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Introduction

Nairobi, a city with a population of 2, 143, 354 people¹ in the southwest of Kenya filled me with fear when I started to think about going there to work in slum areas. I had seen so many pictures and websites about the country which seemed to be so exotic and exciting. My whole life I was fascinated by African countries and their cultures. Even at school I remember writing many reports about Africa. When I made my diploma for special education teacher, in my training period I prepared lessons about various cultures in Africa. That is why I am really interested in the lives of African children and young people. Furthermore I want to combine my two professions because it is important to keep in mind that social and cultural aspects are as important as the pedagogical view of children and young people with special needs. I write my MA Thesis in English because on the one hand my interviews, discussions and most of the literature were written in English and on the other hand I will send a copy to the workers of the project so that they will get an idea what has already been done in the field of “disability studies” internationally.

Before my Stefan and I decided to go to Kenya we contacted the chairman of an organization which pretended to care for children and young people with disabilities. We got to know him through a colleague of the department of social and cultural anthropology in Vienna. He seemed to be very decent but soon we realized that his organization was already gone before we arrived there but he had never mentioned this until we stayed in his house for about a few days. When we arrived at the Kenyatta Airport this chairman and his daughter picked us up and we took a taxi to his place in a suburb called Dagoretti district. On the way to his house at 5 o'clock in the morning we saw hundreds of people walking to their jobs because they could not afford any transport. It was winter in Nairobi and the streets were wet and slippery. We crossed various slum areas, dirty, poor, and frightening.

When we had contact to the chairman per e-mail from Austria, he told us that we could stay at his house but we had no idea what it was like until we arrived there. After half an hour's travel by car we reached his house in a slum area where we got to know his family- his wife and five children. He had never mentioned his family of seven people and that he was living in a slum area. Therefore it was a really new situation because we stayed with seven people in a small terraced house in a slum area. Furthermore it was difficult to move around alone as white people. The first two days we visited cyber cafés to contact our families. Because of the rain season the streets were slippery and it was not easy to move forward by walking and by bus. The next three days the

¹ cf. KNBS f: <http://www.cbs.go.ke/>

chairman took us to KISE, and to the city center to organize some working papers for volunteering in his organization. It did not work and we made a small sightseeing tour through Nairobi. On the next day we went to the same office and received the papers. Until today we do not really understand what these papers were all about.

However after five days we realized that his organization was gone and that he tried to delay our stay at his place. The next few days we stayed with his family, went to the church grounds and I was educating the children. After nine days at his place we decided to move out to the city center. During these nine days he had never mentioned to us what was going on with his organization. Instead, without telling us why, he brought us to a Presbyterian church in Uthiru district nearly every day where a project runs by a community based organization who supports children and young people with special needs (CVO). At the beginning we thought it was his organization but it seemed really dubious because the people from the church did not really understand what we were doing at their place. Nevertheless during these days we got to know the people from CVO very well and started to support them in areas of parents' seminars about disability, a feeding programme which we supported by cooking fat, salt, etc., building a house and starting income generating activities by supporting them with materials. The money for those activities we took from donations which we had collected before we had gone to Kenya, actually for the organization which I mentioned before. Since then we worked with CVO and went on home visits with them. The members and we decided to quit the cooperation with the chairman because he got us into financial problems by bringing teachers for parents' seminars who charged a lot of money. After talking to different people we realized that he was only making money with children and young people with disabilities by taking snaps of them and raising funds which these people never got.

Anyway we moved to the city center and broke up any contact to the chairman because he tried to threaten us by telling that he could deport us. Actually we feared him but the members of the church really calmed us down and went along with us from the church to the bus station nearly every day until we felt safe again. After this strange experience which showed us how easy it was to found an organization, getting donations, without real existence, we were lucky to get to know these people from CVO, even by him- the chairman. The rest of our stay we went to the project CVO, in the sub location Kinoo, nearly every day. A few days Stefan and I worked with the children by teaching some mathematics and other subjects, we participated in parents' seminars, and we worked at the site to construct the house. Most of the time we went on "home visits" and drove around the city to talk and network with organizations for and of people with disabilities, with whom I made most of my interviews.

The home visits had been very important for my research because they offered me the possibility to talk to 38 families with 48 children with special needs. In my MA Thesis I want to concentrate on 24 children and young people with disabilities aged between 2 and 24 years. Nevertheless I will also use the data of all 48 children when I talk about parents' occupations, family sizes, problems with financing medication, basic needs and school enrollment.

These children and young people who suffer from marginalization and stigmata seem to be invisible but if you look closely you realize that although they live under really difficult circumstance they develop strategies to be seen. My main interest is how and why their needs are kept secret and hidden, how mainly private organizations and institutions empower them and how their situation is linked to poverty.

First of all I want to start with the field "disability studies". In my thesis I want to use the term "disability" and "impairment" and avoid handicap, retarded and disturbed because these words maintain negative attitudes among people with disabilities, and "disability" offers a way of understanding the issue in a social, economic, cultural, and individual way. When I talk about mentally challenged or mentally disabled without defining the condition of the child, I do not exactly know what has caused the mental impairment.

I want to describe the International policy agenda, the history of the field, as well as the "social model" of disability and the concept of "disability and liminality" to understand what has been and what is going on in the field internationally, and to give a theoretical framework to analyze the situation especially in developing countries, in particular the situation of children and young people, causes and consequences of their impairments.

After doing so I want to give a survey of the socio- economic and socio- cultural context of disability in Kenya. I want to include there the country profile, economic and political structures the health care system and also cultural and social aspects of defining disability in a developing country like Kenya.

The last chapter I want to write about education issues, challenges, and problems of accessibility to special schools, integration, and inclusive education. In the Appendix I will include institutions and projects who assist and empower people with disabilities in Kenya, especially the CBO which whom I have worked with.

Methodology

Now I want to give an overview of the methodology I have used for my research. 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 children with mental, physical and sensory impairments, as Ingstad commented that: *“... experiences and feelings of people to be explored, permitting and understanding of their lives not accessible by means of quantitative survey or other data collection techniques resulting in numerical information only.”*²

Based on the books by Ingstad and Whyte, *Disability and Culture 1995*, and by Priestley, *Disability and a Life Course Approach 2003*, I developed my interview guidelines. I chose a pluralism of methods to get my data based on participant observation in families, unstructured interviews with experts and the target group, literature research, media watch and a lot of profitable discussions with affected people and their guardians. The interviews were tape recorded and then transcribed.

There are three main questions I will focus on: in how far is the family able to care for a disabled family member; Factors like family size, parents, single mothers, labor situation, and family resources are important. Second it is important if disabled family members participate in social life especially within institutions like employment, school, family, and the community as a whole. The final question is the existence of special institutions, programmes and organizations. Who can benefit and has access to such institutions and why are they necessary.³

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.⁴

Moreover I have visited various institutions as e.g. special schools which I will describe in the appendix. My literature research, I have mostly done at the Kenya Institute for Special Education (KISE) in Nairobi because I wanted to include East African and Kenyan scholars. On the one hand criteria, concepts and practices of research in developing countries are based on the guidelines of

² Robson, Evans: <http://siteresources.worldbank.org...> p.13

³ cf. Ingstad, Whyte 1995:14,15

⁴ cf. Robson, Evans: <http://siteresources.worldbank.org...> p.13

the West which maintains Western power relationships in science. On the other hand people from developing countries exemplify as items for research of scholars from the developed world. Therefore western scholars have to be aware that they maintain power relations in the production of knowledge. That is why participation of local scholars and the objectives of research are included.⁵

I have talked to several people, including the executive director of the organization UDEK, the executive officer of APDK, a social worker from the project “Food for the hungry”, a physical therapist from Dagoretti Children’s Centre, members of the CVO, members of the KISE and three young people with disabilities.

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. Unfortunately in some cases we did not have much time to talk to the families because the project wanted to assess as many children as possible to save time and money.

When we went on home visits we introduced ourselves as a project and explained that we were there to collect data on the circumstances in which the families who were already registered at CVO live, to get an idea of their needs and challenges. Therefore some questioned if the assessment of their situation could lead to any consequences for them and they were informed how the results are going to be used and if they will benefit in some way. In my situation the informants had many hopes that we can assist them and as I have mentioned the CVO has already met the needs of children with disabilities. In one case we decided to build a house for a grandmother with five orphans. Because the project members, actually most of the time eight people, Stefan and me, visited the families at their places we got an idea of their general living conditions and we had the opportunity to assess the situation of the total household. Nevertheless visiting people at their homes is not without a disadvantage because a large crowd of people can lead to discomfort. That is why in most cases just one project member and I talked to the parents.

The area, where the church ground is based is called Kinoo Location in Kikuyu Division within Kabete Constituency. Within the home visits we visited the sub- locations (like small villages) namely Uthiru, Dagoretti, Kinoo, Shauri Yako, Baraniki, Dagotto, Gitaru, Kiuru, Gachui, Gichecheni, Muthiga, Kagondo, Rukubi, Muthure and Kagira.

