concern is that the term “environmental participation” is not clear and does not make sense. Here, it can be assumed that the drafters made an attempt to make reference to the International Classification of Functioning, Disability and Health (ICF) model which has environmental factors as one of the things that can affect one’s ability to undertake activities. But the Constitution of Kenya, on its part does not have or make any reference to participation of people with disabilities but is very clear that the effect (or impact) of the condition is on the ‘individual’ and his or her ability to undertake “ordinary day to day activities”.

By defining “disability” within the Constitution of Kenya and the PDA, the law risks excluding those that do not fit within the definition. It is therefore more appropriate to define “what causes disability” than trying to define “what is disability”. This position is supported by Mute who says that “one weakness of this approach [that was taken by the drafters to define disability] is the consequent impossibility of introducing the “on an equal basis with others” standard which would easily apply if legislation defined the person rather than the state of being. Second, no universal normative standard applies in the definition of disability in Kenya” (Mute and Anonymus n.d.). It is worth noting that an amendment to the definition of disability as contained in the PDA was recently proposed through the Persons with Disabilities (Amendment) Bill, 2010 to include and classify “albinism” as one of the forms of disability under the PDA. But this intervention by the group with albinism may not be the solution to the problem of exclusion because in order to establish that one has a disability, it is not necessary to show that one’s situation fits into any of the categories listed in the definition. This is because where a legislative definition contained the word ‘includes’, the terms or factors listed are intended to be indicative or the type of factors consistent with the definition, rather than limiting the class (Basser, 2002: 254-284).

The second concern in this regard is that even as Kenya opted to have a definition, it

went for the medical definition which in my view is a misunderstanding or lack of appreciation of the theoretical bases and the current international debates around disability. The definitions make that people with disabilities are viewed in terms of “functional limitations” [...] where disability is understood as blindness, deafness or other kinds of changes in bodily structures (Grönvik, 2009) and therefore seen as “as a problem of the individual” (Goering, 2010: 55). A medically based definition does not raise questions of justice, nor does it emphasize the rights of people with disabilities, and leads to these people being seen for their body and looked at them from the point of view of their impairment. (Basser, 2002) It suggests the normative principles of “charity and accommodation” (Jongbloed, 2003:207). In this regard, the position of Rothman seems reasonable: he says that by concentrating on physical, biological aspects of disability which is viewed through the medical, problem oriented, and deficit model tend to create stereotypes and biases which affect the integration of people with disabilities into society (Rothman, 2010: 194-222). Therefore, in order to counter this state of affairs and to ensure that “[the human rights] framework is applied objectively with the rights and interest of the disadvantaged in mind” (Darrow and Thomas, 2005: 477) the legal framework relating to people with disabilities in Kenya should adopt the “social model of disability [which] holds that much of the disadvantage associated with impairment is socially imposed, rather than inherent to the bodily or mental state (a view commonly understood as the medical model)” (Goering, 2010: 54). “The key to equality for people with disabilities, on the social model, is the recognition of socially constructed barriers and their removal” (Basser, 2002: 262).

The third concern is still with the part of the definition in the Constitution of Kenya which says “or is perceived by significant sectors of the community to have a substantial or long term effect on an individual’s ability to carry out ordinary day-today activities”. This sentence subordinates and discriminates against people with disabilities. It confirms that the attitude of the society towards people with disabilities is still a big challenge as there is still so much stigma against people with disabilities and recognition of these people as equal members of society is still a big challenge among communities. The wording in the definition reiterates that ‘disability is an individual problem’ (Donoghue, 2003:203) and therefore suggests the normative principles of

“charity and accommodation” from the society towards and individual that it “perceives” to have a disability. This is quite clearly the apotheosis of promoting stigma against people with disabilities and alludes that “the disabled are those who are incapable of performing normal life activities” (Donoghue, 2003:207). This definition enhances the perception that the body of people with disabilities is the problem and looks at them from the point of view of their impairment (Basser, 2002) and that in order for them to receive benefits or sympathy then it can only be “under the condition that they continue to be defined as abnormal members of society” (Donoghue, 2003:207). Further, it fails to recognize the role that society and the environment plays in “disabling” these people. From the shortcomings highlighted above, it is apparent that Kenya is yet to fully embrace a human rights based approach to the rights of people with disabilities. According to the UNICEF Innocenti Digest, a human rights based approach has the potential “to a shift focus from [...] limitations arising from impairments, to the barriers within society that prevent [people with disabilities] from having access to basic social services, developing to the fullest potential and from enjoying her or his rights. This is the essence of the social model of disability” (UNICEF, 2007). With the state of the rights of people with disabilities being as it is in Kenya, and with the definitions as they are, then the legal framework cannot protect these people against direct and indirect forms of discrimination or eliminate the historical subordination of people with disabilities. Grugel and Piper add that human rights approaches seem to be instrumentally useful, as well as morally robust, for putting some issues on the agendas of states and international organizations (Grugel and Piper, 2009).

3. The issue of (real) participation

It could be assumed that the enactment of the PDA and the constitutional recognition for persons with disabilities and their rights within the Constitution of Kenya was an end in itself and that the same would automatically translate to equality for persons with

disabilities. In fact that is something that a lot of people in Kenya thought would happen. I will argue that this has not been the case because people with disabilities still continue to be short changed by those in power and there is a general lack of commitment towards guaranteeing the rights of these people in Kenya. A human rights based approach seeks to reduce the “negative impacts of discrimination and disempowerment” (Darrow and Thomas, 2005:501). But, from my personal experience I can assert that Kenya has done quite the contrary while translating and domesticating the UNCRPD into national laws and from the analysis I made in the previous paragraph I can affirm that the drafters of the Constitution and the PDA took a minimalist and escapist approach thereby leading to the continued discrimination of persons with disabilities.

The issue of participation of people with disabilities in leadership was identified by the Disabled Persons Organizations as one of the most pertinent in Kenya at the moment. Indeed, this was identified as one of the most contentious issues because despite, constitutional guarantees, people with disabilities still continue being deprived of their right to representation. By saying that appointment into leadership position would end discriminations of these people and solve their problems would be over simplifying the debate. Therefore, people with disabilities appreciate that one of the ways starting to break down the societal and environmental barriers and thereby reducing discrimination against them is by increasing the involvement in or engagement of people with disabilities within positions of leadership, authority, power and politics.

The Constitution of Kenya recognizes the right of all citizens to enjoy their political rights. But, it is apparent that there is a difference in the language between the UNCRPD and the Constitution of Kenya when it comes to participation of people with disabilities in leadership. While the UNCRPD under Article 29 provides for “participation in political and public life”, the Constitution of Kenya under Article 54(2) on the other hand talks of “elective and appointive bodies”. But it is worth noting that the PDA has neither mentioned the right to participate in “political or public life”; nor the right to participate in “elective or appointive bodies” or positions. This may be because the PDA was enacted in 2003, which was before the adoption of the UNCRPD in 2006 and before the promulgation of the Constitution of Kenya in 2010. The

foregoing provisions on political participation (Articles 83(1) b, 99(2) e and 193(2) d) have a huge potential of disenfranchising a huge number of Kenyans, and denying them legal capacity on an equal basis with others. Of note is the fact that the State does not identify the foregoing Articles of the Constitution on political participation as touching on Article 12 of the UNCRPD at all. The UN High Commission has stated that norms of laws disqualifying a person from office or performing a function on the basis of their disability, including norms disqualifying persons with disabilities from running for political positions also need to be abolished. (UN, 2009a). The participation was also one of the issues considered by the Committee on the Rights of Persons with Disabilities that asked for explanation, given that the meaning and effective participation of persons with disabilities within the decision-making method at national and native levels was lacking. Regarding political representation, Mr. Muigai suggested that there were two types of responsibilities that had to be distinguished. One was responsibilities by the Government and the other was responsibilities by the other political parties, which existed in democratic societies. Regarding the equality between men and women, the Government could urge the participation of women with disabilities in representation; however it could not force this upon other parties due to the flexibility of political choice. It does not seem a satisfactory answer.

Rights exist on paper but the challenge of realizing them lies in claiming them and this involves engaging and reforming the structures and institutions charged with upholding them and in expanding people understands of and sense of entitlement to rights. This has been a big problem for PWDs and DPOs in Kenya because despite the clear constitutional and legal provisions, they have not been able to benefit from the reserved positions. As Dr. Kabue⁴⁸ pointed out, “the nominated positions rarely went to special interest groups for which they were created. Indeed, it was only in 1997 that SAFINA nominated Honourable Josephine Sinyo and she only served one term. Further, not a single party in Kenya has ever elected a member who is a person with disability” (Dr. Kabue). This was a flagrant infringement of the constitutional rights of special interest groups by the political parties and the government which utilized the seats to reward

⁴⁸Executive Secretary, Ecumenical Disability Advocates Network.

political cronies or supporters and party stalwarts that failed in the elections. In the realization that “the distribution [of government resources] does not occur by accidents, but is the product of conscious policy choices and political and social struggle” (Darrow and Thomas, 2005:475). Persons with disabilities tried to file a case in Court in 2008 challenging the political parties for denying them their right. But as Dr. Kabue says, “going to Court was a big problem because legal cases on political issues are very expensive. The lawyer who was requested to take up the case demanded KES. 5,000,000 (USD. 62,000) and people with disabilities do not have that kind of money so they gave up” (Dr. Kabue)

The provision on reservation of seats for special interest groups was retained under the Constitution of Kenya, so as to reflect the new governance structures that now comprises of a National Assembly, Senate and County Assembly. It makes reservations through affirmative action and support the nomination of special interest groups into the various seat thereby ensuring that “the vicious cycle of inequality, elite capture, and disempowerment [does not] spiral out of control in the absence of a framework for equality and nondiscrimination in decision making” (Darrow and Thomas, 2005:476-7). They are in furtherance of Article 54(2) of the Constitution of Kenya, 2010 which says that “the State shall ensure the progressive implementation of the principle that at least five per cent of the members of the public in elective and appointive bodies are persons with disabilities. In this regard, Article 97 of the Constitution of Kenya which deals with the Membership of the National Assembly provides specifically under Article 97(1) (c) that “twelve members nominated by parliamentary political parties according to their proportion of members of the National Assembly in accordance with Article 90, to represent special interests including the youth, persons with disabilities and workers.” Article 98 brings out the composition of the Senate and it provides under Article 98(1) (d) that the Senate consists of among others, “two members, being one man and one woman, representing persons with disabilities”. Article 177 provides for the membership of County Assembly and it states under Article 177(1) (c) that a County Assembly consists of among others ‘the number of members of marginalized groups, including persons with disabilities and the youth, prescribed by an Act of Parliament’. Indeed, people with disabilities are perpetually being short changed. In fact, neither the

Constitution of Kenya, 2010 nor the Persons with Disabilities Act, 2003, or any other legislation for that matter, has specified how the five per cent representation will be achieved. Further, no legislation has been passed to promote representation of people with disabilities in Parliament thus perpetuating the discrimination. Secondly, whenever people with disabilities have demanded for their rights to be represented in positions of leadership, those in authority often say that this is not immediate and cite the principle of “progressive realization” to deny people with disabilities this right. All the above mentioned shows that the law is just a mere servant of existing power.

DPOs and people with disabilities have been undertaking lobbying and advocacy by organizing themselves into caucuses and making representation to various committees of parliament, government ministries and commissions that are aimed at challenging discriminatory practices, but this has been with limited success.

The mixed results can be seen in the following cases. In Fredrick Gateau Kaman vs. The Attorney General and Others, Nairobi Constitutional and Human Rights Division Petition No. 157 of 2011 (Unreported). In this case, the petitioner who was an employee at the Void Law Courts had had his leg amputated. He was later certified as having a disability and was consequently eligible to retire at 60 years as opposed to 55 years. The Court held that by firing the petitioner before his retirement age of 60, the respondents had violated the rights of the petitioner by disregarding the provisions of Section 15(6) of the PDA which provides that people with disabilities will retire at the age of 60 years and went ahead to award the petitioner compensation

4. Conclusion: Realizing human rights?

Despite numerous national and international instruments, the situation of human rights of persons with disabilities in Kenya is far from being fully realized. The causes are to be found both at legislative and social level: the two dimensions intersect and influence each other. Despite the apparent modernization of the Kenyan legislative apparatus, at a concrete level, the realization of human rights, especially for people with disabilities (like other poorer sections of society), still remain at the level of the third world.

As already mention in the introduction of this chapter, Kenya has submitted its initial

report on implementation of the Convention on the Rights of Persons with Disabilities. Even if, Githu Muigai, Attorney-General of Kenya, claimed that Kenya had been one of the first States to ratify the Convention in May 2008 after having actively participated in its negotiations, the Committee have expressed strong doubts on the country's situation. Muigai asserts that Kenya was deeply committed to ensuring that the rights, needs and aspirations of persons with disabilities were recognized and respected, but whoever knows the country's condition, it can easily grasp that these are only all talk. The Committee recognizes that Kenya had made a lot of progress with relevance to the promotion of the rights of persons with disabilities, and congratulated Kenya for ratifying the Convention and enacting the Persons with Disabilities Act of 2003, that preceded the approval of the Convention. Some of the positive developments were the introduction of the Social Protection Programme for the Persons with Disabilities; the participation of persons with disabilities in government structures; and also the introduction of the performance contracting practice. However, issues remained. For example, in the past few years, there was no implementation and monitoring of the provisions of the Convention on the Rights of Persons with Disabilities though the Kenyan Gender and Equality Commission had been appointed to play this role. This was a government structure and will probably lead to a conflict of interest. Moreover, the Committee underlined that disability must not be viewed as exclusively associate to equality matter, however as a cross cutting issue within the entire socio-economic and political spectrum. Although the representative of Kenya has tried to answer all questions and in the end the representative of the Committee congratulated the delegation for their interest and answers and stated that he had no doubts regarding the commitment of the Government, this report does not meet the demands of people with disabilities to be recognized their rights and a fundamental shift from commitment into serious practice was needed. It is evident that the State Report is very general, and does not provide data or evidence of any other kind to support its assertions on a number of important issues. No data is provided on the numbers of persons with disabilities who have been provided with assistive devices at a subsidized rate.⁴⁹ No data is provided on

⁴⁹The State Report asserts that the overall disability rate in Kenya is 3.5% which translates to 1,330,312

the number of programs, educational facilities and rehabilitation centers established to give persons with disabilities life skills and education, or on the number of Government hospitals providing rehabilitation services and the number of people attended to there under, or the number of Public Private Partnership (PPP) initiatives that seek to provide additional services aimed at improving the lives of persons with disabilities. There is also no information on the content and/or form of the awareness raising programs that enhance public acceptance of persons with disabilities.

While the recognition of disability rights in national legislation is surely a positive development, actually ensuring that these rights are upheld in practice may be more problematic. In the field of employment, for example, there is an obvious need to tackle highly visible barriers, such as poor workplace access and direct discrimination within recruitment processes. As Abberley observed people with disabilities may also be disadvantaged by the structure of employment, with most jobs “designed around the capacity, stamina and resources of the average worker, nine-to-five, five days a week employment” (1999: 11). This illustrates that a much more flexible approach may be needed, to ensure that disabled people can compete on an equal basis in the jobs market (ibid). Abberley’s observations show how the denial of rights can run deeper than may at first be apparent, due to the various ways in which society “takes little or no account of people who have physical impairments and thus excludes them from participation” (UPIAS, 1976: 14).

A 2012 report carried out by Equal Rights Trust and Kenya Human Rights Commission, states as follows: “ERT’s interviews with persons with different forms of disability found that prejudice, stigma and discriminatory attitudes towards disability prevailed within families, and that the discriminatory treatment which persons with disabilities experienced in the home often had far-reaching consequences for their ability to participate equally in other areas of life.” (Equal Rights Trust and Kenya Human Rights Commission, 2012: 133). Despite the significant changes for the better, the lives of persons with disabilities remain marked by experiences of discrimination, prejudice and

million persons with Disabilities. This is likely to be a gross underestimate in light of the World Disability Report that estimates the prevalence of disability at 15%.

inequality. Those interviewed by ERT reported that persons with physical and mental disabilities are subjected to serious prejudice including within their families. Limited access to assistive devices, specialist services and a lack of reasonable accommodations in public places present ongoing challenges for large numbers of persons with disabilities. Barriers to participation in education are held in place by prejudice, direct discrimination and problems of access. The area of employment is also rife with problems, due in part to relative lack of education compared to persons without disabilities, prejudice among employers about the capacities of persons with disabilities and lack of reasonable accommodation in the workplace. As a result, many persons with disability live in extreme poverty and without welfare support.

Stigma, prejudice, inequality, discrimination are encountered every day: just walking the streets or going into a public place. They seem to be the order of the day, but it is no longer sufficient to express disapproval or condemnation, but there is a need for a change in culture, language and attention and this requires the steadfast commitment of everyone and particularly of politicians regarding application of existing legislation and of the whole community regarding fighting the stigma.

CHAPTER 4 SPECIAL EDUCATION

4.0 Introduction

The concept of the right to education plays a prominent role both in the academic literature and in the documents published by international agencies and NGOs on the subject of education in developing countries. It is used to justify existing policies and all new reforms or policies are expected to correspond with this basic human right. It is also widely recognized in the literature that the original definition of the right to education - as agreed by the international community - is contained in Article 26 of the Universal Declaration of Human Rights (1948).

To highlight the importance of recognizing education as a basic human right, UNESCO dedicated its World Education Report (2000b) to the subject and according to UNESCO's Director General, Koichiro Matsuura: "it was important that education was recognized not only as a human right but also a vital means of promoting peace and respect for all other human rights and fundamental freedoms. And if education's potential to contribute towards building a more peaceful world was to be realized then 'education must be made universally available and equally accessible to all' (UNESCO, 2000: 7). In November 2001, Oxfam then launched a report titled "Education Charges: A Tax on Human Development", and their press release stated the following: "Half a century ago, the Universal of Declaration of Human Rights established free basic education as a fundamental human right. Yet on current trends there will be 75 million children out of school in 2015". New data from the UNESCO Institute for Statistics (UIS) show that the global number of children and young adolescents not enrolled in school is rising at the same time that the international community is setting a new sustainable development goal that includes universal secondary education. According to UIS data for the school year ending in 2013, 124 million children and young adolescents, roughly between the ages of 6 and 15 years, have either never started school or have dropped out, compared to 122 million in 2011. The global number of out-of-school children of primary school age rose by 2.4 million between 2010 and 2013, reaching a total of more than 59 million (UNESCO, 2015). "Governments and

international organizations have paid lip service to the idea that basic education should be free; they have done precious little to address it in reality. In absence of sufficient public finance, the cost of education is being transferred to poor families as part of a creeping privatization of education financing. Households face a bewildering array of education charges, from direct schools fees to indirect costs for books, pencils and uniforms. Parents consistently cite cost as a major factor in deciding to keep children out of school. The evidence is undisputable. Success in achieving universal basic education depends on education becoming affordable to the poor, and this requires the abolition of education charges” (Oxfam Press Release, 2001).

Moreover, since families are stigmatized in society, even children are affected and are excluded in turn. Mothers tend to keep children with disabilities locked in the house, but Even where they do go out into the community, they are often ignored or stigmatized. And the circle repeats itself over and over again: children may not go to school and play with children with disabilities; so they grow up and become adults that may not acknowledge people with disabilities, or be too embarrassed to interact with them. Moreover, being a child with hearing impairments or with learning difficulties means to be doubly excluded because of the barriers in interaction and communication. This kind of institutional discrimination interacts with and reinforces other factors leading to exclusion. As already underlined, persons with disabilities are also ignored on an institutional level. Schools and education systems should be the first step to the inevitable change Kenya needs; it could give the possibility to give a voice to children and to encourage them to take up positions as agents of change.

4.1 Increasing importance of education at international level

1. Universal Declaration of Human Rights

The fusion of both human rights and fundamental freedoms within one document represented a compromise between the two competing ideologies at the heart of the Cold War, a conflict between political and civil rights on the one hand and social and

economic rights on the other. Taking the political circumstances into account, this was a significant diplomat achievement. For the purpose of this thesis, it is sufficient to simply acknowledge that they existed and that they would clearly play some role in the process of drafting the 1948 Declaration and in particular Article 26 concerning the right to education. It states that “Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit”. (1) It also affirms that “education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the UN for the maintenance of peace.” (2) The third paragraph is no less important: “Parents have a prior right to choose the kind of education that shall be given to their children.” It is important to note the inclusion of reference to both first and second generation rights. As paragraph one places a duty on the state to intervene to help guarantee universal access to education, it still remains unclear what constitutes excessive state intervention. Paragraph three was included to ensure that paragraph one was not misinterpreted to mean that the state was also free to determine the system of education, or to deprive parents of their right to choose. It was therefore introduced to eliminate any implication of coercion and provide protection against undue intervention by the state. Paragraph three was also included to reaffirm that it is parents and not politicians who are primary responsible for their children’s education and that this responsibility can only be carried out if parents are free to choose the nature, form and content of education which their children receive. Paragraph three, therefore, places important new restrictions on future government intervention in education, as any attempts to guarantee universal access (implement paragraph one) must not interfere, distort, undermine or usurp the primary role and responsibility of parents. Consequently, paragraph three is perhaps best viewed not as a separate paragraph but as an extension to paragraph one. This seems to have been the foundation for the explicit focus on Human rights education and the further development of this concept and has since been affirmed in a series of global human

rights treaties, which establish the entitlement to free, compulsory primary education for all children and an obligation to develop secondary education, including measures to ensure accessibility for all children (UNESCO, 2007: 7).

2. After the Declaration

Today, human rights education has been institutionalized with the adoption of the UN resolution on the World Programme for Human Rights Education in 2005, which was to be “structured in consecutive phases, scheduled to begin on 1 January 2005, in order to advance the implementation of human rights education programmes in all sectors.” (UNGA, 2005: 2). Following this, in 2006 UNESCO published a Plan of Action for the First Phase of the World Programme for human Rights Education focusing on primary and secondary schools, and in 2007 the second phase (2010-2014) was initiated with a focus on institutions of higher education and civil servants.

However, human rights education has not always been on the agenda of the UN and the Council of Europe. Even though there was some mention before, such as article 13 of the International Covenant on Economic, Social and Cultural Rights it was not until the CoE’s resolution in 1978 “On the Teaching of Human Rights” that human rights education has been seriously taken into account. It is worth mentioning that the African Charter on Human and People's Rights stated that “States parties to the present Charter shall have the duty to promote and ensure through teaching, education and publication, the respect of the rights and freedoms contained in the present Charter and to see to it that these freedoms and rights as well as corresponding obligations and duties are understood,” (OAU, 1986: art.25) thus presenting an African approach to raising awareness about the importance of education. Moreover, article 17 explicitly refers to the right to education and promotion of morals and traditional values recognized by the community. It should be noted that articles 23, 24, 28 and 40 of Covenant on the Right of the Child (1989) and articles 43 and 45 of the International Covenant on the Protection of the Rights of all Migrant Workers and Members of their Families (1990) also contain this right.

Another phase of the development of human rights education started in 1993 with the

UN entering the field, as 171 states adopted the Vienna Declaration and the Programme of Action of the World Conference on Human Rights. For the first time, human rights education was explicitly mentioned, and in 1994 the UN adopted the resolution on a United Nations Decade for Human Rights Education where the importance of education was highlighted, and the decade 1995-2005 was intended to help raise awareness of the concept, not just within the UN system, but also within member states and NGOs. In 1995, UNESCO adopted the Declaration and Integrated Framework on Education for Peace, Human Rights and Democracy, suggesting basic guidelines which could be translated into strategies, policies, and plans of action by the member states (UNESCO, 1995: 8), and in 1997 the European Union launched a similar flagship project of their own, Democratic Citizenship and Human Rights Education.

In September 2000, the United Nations Millennium Summit took place in New York and the Millennium Declaration was subsequently adopted by 189 nations. The Declaration outlined the need to make globalization fully inclusive and equitable and it also identified eight Millennium Development Goals (MDGs), with goal number two concerning education: “achieve universal primary education. To ensure that, by the year 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling and that girls and boys will have equal access to all levels of education”. While there will have been a limit to the number of words that can be used in goal two, it is significant that no mention is made of education being either free or compulsory. The lack of any reference to the rights of parents allows speculating whether these rights are no longer recognized or they are now secondary to the need to achieve universal access to education. Goal two is therefore focused entirely on guaranteeing universal access to education by means possible. However, in October 2001, UNESCO’s High-Level Group on Education for All confirmed that no country which was seriously committed to education for all will be restricted due to a lack of resources.

3. Education for all

The year 2015 became acquired focus at the Dakar World Education Forum in 2000, when the world set to achieve six ambitious targets within fifteen years. Among the targets was the promise that by 2015, “all children, particularly girls, children in difficult circumstances and those belonging to ethnic minorities, have access to and complete free and compulsory primary education of good quality” (UNESCOa, 2000: 17). At the expiry date, opinion as to whether this target has been achieved is highly contested. The progress in terms of access to primary education made since 2000 is “nothing short of remarkable” (UNESCO/ UNICEF 2015: 13). The report celebrates that between 2000 and 2012, the number of out-of-school children globally fell by 42 per cent. While this may be true for the global average, the number of out-of-school children in sub-Saharan Africa seems to have increased with Nigeria hosting one fifth of the world’s out-of-school children. Rwanda is among the top three best performers in the last five years and reduced their out-of-school population by at least 85 %. Many authors agree that the clock arm of access ticked forward in Africa. Despite this, Africa continued to lag behind the rest of the world in pursuing the access goal (UNESCO 2014). Globally, it is estimated that 58 million of children aged six to eleven years and 26 million adolescents (12–15 years) are out school (UNESCO/UNICEF 2015; UNESCO 2014). From these, 30 million children and 22 million adolescents are in sub-Saharan Africa, representing a staggering 52 % and 85 % of the worldwide sum respectively. Despite the marked expansion of education access from year 2000, evidence indicates that the ratio of out-of-school children globally has remained steady at nine percent, and thereby marking a failed promise on the EFA goal on access.

In Kenya, historical trends of access have shown big fluctuations over the decades. At first, the initial decades of post-independence delivered rapid expansion of access across all sectors – primary, secondary and even University. For instance, the growth in enrolment to secondary schools between 1963 and 1980 averaged at twelve percent per year (Kipkoech and Kyalo, 2010: 71-76). However, this growth diminished in the 1980s and 1990s. The 2003 free primary education thereafter delivered an ‘access shock’ to the system with enrolment to primary schools rising by 22 %, from 5.9 to 7.2 million

within the year, and yielding a gross enrolment of 104 %. Though the figures vary slightly, there is consensus that the government's initiative led both to increased access and reduced incidence of late entry (Mugo, Nderitu, Ruto, 2015: 17). However, Bold et al. (2010) warn about the acclaimed gains were only in gross figures, as the net enrolment rates in government primary schools only rose negligibly from 71.2 % to 71.6 % from 1997 to 2006, meaning that what flooded the system was mostly overage learners, while at the same time expanding demand for private school. It should be taken into account also that while free primary education (introduced in 2003) increased access for the disadvantaged, it also brought around a sorting effect, in which children from wealthier households exited the public system. In spite of the efforts to expand access to primary and secondary education, various sources estimate that at least nine per cent of eligible children in Kenya lack access to primary school, while over a quarter of those completing primary school do not access secondary school. Indeed, more than half of age-appropriate children are not enrolled in secondary school in 2015. At the same time, the net enrolment to early childhood education stands at 46.5 % (KNBS, 2014), presenting also a major gap in universal coverage of preschool education. It is estimated thus, that over 1.1 million children are out of school in Kenya, though UNESCO/UNICEF (2015) describes the lack of updated statistics thereupon. From available evidence, the access gap has many faces – geography, gender and household socio-economic status. Accomplishing widespread access will at last request contained and ceaseless activity to deliver the obstructions to educating as school investment is sensitive to costs. The ever-increasing cost of schooling remains a barrier to increased and sustained school access in Kenya. While fees abolishment in public primary schools and subsidy at public secondary schools may have been significant in cost reduction, indirect costs to education (such as uniform, school materials, teachers ,but also meals and examination fees) remain uncontrolled and continue to have influence on enrolment (MoEST 2014; Sifuna 2007). For instance, it was established that in 2014, 37 % of all teachers in public secondary schools were employed directly by parents, through the school boards of management (MoEST 2014). Further, with the introduction of free primary education, there was no commensurate increase in teachers resulting into high pupil/teacher proportion. This has made parents make extra

contribution to employ teachers. To establish the effects of cost reduction, a randomized control trial established that reducing out-of-pocket costs, merit scholarships, and conditional cash transfers all increase school participation (Kremer et al. 2013, 297-300), demonstrating that lightening the burden on family expenditure on education for the vulnerable populations may accelerate coverage.

4. Challenges

Efforts to improve the quality of education in Kenya, by both government and non-government actors have been documented. In their analysis, Nicolai et al. (2014) identify four dimensions of progress in Kenya's education: a rising public demand for higher levels of education sector; political commitment to education and accompanying bold policy moves; key financing reforms, which helped to shift the burden from households to government at all levels; and the active role of communities and the private sector in expanding the supply of post-primary education services. Indeed, the reforms introduced through the Kenya Education Sector Support Programme (KESSP) in 2005 brought in measures to expand infrastructure on the one hand, but also improve teaching and learning through school health and nutrition programs, greater supply of instructional materials, teacher capacity development and introduction of information and communication technologies (MoEST 2005). However, critics of the reforms in the Kenyan system (Mugo/Ruto 2010; Mugo et al. 2015; Kremer et al. 2013) have observed a persistent "one size fits all" orientation in improving learning outcomes. Interventions brought in over the years have been "doing more of the same" (more textbooks, more teachers, more classes) with scanty commitment to what works in improving learning outcomes. For instance, an intervention that halved the class size produced no commensurate improvement in learning, indicating that adding teachers with no matching pedagogical reform may be futile (Duflo et al. 2012a). In another Kenyan study, neither providing additional textbooks nor supplying instructional flip charts increased test scores (Glewwe/Kremer/Moulin 2009).

As the negotiations for the new education goals are going on at the global level, various interventions are being adopted in Kenya for 2015 and beyond. The integration of

information and technology (a laptop for every first grader) was promised by the president during the 2013 elections. Though this is yet to happen, following several procurement hitches, it is probable that increased technology integration will remain a priority. While there is unbridled faith that ICT will improve both learning and accountability in the Kenyan education system (MoEST 2014a), the direct correlation of computer access improving learning has not been proven (Gulek/Demirtas 2005; Kremer et al. 2013). This however does not negate the role of ICT in acquisition of life skills that will aid broader functioning in an increasingly technological world. The other widely-proposed intervention, scheduled for 2014/15, is curriculum review. Investment has been earmarked to review the basic education curriculum to match learning and teaching with emerging needs of the labor market and modern-day living. There is emerging evidence that tailoring curriculum and textbooks to the level of the child is improving learning (Kremer et al. 2013; Pritchett/Beatty 2012). Thus, we can only hope that curriculum review in Kenya would be accompanied with the transitional measure to teach at the right level in accelerating learning progress for the many children already left behind by the curriculum. The third prominent perspective is improving early grade reading and mathematics.

4.2 Kenyan Context

1. Kenyan education system under colonization

The most famous British explorer of Africa during the second half of the nineteenth century was David Livingston, a Scottish missionary, whose explorations helped to open up the interior of Central and East Africa to the rest of the world. Rapid industrial growth, the need for raw materials and new markets and the combined work of Livingston and other European explorers helped to encourage further European interest in developing their overseas territories, resulting in what would subsequently become known as the European ‘scramble for Africa’. To help organize the political partitioning of Africa, Otto von Bismarck, the imperial chancellor of Germany, organized a conference in Berlin of 14 states in November 1884. The Berlin Act of 1885 outlined the ground rules for further European intervention in Africa which included a paragraph

on education which stated that: 'all the powers exercising sovereign rights or influence in the aforesaid territories [...] shall [...] protect and favor all religious, scientific, or charitable institutions which aim at instructing the natives and bringing home to them the blessings of civilization' (The Berlin Conference: The General Act, Feb. 26, 1885). This is perhaps the first statement concerning the development of education in Africa, which was to appear in an international agreement and it reflects the growing interest in education in Africa which was then emerging across Europe and in the USA.

Formal education was introduced in Kenya in the nineteenth century with the introduction of prayer houses by the missionaries when they came to Kenya. This was done mainly along the Kenyan coast: the first school was started in Rabai, near Mombasa in 1846 (Mungai, 2002). The primary purpose of these schools was to promote Christian evangelism. At first they did not enter the interior of the country due to the fact that there were no roads. The situation changed after the construction of the Ugandan railroad. By 1910, thirty-five schools had been founded.

However, during colonialism, schools became place to learn technical training and skilled labor for white settler farms and clerks for the colonial administration rather than to promote the Christian message.

In 1908, the missionaries formed a joint committee on education that later became the Missionary Board of Education (King, 2007). At the same time, the Fraser and Giround Commissions were put in place (Sheffield, 1975). The Fraser and Giround Commissions called for racial consideration in developing the British Protectorate, meaning that there were designed area for the British to settle and separated areas for the Africans. The recommendations included a push for industrial development, technical education and the teaching of religion. Professor Fraser also recommended the establishment of a Department of Education (Sheffield, 1975). In 1909 the government also distributed its first grant to a number of mission schools providing technical education. Together with distributing grants to mission schools, the government also opened separate schools for European, Asian and Arabic children. Furthermore, to ensure that resources were not duplicated the government agreed not to open schools where mission schools already existed. Perhaps the most controversial recommendations were those concerning the content of education. According to Sifuna (1990) both Fraser and the missions viewed

the problem of African education in terms of reducing the rate at which Western influences were corroding the traditional fabric of African communities. The solution therefore was to combine Christian teaching with practical education of a technical nature. The Fraser Report therefore recommended that while academic education should be given to European and Asian children, African children were to receive industrial and agricultural training. Despite Fraser's belief that education should be managed by the missions, he did not rule out the possibility of government controlled schools as this might help to show the friendly attitude of the government (Sifuna, 1990: 29).

After the First World War, the British needed to develop their African colonies, and this led them to re-examine and re-evaluate the education system in the African territories. In 1919 an Education Commission was set up to investigate and make specific recommendations on how to expand educational facilities for the European, Indian, Arab and African communities. The Commission's final report (Report of the Education Commission of the East Africa Protectorate, 1919), recommended the government should increase its support to those mission schools providing both literacy and technical education. Technical education would be the principal goal of African schools and the government would pay two thirds of qualified teachers' salaries and contribute to the building, equipment and boarding expenses. The report concluded that while the native required something more than an abstract moral code in place of his primitive moral law, a definite religious belief was necessary if he was to become an honest and respectable member of society. By the 1920s, education was well established in Kenya with separate schools for the whites, Asians, Arabs and Africans. This became known as the Three-tier system. In the African schools education was more on technical skills, like housekeeping, carpentry and farming in order for Africans to efficiently work in the white settler farms.

Perhaps the most important issue dominating the debate during this period concerned the content of education. During the first three decades of the twentieth century the question of how to educate 'the African' in Kenya not only attracted the attention of the colonial authorities, the white settlers and the numerous missionary societies operating in Kenya, but the debate also extended to the Colonial Office in London, to a number of philanthropic organizations based in the US and finally to the wider religious and

academic community on both sides of the Atlantic. However, as Schilling has previously suggested, while the Colonial Office, the administration in Kenya, the missionaries, and the settlers all had varying degrees of influence in the formulation of African education policy 'Africans were largely excluded from that process' (Schilling, 1970: 25). King also refers to the following correspondence from 1926 which suggests that even some of those who were involved in this decision making process were concerned about the exclusion of the African population: 'I think that perhaps the Phelps-Stokes Report takes it rather for granted that the Africans (whether men or women) are going to be willing to accept without demur whatever type of education we choose to adopt for them. Whereas, as Dr Aggrey made clear, the Africans are liable to have definite and strong views on the matter and to regard with suspicion any curriculum which, as viewed by them, might appear to be designed to keep them at a mental and cultural level inferior to that of Europeans. There will be a great work for our psychologists to get them to accept willingly what we judge to be the best kind of education for them' (A.R. Barlow to B.D Gibson, 24 Feb. 1926, quoted in King, 2003, p.67). These debates concerning the content of education have a direct relevance to the search for the right to education as paragraph two of Article 26 clearly states that: 'Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace' (UDHR, 1948, Article 23, para 2). However, by referring to paragraph two in isolation to the other paragraphs of Article 26, helps to highlight the dangers involved in adopting this method of analysis. For example, the above paragraph, when taken by itself, could have been used by the colonial government in Kenya to help justify total government control over education.

While the colonial authorities would increasingly begin to involve representatives from the local communities in this process, this still does not alter the fact that it was now the government and not parents who were now in control. Responsibility and control over the nature, form and content of education was therefore gradually removed from parents and transferred to the colonial authorities. While there was no official document which

announced this important transfer of power, these were the inevitable consequences of the nature and form of the initial government intervention. However, as soon as paragraph two is combined with paragraph three, outlining the right of parents to choose, then it soon becomes clear that Article 26 is not simply about guaranteeing that all education conforms to specific guidelines. Instead it is about who decides the content of education, and according to paragraph three it is parents and not politicians who have the prior to choose.

2. Kenyan education system after independence

After Kenyan independence in 1963, Kenya began a campaign for free primary education. In 1967, Kenya, with Uganda and Tanzania, formed the East African Community. The three countries adopted a single system of education, the 7–4–2–3, which consisted of 7 years of primary education, 4 years of secondary education, 2 years of high school and 3–5 years of university education.

The three-tier system developed into three types of schools: government schools, which were initially schools for the Europeans and then became entry schools for children with a high IQ and that had performed above average in the entrance examinations at secondary level; private and/or missionaries schools were turned into provincial schools for children who had performed at an average level; and Harambee (a grassroots movement of self-help schools) that were for students who had performed below average. In these harambee schools, emphasis was put on technical training. The quality of harambee schools depended on the economy of the region where the school was located (Republic of Kenya, 2004). The missionaries schools continued to exist, although some were converted into government schools. While Harambee schools supplemented government education, they brought along certain complexities and discrepancies. First of all, Harambee schools were generally expensive but lacked quality since they received little or no government funding. Second of all, the decentralized structure led to disparities in the number and quality of schools, available in various regions of the country (Amutabi, 2003). Beginning in 1988, Harambee schools were absorbed into the provincial or district schools levels in an effort to

equalize them with other government schools (Amutabi, 2003: 127-144). When cost-sharing was introduced in the 1980s, the government's task was to recruit and pay the teachers, while parents were responsible for constructing buildings and providing educational resources through Harambee. However, this did not work as planned because in most areas, parents were financially unable to raise the funds (African Path, 2007).