⁵ cf. Albrecht in Albrecht, Weigt 1993:17

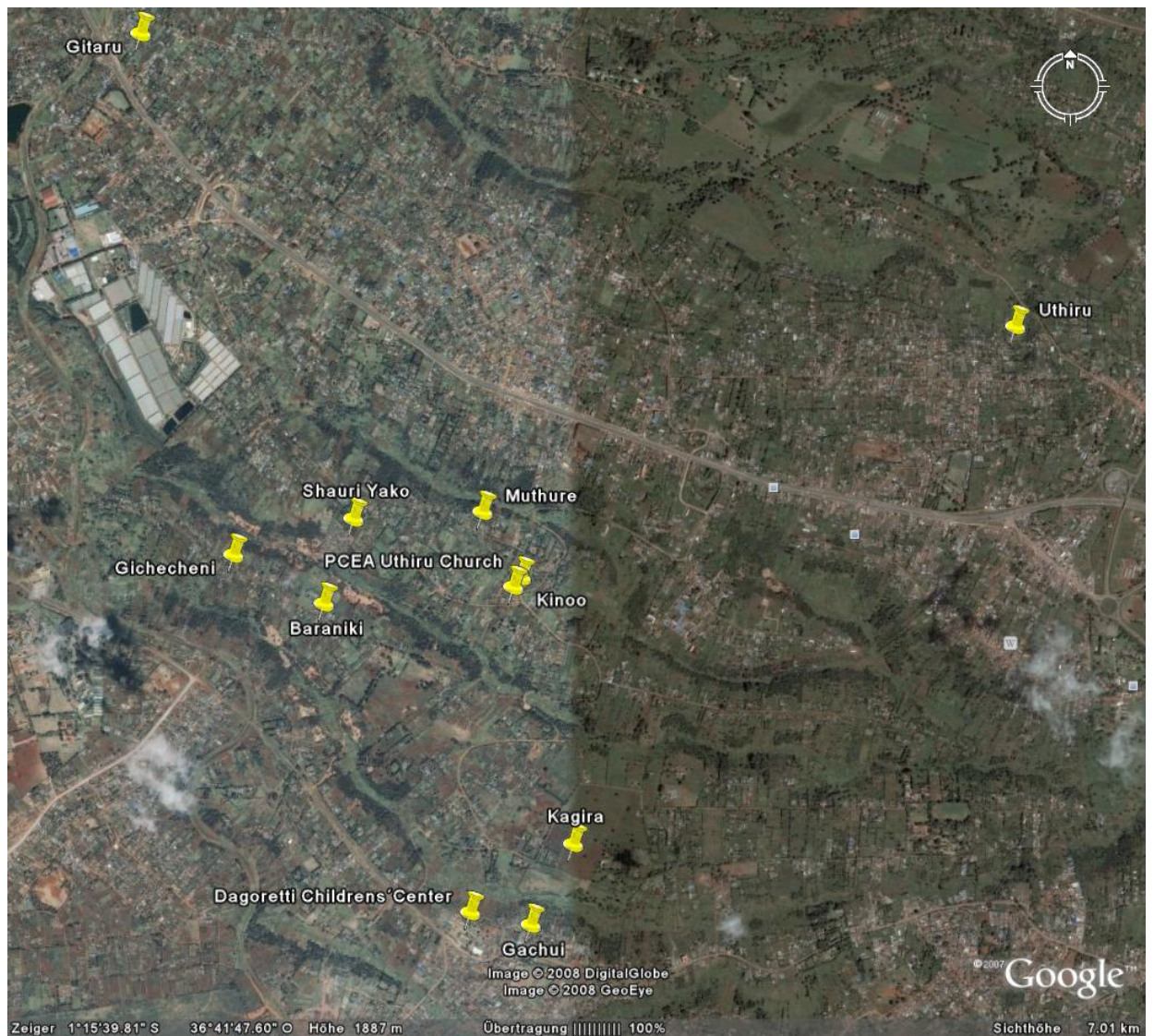
My study is representing a small area in the suburbs of Nairobi. In some areas we found only Kikuyus, the largest ethnic group in Kenya, in other areas we met e.g. Luos but I do not want to analyze the ethnic belonging in my research because it could never be representative for any ethnic group in Kenya. More important I think are the challenges families with disabled members face, without considering the ethnic belonging. I did not choose any ethnic group in particular but they were mainly Kikuyus around the communities which I have already mentioned. I got access by the project members who needed the data to analyze the situation on the ground. Therefore we supported each other to get the possible best information to assist the people in e.g. organizing wheelchairs, let the parents know that CVO is providing parents' seminars on the issues of disabilities etc. The identification was undertaken by CVO until June 2007. Different variables such as names of the child and his/her parents, age, sex, health status, family status, household members, siblings, parents occupation, location, expectations, report from doctors, child abilities, communication skills, talents etc.⁶ were our interview guide and furthermore some questions which I developed on my own.

We 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. We discovered 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.⁷ 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. The share of their life stories may also give a sense of empowerment because only if disabled people themselves can participate in planning and arranging their life situations in the present and future, empowerment can be achieved.⁸ Some informants were happy and thankful for being interviewed and some were tired of organizations because they had made the experience of frauds. To get that trust the parents' representatives explained what the CVO and I wanted to know and what we stood for.

⁶ see my thesis chapter 4.3 "The situation of families of children and young people with special needs in Nairobi area": form of CVO

⁷ see my thesis chapter 4.3.2 „Evaluation Home Visits“

⁸ cf. Freyhoff in Albrecht, Weigt 1993:106



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Abbreviations

ADA- Americans Disability Act

APDK - Association for the Physically Disabled of Kenya

CBO- Community Based Organization

CBM- Christoffel Blinden Mission

CBR- Community Based Rehabilitation

CVO- Christian Vision Organization

DANIDA- Danish International Development Agency

DPO- Disabled People's Organization

DSS- Department of Social Services

EARS- Educational Assessment and Resource Service

EFA- Education For All

ICF- International Classification of Functioning and Health

ICIDH- International Classification of Impairments, Disabilities and Handicaps

ICR- Industrial Rehabilitation Center

ILO- International Labor Office

KADU- Kenyan African Democratic Union

KANU- Kenyan African National Union

Kawe- Kenya Association for the Welfare of Epileptics

KIEP- Kenya Educational Integrated Programme

KISE - Kenya Institute for Special Education

KNAD- Kenya National Association of the Deaf

KSB- Kenyan Society for the Blind

KSDC- Kenyan Society for Deaf Children

KSMH- Kenya Society for the Mentally Handicapped

KSPH- Kenya Society of the Physically Handicapped

KUB- Kenyan Union of the Blind

MDG- Millennium Development Goals

MOEST- Ministry Of Education, Science, and Technology

NCPWD- National Council for Persons With Disabilities

NGO - Non Government Organization

OECD- Organization for Economic Co-operation and Development

PWDs- People with Disabilities

STDs- Sexual Transmitted Diseases

UDEK- United Disability Empowerment in Kenya
UN- United Nations
UDPK- United Disabled Persons Organization of Kenya
UNESCO- United Nations Educational, Scientific and Cultural Organization
UNICEF- United Nations Children's Fund
VSO- Volunteer Service Organization
WHO- World Health Organization

1. Defining disability

In general etymologically disability implies a loss of a needed competency or qualification, whereas inability describes lack of power.⁹

The term disability is widely used and it is likely to mean different things to different people. The translation of such a term into other languages puts it into different linguistic and cultural contexts. That is why people with *“similar biological characteristics might become more or less disabled depending on social and cultural circumstances.”*¹⁰

Therefore particular worldviews, especially those of how disabled people are seen belong to times, cultures and groups as communities who create the reality of people with disabilities. Thus it is important how we understand the relationship between the individual and the dominant culture. It is important to focus on how far disability is recognized as a problem, in what extent impairments hinder the achievement of social life.¹¹

The perception of disability varies between societies and even within ethnic groups. How disability is understood depends on cultural, social, and psychological structures in which it is embedded and how societies deal with it.¹² In the last few decades all, *“disparate conditions of bodily difference and dysfunction have been aggregated and standardized under a universalizing biomedically framed category called “disability”.*¹³

⁹ cf. Ingstad, Whyte 1995:7f

¹⁰ Priestley 2003:13

¹¹ cf. Corker 1998:8,10

¹² cf. Nicolaisen in Ingstad, Whyte 1995:39,52

¹³ Ingstad, Whyte 2007:213

Disability from a cultural point of view raises the question what it means in a certain society to be disabled and in how far is the status of a disabled person defined.¹⁴

In the Kenyan disability act 2003 disability is defined as: *“... physical, sensory, mental or other impairments, including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation.”*¹⁵

The WHO's classification of Functioning, Disability and Health (ICF model of functioning or ICIDH (International Classification of Impairments, Disabilities and Handicaps) 2001 is a framework to describe how people with disabilities live with their health condition. Furthermore environmental factors are included to describe body functions, activities and participation within body, individual and societal perspectives. Moreover the ICF is also looking beyond mortality and disease in the international statistical classification of diseases and related health problems.¹⁶

There are three levels of classifications: “Impairment”- biological and psychological dysfunctions, “disability”- a dysfunction of abilities in daily life activities, “handicap”- a dysfunction of the social role to participate in society life.¹⁷ Therefore the model includes both the individual and social aspects of disability. It is important to understand disability not only as an individual but as well as an interaction in a social group within the family and community.