In 1981, a Presidential Working Party was commissioned to examine curriculum reform of the entire education system in the country. The committee submitted a recommendation to change the 7-4-2-3 education system to the current 8-4-4 system of education, whose overall structure was similar to the U.S. education system. The 8-4-4 system was launched in January 1985, and was designed to provide eight years of primary education, four years of secondary, and four years of university education.

According to Professor Sifuna (1990), there are three events that led to implementation of the 8-4-4 system: the 1966 conference on education at Kericho in Kenya, which stressed the need for integrating rural development, the International Labor Organization mission report entitled "Employment, Incomes and Equality: A Strategy for Increasing Productive Employment of 1972" and the recommendation of the National Committee on Educational Objectives and Policies of 1975. In 1979 the Ministry of Education was changed to the Ministry of Basic Education with an introductory nine-year basic education system program. The rationale was that the previous program was too short and not rigorous enough to give graduates enough practical education. It also recommended that the first six years of primary were to concentrate on numeric and literacy skills and the last two years on basic education with practical orientation. This represented a shift from a focus on enrolment to restructuring the program as a means to cater to the influx of unemployed. However, there have been a lot of controversies that have made this system lose prestige: because of government funding and corruption, government schools have failed and in its place private schools were started.

It should be stressed that Kenya has always linked its education system to the labor market. Kenyan policy makers since 1964 were concerned with the plight of the school leaver, asking questions such as would they be absorbed into the labor market after

school (King, 2007). So the curriculum of schools and colleges reflected this approach: there was the introduction of vocational, agricultural and technical courses in the 1960s and 1970s. In 1984, after the first Education Commission was established and its policies adopted, the goals of schooling were linked to economic growth. These views became very popular with the World Bank, who sought to make the connection between years in primary education and agricultural productivity, as well as the greater productivity in the employment sector and self employment in the urban and rural areas (Ministry of Education, Science and Technology, 2004). During that period, the external consensus about the value of what were called diversified schools had dramatically changed. Kenyan policy makers had no support for what had once been a donor priority.

3. Universal primary education

The Kenyan government committed itself to universal primary education (UPE) first of all by endorsing the Universal Declaration of Human Rights. Other international policy frameworks ratified and signed by the government include (The United Nations Convention on the Rights of the Child (1989), the African Charter on the Rights and Welfare of the Child (1990), UNESCO Salamanca Statement and Framework for Action on Special Needs Education (1994) and the Millennium Development Goals (MDG, 2000). The Kenyan government declared a campaign for UPE as a long term objective after its independence in 1963.

Through various free primary education (FPE) initiatives in (1974, 1979 and 2003)⁵⁰ Kenya attempted to achieve UPE but without the anticipated success. These initiatives resulted in massive enrolment increases which in time led to overcrowded classrooms and to severe shortages of physical facilities, qualified teachers and learning materials. There were also huge numbers of children leaving school early during the primary cycle (Sifuna, 2007). Consequently as a strategy to contain costs arising from the effects of

⁵⁰ Providing free education for children in Standard I- IV in public primary schools. The decree also set a uniform fees structure of Kshs 60 for children in Standard V-VII and promised to abolish school fees altogether in the near future. School fees was successively abolished, starting with Standard V in 1978 and by 1980, the entire public primary schooling was free of formal school fees.

the FPE initiatives, the Kenyan government relied on the International Monetary Fund, Structural Adjustment Programme. This obviously had negative effects on quality as the responsibility for provision of textbooks and various learning materials shifted from the government to the parents and affected many pupils from poorer families. This situation lasted until the declaration of free primary education in 2003 (Sifuna, 2007). In fact there is another important aspect to take into account: the first hidden cost or unintended consequence of abolishing school fees, especially in the slums. As pupils began to transfer from the fee paying private schools to the free government schools, the government schools quickly become overcrowded and many private schools were forced to close whilst others incurred financial hardships as a result of operating at less than full capacity. However, another important, whilst unexpected finding from this research was that a number of parents who had initially moved their children to a free government school (following the introduction of FPE), had subsequently returned their children to a private school. Significant issues raised while talking to parents: the perceived lack of commitment of teachers in the government schools, and the associated issue of the accountability of teachers in private school; overcrowding classes which resulted in less teacher interaction with individual pupils; there was also a sense of a loss of control over their children's education. It should not be underestimated that as school fees would no longer be used to help pay teachers' salaries, the incentive for teachers to continuously attempt to satisfy parents changing needs and demands was now diminished. Another problem concerns the long term impact that the removal of school fees will have on the total level of investment in education, a matter which is obviously important in developing countries. Regarding this matter, it is likely that parents may be willing to invest more in education through the payment of additional school fees, but they may be reluctant to contribute more in general taxation. It is also important to take into account the fact that as soon as increasing taxation becomes unpopular with the general public, then politicians and governments will become increasingly reluctant to increase taxation to help fund improvements in education especially in periods leading up to an election. When parents asked if they agreed to fees abolishing, they were all generally positive. But when asked how they thought education system should be improved, they said investments. In which way they all

were confused and none of them wanted the government to raise taxation because they were all convinced that that money go to corruption. When taking these factors into account it is clear that the abolition of all school fees at government schools is not necessarily required to guarantee education for all and that there are also a number of hidden costs and unintended consequences of abolishing all school fees, which the international community have to date failed to take into consideration. From a human rights perspective, recognizing school fees as a critical link instead of a financial barrier, presents yet another dilemma, as paragraph one of Article 26 clearly states that “education shall be free, at least in the elementary and fundamental stages”. It would therefore appear that the use of school fees in education comes into direct conflict with the idea of education being free.

As for the situation of children with disabilities, one of the thirteen objectives of Kenya’s education laid out in the Sessional Paper No. 1 (Republic of Kenya, 2005) and the most important is “to ensure that all children including girls, children in difficult circumstances, and those from marginalized or vulnerable groups, have access to and complete free and compulsory primary education”. Children with disabilities (should) belong to this group. According to UNESCO, the main objectives of the FPE programme should be: to enhance access, quality, and retention; improve participation, progression and completion rates; reduce the parents’ burden of financing the education of their children in primary schools and implement sector policy goals, including universally accepted conventions on the provision of education (UNESCO, 2010)

Since 2003, Kenya has attempted to develop inclusive practices by keeping children with disabilities in ordinary classrooms, where they learn with their peers (MoE, 2008). The Kenyan government followed the United Nations Standard Rules on the Equalization of Opportunities, Rule no. 6 which not only affirms the equal rights of children, youth and adults with ‘handicaps’ to education, but also states that education should be provided in integrated and general school settings (MoEST, 2005).

Most developed countries have adopted a policy of greater inclusion of students with disabilities and/or special education needs within mainstream schooling (OECD, 2005). These developments require: “re-examination of the role of teachers and consequently their preparation, work and careers. Teachers are expected to develop knowledge on

special education, on appropriate teaching and management processes and in working with support personnel” (OECD, 2005: 98). On the contrary in Kenya, the national education system has been characterized by a lack of systems and facilities that respond to the challenges faced by children with disabilities. The majority of these children do not access educational services. For instance, in 1999 there were only 22,000 children with SEN or disability enrolled in special schools, units and integrated programmes. According to the Ministry of Education statistics, this number rose to 26,885 in 2003 (MoE, 2008).

As mentioned, the abolition of the primary school fee for all grades had the following results: the gross enrolment rate (GER) increased from 64% in 1999 to 76% in 2004; sudden influx of pupils, overcrowded classrooms, acute shortage of teachers, textbooks and materials and large number of over-age pupils; new classroom construction programmes; substantial expansion of education which resulted in increased access by groups that previously had little or no access to schooling (MoE, 2008).

Anyway, these facade improvements such as significant increase in primary education enrolment are not enough. Kenya is still facing problems of extending UPE to marginalized and remote areas, and high drop-out and completion rates (United Nations Children’s Fund (UNICEF, 2007). Other problems are inadequate government funding issues of access, equity and quality (MOEST, 2005). In this situation, children with disabilities have not received adequate attention to ensure their equal access to education.

4. Legislative framework on the Right to education

Education is a fundamental human right guaranteed by the Constitution of Kenya (Article 43 (1) (f), Article 53 (1) (b)] and the various international instruments that Kenya is party to, specifically the International Convention on Economic, Social and Cultural Rights. At national level, the first law regarding education is the Education Act (Republic of Kenya, 1980) that does not make any reference to persons with disabilities. Section 14(2) of the Act specifies that: “No pupil shall be refused admission to, or excluded from a school on any ground of sex, race or color or on other reasonable

ground”. However, it excludes the express criterion of disability as a ground for non-admission.

More recent legislation has recognized the right to education of children with disabilities. The Children’s Act, 2001 (Republic of Kenya, 2001), which domesticates the Convention on the Rights of the Child, reiterates the right to education for all children. This Act emphasizes the core principle of nondiscrimination in access to education as well as the entitlement to free and compulsory basic education. The Act makes specific reference to disability in Section 12 affirming that: “a disabled child shall have the right to be treated with dignity, accorded appropriate [...] education and training free of charge or at a reduced cost whenever possible”.

Section 18 of the Persons with Disabilities Act (Republic of Kenya, 2003b) makes a broad statement on the rights of persons with disabilities relating to education. It forbids discrimination of children with disabilities in access to education by virtue of their disability. It requires learning institutions to take into consideration the special needs of persons with disabilities with respect to entry requirements, pass marks, curricula, examinations, school facilities and class scheduling, among others. Besides this requirement to learning institutions, the Act provides for the establishment of special schools.

However, the role of the Government in effecting these provisions is unclear. Unlike the Children’s Act which provides that education shall be the responsibility of the Government and parents, the Persons with Disabilities Act only requires the National Council for Persons with Disabilities to work in consultation with the relevant agencies of the Government to make provisions for an integrated system of special and non-formal education. This Act does not place an obligation on the Government regarding education for children with disabilities.

The Kenya Education Commission Report (Ominde Report, 1964)⁵¹ was the first national report that made recommendations on the education sector. This report, coming immediately after independence, focused on non-discrimination in education for all children. The report recommended the establishment of special schools for children

⁵¹ This report was followed by the Gachathi Report (1976) and the Kamunge Report (1988), which broadly focused on early interventions, identification and assessment of children with special needs

with disabilities. However, despite their vulnerability, no special measures were proposed to enhance education for children with disabilities, nor was the Government's role stated clearly.

The Government formed the Commission of Inquiry into the Education System of Kenya, also known as the Koech Commission. The report of this Commission (Republic of Kenya, 1999), released in August 1999, contained some findings and recommendations made with specific reference to education for children with disabilities. The Report observed that the goal of education is to provide equal opportunities for all children including those with special needs; hence the formulation of Total Integrated Quality Education and Training (TIQET), which, according to the report, is a comprehensive framework that addresses previously, omitted aspects of education including special education. The Koech report observed that the rapid growth in the education sector had not been reflected in the special education category; hence children with disabilities had not received equal chances of access to education. This, according to the report, had been further combined with the lack of specialized personnel, shortage of specialized equipment, inappropriate curricula and the absence of clear policy guidelines as well as clear legal status of special education. Moreover, the Koech Commission found the Education Act to be outdated since it neglected crucial areas of education including for those with special needs, and hence it (Education Act) could not be used as the basis for a more comprehensive education policy development and implementation. Therefore, according to the Koech Report, education for learners with special needs had largely remained at the margins of implementation of public policy on education. The Koech report suggested a review of the Education Act and the enactment of a Special Education Act as well as the preparation and adoption of a new sessional paper on education to replace the 1988 sessional paper. This report also recommended the development of a specialized curriculum by the KIE⁵².

Besides the already mentioned Education for all challenges, Kenya has other goals to be achieved by 2030. The government has to provide globally competitive quality education and training and research for development. This must be accomplished by

⁵² Many of the recommendation of the Koech Commission have not been implemented, even though they are directed towards enhancing the right to education for children with disabilities.

increasing access to education, improving the transition rate from primary to secondary schools, and raising the quality and relevance of education. Other goals are the integration special needs education into learning and training institutions, and increasing the adult literacy rate to 80%. In addition, the rate of students joining universities should expand from 4.6% to 20% within this period, while simultaneously boosting emphasis on science and technology courses.

On that note, it should be underlined that the number of students in Kenya's universities is soaring, up 28% in 2014 compared to 2013. But, contrary to expectations, government has cut funds by 6% for the upcoming fiscal year, adjusting its higher education spending to US\$ 588 million compared to the US\$ 627, 2 million allotted in 2014/15. The funding cuts will make it difficult for universities to cater to the growing numbers of students taking courses, and they will necessitate strategies to secure funds from alternative sources. Universities will also be challenged by the directive from Kenya's Commission for University Education (CUE) to stop offering diploma and certificate courses by July 2015. These courses have become more common in Kenyan universities both because of increasing student numbers and because they are good sources of revenue, and they are often the result of collaboration between universities and more commercially oriented colleges. The CUE order, which requires that such courses be offered only by colleges and technical institutes in the future, will effectively eliminate this source of revenue for universities. In other words, the country's universities are faced with both decreased government subsidies and the removal of an important alternate source of funding. In that way, the Kenyan government is constantly taking one step forward and one step back, trying to remain in a precarious balance that, as usual, penalizes the weaker sections of the population.

4.3 Special Education

1. Special, integrated, inclusive

Three major concepts are used when describing the kind of education learners with disabilities receive – special, integration and inclusion. These concepts were coined to describe the historical development of inclusive education in the developed world although they are used worldwide. Common positive concepts held by these approaches are: the right to education for all children and a commitment to help them learn in different ways, promoting the child's potential holistically, and supporting different methods of communication for those with a range of impairments (Stubbs, 2008).

The United Nations Convention on the Rights of the Child (1989), the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) and the Salamanca Statement and Framework for Action⁵³ are all powerful tools which have advocated for the abolishment of segregated education that denies learners with disabilities the right to be part of mainstream schooling. The spirit of inclusion is further emphasized in the UN Standard Rule 6 that requires member states to provide education for people with disabilities in integrated settings. These documents represented a strong case for inclusion and provided a unique opportunity to place inclusive education firmly on the agenda of the national governments.

Whereas the concept of special education assumes that all learners with disabilities have problems with learning that require 'special teaching methods' by 'special teachers' in 'special environments', it fails to recognize that the challenges that they face, such as, lack of easy access to buildings and communication barriers can be encountered by any other child. Their learning needs are therefore not special but ordinary needs that require support in a favorable environment (Stubbs, 2008).

Integration and later inclusion are seen in both economically richer and poorer countries as a major strand in education development. Since the 70s in German speaking areas

⁵³It affirmed the principle of inclusive education and the importance of 'working towards schools for all- ie institutions which include everybody, celebrate differences, support learning and respond to individual needs'

there have been coeducational movements for children with and without disabilities. Activated by successful implementations of integration in Scandinavian countries, Italy, Canada and other countries, classes were introduced, where all children in a district were educated together. Firstly pilot projects were accomplished in primary schools and later in secondary schools. The idea was to change the attitudes towards people with disabilities and to avoid separation and segregation in the educational system. In recent years, students with mild to moderate degrees of disability were enrolled in mainstream classes with the necessary support. It reflects the thinking from a medical “separate treatment” model to a “social model” that mainstream education has to be accessible for all learners.

It should be stressed that the notion of Inclusiveness differs from the one of integration. The latter tends to focus more on ensuring that children with disabilities attend mainstream schools rather than on guaranteeing that these children are learning. Indeed, whether or not children with disabilities learn in an integrated system is down to them and teachers and other staff make small, given the demands they face. When problems arise, blame can therefore be attached to the child and not the teachers or education system. (WHO, UNESCO, ILO & IDDC (2011) *Community-Based Rehabilitation Guidelines: Education Component*, Geneva: WHO).

Integration involves placing students with special needs in regular schools, with resource room support and services available, but with programs designed so that students can spend some portion of their time with regular peers. The pupil must adapt to the school and there is no necessary assumption that the school will change to accommodate a greater diversity of pupils (Mittler, 2000). The underlying premise of integration, as the basis on which many understand and accept it, is avoidance of segregation, but without any claim to inclusion.

The main question is not if the child is “integrable”, it is the accessibility to schools and institutions if they have the facilities to integrate children with disabilities or not. Therefore not the child has to be up to standard, but rather the system which has to make sure that all children can be included. Student diversity can be seen as an opportunity to challenge the existing practices and evolve more flexible ones, so that mainstream schools can respond to a wider range of student diversity. That means that

teachers have to be trained initially to work with a wide range of students, more curriculum- based and classroom- focused. The point is not just putting children with children in regular schools; it is much more the question how all children get along in a country's education system and how inclusion and integration is able to avoid segregation of children in different kinds of schools which might reduce the life chances.

2. More about inclusion

Moving from integration to inclusion, the underlying premise is the one that stems from a human rights perspective. The primary objective should be the full participation by all students, including (but not only) children with disabilities, and the respect for their educational and wider social, civil, and cultural rights. Inclusion “implies a radical reform of the school in terms of curriculum, assessment, pedagogy and grouping of students. It is based on a value system that welcomes and celebrates diversity arising from gender, nationality, race, language of origin, social background, level of educational achievement or disability” (Mittler, 2000: 12). Inclusive education has for a long time been associated with children who are considered in need of ‘special educational needs’ or in more specifically, people with disabilities due to its specific focus on those who are more vulnerable to exclusion and marginalization. However, differently from the other concepts, inclusion in education is a process of addressing and responding to the diverse needs of learners through increasing effective participation in their learning within mainstream school systems (Rieser, 2008). Inclusive education is a concept that emerged from the efforts of disability groups that demanded equal treatment and opportunities for disabled people to participate equally in their communities. They rejected the medical model approach which focused on the impairment and attempted to correct that which was seen as ‘abnormal’. As a result, ‘disability groups lobbied to ensure that all human rights instruments specifically mention people with disabilities and emphasize their right to education, whatever the extent or nature of their impairments’ (Stubbs, 2008: 20).

There have been different definitions of inclusive education that seem to focus on

different aspects. UNESCO's (2005:13) definition for example, states that, "it involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the regular system to educate all children". Whereas this definition is seen to lay more emphasis on the actual learning, other definitions refer specifically to the school. In Kenya, for example, the concept is defined as follows: "This is an approach in which learners with disabilities and special needs, regardless of age and disability, are provided with appropriate education within regular schools" (MoE, 2009a: 5). This understanding has resulted in the focus being on placing learners with disabilities in regular schools and aiming at doing away with special schools. Referring to Rieser (2008), the definition of inclusion in education goes beyond the child and beyond the classroom: a process of enabling all children to learn and participate effectively within mainstream school systems, without segregation. It is about shifting the focus from altering people with disabilities to fit into society, to transforming society, and the world, by changing attitudes, removing barriers and providing the right support (Rieser, 2008 – The Commonwealth website). Inclusive education therefore, focuses on the system – the teachers' skills and attitudes, and the whole classroom environment (Rieser, 2008; Stubbs, 2008). Indeed, some of the definitions imply that for education to be fully inclusive the focus should be on the system to provide any form of necessary support at home, within the community and in their learning environments. For example, a deaf child learning in an inclusive education system may not necessarily wear a hearing aid since the teachers and the hearing learners will be using sign language or any other form of communication in order to interact with him/her and accommodate him/her in the classroom. Inclusive education is viewed an opportunity to develop better pedagogy and greater teaching and learning competence and strategies (Miles & Singal, 2010). The authors recognized that emphasis should be put on "all" rather than on a specific group. DFID's disability in education policy has adopted a 'twin-track' approach which includes mainstreaming disability issues in all education programmes and implementing interventions intended to break down specific barriers to disabled children's access to education. The approach "ensures that while the interests and needs of people with disabilities are progressively

integrated into mainstream planning, specific issues that prevent people with disabilities from accessing current education systems are actively tackled” (DFID, 2010: 13).

Stubbs (2008) has an extensive notion of inclusive education in her definition that embraces all phases of life and expands beyond the school. She refers to a wide range of strategies, activities and processes that seek to make a reality of the universal right to quality, relevant and appropriate education. Although it can be seen as an utopist approach, it acknowledges that learning begins at birth and continues throughout life, and includes learning in the home, the community, and in formal, informal and non-formal situations. It seeks to enable communities, systems and structures in all cultures and contexts to combat discrimination, celebrate diversity, promote participation and overcome barriers to learning and participation for all people. It is part of a wider strategy promoting inclusive development, with the goal of creating a world where there is peace, tolerance, sustainable use of resources, social justice, and where the basic needs and rights of all are met (Stubbs, 2008: 40). While Article 24 of the UNCRPD recommends that all learners with disabilities should be able to access an inclusive, quality and free primary and secondary education in the communities in which they live without being excluded from the general education system, its recommendation for delivery of education in environments which maximize academic and social development for deaf, deaf-blind and blind learners has been interpreted as allowing for segregated education (Stubbs, 2008). It is evident that despite the acknowledgement of the equal right to education for all, the type and location of education remains an issue of debate where there are options of segregated special schools, full inclusion in mainstream schools, or some sort of combination (Ibid). Some authors have taken positions basing their arguments on the human rights perspective and strongly condemning placing learners in ‘special’ schools and units as a violation of their human right while others have focused on the level of the learners’ participation in their learning and the learning outcomes within the different learning environments. So context must be taken into account. In Kenya for example, a study by Mundi (2009) revealed that most of the parents of children with hearing impairment prefer taking their children to special schools where they believe the children receive specialized care, attention and education and above all, they are able to interact with other children who

have a similar impairment and use the same language. Parents with such point of view would consider their children not excluded by being in those schools since they offer them opportunities that they lack in regular schools in Kenya. However, the same study noted that some overprotective parents take their children to the school nearest home, a mainstream school or a specialized unit within a regular school. The large class sizes in regular schools in Kenya are likely to be perceived as depriving the learners the opportunity to participate in their learning thus achieving minimal learning outcomes. This illustrates that the concept of inclusion seem to be one that needs to be defined within a particular context since it can be understood differently in different contexts.

Inclusive education has some common features with traditional African education, such as community ownership and involvement, and functional learning methods and content. Consequently, for CBR programmes to be successful in Africa, they should involve the whole community and embrace collective consciousness (Miles, n.d.(b)) rather than individual children. CBR, as a strategy that partly focuses on the social inclusion of people with disabilities, plays a significant role in the achievement of inclusive education through tapping the existing local knowledge, resources and skills within the community. It has the potential to promote collaboration between community leaders, all its members and families. Handicap International (2006:23) notes that ‘the fundamental needs of an estimated 80% of people with disabilities could be satisfied at the community level’. CBR and inclusive education value diversity and are guided by a conviction that every child can learn and every child needs support to achieve their learning needs. CBR plays a crucial role in establishing links and partnerships between family, community members, health workers, organizations for/of people with disabilities, the school, and other social services.

3. Legislative Frameworks

Education and vocational rehabilitation of persons with impairments was started by churches and other voluntary organizations (Abilla, 1988) without the involvement of the local community. The first schools for children with impairments were segregated and sometimes residential since not all villages had an ordinary school and formal

education for young people with disabilities. This was the form of provision in the home countries of the colonial pioneers of special education and there were very few missionaries who were qualified special education teachers (Abilla, 1988). In particular, education of persons with disabilities dates to 1946 with the establishment of a vocational training for the blind at Thika to cater for the Second World War veterans who were either blinded or impaired in their functioning during the war (Ndurumo, 1993). This was followed by the establishment of a school for the mentally retarded in 1948, a school for the deaf in 1958, and a school for the physically impaired in 1968 (Ndurumo, 1993). It is noteworthy that the provision of special education in Kenya was heavily on the shoulders of religious and charitable organizations. Though these organizations have done a fairly good job using the charity model; their manner of provision of special needs education lacked relevance, expert personnel, coordination, standardization of curricula and grounding in legal and policy guidelines which necessitated the government to be called upon to coordinate and provide the necessary supervisory, personnel, expertise in curricula, budgetary support and relevant legal and policy basis in order to make the subsector a dynamic educational enterprise. The major weakness of the outcome of Ominde commission was that the coordination of special needs education was placed on the ministry of social services away from the ministry of education which led to the existence of two parallel education systems one under the mainstream education ministry catering for a majority of learners and the other one for the disabled. The result was inadequate funding and provision of qualified personnel since the ministry of education only focused on the regular education to the exclusion of special needs education. The social services ministry also lacked capacity and expertise to effectively offer relevant education to the challenged learners.

Post-colonial legislative action in Kenya in the benefit of students with disabilities takes the form of articulations of government's goals for the field and formulation of objectives and policy guidelines for the education and training of individuals with disabilities. Literature on the development of special education in Kenya shows that a number of activities were undertaken by the government of Kenya in the interest of people with disabilities in the country after independence which contributed to bringing the issues of education for children with disabilities to the limelight among the policy

makers and to the articulation of objectives for the education of this population in the country (Republic of Kenya 1964b, 1976, & MoEST, 2003). One such action was the creation of the Ominde Commission in 1964 (Republic of Kenya 1964b) to examine the national educational policies of the time and to advise the government on directions for further development (Sifuna, 1990). As noted elsewhere (Sifuna, 1990, & Republic of Kenya, 2003), along with reporting on the state and the necessary future directions on education, the Ominde Commission (1964-1965), partly as a result of urging by people with disabilities in Kenya to look into their affairs, also reported its findings with regard to the education of children with disabilities in the country. The recommendations of the Commission included the need for awareness of the problems that result from disability and for special education and training for all children with disabilities in the country. It also noted the need for teachers in training to be familiarized with the effects of disability at all levels of children's interactions, development and education (Republic of Kenya, 1964). Other recommendations of the Ominde Commission in the area of disability concerned the need for the government to coordinate and to improve both the quality of service and the methods of delivery of those services to individuals with disabilities. These recommendations, contained in Sessional Paper Number 5 of 1968 of the Kenya Parliament, brought the government to the forefront with regard to provision of services for individuals with disabilities in the country. As a result of the Sessional Paper, the Vocational Rehabilitation Division was established and the Industrial Rehabilitation Center along with ten other centers in the country were established in 1971. The Special Education Section was set up four years later to oversee the education of students with disabilities and with time this section was staffed with specialized staff overseeing educational issues of the various disability categories in the country (DRPI, 2003). Through the outcomes of the Commission, the government planned to empower these children through provision of specialized education and other services in order to facilitate their inclusion in and ability to be self-sufficient in their society and finally contribute to national development. The government articulated its intent to create awareness of disability and necessary services for this population, to practice, facilitate, and support integration in mainstream classes, and to establish residential schools for these students when necessary. The National Education

Commission (Gachathi report) of 1976 (Republic of Kenya, 1976) recommended that early intervention and assessment of children with special needs be emphasized. This commission also recommended that awareness of causes of disabilities be created in the society to strengthen preventative measures, that research is conducted to determine the nature and extent of disabilities to inform service delivery, and that early childhood development education centers are established as part of special schools. The Gachathi report also recommended that policy be developed for the integration of learners with special needs. In 1984, centers for the assessment, identification, and placement of students with disabilities, called Educational Assessment and Resource Centers (E.A.R.C) were introduced by the Kenya Ministry of Education and established in many districts (Republic of Kenya, 2009). Children with disabilities were, and still are, assessed, identified, and provided with some services before being placed either in the general education classroom in a neighboring school or in a residential school or being referred to the hospital for treatment for medical conditions. Although these centers were established initially in a few districts, there are currently over 52 E.A.R.C in the country with at least one in every district, along with 345 sub centers carrying out the same duties (Muga, 2003; & Republic of Kenya 2009). Legal Notice Number 17 of 1986 of the Kenya law created the Kenya Institute of Special Education (K.I.S.E), a semi autonomous government agency charged with the responsibility of overseeing and directing many aspects of special education in the country (Republic of Kenya, 2003). Although training of teachers of students with disabilities is conducted in other institutions in the country, K.I.S.E provides courses in various ways for in-service teachers and other personnel in the field of disability, runs centers where model assessments of students for purposes of evaluation is demonstrated, conducts research in special education and serves as a documentation and resource center for the field. Also housed at KISE are model integration and inclusion center, a preschool, and a center for various aids for students with disabilities (Kenya Institute of Special Education, N.D) all for training of teachers for students with various forms disabilities. The recommendations of both the Presidential Working Committee on Education and Training for this Decade and Beyond, Kamunge report of 1988 (Republic of Kenya, 1988) and the Totally Integrated Quality Education and Training Taskforce, the Koech

report of 1999, made recommendations in the area of education of learners with disabilities. While the Kamunge report recommended deployment of Special Needs Education Inspectors in the districts, the Koech report noted the absence of a comprehensive policy on special needs education and recommended that a national special education advisory board be established. The Kamunge (1988) and Koech (1999) commissions made significant contributions on management of special needs education, training of teachers, development of appropriate curricula, adapting examinations to suit learners with special needs, and the inclusion of emerging areas such as education of the gifted and talented, those with specific learning difficulties, the communication impaired among others as learners with special needs. This expanded the concept of learners with special needs beyond those who exhibited sensory, physical and health deviations. Koech (1999) noted that 1000 recommendations from past commissions and working parties had not been implemented due to lack of legal and policy instruments. In response to this, the commission appended to its report a number of draft education bills one of which was the special education bill to address various mechanisms and policy issues to govern the subsector. However, to date, this bill has not been enacted to law. Arising from these recommendations are the Children's Act (2001) and the Persons with Disabilities Act (2003) which currently address the issues of persons with disabilities. It is noted that these two acts are not sufficient owing to the fact that they are general laws and therefore not very specific to special needs education. There is need to provide a legal framework that is relevant and particular to special needs education.

When primary education was declared for free (2003), many children with special needs joined both special and regular schools but often dropped out because of lack of support in terms of assistive/ functional devices, learning resources, environmental adaptations, mandatory medication and a suitable curriculum. Most special schools are boarding and parents have to pay for these facilities because free primary education does not cover boarding fees and other obligatory requirements. That is why many of these children drop out and also because they cannot follow the other kids because of lack of devices (MOEST a 2003:24, 26). In 2003, the Kenya government also enacted the Persons with Disabilities Act (Republic of Kenya, 2003), another step in the progress of education for

students with disabilities. Although this Act was criticized by the Kenya Society for the Mentally Handicapped (KSMH) for failing to provide direct policy on early identification of children with disabilities, it is a law that benefits individuals with disabilities because it prohibits all forms of discriminative treatment of persons with disabilities such as in access to education and training and “provides for adaptation of infrastructural , socioeconomic and environmental facilities to ensure a conducive environment for persons with special needs and disabilities” (Republic of Kenya, 2009: 21). Another taskforce, the Dr. Kochung Taskforce of 2003, (Republic of Kenya, 2003) set up for the purpose of appraising the status of special needs education in the country, recommended in service and training of teachers for children with special needs, increased budgetary allocation and equipping to strengthen EARCs, inventory of assistive devices and equipment available in schools, and surveys to establish the number of children and youth with disabilities in and out of school settings. Due to these policy guidelines, special education continues to grow in Kenya as is clear from the number of special education institutions in the country, the number of schools with special education units and the number of students with disabilities receiving services in the country. The number of those receiving special education services in the country stood at 221,995 in 2008 while the number of special education institutions in the country increased from 926 in 2002 to 1579 in 2008. Three thousand four hundred and sixty four special needs institutions exist in the country, 54.1 % of which are in primary education, 38.2 % in Early Childhood Development Education (ECDE), 3.4 % in Non-formal Education Institutions, and 4.3 % in secondary education. Of the 3464 special education institutions in the country, 2,713 are integrated while 751 are special schools (MOE, 2008& MOEST, 2012).

The recommendations of the Kochung Taskforce, along with the emphasize on the importance of Special Needs education by sessional paper number 1 of 2005 led to the development of the National Special Needs education policy in 2009, a (maybe big) step forward in the development of the Special Needs education field in the country. At least because it showed a supposed commitment on the Government’s part. The stakeholders in this policy are given as the Minister and Permanent Secretary – Ministry of Education Science and Technology (MoEST) representatives from: Non-

Governmental Organisations, faith and community -based organizations, private sector service providers, members of parliament and Union representatives (Kenya SNE Policy, MoE, 2009 p10 and KESSP, 2005). Kenya Institute of Special Education officials, head teachers and teachers, as well as parents, are not mentioned. The policy has put forward positive aspects about early intervention which relate to continuous reviewing of the curriculum by the Kenya Institute of Education. The KIE will also develop training manuals, guidelines and develop assessment tests, ‘administrator’s and norms manuals’ as well as develop referral tools to conform to the recommendation after the review. It has included professional development for ‘assessment teachers’ (MoE, 2009: 22) and expressed that it shall organize mechanisms for engaging parents, professionals and other ministries in the assessment and rehabilitation procedures through joint committees, planning meetings, implementation at all levels and pooled resources. Itinerant and Vision Support teachers work closely with the Early Assessment Centre Coordinators and other agencies and staff like medical doctors and psychologists at the district level (Multi-disciplinary team) in the assessment of children said to have SEN. In addition to the Diploma in Special Education, the 99 assessors have additional training in the education of children with visual impairment (Lynch, et al., 2011). Kenya applies “a multidisciplinary approach which is only conducted informally since it has not been formalized” (MoE, 2009: 22). The proposed procedure of referral and placement is unclear. In practice, the referral may be initiated by the parent or principal caretaker. Consequently, the children of poor families are amongst the least likely to receive an assessment prior to school and the most likely to carry an undiagnosed impairment. Nowhere in the Kenya SNE Policy document or subsequent guidance documents, is the assessment process clarified. In the early years of a child’s schooling it can be difficult for a teacher to know individual strengths and weaknesses given that class size varies from 45 to 120 children with one teacher in class.

To enhance provision of accessible, safe and friendly learning environment and facilities for learners with special needs (MoE, 2009 p24) Environment is a facet argued by the International Classification of Function, Disability and Health (WHO, 2001) to significantly modify participation and achievement. Fundamental elements of an environment include physical, forms of support, relationships, attitudes, services,

systems and policies within a particular context. Guidelines established for the general environment and or features of the school and classrooms for children with SEN or disabilities may pertain to different aspects such as physical layout, use of different aspects including: lighting, noise levels, stationery, equipment, tactile and audio features, Braille, working spaces, furniture adequate for the diverse needs of the children. However, the reports have not discussed how teachers in public primary schools endeavor to have a learning environment that is conducive for these children.

However, this may be considered a virtuous act from the Kenyan government's part to finally have put a policy together which forms the basis of the operation systems in Special Education. But this is not enough, there may be benefits from further reflection, re-examination, synchronizing and revision of the different parts against the current legal provisions in Kenya pertaining to the child, parent and society at large. Inputs from schools, teachers, children, and multi-disciplinary teams need to be considered vital and in-depth analysis to compare the policy with the different national and international agreements has to be carried out in a bid to achieve universal primary education.

As explained above, the Government of Kenya has taken both legislative and programmatic measures towards addressing disability. Programmatic measures include cash transfers and strategy papers. Under cash transfers is the National Development Fund for Persons with Disabilities,⁵⁴ the Economic Empowerment Project, 2010,⁵⁵ and the Cash Transfer Programme for Persons with Severe Disabilities.⁵⁶ The key strategy paper in the country currently is Vision 2030.

In particular, The National Development Fund for people with disabilities⁵⁷ was

⁵⁴Established under Section 32 of the Persons with Disabilities Act (No. 14 of 2003).

⁵⁵Kenya UPR Stakeholders Coalition, Annual Progress Report, 22nd Sep 2010 – 21st Sep 2011, 'An assessment by stakeholders of government's performance in implementation of UPR recommendations', Nairobi Kenya September 2011.

⁵⁶<http://www.gender.go.ke/index.php/Gender-and-Social-Development-Divisions/social-welfare-persons-with-disabilities-programme.html>

⁵⁷ National Development Fund, available online at <http://ncpwd.go.ke/national-development-fund-for-persons-with-disabilities/> . The Fund currently supports the following funding categories:

1. Assistive devices and services – To improve mobility and access . Includes wheelchairs, crutches, surgical shoes, hearing aid, white cane and others.
2. Educational assistance – Scholarships for persons with disabilities who wish to pursue education but cannot do so because of financial difficulties.

established under Section 32 of the Persons with Disabilities Act and operationalized in 2010. It has begun to disburse funds to persons with disabilities, and organizations and institutions that provide services to persons with disabilities. In 2009-2010 the Government allocated KES 200 million to the Fund.⁵⁸ This fund provides only limited financial support to people with disabilities and their families on a means-tested basis.

The Government through the Ministry of Gender, Children and Social Development also began the Economic Empowerment Project in the year 2010. Through the project, the Government is disbursing funds on a continuous basis directly to groups of persons with disabilities for promoting the economic independence of persons with disabilities.

4. Challenges

Under the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, governments around the world, including Kenya, have taken upon themselves the responsibility of ensuring that all children, irrespective of ability or disability, enjoy their rights without discrimination of any kind. These two Conventions bear witness to a growing global movement dedicated to the inclusion of children with disabilities in community life. A look at the history of special education internationally and nationally suggests that although there has been progress through the various stages, it cannot be claimed that educational services for people with disabilities have been adequate. For various reasons varying from negative attitudes and resources to a lack of clear policy guidelines, the education of children with disabilities continues to be troubling. Much of the literature on its early stages is essentially western, leading to a situation where developing countries may pick up the concept of inclusion as a practice without considering its historical development and practicality.

3. Economic Empowerment & Revolving Fund – Help for groups of persons with disabilities to set up small businesses or revolving fund schemes.

4. Infrastructure & Equipment – Assistance or social care and education institutions that provide services to Persons with Disabilities.

5. Cash transfers - Support for households of persons with severe disabilities who are in extreme poverty.

⁵⁸Kenya UPR Stakeholders Coalition, Annual Progress Report, 22nd Sep 2010 – 21st Sep 2011, ‘An assessment by stakeholders of government’s performance in implementation of UPR recommendations’, Nairobi Kenya September 2011, p.24.