Although the ICF gives a framework to analyze the situation, the social aspect “handicap” has not often been systematically used.¹⁸ That is why both the individual/medical and the social model are relevant in understanding the full consequences of disability because it is important to *“... give voice to an experience that medicine cannot describe.”*¹⁹

The ICF- model is constructed to be neutral on cultural aspects and other factors as gender, economic and social class. In other words it does not include the variety of responses to disability in different situations within different cultures.²⁰ The United Nations defines a person with disability as: *“The term persons with disabilities is used to apply to all persons with disabilities including those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others.”*²¹

¹⁴ cf. Devlieger in Ingstad, Whyte 1995:94

¹⁵ The PWDs Act 2003: No. 14 Article 2

¹⁶ cf. WHO a: <http://www.who.int/classifications...>

¹⁷ cf. Matthesius et al. 1995:5

¹⁸ cf. Matthesius et al. 1995:8

¹⁹ Thomas 2007:27

²⁰ cf. Grut, Ingstad 2007:19 <http://siteresources.worldbank.org...>

²¹ UN a: <http://www.un.org...>

The definitions from UN and WHO explain that disability is not simply a health issue because there is a complex interaction between social and cultural institutions and health conditions which influence the extent to which a person is actually disabled, or not able to do something, as Shakespeare commented that: *“... the experience of disabled people is dependent on social context, and differs in different cultures and at different times.”*²²

Therefore the category “disability” is socially constructed and it is an anthropological conundrum as Kohrman confirmed: *“how and why at the close of the last millennium some of the most powerful institutional artifacts of modernity- nation states- came to define, standardize, and medicalize aspects of human existence under and within a relatively new social category: that is, disability.”*²³

Disability is both an individual private and a public experience because as I have mentioned it means different things to different people. On the one hand it could present a catastrophe to be avoided, a shameful condition to be hidden, like in some families which I want to describe in my thesis. On the other hand it could be a source of empowerment and a symbol of self- identity and self- worth²⁴ like Salome Kimata from UDEK, a disabled woman who founded an organization for people with disabilities to empower them in various fields of life.

1.1 The international policy agenda

In 1975 the UN General Assembly made its first declaration on the rights of disabled persons. The UN proclaimed in 1981 as the international year of disabled persons²⁵ and 1982 the world programme of action concerning disabled persons followed. The decade from 1983- 1992 of disabled persons kept disability on an international level; African, Asian and Arab decades were declared. The Americans Disabilities Act (ADA) was established in 1990 followed by the national legislation in countries like Britain, Australia, Germany, Austria, Finland, Japan, and Hong Kong who adopted laws to prohibit discrimination on the basis of disability. Similar steps were taken by some developing countries like China, Brazil, the Philippines, South Africa, Malawi, and Uganda.²⁶

²² Shakespeare 2006:29

²³ Ingstad, Whyte 2007:213

²⁴ cf. Albrecht 2001:1

²⁵ cf. Priestley 2001:4

²⁶ cf. Ingstad, Whyte 2007:4

In the UN Decade of disabled people (1983-92)²⁷ a global meeting was held to develop a guiding philosophy to indicate the priorities for action in the years ahead. Draft outlines for the declaration on disability rights were developed but rejected because the (unofficial) reason was that one did not want the Universal Declaration of Human Rights to be mitigated by too many separate declarations for minority groups. The official version was that the existing human rights should guarantee persons with disabilities the same rights.²⁸ Anyway in 1985 the Universal Declaration of Human Rights started to include disabled people.

To create a legally binding convention on disability rights ran into difficulty and the UN adopted the standard rules on the equalization of opportunities for disabled persons in 1994. These rules address participation in eight specific fields of life: accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.²⁹ However this instrument had no legal enforcement mechanism. That is why disability rights organizations pursued demands for a convention, and in 2001 a Committee was established by the UN. In 2006 an agreement was reached on the text of a Convention to Protect the rights of persons with disabilities.

In 1995 the Danish council of organizations of disabled people commissioned an index to follow the implementation of the UN Rules but the results of the research of forty- six countries provided that the implementation will have a long way to go. An UN survey of 88 governments found out that 80 percent of states reformulate their ideas of disability in response to the UN Rules. Since the introduction of the UN Rules, consistently various states have introduced anti- discriminatory legislations.³⁰

The challenge is to see if and how the world has changed for the majority of disabled people and their families, living in a great variety of particular situations because the conditions of life for most people with disabilities may not be changing as fast as political awareness.³¹

²⁷ cf. Priestley 2001: 4

²⁸ cf. Ingstad, Whyte 2007: 237

²⁹ cf. Priestley 2001: 4f

³⁰ cf. Priestley 2001: 5

³¹ cf. Ingstad, Whyte 2007: 5

1.2 History of disability studies

Disability studies are an interdisciplinary and political science which has its origins in political analytics and disability movements from the 70ies.³² The field of disability studies has grown in the last decade and brought together many backgrounds and disciplines. Furthermore it challenges and enriches anthropology in how cultural circumstances (such as assumptions about personhood) and social ones (such as the existence of disability institutions) shape the meaning of disability in different local worlds.³³ Important are the different realities that constitute disability in different places like in my research in a developing country like Kenya. Disability studies deal with the relationship between individual experiences, between *“agency and structure, between embodied corporeality and objective social positioning, between differences and commonality.”*³⁴

I will discuss in my thesis whether disability is socially constructed or not. It is important that disabled people are not only objects of analysis but also subject of science and research. Their experiences and needs are put into the centre and become visible.³⁵

In the 1980's disability studies became an important field of intellectual endeavor. It reached across many disciplines like sociology, social psychology, political science, law, history, geography, development studies, public health, social work/ policy, education, philosophy, literature, and the arts.³⁶ Furthermore writers have taken into consideration social policy, gender studies, and cultural studies to offer theoretical and methodological resources of greatest relevance.³⁷

Whereas nearly every country of the world has disability movements, disability studies as an academic discipline is still an under- researched field.³⁸

The early pioneers were sociologist in the study of stigma, deviance, labeling, and chronic illness. They provide concepts for the study of disability. Therefore disability studies are distinguished as a field on its own and enrich other disciplines as the field of anthropology too. I should like to repeat once again that ethnographies and empirical material on the lives and experiences of disabled people are of a great relevance to the study of disability because they provide a variety of analytical perspectives.³⁹

³² cf. Waldschmidt 2003:7

³³ cf. Ingstad, Whyte 2007:1f

³⁴ Priestley 2001:243

³⁵ cf. Waldschmidt 2003:8

³⁶ cf. Ingstad, Whyte 2007:4f

³⁷ cf. Thomas 2007:7

³⁸ cf. Waldschmidt 2003:8

³⁹ cf. Ingstad, Whyte 2007:6f

The socio-cultural approach returns from seeing disability from the perspective of the “normal society” to the perspective of disabled people themselves to understand the majority society.⁴⁰ Anthropologists are hence interested in people’s own experiences of what is disabling in their world rather than in some universal definition. As Ingstad and Whyte confirmed these experiences must be connected to the process of defining disability and shared criteria brought into play in particular settings.⁴¹

So far in Germany and Austria disability was mainly explored by health professionals, psychologists, special needs pedagogues, and rehabilitation scholars. For a long time the medical or individual model was postulated but it is changing and social and cultural perspectives are included.⁴²

Disability studies in the North take an activist position. In the South, activism for change is often supported by development cooperation, through programmes or projects by NGOs and CBOs including DPOs- disabled people’s organizations. Community- based Rehabilitation (CBR) is a fundamental policy in developing countries where communities are expected to manage their life situation with people with disabilities included, because often the institutional infrastructure is missing⁴³ like in my own research where I worked with a community based organization in Nairobi area and networked with NGOs and DPOs.

1.3 The “social model” of disability

The social model emphasizes that people become disabled through disabling (social) barriers, rather than through their individual physical functioning or impairment.⁴⁴ The main question is how disability is understood as a social phenomenon.⁴⁵

Thus disability is not just one’s individual inabilities or limitations, it can be seen as a form of oppression by society. Sociologists in disability studies use a social oppression paradigm linked to marginalization which can be connected with class, gender, race, age, and disability factors.⁴⁶ It promotes that disability leads to social exclusion because of barriers which oppress disabled people.

⁴⁰ cf. Waldschmidt 2003:16

⁴¹ cf. Ingstad, Whyte 2007:11

⁴² cf. Waldschmidt 2003:8

⁴³ cf. Ingstad, Whyte 2007:8

⁴⁴ cf. Priestley 2003:3

⁴⁵ cf. Thomas 2007:4

⁴⁶ cf. Corker 1998: ix, Thomas 2007:4

During the 1960s, 1970s and 1980s there were different social- contextual approaches to disability but the British disability studies sometimes have been guilty of marginalizing or ignoring the contribution of others social- contextual approaches to understanding disability and researching disabled people's experiences, mainly those from other countries.

The social model replaced the medical or individual model, which stands for the dominance of professionals.⁴⁷ The social model has its roots in the writings of disabled people (e.g. within the Union of Physically Impaired Against Segregation in the UK (UPIAS) and within Disabled Peoples' international.⁴⁸

Oliver, a British sociologist, coined the phrase social model of disability and he focused on an impairment/disability distinction. He mainly influenced these ideological developments and it has come to be defining characteristics of disability studies in the United Kingdom.⁴⁹

Both the social and individual model can be divided into two parallel themes. The individual model focuses on the one hand on the characteristics of the body and its physical or cognitive functioning (biological model) and on the other hand on aspects of individual identity (psychological model). The social model of disability could be classified into the cultural model which focuses on the role of cultural values and the structural model which stands for political economy and disabling environments.⁵⁰ The disability movement swung from one extreme to another- first disability was associated with dependency, invalidity and tragedy and second it was defined entirely in terms of social oppression, social relations and social barriers.