In this process, the role of the Non-governmental Organizations in support to inclusive education implementation cannot be overemphasized. Indeed, NGOs contributed immensely towards the transition (in 2002) from authoritarian to democratic rule through their efforts to advance political rights and freedoms as well to broaden the democratic process. In collaboration with the government, they have made immense contributions in ensuring implementation of Inclusive education practices especially in regular primary schools in Western Kenya. Efforts have been made in areas such as awareness creation, capacity building for teachers, provision of teaching and learning resources, support in the development of barrier free environments in schools, empowerment of parents with knowledge skills and attitudes towards inclusive education, educating community members and professionals in allied service systems on inclusive education philosophy. Despite some efforts the government has put in place, a number of challenges have persisted in regard to the implementation of inclusive education in Kenya. The most significant limitation seems to be the apparent lack of clarity in the inclusive education policy, i.e. ambiguity about the goals for inclusion and the means through which this can be achieved. The others are to do with various issues around the poor implementation of the policy. According to MOE (2009), inappropriate infrastructure, inadequate facilities, inadequate capacity of teachers to manage learners with special educational needs in regular schools, inadequate and expensive learning materials, societal negative attitude and inadequate supervision and monitoring of the schools have been impediments to implementation of inclusive education. Although teacher education in Kenya currently models teachers on how to accommodate diverse needs in a classroom in line with the social model of disability which is rooted firmly in the human rights paradigm that argues for inclusion and the removal of all barriers that hinder full participation of individuals with disability, this is a new phenomenon. The old medical model approach created attitudes regarding the separate education of learners with disabilities that have become strongly embedded in the Kenya teaching culture and reorienting such teachers, according to Danohue and Bornman, (2014), to new ways of educating learners after many years in the profession remains a significant challenge to inclusive practice. There is need for the enforcement of inclusive education policy and legal framework to realize equitable and quality education. Capacity building

on inclusive education approaches should be organized for the Curriculum Developers, Education Administrators, Quality Assurance Standards Officers (QUASO) and the Examination Councils officers. We call for open and dynamic learning environment where the needs of students are at the heart of the system. The system should be able to support teachers, students and their families to recognize and work with diverse strengths, interests and abilities, to connect learning to family and community background, create diverse learning opportunities and networks, use diverse teaching approaches and balance academic achievement with the development of knowledge, skills and values. While it is essential to focus and work on quality service by putting in place specific service standards with agreed service pathways for students, there is also a need to provide training that will enable special education officers to be skilled and to keep learning, including supervision, reflective and practice and research. Roles of various sectors, such as people with disabilities, parents, policy makers, educationalists, health officers and community development professionals and crucially, the society at large should be clearly defined including family involvement, enhancement of inclusive community services, the promotion of advocacy and community education strategy. Inclusive education is never an ending process. We can talk of inclusion when the government and the society are committed to a development journey steered by inclusive values. Those values include recognition of diversity, working together, participation in the contribution of ideas and be able to be heard and valued as everyone feels safe and secure in the learning the environment.

Polat (2011) has pointed out that resources and improved infrastructure are not the only adjustments for inclusion and that dealing with attitudinal barriers among school educators and in the wider community is a key aspect of making inclusive education take place. The meaningful participation of children and adults with disabilities in the school and the community is influenced by the cultural attitudes and values of its citizens. If a society expresses disregard and prejudice towards people with disabilities, then discriminatory practices will continue to be propagated (Polat, 2011 50-58).

Concern for inclusion is rooted in the recognition that all children are full members of society: that each child is a unique individual who is entitled to be respected and consulted, who has skills and aspirations worth nurturing and needs that demand

fulfilment and whose contributions are to be valued and encouraged. Inclusion requires society to make physical infrastructure, information and the means of communication accessible so all can use them, to eliminate discrimination so none is forced to suffer it and to provide protection, support and services so every child with a disability is able to enjoy her or his rights as do others. Inclusion goes beyond 'integration'. The latter implies that children with disabilities are to be brought into a pre-existing framework of prevailing norms and standards. In the context of education, for example, integration might be attempted simply by admitting children with disabilities to 'regular' schools. This would fall short of inclusion, which is possible only when schools are designed and administered so that all children can experience quality learning and recreation together. This would entail providing students with disabilities with such needed accommodation as access to Braille, sign language and adapted curricula that allow them equal opportunity to learn and interact.

CHAPTER 5 CASE STUDY

5.1 Research methodology and limits

1. Justification of the study

Persons with disabilities, and especially children, are disproportionately denied their rights to education which undermine their ability to enjoy the full rights of citizenship, find gainful employment and take up valued roles in society (UNICEF, 2013) The Constitution of Kenya, 2010 makes primary education free to all, yet no study that has been undertaken to describe the situation of children with disabilities in terms of their rights to education, not to mention the assumption that they are enjoying the same rights as other children in Kenya. Many children with disabilities do not have the opportunity to participate in sharing the country's resources because they are among the last in line for resources and services, especially where these are scarce. They are the objects of pity discrimination and abuse.

Winzer (1993), states that a society's treatment of those who are weak and dependent is a significant indicator of its social progress and social attitudes towards the education and care of people with various disabilities. It also reflects general attitudes concerning the obligations of a society to its members. She adds that along the range of human behavior from normal to abnormal there is some point at which a social judgment is made and the individual comes to be regarded as exceptional, disabled, different or deviant. The extent to which societies accept and address differences is varied.

For the scope of this thesis it is very important to understand how the perception of disability is at all levels of society. Whilst it emerges quite clearly that the government's commitment is only apparent, through targeted interviews I tried to understand and analyze what is the situation as regards the human rights of people with disabilities amongst the most disadvantaged (and often forgotten) sections of the society.

The aim of this thesis is to analyze the extent to which people with disability and especially children enjoy their human rights with a focus on education. The transition from commitment to compliance of human rights is still very far to reality. As it is also

clear from my analysis commitment to international human rights norms does not by itself lead to compliance.

The study examined disability in general, focusing on physical disability, hearing and visual impairments and mental disability because the subject of disability is very wide and could not be fully covered.

2. Methodology

I have chosen a qualitative research method to collect information of the daily routine of people with disabilities, like cultural factors, inaccessible infrastructures and lack of resources which influence the life of these people. Unstructured interviews, participant observation are particular important for marginalized groups such as children with disabilities in developing countries to gain insight into their life worlds and to get a chance in participating in their activities. It is important to focus on various aspects of their lives as their relationships with family, peer groups, teachers, adults, etc. their experiences and perspectives.

Most of the children with special needs I met at their homes. I got a chance to talk to their guardians and if they were old enough to talk to themselves.

My study is representing small areas around Kenya (Nairobi slums and Nyahururu). In some areas I found only Kikuyus, the largest ethnic group in Kenya, in other areas I met Luos but I do not want to analyze the ethnic belonging in my research because it could never be representative for any ethnic group in Kenya. More important I think are the challenges families with disabled members face, without considering the ethnic belonging. But I have to recognize that my interviewees were mainly Kikuyus.

I visited families in populated areas with cultural diversity, as well as in sparsely populated areas. As I was dependent on local assistance to identify my informants, I chose places where CVO was working. I met informants who were known by the organization and who had already benefited by them as well as families who had not been informed about the possibilities of assistance. All families lived in lower level situations and some even lived under seriously poor circumstances in slums. To understand the families and the children, the project members translated for me from Kikuyu into English and sometimes Swahili to English. I tried to find people who

represent a small area but a range of life situations or challenges as possibly related to the topic of my research. I wanted to bring forward the perspective of these people by learning from

themselves as experts on their life situation. I met a lot of people with disabilities , but the majority were children or people with severe disability and they were not able to sustain an interview. In any case the share of their life stories may also give a sense of empowerment because only if people of disabilities themselves can participate in planning and arranging their life situations in the present and future, empowerment can be achieved. Some informants were happy and thankful for being interviewed and some were tired of *wazungu* always getting their noses in everybody's else business.

3. Limitations of the study

Given that this is an exploratory, rather than a representative study of the situation of children with disabilities in Kenya, the first limitation is the number of people interviewed. . One problem that was faced during this study was a language barrier. All of the interviews with family members, and community members were conducted in Kiswahili or in Kikuyu with the aid of a translator. They translated in English which was not the mother tongue of any of us. There were numerous times during the interview that the translator gave abbreviated accounts of a participant's account or story. Abbreviated stories usually lose small details that could help further understand the story holistically. Also during this study, certain words and/ phrases could not be translated directly from English to Kiswahili and vice versa. These small errors in translation could have caused major changes in meaning, thus providing the study with inaccurate information.

Another limit is colonial legacy (together with skin color and gender). In this case "White privilege" did not work in my favor. Traditionally, women's opinion in Kenya is considered useless. They are considered as intelligent as children, so their opinion does not count. Nowadays the situation is gradually changing but my condition of a white European girl did not help my research. I experienced two different behaviors: the first was respect for the white (colonizer), so they did lie or omit something to make a good

impression on me and hoping to receive money; the second was a kind of rejection for the white (colonizer) that exploited the country and now is coming back to pretend to help the black people. The ‘culture gap’ could also be addressed, to some extent, by ensuring that I entered the field having gathered and absorbed as much relevant local contextual information as possible in advance, so as to ensure that research could be conducted with sensitivity and an awareness of local realities. Another danger, as partly mentioned, in relation to my personal identity, was that participants may perceive me as someone with influence or power, who may be able to transform their lives in some way, in exchange for their participation. This risk was minimized by being accompanied by a local “guide” to make sure that participants understood the purpose of the study. Another problem that affected this project was time. The main methodologies used in this study were qualitative, which usually take several months to conduct and interpret. However, this entire project was conducted in only a month. If more time was allotted, more interviews would have been conducted, thus providing the study with more in-depth and personal accounts. In future studies, the researcher should spend at least a month to six weeks to conduct interviews and another 6 weeks to input and interpret data.

5.2 Data collection

The interviews were made thanks to the following associations and NGOs working on the field: World Friends, DeafAid and Saint Martin-CSA. Twenty five interviews were conducted with family members of people with disabilities to further understand the challenges disabled persons face both in a rural and urban environment: in particular in Kibera, Mathare, Korogocho, Babadogo and Nyahururu. These interviews provided firsthand accounts of problems and issues faced by people with disabilities and their caretaker in various slums of Nairobi (Kibera, Mathare, Korogocho, Babadogo) and in Nyahururu. Unfortunately I did not have the chance to interview any father. Twenty six interviews were conducted with volunteers, staff members and community members to understand the community’s perception of disability in the different areas. The

community interviews also provided us with social and cultural stigmas regarding people with disabilities that have developed over the years. Investigating these stigmas helped to further understand the cultural and social discrimination against individuals with disabilities. I interviewed 10 female and 16 male. The interviews were conducted randomly and only targeted individuals that were 18 or older. Finally, I interviewed also ten teachers from different schools, but I did not have the chance to meet them and see the schools.

1. Interviews with the parents

I was able to involve twenty five mothers that have a son or a daughter with disability. They have different kind of disability and the age range is very wide: from one year to thirty. As mentioned, no fathers came in any rehabilitation sections or I did not find any in the houses I visited.

Type of Disability	Number of Responses
Physical	12
Mental	2
Speech	1
Visual	2
Hearing	4
Multiple	4
	25

Disabilities are caused by a variety of reasons. However, about half of the participants (12) believed that the disability was cause by a childhood illness or they were simply born like that. Another ten participants believed that the disability was caused congenitally. Only two participants said that the disability was caused by an accident.

They specifically stated their disability was the result of witchcraft, however, more participants believed that witchcraft played a role in cause of their disability as well.

Every single mother stated that their child's disability has had a negative effect on their daily activities and it affected they disability has also affected their mobility and productivity too. They are unable to participate in normal activities like work because taking care of the disabled individual take up so much time and effort. One mother even was worried because she was getting old and was not able to take care of her child properly. He is 30 years old now and she did not feel she was strong enough to get him get up, go to the toilet etc.

To better understand whether they accepted their children's condition and how they were feeling about it, I also asked the mothers if they were or ever had felt guilty for their children's disability. The question was probably too “difficult”. I perceived that families may experience shock, a sense of denial and guilt, increased sadness, and may not accept the differences of the child, but they are not willing to share it.

More than half (18) stated that they have received rehabilitation services when they accessed health services. Five more participants received medication as their form of treatment. One participant only received counseling, while another did not receive any service when going to the health facility. But most of them had to drop because of money. For example two of them received treatment for their children at Kenyatta Hospital, but they had to pay 100 Ksh per session, plus transport. They could not afford it. Now they all pay a little or no money for treatment.

In a rural environment, traditional medicine is often used as a reliable form of treatment for different illnesses and condition. However in Nyahururu, less than half (8) of the twenty five participants have used traditional medicine. Most of these individuals used traditional medicine because they associated the disability or their children with unnatural phenomenon like witchcraft or spirits. Only two participants who used traditional medicine stated there was some kind of improvement. Some of these participants stated that have not or would not use traditional medicine because they were Christians.

Lack of education is a major problem that people with disabilities often face especially in a rural areas and slums. About two thirds (16) of the participants have never been enrolled in school, some are under school age, but mothers were very worried about their education. Only two affirmed that they have not thought about that yet and one seemed resigned to the situation.

Respondents were interviewed to establish how easy it was to transport or access school for their children with disabilities. The vast majority of the respondents (who has child that goes to school) indicated that it was not easy for children with disabilities to access primary schools. The challenges faced include; the fact that the parent must carry his or her child to school daily, most special need schools are not within their reach and in many cases are very expensive. In addition, most public schools do not have facilities such as physiotherapy and speech therapy equipments. In some cases, school administrators denied admission to children with disabilities due to lack of facilities or simply because they could not handle children with disabilities. The attitude of school community towards disability is culturally negative. These barriers prevented children with disabilities from enjoying their rights to education.

When asked if there is any education or employment opportunities for individuals with disability in the community, majority of the participants stated no.

In order to know what services should be provided in their area and in Kenya in general, the participants were asked what services should be offered in the community. Twenty-four participants in their interviews stated that there should be access to special education when asked what types of services should be offered in the community. Another 13 participants stated that there should be technical skill training provided to individuals with disability in the community. Seven more participants stated that there should be more free health services, while three participants suggest that individuals with disabilities should be given economic assistance to help with providing basic needs like food, clothing, and school fees. Only one was under “Cash Transfer program” and received 2000 ksh per month, due to the severe disability of her son. Few participants stated that employment opportunities are need for people with disabilities in the community.

I asked participants how their children are treated in the community to determine if there were any cultural or societal discrimination against people with disability. A little more than half (14) stated that they are treated well by the community. However, the other 11 mothers said that all the family was treated poorly by the community. Some said that community members look down upon them by laughing and calling them names. Two mothers with school aged children stated they [children] have even been physically acted by other children in the community.

To find out how many persons with disabilities are registered with the National Council for Disability in Kenya, we asked participant if their children had a Kenyan disability ID card. Only ten out of the twenty five participants stated that they had registered with the National Council, however, four participants are currently in the process of registering. These participants have already filled out their submitted their application but are waiting to receive their ID. The participants that have registered stated registering with the National Council for Disability is a long and expensive process. On the other hand, majority of the participants stated that they were not registered. About half of participants in this cohort would like to register but do not have the funds to pay the application fee. The other half just does not want to register for various reasons.

To examine participants' knowledge of people with disabilities right in Kenya, I asked if they had ever heard about any legal instruments protecting people with disabilities. A little more than half of the participants (16) stated they heard of the Disability Act. Of the 16 participants who stated that they had heard of the persons with disability act, only one purpose knew that the purpose of the act was to create a more inclusive environment for persons with disabilities. But none of them was able to explain clearly which rights.

2. Interviews with community members

During this study, community members were asked a series of question with the aim to

understand the societal and cultural stigmas associated with disabilities in the areas taken into consideration. Even though people gave different answers, the underlying themes were very similar. Most of the community members stated that people with disability are unable to provide for their basic needs and have to be assisted with members of the family. A few people stated individuals with disabilities are just individuals just like everyone else but suffer from a physical or mental illness that limits their productive.

Almost three-fourths (20) of the community members interviews declared that life would be different if they had a child with disability, because the child would require a lot of attention and care. A few stated that they would have to earn more money to provide for the medical services. On the other hand, eight community members stated that their life would be the same.

The community members gave a different response when asked about the common beliefs associated with disability within their community. Many of them believe that disability is associated with unnatural phenomenon. Out of the twenty-six interviews, 18 community members said that disabilities are caused or associated with curses (9), witchcraft (5) and demons/spirits (4). Other interesting beliefs associated with disabilities are adultery, incest, and gaining wealth. Disabilities associated with medical illness or accidents were only heard three times throughout the community interviews. Another four persons stated that disability is a natural thing designed in God's plan.

Slightly more than half (15) of the community members stated that they have frequent interaction with community members. Of the people who frequently interact with individuals, four participants stated that they interact with disabled individuals at work. Thirteen community members do not have frequent contact with disabled persons. None of these participants gave a reason why they do not interact with disabled community members.

About one-third of community members (7) interviewed during this project was aware of the Person with Disability Act that was passed by Parliament in 2003. Almost

everyone knew that the new Constitution protect is some ways the rights for people with disabilities, but they could not really explained how. Majority of these community members learned about the act through media, radio or newspaper or word of mouth.

The staff members all agreed that the community, the government and outsiders should all have a role in improving services for people with disabilities. They underlined the importance of learning more about the capabilities of people with disabilities in order to maximize their participation in the community and help them to achieve their potential. Suggestions included raising awareness, initiating support groups and interacting with people with disabilities to learn more about them.

They also indicated that people with disabilities could be advisors to the government and partake in community development; but on the other hand they acknowledged that many people do not take part because they do not see the government being responsive to their needs and they do not see how their participation could influence government decisions.

3. Interviews with teachers

The questionnaire was designed to examine the teachers' perception of the trends of rights to education for children with disabilities. The vast majority of teachers (7) of children with disabilities had taught for more than 7 years and the other 3 for 4-5 years. According to Kenyan law, learners with disabilities were entitled to qualified and skilled teachers for them to enjoy their right to education and complete the full cycle of basic education. Six out of ten respondents interviewed stated that they had undertaken special needs training. It was however, shocking to note that when asked how they handled the educational needs of different children with disabilities in their school, only 3 out of 10 of respondents were able to explain the need to identify learning needs of different children with disabilities rather than just place them in a unit as many respondents had described. This indicated that in many cases the rights of children with disabilities were abused in the institutions surveyed.

The study established from teachers whether the existing curriculum and examinations were accessible, inclusive and friendly to learners with disabilities. The unique characteristics, interest and attitudes of children and diversity in learning styles demand differential teaching methods to be used by a teacher in the classroom to facilitate learning. In order to meet the diversity, there was need to develop an inclusive curriculum aimed at providing quality education that could enable all children to learn effectively and participate equally in class. It should also provide children the dignity and confidence to learn.

The findings of the study showed that the majority of teachers reported that the current curriculum and examination were not designed to meet the needs of learners with disabilities. They explained that curriculum and examination were basically theoretical and therefore does not suit most special needed children who need to be equipped with practical skills for life. In the broadest sense, the rights to education of children with disabilities were denied by not having an inclusive curriculum.

It is the responsibility of teachers to ensure that reasonable accommodation for the learners with disabilities was provided in school. This calls for the provision of reasonable accommodation which refers to necessary and appropriate modification and adjustments, without imposing a disproportionate or undue burden, where needed in a particular case, to ensure children with disabilities enjoy or exercise on an equal basis with others, all human rights and fundamental freedoms. Respondents were asked to determine whether they understood the term reasonable accommodation and how they applied it in learning. It was not surprising that only 3 of the respondents were able to describe what reasonable accommodation entailed and how it was practiced in schools. This explained the fact that in many cases, rights of children with disabilities were infringed by teachers unconsciously or consciously.

Teachers were asked if they thought that inclusive approach was the best method to guarantee children's' right to education.

Six of participants agreed that inclusive education as an approach was critical in promoting access to education for children with disabilities. Inclusive education enabled children to learn together in the same classroom, using materials appropriate to their

various needs, and participating in the same lessons and recreation. In an inclusive school, children with disabilities did not study in separate classes; instead, teaching methods, textbooks, materials, and the school environment were designed to fit girls and boys with a range of abilities and disabilities. But they did not deny that, in some cases, special education can be more appropriate and productive. They confirmed that sometimes even parents prefer to take their children to special schools because they think that teachers take better care of them.

Another field to investigate was whether the schools were accessible to children with disabilities in terms of toilets, playing ground and classroom. The teachers answered that most of the schools are not accessible. There were no modified toilets for children with disabilities, no ramps for children with physical disabilities and there were some objects on the schools playing ground that could significantly prevent participations of children with disabilities.