Oliver emphasized that disability, according to the social model, is all the things that hinder a disabled person to participate in social life because it is *"ranging from individual prejudices to institutional discrimination, from inaccessible buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on."*⁵¹

Anyway Shakespeare sees a danger in the social model of disability, he drew attention to the fact that: *"if disabled people share a common experience of oppression, regardless of impairment- just as black people share a common experience of racism, regardless of ethnic origins- then to organize and analyze on the basis of impairments becomes redundant."* Furthermore *"to mitigate or cure medical problems may be regarded with intense suspicion."*⁵²

⁴⁷ cf. Shakespeare 2006:18

⁴⁸ cf. Priestley 2003:3

⁴⁹ cf. Shakespeare 2006:13,15

⁵⁰ cf. Priestley 2003:15

⁵¹ Oliver 1996:33 in Priestley 2003:15

⁵² Shakespeare 2006:31

He appealed that it is important to understand disability in terms of individual experience because he claimed that the number of disabled people becomes irrelevant if disability is just seen as a product of structural exclusion.⁵³ Therefore the separation of disability from impairment within the social model hinders the explanation of psychological and physical consequences for the individual.⁵⁴

I agree with Shakespeare that disability is a combination of both models because on the one hand the situation of a person with disability depends on the individual life situation and on the other hand it relies on social circumstances. Therefore Shakespeare stated that people are disabled by society and by their bodies.⁵⁵

Moreover not only is the disabled family member disadvantaged but so is the whole family.⁵⁶ Therefore it is important how the family, guardians, friends etc. deal with the situation, in how far they support the person in his/her individual ability.

The social circumstances outside the home situation depend highly on the resources of the family and influence the whole development of a disabled child in education, employment etc. In a developing country like Kenya it is much more difficult because parents and families are often not able to fulfill basic needs of a disabled child. In other words an institutional discrimination takes place where children and young people have no access to education, employment, health care service, rehabilitation etc.

⁵³ cf. Shakespeare 2006:31f

⁵⁴ cf. Corker 1998:4,5

⁵⁵ cf. Shakespeare 2006:56

⁵⁶ cf. Freyhoff in Albrecht, Weigt 1993:111

1.4 Disability and “Liminality”

Another theoretical framework to analyze the situation of disabled people is offered by the anthropological study of rituals because it can be used to explain a liminal state of the disabled, “... *caught and fixated 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.*”⁵⁷

Disabled people have similar characteristics as other marginalized groups. They are outsiders and have been seen as separate and apart 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*⁵⁸, 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. During the transitional phase from separation to reincorporation those to be initiated stay in a liminal zone or threshold. They are marginal to society because they have lost their old status and have not yet acquired a new one. In many western countries these rites are tame and pallid. In many non western countries puberty rites mark the transition from childhood to adulthood by isolation from the community to return in another social role. According to Murphy et al., Victor Turner built his analysis of the qualities of liminality. 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 unpredictable and problematic and they are seen as socially dangerous people.⁵⁹

When the individual is reincorporated, he/she is seen as a complete individual, unsegmented by other social differences. Therefore liminality passes an individual from one stage to another which Turner calls a transference from inter- structure to anti- structure. The disabled dwell at the edge of society, in other words as interstices of social systems.

⁵⁷ Murphy et al. 1988:235

⁵⁸ Original published in 1909

⁵⁹ cf. Murphy et al. 1988:237

Disability is also 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 disabled experience no such transition because they do not come back in a defined social role and thus they remain undefined. Rather the social distance between them and the society is not narrowing but it is getting bigger and leads to physical isolation and noncommunication. Societal attitudes and prejudices strengthen the individual's decision to remain at home and his/her liminal stage becomes permanent.⁶⁰

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 in their community. Moreover for those who become disabled later they are separated in rehabilitation institutions and hospitals.⁶¹

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."*⁶²

1.5 Disability in developing countries

According to the World Health Organization (WHO) 650 million people world wide⁶³ experience various forms of disability as a result of mental, physical or sensory impairment. Physical and social barriers exclude them from society and prevent them from active participation in the development of their nations. In developed countries life expectancy and technological advances allow people to survive with impairments but in developing countries the situation is much more difficult.

Particularly programmes for education, rehabilitation, governmental support, etc. offer a variety of assistance for disabled people in developed countries whereas in developing countries those services are provided only for the minority of people.⁶⁴

⁶⁰ cf. Murphy et al. 1988:238,241

⁶¹ cf. Murphy et al. 1988:239

⁶² Murphy et al. 1988:241f

⁶³ cf. WHO b: <http://www.who.int...>

⁶⁴ cf. Neubert, Cloerkes 2001:50

Yet 80 percent of worlds disabled people live in developing countries caused e.g. by diseases, inhumane work conditions, war and accidents.⁶⁵ While people with disabilities in developed countries focus on the need for equality and anti- discrimination legislation, the situation for people with disabilities in developing countries is still calling for basic survival needs to be met.⁶⁶ The linkage between poverty and disability, in particular in developing countries is bi-directional⁶⁷ because 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.⁶⁸ Salome Kimata from UDEK pointed out that inaccessibility to education, employment or health system leads to exclusion from society.⁶⁹ This reflects the desperate problem of poverty as a major cause of disability and points to the importance of an accessible welfare system and employment, and an education system for all.⁷⁰ Duncan Mwangi commented that Kenya has to cope with poverty because *“Disability and poverty is very much connected. Then education ... medication ... they are also very expensive.”*⁷¹

To understand the linkage between disability and poverty according to Wolfensohn and Bourguignon, who have worked on development and poverty reduction World bank 2004, Ingstad and Grut explained that the focus has changed from income and consumption to access to food, shelter, education, health, social and political participation, security and freedom, environmental quality, social justice and human rights. It is important to focus on both global standards (as people living with one US dollar per day) and local standards especially in a developing country. According to Ingstad and Gruts survey in Kenya, there are many aspect of life which should be considered: *“lack of income/subsistence and material welfare, lack of basic needs such as food, clothing and housing, lack of health and access to health services, lack of education and occupational training, capability- seen as the opportunity to achieve acceptable levels of basic functioning, lack of opportunity to participate and/ or decide in organizational and political matters, lack of knowledge about civil rights, lack of participation in leisure and community activities, lack of experience of respect and self- respect.”*⁷²

⁶⁵ cf. Ingstad, Whyte 2007: 5, UNESCO a: <http://unesdoc.unesco.org...>

⁶⁶ cf. Turmusani in Priestley 2001:193

⁶⁷ cf. Braithwaite, Mont 2008 <http://siteresources.worldbank.org...>, Grut, Ingstad 2007:20 <http://siteresources.worldbank.org...>, Priestley 2001:9, Stone in Priestley 2001: 52, Albrecht in Albrecht, Weigt 1993:9,11, Wülser in Albrecht, Weigt 1993:73, Vespermann in Albrecht, Weigt 1993:235

⁶⁸ cf. WORLDBANK a: <http://web.worldbank.org...>

⁶⁹ cf. Interview Salome Kimata- UDEK 3.9.2007

⁷⁰ cf. Turmusani in Priestley 2001:194, Werner 2003:A4

⁷¹ Interview Duncan Mwangi- APDK 10.09.2007

⁷² Grut, Ingstad 2007:20 <http://siteresources.worldbank.org...>

Therefore the birth of a disabled child is often caused by poverty, malnutrition, war and other collectively or individually imposed social processes⁷³ because the prevalence of impairment is at least higher among those who live below the poverty line. Loss of economic power leads to lack of confidence, low self-esteem, and feelings of injustice and powerlessness and vulnerability is increasing. What makes people vulnerable is to live in a situation where any unexpected experience, as to give birth to a disabled child, can tip the balance from survival in extreme hopelessness.⁷⁴ Few facilities in rural areas and urban slums, no access to clean water, electricity, and sanitation make the situation for disabled people very difficult and can cause ill health and impairment.⁷⁵

Starvation, wars, and flight lead to increasing urbanization and therefore to destabilization of families and communities. Cultural values, norms and practices and the social security of the family and community are getting lost which are essential for people like old, ill, fragile, vulnerable, and disabled community members.⁷⁶

Thus especially lack of various resources as a result of poverty can lead to disability. That is why coalitions of activists from the North and South have worked together and developed organizations, special education programmes, and rehabilitation projects in developing countries.⁷⁷ *“Not only different values and conceptions of personhood but lack of resources, including social and health services, characterize the life worlds...”*⁷⁸ of people with disabilities.

Priestley drew attention to the fact that: *“In a global context, poor people are more likely to be affected by impairment and disability, and disabled people are more likely to live in poverty.”*⁷⁹

Not only caused by disabling attitudes or prejudices but also deeply rooted structural inequalities arising from economic, technological, and political development influence the life situation of people with disabilities.⁸⁰ Therefore it is important to understand the importance of human rights for persons with disability in a local context, and especially in the context of poverty.⁸¹

⁷³ cf. Shakespeare 2006:34, Stone in Priestley 2001:53

⁷⁴ cf. Stone in Priestley 2001:53

⁷⁵ cf. Ghai in Priestley 2001:29

⁷⁶ cf. Vespermann in Albrecht, Weigt 1993:228

⁷⁷ cf. Ingstad, Whyte 2007:5

⁷⁸ Ingstad, Whyte 2007:5

⁷⁹ Priestley 2001:9

⁸⁰ cf. Priestley 2001:9

⁸¹ cf. Ingstad, Whyte 2007:238

Ingstad, who has worked for almost two decades in rural Africa pointed out that she sees “some dangers involved in the way universal human rights for people with disability are being promoted in developing countries.” She strongly believes “that anthropology has a contribution to make by bringing forward the lived experiences of disabled people who cannot themselves participate at the negotiation tables and government offices where decisions affecting their lives are being made.”⁸²

That is why it is very important to inform people with disabilities about their rights because as my informant Duncan Mwangi pointed out, these people do not know their rights; they should be informed by education campaigns.⁸³ “That can be done very well by educating them and also by what we call social groups for parents like here we have mothers who come together. Coming together to be able to learn from one another and after learning they share.”⁸⁴

2. Children and young people with disabilities in developing countries

Out of 650 million disabled people worldwide, UNICEF has estimated that around one quarter or 150 million⁸⁵ are children who comprise one of the most socially excluded groups in all societies today. The majority receives no education and therefore is invisible on the national policy agenda. It has estimated that 140 million children are out of school, a majority being girls and children with disabilities. 80 percent of these children live in Africa and⁸⁶ 98 percent of children with disabilities in developing countries do not go to school.⁸⁷