Given that it is fundamental that teachers know the rights of children with disabilities to put them into practice and conveying them to the community, teachers' answers are very disappointing. Although all respondents surveyed indicated that they were aware of existing legislations and policies protecting the rights of children with disabilities, it was surprising that only 4 out of 10 teachers were able to answer the question correctly regarding existing human rights laws that protect and promote the rights to education for children with disabilities. The respondents stated that they were aware of the Persons with Disabilities Act 2003, the United Nations Convention on the Rights of Children with Disabilities and the Children Act. But, none of the respondents was able to mention the Constitution of Kenya 2010 which clearly provides that every child has the right to free and compulsory basic education.

With regard to who was responsible for protecting and promoting rights of children with disabilities in the school, all teachers indicated that everyone at school was responsible for ensuring that the rights of children with disabilities were respected and protected. Only few of them were able to cite mechanisms in place, and what actions should be taken in the event that the rights of a disabled child were violated.

5.3 Good examples of associations working with people with disabilities in Nairobi and Nyahururu

1. DeafAid

Deaf Aid is a Norwegian based International Non-Governmental Organization working in East Africa since 2005. They are very keen on providing a strong education background for deaf children and monitoring deaf youth to be self reliable individuals. It works in order to promote a Kenyan society more inclusive with the deaf with focus on children and youth. The Kenyan Office is in charge of developing programs in line with strategic plan for the organization. The Organization began by laying the ground for setting the social infrastructure for capacity development and prevention of deafness in Kenya. To effectively attain this, the organization developed a strategic plan, which outlined the goals and activities to be prioritized within the four year strategic plan 2005 – 2008. Buoyed by favorable results, their desire was to consolidate gains and many pressing needs that became constant reminders, calling for evidence informed right-based programming as opposed to the rampant and widespread charity/welfare based programming that has characterized services provided to the deaf and people with disability for more than 40 years, much without substantial improvement in livelihood of hearing impaired and hard of hearing people. For this reason, Deaf Aid developed a new strategic plan that was still in progress during my visit in April 2015.

Deaf Aid's intrinsic philosophy is to empower the hearing impaired and hard of hearing children and youth to make them have the right life foundation and opportunities that could help them break the present-day and would-be social-economic and cultural barriers so that they acquire and exploit these opportunities that would make them fully independent. Based on the many discouraging realities which affect many deaf and hard on hearing children and youth, the new strategic plan outlined a pragmatic and data driven commitments and systematic pronged actions that would ensure the economic, social and cultural (ECOSOC) rights for the deaf related to the conditions necessary to meet basic needs for food, shelter, education, healthcare and gainful employment, were

ultimately attained. By implementing a raft of activities under each goal, Deaf Aid envisaged to attain some basic but fundamental immediate results, such as: enhanced capacity of inclusion of the deaf children in an appropriate education setting sensitive to the child's special needs and improvement of the teaching to deaf infants and children; health, Social and Educational needs of the hearing impaired children in target areas identified within critical periods and subsequent remedial services provided; improved readiness for deaf children to join primary school translated by the increased enrolment rate; better attitude of teachers towards their deaf students; enhanced capacity of service providers to the deaf; wide access for the deaf to information and services.

For effective and efficient delivery of services the plan is organized in 3 main projects: Education Support Program (ESP), Early Identification Program (EIP) and Deaf Youth Empowerment Program (DYEP). The first one and more important to this thesis is the Education Support Program. Recognizing that only a few hearing impaired and hard of hearing children were enrolled in schools in Kenya, quite a number starting schooling late and many of them dropping out because of a myriad of difficulties like impoverished families and the deaf-insensitive inappropriate learning environments key among them, this program aimed to reach out to the deaf children and their families and provide them with necessary support to access relevant education just like their hearing peers. By focusing more resources and efforts by investing in the Deaf Children's education in Kenya and also working with relevant government institutions to institute policy frameworks and supporting the implementation and monitoring of existing policies that would realize the greatest and sustainable impact, this program would additionally ensure that deaf children have access to quality education beyond the life of Deaf Aid in Kenya. Noting the challenges of lack of Early Childhood Development schools for the deaf, and inadequate number of special school for the deaf, Deaf Aid piloted 2 ECD and primary schools in Nairobi's two slum areas. One school is based in Kibera while the other is based in Kariobangi. Since establishment, these schools have seen a steady growth and enrolment rate. A total of 81 pupils are enrolled in the school with an average annual enrolment growth rate of 20%. These schools provide a holistic and broad based learning framework that not only imparts numeracy, cognitive and literacy skills but life skill as well. The schools management approach embraces full

participation and involvement of the beneficiaries as the gateways to the local communities, a key feature which has placed the management of the schools in the hands of parents and the surrounding communities. This is within Deaf Aid's long desire to put ownership of the projects within the hands of communities after certain period of capacity building. Deaf Aid has therefore incorporated this strategy by facilitating the formation of Parents Teachers Association (PTA), through which parents and teachers will cooperatively work together towards sustainability of the programs. In addition to the two schools, a fair number of deaf children in various special schools around the country are also supported through scholarship bursaries, school feeding program, school uniforms and other basic learning materials. In the period under review, up to 21 students, 8 male and 13 female both within the age brackets of 7 to 16 years, were sponsored to access quality education. The Organization also has a very close working relation with many schools through which other forms of support that improve the learning environment for the deaf children is channeled. The Education Support Programme is also fully integrated with a holistic and comprehensive medical scheme that serves all enrolled and supported children within Kibera's program catchment area so that they have a regular access to comprehensive quality health care services. This has been made possible through a result of another strategic partnership with nearby medical institution which provides the medical services within the framework of the partnership. Through its strategic partnership and collaborative goal programming with key Government Institutions in the Education Sector, the following results were realized within the period between 2009 and 2012: The organization entered into a Memorandum of Understanding with the Ministry of Education (MoE) to enhance the Equal Opportunities Initiative for Deaf Children's Education (EQUOIP) whose main goal was to entrench and mainstream the Kenyan Education's Strategic plans and activities towards a more inclusive and enabling environment for the deaf child. In the MOU, whose implementation has since taken off and is in advanced stage, both parties committed to work in partnership and with other relevant stakeholders to realize the set objectives; In partnership with the MoE and its agency institutions mainly KISE, KIE and KNEC, the Kenya Sign Language Curriculum was fully developed in 2009 and is at the advance stage of implementation with the development of

Interpreter's training manual underway. The major milestone, the first in Kenyan history, the Kenya Sign Language became examinable subject, the first lot of examinees being the KSCE 2012; National Workshop on Quality Assessment for Educational Rehabilitation Resource Centers in 2012; Capacity Building and technical support to the EARCs.

Valuing Sign language as an actual right for the deaf people, Deaf Aid after a needs assessment identified communication challenges between parents/guardians and their children that needed urgent long lasting mitigation. This barrier was not providing a constructive learning home environment for many of these hearing impaired children. Further, it became an impediment to effective parental care. Deaf Aid therefore started offering Kenya Sign Language training to parents whose children are deaf in Nairobi and in Kisii. Between the year 2009 – 2012, 150 parents undertook the training. This has immensely contributed to improved quality of life for the deaf and hard of hearing children. Parental care has improved in much equal measure just as home learning environment and support has. In the course of implementing this training program another need emerged that as well needed a pragmatic approach. Most parents could not attend the trainings due to their low socio-economic statuses that necessitated them to engage in menial and unskilled labor jobs within their locales of residence or in the neighboring areas of residence to sustain their families. The nature of these jobs is such that they can only provide that daily survival sustenance without guarantee for financial independence or meaningful socio-economic development. As analyzed in chapter two of this thesis, the end effect is perpetual vicious cycle of poverty for these families. Deaf Aid did Needs Assessment to determine the socio-economic needs of the parents and thereafter, in participatory approach designed the Parent Empowerment Initiative program as a component of the ESP. Premised on the ECOSOC rights, the goal of this project was to enhance the socio-economic status of parents of the deaf and hard of hearing children so that they could become individuals that can engage in gainful socio-economic activities that up lift their economic life as well as improving their livelihoods. From 2009, initial batch of 20 parents successfully underwent training on tailoring, knitting, dress making and hair dressing in Kibera Slums of Nairobi, while a group of parents in Kisii were supported to start a Dairy Farming Project. In both

Nairobi and Kisii, the beneficiaries are organized in formal and registered groups and with a full management of their activities in the hand of members. The groups have a saving scheme, designed towards group investment plans for economic empowerment of each individual member.

The second program is the Early Identification Program. The primary justification for Early Identification Project of hearing impairment in infants and children relates to the impact of hearing impairment on speech and language acquisition, academic achievement, and social/emotional development. The first 3 years of life are the most important for speech and language acquisition. Consequently, if a child is hard of hearing or deaf at birth or experiences hearing loss in infancy or early childhood, it is likely that child will not receive adequate auditory, linguistic, and social stimulation requisite to speech and language learning, social and emotional development, and that family functioning will suffer. The goal of early identification and intervention is to prevent, care for and (re) habilitate hearing loss so that no one is needlessly deaf and has equal opportunities with others to lead a dignified life. In effect, this project has a close link with the Education Empowerment Project, and to a very large extent complements it. This program was developed to complement Educational Assessment and Resource Centres, a laudable government initiative designed to carry out early identification, assessment, intervention and placement of children with disability in education system in an inclusive approach. The centers are located at the district level in headquarters and many of them lack modern equipment and facilities in addition to being heavily understaffed. Moreover, there is a very limited or no approach to integrate the functions of the EARC in a more general multidimensional and multi-stakeholder community based approach, an identified gap in which the EIP project endeavored to complementarily fill through which a complete versatile Mobile Hearing Setup – i.e., a branded track equipped with requisite equipments, medical devices and commodities and human resources (community mobilization team, triage nurses, medical transcriptionists, ENT specialists and Audiologist) would deliver community outreach services. It is also in this perspective that Deaf Aid pioneered the Green House Early Child Development Center (ECD) for deaf children in Kenya. To date, the ECD remains the only one exclusively dedicated for deaf child early development in Kenya.

Due to the challenges in public health sector in Kenya, and lack of proper coordination by Education and Health Ministry, and many years of neglect the target beneficiaries have faced and endured, the program focuses on children between 0 to 16 years so that all the children both at home and school in less privileged populations both rural and urban areas are effectively reached. Through the Mobile Hearing Clinics delivered through community outreach strategies. The other important component in this programme is preventive health education that helps to create awareness on hearing loss. The camps are delivered through strategic partnership with key partners and communities. The Project embraces a robust community mobilization strategy that involves the key community social network segments including churches and community based organizations. One of the Key partners in this project is the Gertrude's Children Hospital. In the period under focus, 25 medical camps were delivered within Nairobi and its environs and other rural areas with 2500 children screened, many cases treated and some referred for further specialized treatment and (re) habilitation services.

The third program is Deaf Youth Empowerment Program (DYEP) specially designed and delivered project that turns deaf youth, who have for years suffered neglect and severe form marginalization and its heavy consequences, into economically productive members of society through adequate training and other socio-economic support. In 2009, DYEP single out the need to provide quality and advanced training for deaf youth to propel them into the information and technological market; which is now the driving force of developing economies of the world. It partnered with Cisco foundation that saw it become the first initiative in Africa which trains Cisco's materials using sign language. Interestingly, the program receives several applicants from various other neighboring countries, a fact that demonstrates an existing gap in Deaf Youth Trainings in many countries and concurs with several other scientific publications on this matter. Being unique in many aspects and dimensions, the project has indeed evolved and expanded, ripping heavily and getting enriched from Deaf Aid's sphere and several years of expertise in Deaf Youth related issues. The project design incorporates data driven critical thinking and practical case scenario, a fact that ensures the training programs are not only designed to suit the needs of the target beneficiaries but are

equally highly competitive and specially delivered, so that in the midway and at the end they acquire education, pursue a career and live a life that is comparable to that of their hearing peers.

The hallmark of this unique and distinctive program, is that it encompasses of the seven domains of access to learning plus: physical and emotional well being; cultural and arts; literacy and communication; learning approaches and cognition; numeracy and mathematics; science and technology. The teaching processes embrace pragmatic approaches using sign language as the medium of instruction to the trainees. The teachings and instructions are personalized, focused and practical, with the Cisco simulation materials providing a niche for easy delivery to the interest of the trainees. The program achieved as follows: 100 deaf youth annually enrolled in training programs; 100 deaf youth annually graduate in IT faculties; IT concepts signs developed to support effective delivery of trainings; 100 deaf youth get internship opportunities to sharpen their skills on annual basis.

In my opinion, DeafAid is making an important contribution to the communities addressed in Nairobi (and other parts of Kenya). One of its strengths is that The Deaf Aid programs are built within Rights Based approach to intervention and are effectively aligned and mainstreamed within the fundamental principles and objectives of UN charter on persons with disability, the universal Declaration of Human Rights and other general charters of UN and its special agencies and the relevant Kenyan laws and policy frameworks towards the goal of equalization of opportunities and full participation in society by the Deaf Children, Youth and their families and community at large. The hallmark of this is that every particular intervention was designed to meet a particular fundamental right and as a fundamental ingredient of an effective right based advocacy strategy. A critical look at the ESP and DYEP programs in particular and their design frameworks, their intent to enhance the Physical well being; Social, Economic and Cultural; Literacy and Communication; Learning Approaches and Cognition; Numeracy and Mathematics and Science and Technology among the deaf children and youth as

proposed by the Learning Metrics Task Force⁵⁹ is strongly pronounced. It is also noticeable that Deaf Aid works with relevant stakeholders within the thematic areas of Education, Health Care and Socio-economic empowerment in its programs. Key among these collaborative institutions is the government of Kenya and in particular the Ministry of Education (MoE). Thirdly, the programs and projects implemented had the focused on the needs that existed and to a large extent met the needs of the beneficiaries. The program beneficiaries acknowledge with fairly high level of satisfaction and identify with the projects results and impacts. Another remarkable positive finding was the Kenya Sign Language training for the parents that is fundamental to enabled parents to have effective participative involvement in their children's development and education.

2. Saint Martin-CSA

In 1997, don Gabriele, a young priest in Nyahururu parish, was asked to bless a home in a rural village. While blessing the house with its people, animals and property, the priest bumped into Thomas a man with mental and physical disabilities, who was sitting on a dirty floor behind a door. This unexpected encounter became a turning point with far reaching implications: how was it possible, the priest asked himself, that he had been requested to bless even the animals but not that very needy human being who seemed to have been neglected and forgotten and who was considered insignificant in the house. He wondered if, as Christians they neglected some of the core duties in society. Don Gabriele, then, decided that he could not stand by and watch the situation without doing anything. It was necessary to find a solution: a new home for Thomas, a place where he could be respected and loved. In response to these questions a group of volunteer parishioners was mobilized to start a Community Programme for People with Disabilities. Unfortunately, Thomas himself would never benefit from the initiative. He

⁵⁹ The UIS and the Center for Universal Education (CUE) at Brookings have joined efforts to convene the Learning Metrics Task Force (LMTF), which is working to improve the learning outcomes of all children and youth by strengthening assessment systems and the use of assessment data. Available at <http://www.uis.unesco.org/Education/Pages/learning-metrics-task-force.aspx>

died a few weeks after the meeting with the priest. However Thomas did not die in vain: he inspired this group of volunteers to dedicate themselves to the people with disabilities in the community. It was later launched a census to identify how many people with disabilities lived in the community, as in the Parish of Nyahururu they were aware of only a dozen cases. In the following months the volunteers identified more than a thousand people with disabilities living in conditions of human degradation. As already underlined, in fact, these people and their families are excluded from social life, as persons with disabilities are considered a curse, a punishment for a very serious sin committed by a relative or an ancestor. This affects families so much that children with disabilities are hidden, ignored and even eliminated to protect the "honor" of the family. During the same year, a baby girl with disability died because of repeated sexual abuse. When volunteers reported to the police, they found out that they refused to deal with it, because the girl was a case not to be taken into account as she did not have civil and human rights. Therefore, a second group of volunteers was created: they fully devoted themselves to cases of serious human rights abuse.

This was the beginning of St. Martin-CSA. The committee of volunteers was going to take the whole community very far. They had to learn about disabilities, how these could be managed and with interventions appropriate for each case. But, first they had to find out how many people with disabilities were actually present in their parish. And surprisingly, after going to the churches on Sundays and creating awareness among the Christians, hundreds of children with disabilities were identified and registered. For many years these children had been hidden so well that nobody knew about their miserable existence. The same year, a second group of volunteers was mobilized to look into issues of violence in the society. Unfortunately violence had become a common phenomenon, the common response to any arising problem or disagreement. Even the volunteers, who went for the first seminars about Active Non-Violence had difficulty believing in the alternative ways of solving problems rather than violence. But soon after the seminar, they enthusiastically embarked on training sessions themselves to target groups within the communities and spread the methods of Active Non-Violence. In the early years, all activities were carried out by volunteers. There were no staff members and resources were very minimal. In the course of 1999 several offices of the

former Catholic Dispensary became available and an old Landover was bought to facilitate transport.

In 1999, there rose a need to formally register the activities of the volunteers as an organization. Saint Martin of Tours was chosen as the patron saint after whom the organization was named: is living example, his solidarity with the poor, and his non-violent lifestyle inspired many to emulate him. A new phase began in the development of the St. Martin, which focused on organization. It was apparent that there was enormous goodwill among the volunteers, but that there was not enough professionalism to make an impact. The heart had been developed, but the “head” had been neglected. During this period, structures, procedures and policies were put in place. Strategic plans were developed through participatory methodologies and work was implemented according to clearly spelt out objectives and targets, against which progress could be monitored and evaluated. At the beginning of this phase, two new community committees were constituted to address two other serious problems within the community: the street children in Nyahururu town, who were scavenging the garbage heaps, and the high number of HIV/AIDS related deaths. A number of food-for-work projects were also undertaken in response to a serious drought in the year 2000. By the year 2002, a Community Programme for Micro-Credit was established to economically empower the beneficiaries of the organization. In these years there was a rapid expansion of staff. The work, previously done only by volunteers, was now supported by employed workers on the payroll. This facilitated the training of more community volunteers and the implementation of work, which could not be done by volunteers, such as the running of the street children rehabilitation centers.

St. Martin has a philosophy, a set of beliefs and thoughts that address the behaviors and activities of all those who work there. The inspirations are taken from the Bible and the life of Jesus, so the spiritual formation is an integral part of all activities. Apart from the religious matter, St. Martin has a particular way of dealing with the problems in the community and this approach is working very well.

St. Martin does not directly target the vulnerable people in the community, the focus is on the ‘able’ people who have gifts, talents and resources, however small or great they may be which could be shared with the needy people around them. By involving these

people St. Martin indirectly cares for those who are vulnerable. For this reason the motto is: “Only through Community” (the written also appears on the entrance gate of the headquarters of the organization.). Solutions for problems of the beneficiaries are always found by the community and in the community itself. St. Martin believes that nobody is too poor to have something to offer: be it time, expertise, skills, finances, farm produce or other things. They also create awareness on the needs of the vulnerable and promote solidarity by mobilizing people to provide assistance where there is immediate need, such as for medical treatment or lack of food. There are also volunteers who work on the management level as committee members, where they give direction to the programmes. Others give free professional services such as doctors and lawyers. Each volunteer contributes according to his or her own strength and ability. For this reason, Saint Martin has a Community Mobilization Department to enhance community involvement in all programmes and co-ordinate all issues concerning community volunteers.