UNICEF's Multiple Indicator Cluster Survey (MICS) shows that the percentage of children with disabilities varies significantly across countries, from e.g. 2 percent in Uzbekistan to 31 percent in Central African Republic. These variations in the percentage of people living with a disability can be caused by the nutritional status of children, environmental risks, the appearance of accidents and conflicts, chronic and infectious diseases, the quality of public health services and it might appear that the data is not comparable.⁸⁸

⁸² Ingstad, Whyte 2007:239

⁸³ cf. Interview Duncan Mwangi- APDK 10.09.2007

⁸⁴ Interview Duncan Mwangi- APDK 10.09.2007

⁸⁵ cf. Disability World 2003. <http://www.disabilityworld.org...>

⁸⁶ cf. UNESCO a: <http://unesdoc.unesco.org...>

⁸⁷ cf. UNESCO b: <http://www.unesco.org...>

⁸⁸ cf. UNICEF a: <http://www.childinfo.org...>

Furthermore the number of children with disabilities reported varies even within one country because of access to health care services to prevent disability and also in terms of diagnosis, treatment, rehabilitation, and support services. It is so not only in my research where I met various families who did not have any diagnosis on their disabled children but also in the research of Whyte in East Africa where she had met many families who had never been given any diagnosis, or explanations.⁸⁹

Children with disabilities are very vulnerable and particularly suffer from discrimination by individuals, institutions like health and education services, including families and state. These children, especially in developing countries often have no access to basic social services, especially education as well as a lack of recognition of their equality concerning human rights by their families, peers, and communities. Furthermore they are more vulnerable to sexual abuse⁹⁰, exploit, and neglect, due to the same misperception which leads to other forms of discrimination as a result of their specific physical or mental difference.⁹¹ As Salome Kimata pointed out: *"People with disabilities, yes, they have rights but you find that their rights are abused because they are discriminated on disabilities issues"*⁹²

When she talked about discrimination, she talked about children in school who were sent away because of physical impairment. She told us that principles of some schools say these children were bothering the other children and they have to send them away.⁹³ Like in my own research two children (and two adults in their past) were expelled from school because of their impairment.

This discrimination needs to be addressed because it has to be recognized that disability is not caused simply by a medical condition but also by the social restrictions which result from discrimination in various areas.⁹⁴ Nevertheless the individuality of a disability has to be taken into consideration as Shakespeare argued: *"... but even in the absence of social barriers or oppression, it would be still problematic to have an impairment because many impairments are limiting or difficult, not neutral. Moreover ... in most cases, disabled people are experiencing both intrinsic limitation of impairment and the externally imposed social discrimination"*.⁹⁵

⁸⁹ cf. Whyte in Ingstad, Whyte 1995:230

⁹⁰ cf. Priestley 2003:100

⁹¹ cf. UNICEF b: <http://www.childinfo.org...>

⁹² Interview Salome Kimata- UDEK 3.9.2007

⁹³ cf. Interview Salome Kimata- UDEK 3.9.2007

⁹⁴ cf. UNICEF b: <http://www.childinfo.org...>

⁹⁵ Shakespeare 2006:41

When Salome Kimata talked about accessibility to schools, she pointed out that it is not possible for many children to visit a primary school because of the poor infrastructure of some buildings. If there is a school with a toilet (just a hole with timber on it) or when the sizes of doors or corridors are very narrow, it is not possible for a child in a wheelchair to attend this school and move around.⁹⁶ *“A high percentage is disability unfriendly and that has also contributed to the increasing of illiteracy levels within the disability fraternity.”*⁹⁷

This promotes the social mode of disability that social barriers lead to exclusion from society. In some cases it will be necessary to work toward providing specific services to meet their needs. Early detection and intervention in health and specialized education for children with intellectual or sensory disabilities is very important. *“Efforts to address discrimination against children with disabilities will also have the positive effect of preventing the development of discriminatory attitudes towards those with disabilities in subsequent generations.”*⁹⁸

A Child's functioning in a specific domain is an interaction or relationship between his/her health condition and the contextual factor surrounding his/ her life – environmental and personal factors. Important are the associations between existing impairments in children's activities and participation in life situations, and their contextual factors.⁹⁹

Young people with disabilities suffer a similar problem like children with disabilities. Lack of education gives less knowledge where to go for help and where to listen to informative programmes.¹⁰⁰ They often suffer from discrimination and prejudices which leads to social isolation and loss of self- esteem. 80 percent of young people with disabilities live in developing countries and it is also an under- researched area with limited data. 98 percent of children and young people with disabilities in developing countries do not attend school because of inaccessibility and lack of appropriate facilities. Exclusion from education limits their employment opportunities. Thus unemployment rates of people with disabilities are always higher than of non-disabled people in every society.

⁹⁶ cf. Interview Salome Kimata- UDEK 3.9.2007

⁹⁷ Interview Salome Kimata- UDEK 3.9.2007

⁹⁸ UNICEF b: <http://www.childinfo.org...>

⁹⁹ cf. UNICEF b: <http://www.childinfo.org...>

¹⁰⁰ cf. Grut, Ingstad 2007: 38 <http://siteresources.worldbank.org...>

The results of unemployment are far-reaching when people with disabilities are discriminated, especially for young people. They are denied full use of their productive abilities and if they found an employment, their incomes are depressed and they are overrepresented in the ranks of the poor. In other words equitable opportunities in education and the labor market can ensure less poverty.¹⁰¹

To address thus innovations such as the internet are very important to break down barriers and increase their sense of belonging and interaction with their peers.¹⁰² These young people are no longer children and therefore not addressed in e.g. EFA (Education for All) discussion.

Nevertheless young people with disabilities are increasingly recognized as being vulnerable and at risk. Unemployment affects social interactions, psychological well-being, and lifestyle.¹⁰³ That influences the well being of young people with disabilities and they are becoming angry and hopeless without a future, sometimes homeless. They need a platform, a window for the adult world to get future perspectives.¹⁰⁴ Employment especially for young people can achieve greater independence; productive work can enhance their self-esteem and dignity of an individual and development of friendships could be the benefits.¹⁰⁵

2.1 The problem of data collection

The change in nations' commitments to children with disabilities is critically dependent on the availability of data. It is the only way to establish policies, strategic plans and effective services and supports. There is an urgent need to improve the quality and further the availability of international data on children with disabilities because educational reform is crucially dependent on such data.

In 1990 the UN passed a resolution declaring that "developing countries" should create methods of "data collection" on various disabilities *"to be used as essential tools and frames of reference for launching action programs to ameliorate the condition of disabled persons."*¹⁰⁶

¹⁰¹ cf. Szymanski, Parker 2003: 12,13

¹⁰² cf. UN a: <http://www.un.org...>

¹⁰³ cf. Szymanski, Parker 2003:18

¹⁰⁴ cf. Bernard 2000:13,14 <http://unesdoc.unesco.org...>

¹⁰⁵ cf. Szymanski, Parker 2003:373

¹⁰⁶ Ingstad, Whyte 2007:222

The general director of Rehabilitation International (RI) explained: *“that 10 percent of the world’s population is disabled. He wanted to make this issue big because people don’t tend to think an issue is big unless you have big numbers.”*¹⁰⁷

Without data on these children it will not be possible to ensure that they are included in achieving the goals of two major global initiatives: Education for All (EFA) and the Millennium Development Goals (MDG)¹⁰⁸ which says: *“Target 3: Ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling.”*¹⁰⁹

Although the World Bank, UN, WHO, OECD, UNICEF and others work on collecting data on children with disabilities, a substantial amount of which focus on developing countries do not currently exist. They do not give a basis for meaningful international comparison and further are of unknown reliability and validity. Even the MDG and EFA are essentially silent on the topic of disability as far as data concerned, although they have espoused a rhetoric acknowledging the importance of including children with disabilities within these initiatives. The lack of data leads to the justification in excluding children and young people with disabilities and further this exclusion does not see data as a priority. Although problems of poor attendance, repeaters, dropouts, and poor performance are included, they ignore children with disabilities. There is a great importance of inclusion to address the problem of data collection on children with disabilities.¹¹⁰

In Kenya lack of evidence- based data on the nature and extent of disabilities as well as other factors challenges the planning for people with disabilities. Only small scale studies and special rehabilitation/educational institutions are available but have never been adequate to give an overview of Kenya’s people with disabilities e.g. the head of the assessment center at KISE pointed out that there are no data on how many children with disabilities exist in Nairobi area. The institute has only assessed children who come to KISE. The children’s name, age, disability and their parents are registered by hand in a book; it is not done per computer.¹¹¹

That is why the Kenya national survey for persons with disabilities provides stakeholders to update information for planning, implementing, monitoring, and evaluating various activities, programmes, and projects to improve the situation of people with disabilities.

¹⁰⁷ Ingstad, Whyte 2007:223

¹⁰⁸ cf. Robson, Evans: <http://siteresources.worldbank.org...>p.1

¹⁰⁹ WORLD BANK b: <http://ddp-ext.worldbank.org...>

¹¹⁰ cf. Robson, Evans: <http://siteresources.worldbank.org...>p.35f

¹¹¹ cf. Short interview HAD- KISE 25.9.2007

This survey is supported by the National Coordinating Agency for Population and Development (NCAPD), collaborated with the Kenyan National Bureau of Statistics to undertake the survey; the Ministry of Gender, Culture and Social Services and organizations for and of people with disabilities. Financial support is received from the United Kingdom's Department for International Development (DFID), the World Bank, and the United States Agency for International Development (USAID) under the Statistical Capacity Building Project (STATCAP) project. The United Nations Population Fund supported the design of the survey instrument.¹¹²

2.2 Major causes and consequences of childhood disability

In developing countries, disability has different causes from those in the developed world caused by a mixing of factors. The proportion of disability caused by communicable, maternal, and prenatal diseases and injuries is much higher than it is in developed countries.¹¹³ Josephat Gichana a physical therapist (PT) from Dagoretti children's center argued that in Kenya many mothers deliver their children at home and thus nobody can diagnose if the child is healthy. Furthermore children are often not taken to any treatment if they become ill after birth. He mentioned meningitis as a disease which can affect the whole development of the child if it is not taken to any treatment. Diseases can spread if the child is not taken to any immunizations.¹¹⁴ Brain damages can be avoided when mothers take added precautions during pregnancy. Birth defects can also be caused when mothers take medicines during pregnancy.¹¹⁵

Other causes are (road) accidents and traumatic injuries, land mines, and violence. For example 2,000 people are killed or injured monthly by landmines in more than seventy countries in the world. Therefore world peace has become a disability issue.¹¹⁶ Other factors such as population increase, aging, and medical advances let the number of people living with impairments grow. The demand for health and rehabilitation services has therefore increased. Depending on the country's overall level of socio- economic development, numbers vary worldwide.¹¹⁷ Early Intervention can prevent 70 percent of childhood disability which is caused by vaccine preventable diseases such as polio, as well as malnutrition and micronutrient deficiencies.

¹¹² cf. KNS for PWDs: 2008:1f

¹¹³ cf. Elwan 1999:16 <http://siteresources.worldbank.org...>

¹¹⁴ cf. Interview Josephat Gichana- DCC 4.9.2007

¹¹⁵ cf. Werner 2003:14

¹¹⁶ cf. Priestley 2001:8

¹¹⁷ cf. KNS for PWDs: 2008:1, UNICEF a: <http://www.childinfo.org...>

Although in the last years fewer had been affected from poliomyelitis and measles¹¹⁸ or due to vitamin A and iodine deficiencies, many children in developing countries have no access to basic preventive services. Malnutrition can lead to chronic vulnerability, to diseases as well as to intellectual disabilities. More than half of all child deaths worldwide are caused by malnutrition.¹¹⁹ In Kenya in 2003 19, 9 percent of children under 5 are underweight caused by malnutrition.¹²⁰ Iron deficiency and anemia in infancy and early childhood can lead to an underdevelopment of the psychomotor functions and impair cognitive development. Another aspect is that malnutrition can lead not only to lifetime disabilities but also to a weakened immune system which delays the capacity for learning.

Detailed estimates of mental disabilities vary widely and often within the same country. It is a complexity of various influences whether urban or rural, social- cultural and socio- economic causes.¹²¹ However Iodine deficiency, which is the world's leading cause of preventable mental retardation can delay intellectual development and therefore causes various mental disabilities. 100 million young children are affected by Vitamin A deficiency which can cause blindness.¹²² Diseases like trachoma and river blindness are frequent in less developed areas of the world where there are also specific environmental risks. Trachoma, a bacterial disease, affects about 84 million people of whom about 8 million are visually disabled. It concerns people in many of the poorest and most remote poor rural areas of Africa, Asia, Central and South America, Australia and the Middle East, mainly vulnerable members of a community namely women and children.¹²³ Worldwide the spread of trachoma is related to inadequate sanitation facilities.¹²⁴

Another cause of disability could be abortion if it does not work.¹²⁵ In Kenya it is prohibited, that is why women are forced to undergo an abortion on their own or with the help of others in an illegal situation.¹²⁶ That is why many women die or if they survive their babies and also the mother herself could be injured. A friend of mine told me about a girl in his area, who has tried to abort her child with malaria drugs and thus died of an overdose. Another issue is the misuse of drugs and medicine in pregnancy which can influence the development of a child within this time.¹²⁷

¹¹⁸ cf. Elwan 1999:16 <http://siteresources.worldbank.org...>

¹¹⁹ cf. UNICEF c: 1999:2 <http://www.unicef.org...>

¹²⁰ cf. WHO d: 2006 <http://www.afro.who.int...>

¹²¹ cf. Elwan 1999:17 <http://siteresources.worldbank.org...>

¹²² cf. UNICEF c: 1999:1f <http://www.unicef.org...>

¹²³ cf. WHO e: <http://www.who.int...>

¹²⁴ cf. Elwan 1999:16 <http://siteresources.worldbank.org...>

¹²⁵ cf. Short interview Kenneth Ndua - Food for the Hungry 8.9.2007

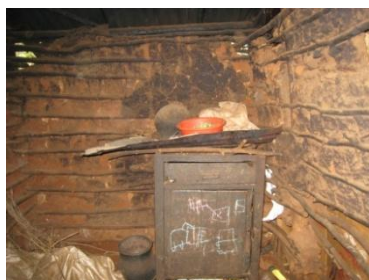
¹²⁶ cf. BBC News. <http://news.bbc.co.uk...>

¹²⁷ cf. Short interview Kenneth Ndua- Food for the Hungry 8.9.2007

2.3 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 in Kikuyu division, where most of my research took place, some of the families have their own land and a house but some of them live in slum areas (Shauri Yako). 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 (see pictures). In Kenya 94 percent in rural areas and 17 percent in urban areas use solid fuels which means cooking with carbon.¹²⁸ Just a few of the families I have visited had electricity and I haven't seen sanitation facilities at all which means no toilet or shower. In Kenya only 46 percent of population in urban areas and 41 percent in rural areas use adequate sanitation facilities.¹²⁹



kitchen



sooty walls from cooking



sleeping room (family from Gichecheni)

© (Pictures taken by Katharina Bittner)

Moreover all 38 families I have visited through home visits had no access to clean water. In Kenya 39 percent of the people have no access to clean water source (17 percent in urban areas; 54 percent in rural areas).¹³⁰

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.¹³¹

¹²⁸ cf. WHO d: 2006 <http://www.afro.who.int...>

¹²⁹ cf. UNICEF d: <http://www.unicef.org...>

¹³⁰ cf. UNICEF d: <http://www.unicef.org...>

¹³¹ cf. Grut, Ingstad 2007:35 <http://siteresources.worldbank.org...>

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 are responsible for high infection rates in low income countries.

Cooking pots and charcoal burners in, or near, sleeping quarters can cause communicable respiratory diseases, mostly in crowded housing situations.¹³² Also skin infections and diseases, such as leprosy, can spread in crowded and unsanitary conditions.¹³³

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. HIV/Aids, Sexual Transmitted Diseases (STDs), leprosy, polio, and measles can increase the risk of infection if it is not fully understood.¹³⁴ According to a social protection paper from Elwan, Silberberg notes that in sub- Saharan Africa there is little information on disabilities and epidemiological knowledge and professionals are rare.¹³⁵ Duncan Mwangi commented that: “*So poverty again. The other thing is lack of knowledge and then we also have accidents which are contributing and even war like gun shots.*”¹³⁶

Disabilities like blindness and deafness are closely linked to poverty and furthermore a decrease in income. Although many diseases could be preventable, due to costs of medication it is not affordable for most of the poor people in low income countries. 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.¹³⁷ Nearly all children I have visited live in large families which means that most of the children did not have less than three siblings. Therefore in most of the cases the families live in overcrowded housing situations, and cooking inside and animals near the home are very common.

¹³² cf. Werner 2003:13

¹³³ cf. Douglass 2003:5, WHO f: <http://www.who.int...>

¹³⁴ cf. Douglass 2003:6

¹³⁵ cf. Elwan 1999:17 <http://siteresources.worldbank.org...>

¹³⁶ Interview Duncan Mwangi- APDK 10.09.2007

¹³⁷ cf. Buchan 2003:10f

3. Disability in the context of a socio- economic structures in Kenya

“The basic approach is to start where people live, with their concerns and resources and the particular political ecology in which they are interacting.”¹³⁸

Therefore it is important to ask how relations with institutions, organizations, and media messages may affect the situations and the understanding of disabled people in a local context.¹³⁹ It is a fundamental question in how far being disabled is different in various cultural, social and economic contexts. If I compare cities in developed countries like Vienna and those in developing countries like Nairobi I come to the conclusion that it is fundamentally different in many ways. It is not only different from the biomedical point of view but from many other perspectives. Social, cultural, economic, and physical conditions play at least as important a 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 maintained 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.”¹⁴⁰*

These possibilities are dependent on accessibility to economic structures like information, education, employment etc. which is often not offered to people with disabilities. With accessibility I mean e.g. various communication barriers when it comes e.g. to Computer Technology. As my informant Salome Kimata pointed out: *“What I’m saying now when it comes to computer technology you realize ... that people with disabilities they have various communication barriers. If you think of a deaf student in class unless the instructor is talking then this student will never be able to be trained. 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. If you think of an albino these are people who have got low vision unless you come up with desires so that those characters are able to follow or you are able to reduce the light permitted like a special screen on top of a screen on the computer that affects you eyes. If you don’t do this they are never being able to be trained.”¹⁴¹*

¹³⁸ Ingstad, Whyte 2007:3

¹³⁹ cf. Ingstad, Whyte 2007:3

¹⁴⁰ Ingstad, Whyte 2007:250

¹⁴¹ Interview Salome Kimata- UDEK 3.9.2007

So if people are barred from communication they are barred from information. Particularly deaf people if they have never been trained in sign language. Salome Kimata even talked about children who never learn sign language and therefore cannot communicate with their parents and guardians. She wants to ensure the communication between the hearing and the hearing impaired because deaf people are not understood if doctors e.g. treat them. They are not even in a position to communicate and tell what is wrong with them.¹⁴²

Inaccessibility is one of the main challenges for people with disabilities in Nairobi area especially when it comes to economic resources.