Only where the community falls short financially, will the organization raise funds from outside. Getting money from a donor organization would have been a ‘simple’ answer to the problem, but it would also have created dependency. Withdrawal of the donor support would automatically mean the closure of the school and would not have promoted the responsibility of the people. Besides the risk of dependency, it would also mean that they assumed that resources were not available locally; that the generosity within the community would not be sufficient. But Saint Martin trusts more the generosity of the local people. They believe that this experience allowed these severely handicapped children to accomplish an important mission: to change the hearts of the people of their village. Besides the available potential in the community, the beneficiaries themselves also have a potential. They have hidden talents and abilities, often overshadowed by many issues and problems, which overwhelm people and make them lose hope, self-esteem and belief in their capacity. Saint Martin aim is to bring out the best in every beneficiary and to make them realize that they can do something for themselves. In whatever the community undertakes with the beneficiaries, there must be a contribution from themselves (be it financial, time, or other possible ways) that will make people see that they are not helpless but that they have dignity and potential.

In 2009 Saint Martin started collaboration with L'Arche International and L'Arche Kenya was established. We currently have two homes (Effatha and Betania) and several workshops. In fact Marleen Crafts is also part of Saint Martin, which in 2002 was looking for a new way to support the community. Currently there are five workshops: leatherwork, woodcarving, cards, candles and bakery. The artisans are people who lack opportunities for stable incomes: people with disabilities, former street children, people with HIV/AIDS and survivors of violence. We are passionate about providing them with skills and incomes which allow them to build better lives for themselves and their families. Some of our artisans are people with intellectual disabilities and by creating beautiful crafts they have a chance to access occupational therapy.

In Effatha and Betania, people with intellectual disabilities live together with people without disabilities who come to assist and they live together all day every day. The family-like environments are supported by the local community who volunteer, visit and encourage the positive perception toward people with disabilities among the community. L'Arche is a place of welcome where people are transformed by an intense experience of community, relationships, disability and difference. "To live with" is different from "to do for". It does not simply mean go there twice a week to eat together, it means that people share everyday life; they create relationships of thanksgiving and interdependence.

During the past fifteen years, Saint Martin has developed several projects. For example, between 2005-2007 the Programme's 3-year strategic plan, which is being implemented in partnership with CUAMM⁶⁰ (the main funding partner). The goal of the programme was to increase capacity in the Community that can reduce incidences of disabilities and improve the social, medical and economic status of people with disabilities. During the period, the programme strengthened working relations with the community and other stakeholders in the medical and social rehabilitation of people with disabilities. Through this collaboration, 87 persons were linked to various learning institutions and 71 families were assisted to pay hospital bills and meet other needs.

⁶⁰Doctors with Africa CUAMM is the first NGO in the field of healthcare to be officially recognized in Italy. Currently it is the leading Italian organization engaged in Sub-Saharan Africa, working towards the promotion and safeguard of African population's health.

Continued awareness creation and capacity building in the community led to the establishment of one special school for mentally handicapped children within an existing public primary school.

Remarkable participation of community in the rehabilitation process through volunteers and Community rehabilitation workers was evident. This was made possible through a strategy in which programme staff focused more on empowering and motivating the volunteers and then reduced their involvement in follow-ups and home visit.

After the evaluation exercise, there was encouragement in that the various components of the programme were evaluated to be on the right track. The perception on disabilities was seen to be improving, from denial and unacceptability to acceptance and improved care for the disabled children. Parents in support groups for the disabled children started receiving loans from the savings and micro-credit programme. It was also found that the Traditional Birth Attendants were doing a commendable job in assisting expectant mothers who could not access maternity facilities, in this way preventing disabilities occurring at birth.

During the last two years, 43 Community volunteers underwent training on awareness creation and community mobilization. They were able to organize 19 awareness sessions and 2 open days on the needs of Children with Disabilities. 27 empowered Community Rehabilitation Workers offered basic rehabilitation services to an average of 90 children with disabilities in the community. 22 parents of children with disabilities were empowered through training on how to manage disabilities in their children. The technology of using old carton papers to create affordable aids for children with disabilities (Appropriate Paper Technology) grew a notch higher. A training on APT was offered by Cerebral Palsy Africa and a sharing forum on the same was organized by Disability in Wales and Africa. This has set rolling a new chapter of interesting activities that will grow into the future. 250 children with disabilities were socially accepted and integrated and 9 of them started economic empowerment activities. 900 other children with disabilities received treatments through physiotherapy clinics in the 21 outstations. 65 of them increased their level of physical independence and capacity to carry out Activities of Daily Living. 143 children with disabilities were placed in different learning institutions for learning and rehabilitation. 182 children were supported with

various Aids and appliances including those that were made out of used carton paper. 57 events were organized through community initiatives to raise resources which benefitted 25 children with disabilities.

3. Differences and similarities

As already analyzed, disability in Kenya is a major issue both in urban and in rural areas that cuts through all levels of society. Even though the Kenyan government has implemented several laws and policies for people with disabilities, majority of these individuals do not know their rights, privileges, and protections under the new laws and policies that are set in place. For these laws and policies to be effective, there has to be participation from individuals with disabilities from all over the nation. Currently, this has not happened. People with disabilities are still a marginalized group that have limited or no access to medical and rehabilitation services, education, and employment.

As expected the two zones have differences but also many similarities: if we take into account the Nairobi slums, access to services is not well secured as in the city center and this makes them very similar to many rural areas. For example, in rural areas as Nyahururu there is low toilet coverage, in Nairobi the coverage is higher but the toilet are very unsanitary. The situation gets worse in slums areas.

The main difficulties when working with people with disabilities in rural areas is reaching the place where they stay. A lot of children that need rehabilitation do not have a rehabilitation centre or a hospital near their houses and the parents have to take them by matatu or by pikipiki, but this costs money. Or they carry little child on their back, but when the child grows up this become impossible. Moreover, sometimes they live in very inconvenient zones that can e reached only with a motorbike.

In slum areas children often suffer from poor nutrition and health care, from inadequate water, sanitation, and shelter and live in families with an unstable income and limited opportunities. Food insecurity is growing among urban population, due also to migration from rural to urban parts of the country. On the other hand the situation is slightly better in rural areas (at least in Nyahururu) where people rely on agriculture can easily access food.

All these factors lead to social exclusion and inaccessibility to various fields of life especially education and health services which make the situation even worse

Despite the fact that KISE operators claimed to reach all areas of Nairobi and all the population, staff members said that because of lack of assessment services, parents often do not understand the condition of their child and they have no idea what exactly has caused the impairment. Some of them have never seen a doctor. Most of the assessment centers charge money which is not affordable for the majority of the parents. The main challenge almost all poor areas share is that the parents cannot afford any assistance like education and health services. They need to be trained and supported by professionals but they neither can afford nor do they know where to go for counseling. Further they are not able to pay for a special school which makes it difficult for the children to improve and develop skills.

As it is clear from my short description is that both organizations have a human rights-based approach founded on the conviction that each and every human being, by virtue of being human, is a holder of rights. Their programs are not designed only for charity or simple economic development, but it is a process of enabling and empowering those not enjoying their economic, social and civil rights to claim those rights. In particular, Saint Martin has a community-based rehabilitation approach focuses on enhancing the quality of life for people with disabilities and their families, meeting their basic needs, and ensuring inclusion and participation at socio-economic level. Its strategy involves working closely with persons with disabilities and their families to overcome physical and sociological barriers within their communities through a holistic approach to a person and their environment in the areas of health, education, livelihood, social inclusion, skill development and empowerment.

One of the main differences between the two organization (that maybe it is not due merely to geographical differences) is the staff resource: DeafAid during an evaluation report in 2013 found out that human resource capacity was quantitatively and technically insufficient in some areas of the programs and this had negative effects on the efficient and effective delivery of some projects. Equally it can have other negative effects on the part of some staff who have a heavy workload and who work overdrive to achieve results. For example, they had a lot of problems in the Kisii Youth Center where lack of

adequate number of staff has affected delivery of program targets. On the contrary, Saint Martin created a dense network of volunteers distributed throughout the territory that is critical to reach all the beneficiaries.

CONCLUSIONS

This work is the result of my analysis on the situation of human rights of people with disabilities in Kenya, with a particular attention on children and young people's education. My research was undertaken in four slums of Nairobi and in the rural area of Nyahururu. In order to understand the complexity of the situation I have focused on factors which limit their access to rights and their participation in all fields of social life. It was not possible to offer comprehensive or representative material because I had only access to a small number of people. However the chapters do present a wide range of factors, as well as experiences and issues, and from different perspectives, political, theoretical and personal. The stories raise questions not only about disability, but also about class, gender, race and ethnicity which I could not take into consideration because there is not enough space to concentrate on these specific topics. The perception of disability varies between societies and within ethnic groups. How people understand disability depends on many aspects, such as cultural, social and psychological ones. I underline that the category of disability is partly socially constructed, but is related both to private and public experiences meaning different things to different people. It could represent a catastrophe, a condition to be hidden, like in some families I visited, as well as a symbol of self-identity. The concept of "liminality" as well as "the social model" may also help to understand that disability is a concept that arises from society, rather than rooted and fixated in biology as the medical model postulates. People with disabilities experience a separation from society that has almost become as permanent as their physical condition.

Furthermore I have analyzed the international policy agenda to give an overview of political activism and the birth of association of people with disabilities. The history of disability studies made me understand which models exist and who pioneered the field. The disability movement varies from one extreme to another: First disability was associated with dependency, invalidity and tragedy, later it was defined in terms of social oppression, social relations and social barriers. Quoting Oliver, who was one of the first to realize that there was a need for a change in the perception of disability, the social model includes all things which hinder disabled people in participation in social

life from individual prejudices to institutional discrimination, from inaccessible buildings and transport to segregated education and employment. This model illustrated how social barriers limit the participation of people with disabilities in all cultures but it does not explain what it means to have a disability in modern society and how people experience their impairments. The rights-based perspective, which has been embraced by international development agencies, encourages to move away from the perception of people with disabilities as objects of sympathy and charity, to viewing them as citizens with rights that should be empowered to enjoy the full participation in society. However, the question remains: whether the adoption of the rights-based perspective actually translates to real and positive changes in the lives of disabled people, or the use of rights-based discourse may arise simply from the need to attract donor funding, rather than a real desire to challenge the power structures that lead to discrimination and marginalization.

Starting from the non-obvious proposition that every human being share the same rights, I tried to demonstrate how traditional beliefs, stigma and religion still influence the perception towards people with disabilities. Considering that Kenya has signed all the major international Covenants, the government cannot back out anymore and it must be sanctioned internationally for the failure to respect such agreements. Government should be aware to the real situation of these people and start doing something concrete rather than hide behind unconvincing legislative measures. Various barriers ranging from environmental, communication, social to economic, prevent persons with disability from attaining acceptable quality of life in Kenya. For instance, during the 2007/2008 post election violence in Kenya, persons with disability (some of them children) were helpless and as a result heavily bore the brunt of pathetic and human dignity degrading vices including forceful evictions, rape, sexual and gender based violence.

At this point it is clear that people with disabilities in Kenya like in most developing countries are a marginalized population and face problems as a result of their disability. Most have no access to education, health, employment or (re)habilitation and majority of them experience hardship as result of wide scale social, cultural and economic prejudices, stigmatization and more often abuse and violence. Attitudes and practices embedded in cultural believes, taboos, rites of passage, and religion create near

insurmountable obstacles to the participation of hearing impaired persons in social cultural activities. Additionally, deaf girl child and women are more marginalized due to their gender and disabilities. However, economic and social deprivation should no longer be considered the result of natural conditions ordained by God or fate, as has historically often been the case. People with disabilities are not the result of a sin, they are not victims of curse or bad fate and do not need to be witch crafted. The government should be the first to respect people's rights and advocate more for the inclusion of people with disabilities. But in Kenya, as in many other countries, this is not the case. Firstly, despite a strong constitutional framework, there is poor enforcement or weak monitoring to ensure their efficacy in protecting the rights of the deaf and social inclusion. Secondly, there is no form of sustainable social protection for people with disabilities which exacerbates the level of poverty that they encounter. Thirdly, the Ministry of Gender Women Affairs and Social Development is the lead government department for disability issues in Kenya. However, the services that they provide are based on a charity/welfare approach to disability issues, with demand for such services far outstripping supply.

Another issue is the problem of data collection because to change the nations commitment is dependent on the availability of data. Although Kenya has made progress on data collection it is nearly impossible, without political priority, to access vulnerable children who are hidden, living in urban slums or in rural areas far away from civilization. As I have already mentioned, in Kenya there are many causes of disability ranging from inhuman living conditions, to preventable diseases as well as genetic factors and lack of basic prenatal knowledge. No access to clean water, pollution, toxic substances or insecticides can lead to diseases and as a consequence to disabilities. But it needs to be stressed that the main cause is poverty. Lack of clean water, exposure to sewerage, exposure to insects, and other disease factors, as well as household crowding, lack of access to preventative or curative medical care are all responsible for high infections in low income areas of the country. The vicious circle of poverty makes schools not affordable for the majority of parents of children with disabilities: no access to education means no access to a satisfactory job, a decent future and a dignified life.

Even if there are some international NGOs that do supply services to persons with disability, their geographical coverage is very limited. Consequently, for the vast majority of these people, particularly those living in rural areas, there is little access to basic services whatsoever. Again, this situation compounds the level of social exclusion that they experience. There are a plethora of Disability Peoples Organizations that exist in Kenya, that operate at the national, counties and local levels. However, with a few notable exceptions, the vast majorities of DPOs which focuses on the people with disability have themselves adopted a charity/welfare approach to disability issues, and have little understanding of a rights-based agenda or the principles of the social model of disability.

As a matter of fact a lot of associations have a serious negative impact upon their ability to effectively lobby the Kenyan Government to implement a rights-based agenda to disability issues. In addition, the vast majorities of the leaders of the disability movement are based in urban areas, and have little comprehension of the issues encountered by disabled people living in rural communities.

Even though the Kenyan Government has enacted and enforced an anti-disability discrimination legislation and ratified the UN Convention on The Rights and Dignities of Persons with Disability and the UN Convention on the Rights of the Child, a lot remains to be done. First of all children with disabilities must be early identified, then rehabilitated and taken to schools appropriate for their special learning needs. Second, the youth with disabilities are imparted with appropriate skills to enable them access employment opportunities or start their own businesses. There is need to develop an effective and efficient administrative infrastructure for effective implementation and monitoring of relevant laws and policies that increase social inclusion of the children and youth with disabilities in society.

Data on access to Early Child Education is even disheartening. Normal children are having an undue advantage over their counterparts with disabilities when it comes to access to early child education. For a long time, Kenya has been faced with shortage of special teachers. There are only two public universities that offer training on special education at the undergraduate level, Kenyatta and Maseno Universities. Kenya Institute of Special Education (KISE) provides specialized training at diploma level to teachers

already trained to teach ordinary schools but with interest in special education. As a result, there is unmet demand for teachers trained on specialized education and most private and community based schools have to make do without these specialized trained lot as most KISE graduates are directly posted to public schools by the Kenya Teachers Service Commission (TSC). And even at the public schools there is still a huge demand with the teacher student ratio not meeting the international set standard of 1 teacher per every 12 students. Moreover, as already recommended by the Koech report, children with intellectual disabilities who do not sit academic examinations should be issued with national certificates so that they may have a basis of social, economic and political engagement with society.

As result of my interviews, the greatest barriers to inclusion are caused by society not by medical impairment: social stigma and negative parental attitudes to disability which may spring from religious and cultural beliefs play a crucial role. The analysis of socio-economic history shows that ignorance, neglect, superstition and fear are social factors that have exacerbated isolation of persons with disabilities. The government should promote awareness training programmes on the rights of people with disabilities through the media, workshops and Information, Education and Communication materials highlighting the skills, merit, abilities and contribution of Persons with disabilities in society. Public awareness on the rights of persons with disabilities should be mainstreamed and undertaken at all levels of education system. To do so, it is essential that Government realize that these people are also a part of society and that they have the same rights as others and that it is important to avoid their invisibility because disability is not inability.

In conclusion, Kenya is still a distant from realizing the benefits of full implementation of UNCRPD which covers the whole range of civil, political, economic, social and cultural rights, including the right to education, work, health, justice, life, independent living, personal mobility and participation in recreational activities. Evidently, there are critical issues that Kenya needs to address in order to provide services to deaf and hard on hearing children and youth. The government, the development partners, international and national NGOs with interests on disability issues and the DPOs and communities must work in unanimity and embrace collaborative goal programming and

implementation that will ensure that all the disadvantages faced by these children and youth are eliminated through a right based approach as cherished by the principles and objectives of the UNCRPD, the Kenyan Constitution, the enabling legislations and socioeconomic development projects.

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TABLE 1

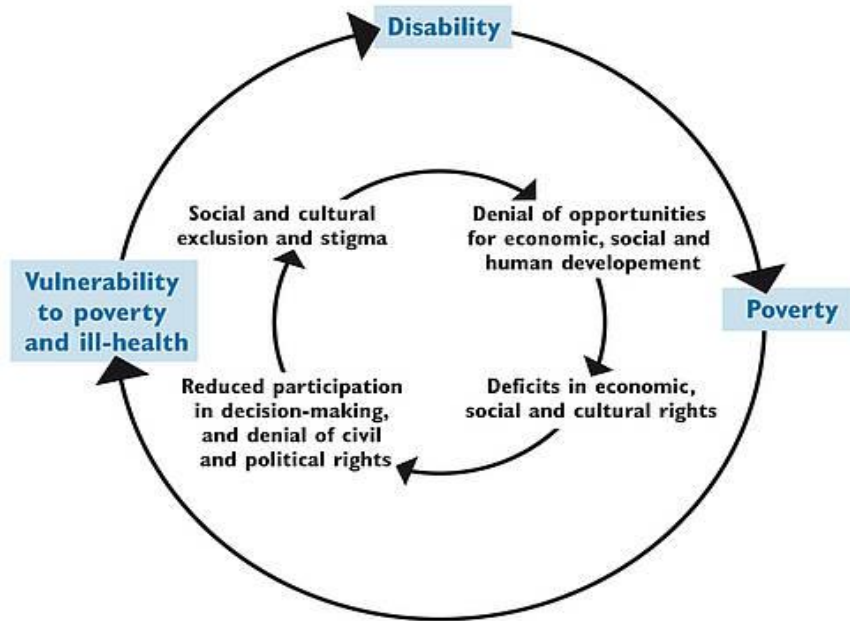


TABLE 2

Diagram 1: Relationship between the characteristics of poverty and disability

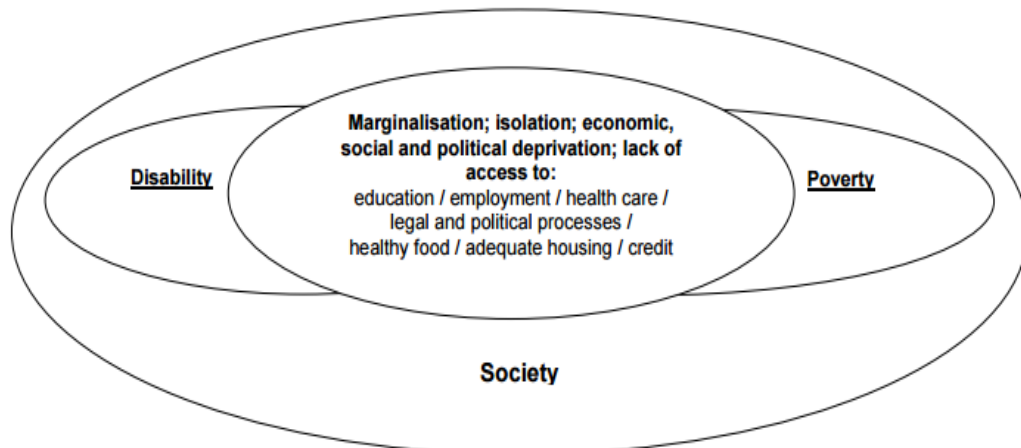


TABLE 3

Interview questions

What is your name? And your son/daughter's?