3.1 Country and population

The Republic of Kenya is 582,646 km² with a population of 36, 139 Million people.¹⁴³ It is divided in provinces; the capital Nairobi and province, central province, coast province, eastern province, north eastern province, Nyanza province, Rift Valley and western province. The country borders on Sudan and Ethiopia in the north, in the east on Somalia, in the south on Tanzania and in the west on Uganda.¹⁴⁴ 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.¹⁴⁵ The TI Corruption Perceptions Index 2004 ranks Kenya with Cameroon, Iraq, and Pakistan at the 129th out of 145 positions.¹⁴⁶

Kenya is poor concerning mineral resources and only 20 % of the territory is suitable for agricultural use.¹⁴⁷ Particularly the Kenyan Highlands in the north and south of Nairobi comprise one of the most successful agricultural production regions in Africa. The highlands are the site of the highest point in Kenya: Mount Kenya, which reaches 5,200 meters. The country has nearly all vegetation- and climate zones. That is why Kenya is a principal magnet of tourism.

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 Kalenjin. 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”.

¹⁴² cf. Interview Salome Kimata- UDEK 3.9.2007

¹⁴³ cf. KNBS b: <http://www.knbs.go.ke...>p.8,10

¹⁴⁴ cf. Geiser 1986:13

¹⁴⁵ cf. Nohlen 2002:459

¹⁴⁶ cf. TI <http://www.transparency.org...>

¹⁴⁷ cf. Guimbous 1993:1

The relatively high growth of population of 2,75% and the shortage of farmland leads to migration into cities. 21 percent of the population lives in the cities. The average annual growth rate of urban population is 3, 7 percent (1990-2006).¹⁴⁸

In Kenya poverty and inequity are still the major challenges. 46, 1 percent of the population still has levels of consumption that do not meet basic food and other needs. Although the percentage of poverty has declined from 29, 6 percent in 1997 to 19, 1 percent in 2005/6, the consumption level of one in five Kenyans is inadequate to meet basic food needs alone, which means that 16, 7 millions of Kenyans live below the poverty line¹⁴⁹ (living on less than 1.08 US dollar a day).¹⁵⁰

Kenya is ranked 148 out of 177 on the 2005 UNDP Human Development Index (HDI). The four key indicators used to calculate the HDI, longevity, educational attainment, standard of living and adult literacy rate. Longevity, measured as life expectancy at birth 2005 was 52, 1 years.

Educational attainment (combined primary, secondary and tertiary gross enrolment ration) was 60, 6 percent. The standard of living, measured as per capita GDP, was 1,240 US dollar in 2005 and the adult literacy rate was (ages 15 and older) 73, 6 percent.¹⁵¹ Furthermore 39 percent of the people have no access to clean water source (17 percent in urban areas; 54 percent in rural areas¹⁵²) and 20 percent of the children are underweight (0-5 years).¹⁵³

3.1.1 People with disabilities in Kenya

Like in most developing countries people with disabilities in Kenya are a marginalized group. They often suffer from economic prejudices, stigmatization and also abuse and violence. Therefore it is a phenomenon which influences all fields of life and which needs support in all sectors. It is recognized that people with disabilities are not a homogenous group because they are mentally, physically and/or socially challenged. They are a marginalized group and the majority has no access to education, health care system, rehabilitation and employment. Although the government and other stakeholders have provided services to disabled people many have not received any treatment, especially children with special needs who are the most vulnerable in all societies. Most of these children live in extreme poverty. That is why there is a major need to develop strategies to empower these people and reduce poverty.¹⁵⁴

¹⁴⁸ cf. UNICEF d: <http://www.unicef.org...>

¹⁴⁹ cf. WORLDBANK a: <http://web.worldbank.org...>

¹⁵⁰ cf. UNICEF d: <http://www.unicef.org...>

¹⁵¹ cf. UNDP: <http://hdrstats.undp.org...>

¹⁵² cf. UNICEF d: <http://www.unicef.org...>

¹⁵³ cf. UNDP: <http://hdrstats.undp.org...>

¹⁵⁴ cf. Grut, Ingstad 2007: 11 <http://siteresources.worldbank.org...>

The first services for people with disabilities go back to missionary era when in 1946 the Salvation Army Church established a rehabilitation programme for blind men. Later this programme was changed into the first school for blind children in Kenya, the Salvation Army High School.¹⁵⁵ Special institutions were established by Catholic, Presbyterian, Anglican, and Methodist churches for visual, hearing and physical disabilities. Other services were provided over time as the Kenya Society for the Blind, the Association for the Physically Disabled of Kenya, the Kenya Society for the Mentally Handicapped, and the Kenya Society for Deaf Children. National Associations and community based groups and Disabled People's organizations (DPO) were established by persons with disabilities to advocate for the rights of disabled people. The Kenya Union for the Blind is the oldest organization which was founded in 1959.

Other organizations which are important are the following: The Kenya National Association of the Deaf (KNAD) in 1987, the Kenya Society of the Physically Handicapped (KSPH), the United Disabled Persons Organization of Kenya (UDPK). UDPK became an umbrella body for people with disabilities organizations including smaller district and community ones and it has closely worked with the government to raise the awareness, to identify needs, to provide services for people with disabilities and to organize events as the UN international day for persons with disabilities.¹⁵⁶

The Kenyan Population Census of 1989 estimates 0, 7 percent of the Kenyan population living with disabilities.¹⁵⁷ A preliminary report from the Kenyan national survey for persons with disabilities is available which I will use to describe the situation more precisely. This data is based on interviews with members of nearly 15.000 households across Kenya's 69 districts. By sex 49 percent males and 50, 4 percent females responded to the survey.¹⁵⁸

The Kenyan national survey for persons with disabilities differs from the Kenyan population census because the national survey figured out that Kenya has an overall disability rate of 4, 6 percent which translates to 1, 6 million people living with disability. 1, 6 percent of Kenyans or 554,440 people are living with physical impairment followed by visual impairment of 1, 4 percent or 488,136 people, hearing impaired 0, 5 percent and speech impaired 0, 2 percent.

2, 4 percent of the Kenyan population are children with disabilities aged 0- 14 years and 3, 6 percent are young people with disabilities aged 15- 24 years.

¹⁵⁵ cf. Lusiji 1989:6

¹⁵⁶ cf. Grut, Ingstad 2007:11,12 <http://siteresources.worldbank.org...>

¹⁵⁷ cf. UN b: <http://www.un.org...>

¹⁵⁸ cf. KNS for PWDs: 2008:7

The highest number of people living with disabilities was counted in Nyanza Province where 6, 8 percent of the whole population live with disabilities or 341, 4115 people, the lowest in North Eastern Province (2, 6 percent or 41, 685 people).¹⁵⁹

When I compare these data (4, 6 percent) with the data of www.disabilitykenya.org and with the report of taskforce on special needs education of the MOEST 2003, I come to the conclusion that they have estimated nearly the double of people with disabilities living in Kenya. They estimated about 3 million people: 1, 3 million with physical impairment, about 500,000 with hearing impairments, 200, 000 visual impairments of various degrees, multiple disabilities about 100, 000, and others almost 100, 000.¹⁶⁰

3.2 Economy

In Kenya agriculture plays the most important role in the national economy. A Labor Force Summary in 1998/9 of the Kenyan National Bureau of Statistics pointed out that 63, 1 percent of the working population is employed in the agricultural sector. 6, 1 percent of the population is employed in service industries, social and personal services.¹⁶¹ The most important agricultural products are maize, tea, wheat and coffee.¹⁶² In addition there are oat, sugar cane, sweet potato, dairy farming and animal husbandry. Tourism plays an important role, even before export of tea and coffee. Tourism earnings grew by 14, 9 percent from Ksh 48.9 billion in 2005 to Ksh 56, 2 billion in 2006. 1.6 million International arrivals were counted.¹⁶³

Since the 1980s, due to the high growth of population and crop loss because of drought, Kenya has to import goods from foreign countries.¹⁶⁴

These problems arise by high dependency on the world market, which results in unsteady profits from export goods and affects production and national price levels. In general it has proved true that alteration of agricultural patterns for marketing purposes often leads to reduced cultivation for personal use and, in consequence, increasing numbers of malnourished children. This creates increased proneness to diseases as well as disabilities.¹⁶⁵

¹⁵⁹ cf. KNS for PWDs: 2008:8

¹⁶⁰ cf. DK.org: <http://www.disabilitykenya.org...>

¹⁶¹ cf. KNBS d: <http://www.knbs.go.ke/>

¹⁶² cf. KNBS b: <http://www.knbs.go.ke...p.82>

¹⁶³ cf. KNBS c: <http://www.knbs.go.ke...p.32>

¹⁶⁴ cf. Nohlen 2002: 460

¹⁶⁵ cf. Guimbous 1993:2

The most important export goods are tea and coffee, fruits, flowers and vegetables. The commercial economy is based mainly on the processing of agricultural and pastoral products. Besides that there exist textile, leather/shoe, wood (furniture, paper), vehicle, and chemical industries.¹⁶⁶

For the majority of the population the basic food is Ugali (mush) and Sukumaviki (similar to spinach) which thrives and prospers on small land areas around the houses.¹⁶⁷

3.3 The labor market situation

One of the gravest socio- economic problems of Kenya is the labor market situation. The relatively high growth of population (2, 75 percent) leads to scarcity of jobs, especially in urban areas. 78, 8 percent¹⁶⁸ of the population lives on self-sufficiency, in rural areas. Except for some farmers and plantation owners, the rural population suffers from increasing soil scarcity. Infrastructural and institutional improvements (road development, water supply, schools, and health services) have mainly functioned only as a means of easing the symptoms. Lack of jobs leads to increasing importance of the informal sector. The number of employees in the informal sector increased from 4, 668 700 people (2001) to 6, 407 200 people (2005) which means 1, 738 500 people in four years.¹⁶⁹

In Kenya only 46 percent of the population is economically active which means an unemployment rate of 54 percent.¹⁷⁰ Especially young people are faced by the problem of joblessness. They face a disproportionate risk of unemployment and financial dependency.¹⁷¹ Casual work is the most common possibility to get some income.¹⁷² Like in my research, the fathers and mothers of 13 children work casually and have no regular income (48 children 38 families).