(I asked names only to break the ice and make them feel more comfortable. I did not use any name in the case study)

What is your age? What is his/her age?

What is your marital status?

What is the highest level of education you received?

What is your occupation?

What is your religion?

How many people stay in your household?

What type of disability does your son/daughter have?

What caused this disability?

Describe how his/her disability affects your everyday life.

Would your daily activities be different if he/she did not have a disability?

What are his /her disability needs?

Where do you get health services? How do you get there?

What type of services for your child have you received in the past? And today?

Do you pay for the health services you receive? If so, are you able to pay the fees?

Does anything prevent or discourage you from seeking health services?

Have you ever been to a counselor or social worker?

Have you ever tried traditional medicine? If so, what happened? What was the reasoning behind using traditional medicine?

Is there any educational or employment opportunities for persons with disabilities in this community?

What services should be offered in this community for persons with disabilities?

How are you and your son/daughter treated by your family?

Have you ever been hid, isolated, or abused in any way?

How are you treated in the community?

Have your son/daughter ever been teased or called names?

Are you registered with the National Council for Persons with Disability?

Do persons with disabilities have special rights and privileges granted by the Kenya Constitution or any other national or international law?

Interviews with teachers

What is your name? And how old are you?

For how long have you been teaching? How long in special schools?

What do you think about curriculum and examinations?

How can they be implemented?

Do you understand the term “Reasonable accommodation”? What it stands for?

Do you think that inclusive approach is the best method?

Are schools inclusive for children with disabilities?

In your opinion, how are children with disabilities treated in the community?

Is there any educational or employment opportunities for persons with disabilities in the community?

What services should be offered for persons with disabilities?

Do persons with disabilities have special rights and privileges granted by the Kenya Constitution or any other national or international law?

RIASSUNTO

Il mio lavoro di tesi si basa sulla mia esperienza personale in Kenya e nasce durante uno dei viaggi che ho svolto nel paese africano durante il quale mi sono imbattuta nella campagna chiamata "Nessuno escluso" portata avanti da World Friends e CISP per combattere la difficile situazione che affrontano le madri dei bambini disabili che vivono nelle baraccopoli di Nairobi e per sostenere l'inclusione sociale di questi bambini. A questo scopo è stato realizzato anche un video chiamato "Rifiuta la Discriminazione", una docu-fiction che ha per protagoniste alcune madri di bambini con disabilità le quali raccontano la propria esperienza, le difficoltà che ogni giorno devono superare, le speranze che nutrono per un futuro migliore per i propri figli. Da qui è iniziato il mio interesse per l'argomento. La questione della disabilità è ancora più complessa e problematica per chi vive in un paese africano e soprattutto nelle zone più degradate di una metropoli africana. La vita già difficile di queste persone viene molto influenzata dalla nascita di un bambino con disabilità. È da queste premesse e dalla mia esperienza diretta che si sviluppa un lavoro di ricerca che ha lo scopo di mettere in luce le condizioni delle persone con disabilità in Kenya, con una particolare attenzione ai bambini, di dare voce a chi non ce l'ha e di portare fuori dal Kenya delle problematiche che influenzano e condizionano le vite di milioni di persone.

Il lavoro è suddiviso in cinque capitoli. Il primo capitolo offre una panoramica storica, sociale ed economica del paese. Ho ritenuto rilevante anche inserire una piccola parte sulle credenze tradizionali in quanto sono molti forti nel paese e rivestono un'importanza significativa, soprattutto nel momento in cui si affronta la tematica della disabilità. Infatti, le credenze tradizionali influenzano notevolmente il pensiero della popolazione (soprattutto quella che vive nelle zone rurali) quando si tratta di dare una spiegazione alle cause della disabilità e le forze che fanno sì che una famiglia ne sia "colpita": si parla infatti di peccato, di maledizione o altre colpe imputabili alla madre o ad un membro della famiglia; anche ridere di una persona con disabilità può far incorrere nella disgrazia di avere un figlio o una figlia con lo stesso problema. È un elemento da tenere in considerazione quando ci si rivolge ad una determinata parte della popolazione ed anche in virtù del fatto che il Kenya è un paese fortemente religioso. Questo capitolo contiene, inoltre, una breve descrizione della storia politica recente del

paese e del contesto nel quale sono nate le prime associazioni di persone con disabilità. Vengono descritte brevemente anche le misure che il governo ha deciso di mettere in atto per il futuro (la cosiddetta “Visione 2030”) in cui il governo si impegna per indirizzare gli investimenti pubblici verso obiettivi prioritari dal punto di vista economico-sociale, come la creazione di una rete adeguata di infrastrutture per i trasporti, per l’energia e per l’accessibilità all’acqua potabile. Inoltre, ho descritto brevemente le aree critiche che ho visitato e che sono molto significative per il lavoro di ricerca che ho svolto: si tratta delle slums di Nairobi e della zona rurale di Nyahururu. In particolare, Nairobi è considerata il cuore economico e politico dell’Africa orientale ed è il luogo dove sono più forti ed evidenti le problematiche economiche e sociali di questa parte del continente, dove si toccano con mano le disparità tra classi sociali, con una crescita rapida della classe media a discapito di chi vive ancora in una povertà estrema. Queste disparità hanno delle conseguenze ancora più svantaggiose per chi vive in condizioni di disabilità.

Il secondo capitolo illustra i differenti modi di parlare di disabilità e di darne una definizione. È indubbio che il linguaggio esprime la cultura di una società ed è indicativo degli atteggiamenti che al suo interno si assumono rispetto a specifiche rappresentazioni della realtà. Per questo motivo, ho messo in evidenza come definizioni inadeguate o irrispettose possano far percepire all’individuo a cui si riferiscono un senso di esclusione ed incapacità, creando una vera e propria barriera al suo inserimento nella società. È pur vero che molte associazioni di persone con disabilità accettano il termine disabile o con altri nomi “non politicamente corretti”. Anche tra i miei intervistati, molti hanno espresso indifferenza nell’uso del linguaggio e percepito un velo di ipocrisia nel voler adottare a tutti i costi un linguaggio appropriato e rispettoso, senza assicurarsi che, nella pratica, i loro diritti non vengano violati ogni giorno. Ho voluto evidenziare ed analizzare anche altri aspetti strettamente legati al problema della disabilità, tra cui la povertà, e come questi aspetti si intersecano e si influenzano tra loro. L’aumento della disabilità è infatti associato a tassi elevati di analfabetismo, stato nutrizionale carente, bassi livelli di vaccinazione, basso peso alla nascita, problemi durante il parto, elevato tasso di disoccupazione e sottoccupazione. Inoltre, le persone con disabilità entrano in un circolo vizioso che le portano a essere tra le più povere del pianeta, con un tenore di vita di gran lunga inferiore rispetto a quello della popolazione “normodotata”. A soffrire

in modo particolare per le conseguenze sociali della disabilità sono soprattutto le donne e i bambini. Le prime subiscono una doppia discriminazione, correndo spesso il rischio di essere vittime di abusi sessuali. I bambini sono spesso considerati socialmente inutili e sono respinti dalla stessa famiglia d'origine; restano privi di istruzione scolastica, anche perché le scuole sono spesso lontane dal luogo di residenza e quindi non accessibili. Un altro tema centrale è quello della stigmatizzazione. Secondo Goffman che per primo ha definito il termine "stigma", esso costituisce una frattura tra l'identità sociale virtuale e l'identità sociale attuale, tra quello che è socialmente accettato e ciò che è considerato diverso. È qualcosa di profondamente radicato che necessita di un cambiamento culturale, di linguaggi e di attenzioni che esige la convinta adesione di ognuno ed in particolare dei media e degli esponenti politici. È stato di fondamentale importanza anche analizzare i diversi modelli di concezione della disabilità. Si parte dal modello individuale o medico che concepisce la disabilità come un deficit corporeo, psichico o mentale che colpisce una persona, limitandone la partecipazione sociale. Questo modello segue una logica di causa-effetto: una malattia o un trauma provoca un deficit nell'organismo, a cui consegue l'incapacità di fare determinate cose, la quale produce uno svantaggio sociale o un handicap. Secondo questo approccio, la disabilità deriva quindi chiaramente da un difetto di un individuo. Dal rifiuto di questo modello, si è sviluppato a partire dagli anni '60-'70 il modello sociale che interpreta la disabilità come conseguenza di fattori sociali: la base concettuale è la distinzione tra "menomazione" (condizione fisica dell'individuo) e "disabilità" (imposta dalla collettività). Oliver – uno tra i maggiori teorici del modello sociale - non nega il "problema" della disabilità ma lo colloca all'interno della società: non sono le limitazioni individuali a generare il "problema" bensì il fallimento della società a provvedere con servizi appropriati ai bisogni e alle necessità delle persone con disabilità. Infine si arriva al modello basato sui diritti umani. Il limite non è solo della persona con disabilità, ma è dell'intera realtà sociale che non promuove diritti di cittadinanza per tutti. La disabilità viene considerata una condizione da cui partire per fronteggiare le difficoltà, non un limite invalicabile per una vita autonoma. L'approccio alla tutela dei diritti umani è basato sull'empowerment delle capacità della persona. Tuttavia una questione rimane aperta: non è sempre chiaro se l'adozione di una prospettiva basata sui diritti umani si traduca in un reale e positivo cambiamento nella

vita delle persone con disabilità, o questo sia solo un modo per attirare donatori, piuttosto che un reale cambiamento dei giochi di potere che quasi sempre portano alla discriminazione e alla marginalizzazione.

Il terzo capitolo affronta in maniera ampia l'apparato legislativo relativo ai diritti delle persone con disabilità sia a livello internazionale che regionale che nazionale. Ho inserito anche un'analisi del rapporto (l'unico) presentato nel 2011 dal governo keniano sull'implementazione della Convenzione sui Diritti delle Persone con Disabilità ratificata nel 2008. La Commissione riconosce che il Kenya ha fatto diversi progressi riguardo la promozione dei diritti delle persone con disabilità, ma rileva la necessità di adottare misure concrete e corrispondenti alle reali esigenze della popolazione. In più questo capitolo si focalizza sulle nozioni di vivere indipendente (avere autonomia) e di capacità giuridica delle persone con disabilità. La discriminazione che colpisce in questo caso le persone con disabilità mentale finisce per negare loro tutti i diritti civili, politici, economici, sociali e culturali.

Il quarto capitolo è incentrato sul diritto all'educazione dei bambini ed in particolare l'accesso all'educazione dei bambini con disabilità o con necessità educative speciali. La prima cosa da tener presente è che, ufficialmente, la definizione di educazione si trova nella Dichiarazione Universale dei Diritti Umani del 1948, articolo 26. Dall'analisi di questo articolo, si passa all'indagine del sistema educativo keniano e quali sono stati i suoi sviluppi dalla colonizzazione fino ai nostri giorni. I sistemi e pratiche educative coloniali avevano il solo scopo di instillare la disciplina, la cultura e la conoscenza britannica nei bambini africani. Pertanto, le pratiche tradizionali erano considerate primitive e l'educazione coloniale mirava ad estinguerle. Sono gli anni in cui si iniziano ad adottare le divise in stile occidentale e l'inglese come lingua di insegnamento. Quando il Kenya ha ottenuto l'indipendenza nel 1963 è iniziata una campagna per l'istruzione primaria gratuita. L'aumento massiccio delle iscrizioni alla scuola pubblica ha mandato nel caos l'organizzazione e l'offerta scolastica; se a questo si aggiungono l'assenteismo di molti insegnanti, lo scarso potere contrattuale delle famiglie e l'allontanamento e il disinteresse dei genitori si può notare come il nobile principio della gratuità, quando non pienamente compreso, diventi una fonte di fallimento educativo. A questo proposito, è interessante porre l'attenzione sul fatto che dal 2003, in modo apparentemente contraddittorio, le iscrizioni alle scuole private sono aumentate dal 4,4%

al 10,5%. Nel 1967, insieme all'Uganda e alla Tanzania, con le quali formava la Comunità dell'Africa Orientale (East African Community), il Kenya ha adottato un sistema definito 7-4-2-3, che ha mantenuto fino al 1985 anno in cui l'allora presidente Daniel arap Moi ha inserito il nuovo sistema 8-4-4 ancora in vigore (8 anni di educazione primaria, 4 anni di educazione secondaria e 4 anni di università). L'impronta britannica nel sistema educativo keniano è molto forte e anche la lingua inglese resta un importante veicolo di codici culturali che non sempre però riescono ad amalgamarsi in modo armonico con le molteplici differenze antropologiche e sociali presenti nel Paese. Per quanto riguarda l'educazione dei bambini con disabilità, ho ritenuto importante fare una distinzione tra i termini speciale, integrato e inclusivo e poi focalizzarmi su quello che dovrebbe essere l'obiettivo finale, cioè la piena inclusione dei bambini con disabilità nel sistema educativo keniano.

Infine il quinto capitolo è un caso studio che si basa sulle interviste a genitori, comunità ed insegnanti condotte tra aprile e maggio 2015. Queste interviste, che sono risultate utili durante tutta la stesura della tesi, sono state condotte grazie all'aiuto e all'assistenza delle associazioni World Friends, DeafAid e Saint Martin – CSA. Di fondamentale rilevanza è stata la visita al Saint Martin durante la quale ho potuto toccare con mano cosa vuol dire vivere e lavorare con persone con disabilità, quanto il “lavoro di squadra” sia importante e quanto sia essenziale costruire una rete capillare di persone per poter lavorare in zone spesso impervie ed irraggiungibili. Il lavoro del St. Martin si basa su una forte rete di sensibilizzazione e formazione specifica fatta sia dagli oltre settanta dipendenti sia dai volontari nei villaggi, nelle chiese, nelle scuole e nelle carceri. La prospettiva non è quella dell'assistenzialismo, bensì dell'empowerment, dello sviluppo locale puntando sul senso di comunità, della condivisione e dell'accoglienza delle differenze fino a farle diventare peculiarità. Lo spirito ed i valori del St. Martin sono racchiusi nel motto dell'ente: *Only through Community* (Solo attraverso la comunità), scritta che appare anche sul cancello d'entrata della sede dell'organizzazione. Le persone vulnerabili sono una risorsa per la collettività e non un problema; sono membri importanti e di conseguenza la comunità ha la responsabilità di assisterli e coinvolgerli. Le risorse che servono a quest'assistenza si trovano nella comunità stessa, così come le soluzioni ai problemi dei beneficiari. Questo approccio viene portato avanti nella

convinzione che, nella condivisione, tutte le persone, ricche e povere, forti e deboli, potranno trarne beneficio e crescere nella loro più piena potenzialità.

Come illustrato dalla mia analisi, le problematiche riguardanti la disabilità, la povertà e la tutela dei diritti umani sono molteplici e complesse. Le soluzioni, viste da una prospettiva occidentale, sembrerebbero semplici e scontate, ma non è così in un paese come il Kenya: un paese che sta crescendo molto velocemente e in cui le risorse economiche non sono così scarse; ma anche un paese profondamente corrotto e per certi versi smarrito, dove le risorse che bisognerebbe impiegare in riforme sociali radicali si perdono nelle tasche dei politici, delle forze dell'ordine e nell'omertà degli organismi di controllo. Per questo motivo, nonostante un forte sistema costituzionale i sistemi di controllo e monitoraggio sull'effettiva attuazione delle leggi sono molto carenti. A questo si aggiunge la mancanza di un sistema di protezione sociale adeguato e sostenibile che permetta di sradicare la povertà dei gruppi più vulnerabili.

In un simile contesto, anche le ONG internazionali fanno fatica a lavorare. Anche se ne esistono svariate che forniscono servizi alle persone con disabilità, la loro copertura geografica è molto limitata. Di conseguenza, per la stragrande maggioranza di queste persone, in particolare quelle che vivono in zone rurali, è scarsissimo l'accesso ai servizi di base di qualsiasi genere. Ancora una volta, questa situazione aggrava il livello di esclusione sociale che le persone con disabilità sperimentano. Ci sono, inoltre, una miriade di piccole e medie organizzazioni di persone con disabilità esistenti in Kenya, che operano sia a livello nazionale che a livello locale. Tuttavia, salvo qualche eccezione, la maggioranza di queste organizzazioni ha adottato un approccio assistenziale o improntato alla beneficenza e hanno una scarsa conoscenza di programmi basati sui diritti umani o ai principi del modello sociale di disabilità.

Anche se il governo keniano ha rafforzato la legislazione relativa alla discriminazione contro le persone con disabilità e ha ratificato le Convenzioni sui diritti delle persone con disabilità e sui diritti dell'infanzia ha molta strada da fare per l'inclusione delle persone con disabilità nella società e per l'accesso dei bambini all'educazione. Innanzitutto, ci sarebbe bisogno di un programma per l'identificazione precoce dei bambini con disabilità per permetterne la riabilitazione e il loro inserimento in scuole in grado di rispondere ai loro bisogni. In secondo luogo, i ragazzi e gli adolescenti con disabilità dovrebbero ricevere competenze adeguate

necessarie al loro inserimento nel mondo del lavoro e ad un conseguente (anche minimo) auto-sostentamento. Infine, ci sarebbe bisogno di rafforzare l'apparato amministrativo affinché si facciano delle leggi mirate e che soprattutto queste vengano rispettate e messe in atto senza indugi. Il governo dovrebbe creare dei programmi di sensibilizzazione specifici rivolti alla popolazione e diffondere a livello pubblico la consapevolezza sui diritti delle persone con disabilità. In questo senso, un elemento chiave deve essere il riconoscimento che l'esclusione e la segregazione delle persone con disabilità sono determinate dalla logica dei pregiudizi e delle presunzioni sulla disabilità, logiche che purtroppo molto spesso sono alla base anche delle decisioni politiche e sociali che producono discriminazione. Inoltre, bisogna far comprendere chiaramente che le barriere, gli ostacoli e le disparità di trattamento nei confronti delle persone con disabilità sono causate dalla società, la quale, dimenticando che vi sono persone che comunicano senza parlare, che si muovono senza l'uso degli arti, che leggono a occhi chiusi, diviene responsabile della loro eliminazione. La Convenzione sui diritti delle persone con disabilità sottolinea che è la società a doversi riabilitare, offrendo pari opportunità e non discriminazione a tutti i cittadini. Come risulta evidente anche dalle mie interviste, i maggiori ostacoli all'inclusione sono causati dall'ambiente, non dalla disabilità in sé: lo stigma sociale e gli atteggiamenti negativi (anche dei genitori) che possono scaturire da credenze religiose e culturali giocano un ruolo cruciale. L'analisi socio-economica e culturale del paese mostra che l'ignoranza, la negligenza, la superstizione e la paura sono fattori sociali che hanno aggravato l'isolamento delle persone con disabilità e che sono difficili da scardinare.

Vi è un urgente bisogno di educazione ai diritti umani per i genitori e gli insegnanti di bambini con disabilità come strategia principale per ridurre al minimo le violazioni dei diritti umani. Particolare attenzione dovrebbe essere data ai mezzi per segnalare ogni forma di violazione dei diritti umani. Per fare ciò, è essenziale che governo si renda conto per primo che queste persone sono parte integrante della società, che godono degli stessi diritti e che è importante evitare la loro invisibilità, perché la disabilità non è inabilità.