T. is a six-year-old girl who lives in Gitaru. She suffers from HIV/Aids and pneumonia. She seems to be a shy girl and does not talk. She moves very slowly because her body is weak because of the diseases. She lives at a very low living standard and the house smells of urine. T. has one brother and a sister and she shares her bed with her single mother. Although the girl receives medical care, her mother does not know how to sustain because she works casually and has to look for a daily income. Thus it is difficult to continue with the medical treatment of her daughter.

¹⁶⁶ cf. Nohlen 2002:460

¹⁶⁷ cf. Geiser 1986: 17

¹⁶⁸ cf. HDI: <http://www.afdb.org...> p.29

¹⁶⁹ cf. KNBS a: <http://www.knbs.go.ke/>

¹⁷⁰ cf. HDI: <http://www.afdb.org...> p.39

¹⁷¹ cf. Priestley 2003:108

¹⁷² cf. Guimbous 1993:2

This example is characteristic for Kenyan society which shows extreme social inequalities. A relatively small upper class has the power of leadership and influences the national economy, partly in dependence on foreign interests. There is a small middle class which possesses important positions in industry and the training and service sector, and some also own land.¹⁷³ In contrast to these people there is a very large group of poor. In 2005, 23 percent of the population was living on less than 1.08 US Dollar a day.¹⁷⁴

3.3.1 *The labor market situation for people with disabilities*

People with disabilities in Kenya work mainly in specific areas: like traditional work as a tailor, carpenter, recorder, car mechanic, artisan, farmer, etc. That shows that disabled people work in handicraft professions. When I visited the Bombolulu workshop and cultural center in Mombasa where people with disabilities work, I saw that they are employed in professions I have mentioned above and that they have no chance to advance or to cross industry lines.

Some people with disabilities can start a business if somebody supports them. I met a physically disabled man who got a tricycle which he moved with his hands. Because of the mobility, which the tricycle offered to him, he was able to sell different things which he prepared on his own as e.g. baits for fishing. Therefore some people have managed a small business to sell things like cigarettes, matches etc. but the competition is high. Only a few people with disabilities work in upper class jobs like in offices, banks etc. Furthermore people with disabilities are often paid less than their able counterparts.¹⁷⁵ Unemployment has its roots in education as Salome Kimata stated: *"The government is not sensitive for the issues of people with disabilities ... education has become unaffordable. So even when it comes to competence on the job market we cannot equally compete. If you have your own company you are the director you are looking for ... I'm disabled maybe I have never seen a class at all would I apply for that job?"*¹⁷⁶

That is why UDEK offers courses for disabled people to break the circle of poverty and thus to fight against discrimination in employment areas. Salome Kimata explained that disabled people are less paid for the same work as non disabled people.

¹⁷³ cf. Guimbous 1993:3

¹⁷⁴ cf. UNICEF d: <http://www.unicef.org...>

¹⁷⁵ cf. Gaab 2001:38, Grut, Ingstad 2007:49 <http://siteresources.worldbank.org...>

¹⁷⁶ Interview Salome Kimata- UDEK 3.9.2007

“So if they employ you for 3.000 you work and the kind of work that you are doing if you didn’t have a disability I would pay that person 20.000 but I pay her 3.000 cause I know the chances of getting a job when you are disabled are very unlikely. You see that is discrimination.”¹⁷⁷

Furthermore Salome Kimata talked about her accountant who was working in a state company in Kenya. The woman was paid less than her able bodied colleagues, although she did the same work. Therefore even if people with disabilities are qualified for a post, it is difficult to find a job.¹⁷⁸ That is why a high number of people with disabilities do not have any employment. Most of them have no alternative as begging on the streets; mainly in regions where they expect wealth like hotels, cinemas, shopping streets etc. Therefore this leads to disputes because everyone wants to stay at the best places.¹⁷⁹ I got to know a physically disabled woman, affected by polio, who was begging on the streets and sometimes selling sweets. I made an interview with her when I visited UDEK and she pointed out that although it is forbidden, she has to do it because otherwise, she could not afford the bus fare to e.g. the courses at UDEK and she would not be able to support her child. Moreover she had even completed secondary school and joined computer courses at UDEK but nevertheless she had not found any employment.¹⁸⁰ Another physically disabled woman who attended computer courses at UDEK argued that she has finished secondary school too but she has never been employed. Her most important dream is to find an employment to support her family with seven siblings.¹⁸¹

Furthermore I have seen a discussion on KTN on television on the second of August 2007 in News line Life and people with disabilities were discussing discrimination and marginalization of people with disabilities and that they have not enough resources to access services like their non disabled counterparts. They feel that people with disabilities are less likely to be employed even if they are qualified. Furthermore they were talking about stigma and disability. In Kenya until today there exist people who think that disabled people or their parents have done something wrong.¹⁸²

A third of people with disabilities in Kenya aged 15 years and above (33, 3 percent) work in their own family business and about a quarter do not work at all (24, 2 percent). 16, 3 percent work for pay and one out of ten (10, 3 percent) indicated that they were homemakers (doing housework- 21, 8 percent women, 2, 7 percent men).

¹⁷⁷ Interview Salome Kimata- UDEK 19.9.2007

¹⁷⁸ cf. Interview Salome Kimata- UDEK 19.9.2007

¹⁷⁹ cf. Gaab 2001:40

¹⁸⁰ cf. Interview W. W. 5.9.2007

¹⁸¹ cf. Interview A. N. 5.9.2007

¹⁸² cf. KTN discussion august 2007

In urban areas people with disabilities are more likely to be employed than in rural areas. A quarter of people with disabilities in urban areas (25, 4 percent) worked for pay and only 8, 8 percent of those in rural areas. A third of people with disabilities in rural areas (33, 7 percent) did not work and 21, 8 percent in urban areas. Those who work in their family businesses are more likely in rural areas (32, 1 percent and urban areas 21, 3 percent). In Nairobi there is the largest proportion of people with disabilities who work for pay (31, 5 percent, whereas the smallest in North eastern province (2, 7 percent). Males are more likely to be employed than females (17, 7 percent and females only 7, 5 percent).¹⁸³

	worked for pay	worked on family business	did not work but was employed	did not work ¹⁸⁴	never employed	homemaker
0-14	0	0	0	40, 4	29,5	30, 2
15-24	8, 2	13, 6	0, 9	32, 4	19, 2	8, 6

¹⁸⁵

This data shows that high numbers of people with disabilities do not have an employment. Just a few work for pay and most of them work at home.

3.4 Health care system

The major public health challenges in Kenya are HIV/Aids, tuberculosis and malaria. Malaria kills a child in Africa every 30 seconds. Those who survive malaria often suffer from learning impairments or brain damages. Especially pregnant women, who cannot take any malaria drugs, are at risk to get malaria because it is the major cause of prenatal mortality and low birth weight. Malaria, depending on the areas and on the type, is hence one of the gravest challenges in the health situation of Kenya. In 1984 the first HIV/Aids cases were reported and the disease has been spread over the whole country until now where 1 in every 18 adult is infected.¹⁸⁶

In 2005 1, 500.000 people (all ages) (high estimate) and 740.000 women (aged 15+) lived with the HIV virus. Compared to a developed country like Austria where 1136 AIDS-patients (2008) live¹⁸⁷, it is a high number in Kenya with 1, 500.000 infected people in 2005.

The HIV prevalence in Kenya among people aged 15-49 years was 6, 1 percent in 2005. In 2005, UNICEF estimated 150.000 children (aged 0-14 years) were living with HIV (2005).

¹⁸³ cf. KNS for PWDs: 2008:15

¹⁸⁴ The data from the national survey does not explain the difference between did not work/never employed.

¹⁸⁵ cf. KNS for PWDs: 2008:15

¹⁸⁶ cf. Grut, Ingstad 2007:9,10 <http://siteresources.worldbank.org...>

¹⁸⁷ cf. Aids Hilfe Wien: <http://www.aids.at...>

1100.000 children (aged 0-17 years) are orphaned by Aids and 2300.000 children (aged 0-17 years) are orphaned due to several causes.

Among young people (aged 15-24 years) in 2005, it was 1, 3 percent male and 5, 9 percent female. Between the years 2000- 2006 only 47 of young men and 34 percent of young women (aged 15-24 years) have comprehensive knowledge of HIV.¹⁸⁸ Salome Kimata pointed out that these girls and women with disabilities are highly vulnerable when it comes to possibilities of sexual abuse by casual sex partners and these girls are even more at risk to get HIV/AIDS.¹⁸⁹ In addition, I found this information on www.disabilitykenya.org *“Children with disabilities are subject to a range of risks including that of being abused and more vulnerable to HIV.”*¹⁹⁰

Another significant point is that some people believe that disabled women are not sexually active. That is why they do not expect to be infected.¹⁹¹ Therefore there is a high risk to be infected by HIV/Aids because only 47 percent of young men and 25 percent of young women use condoms.¹⁹² Ingstad explained: *“They cannot negotiate for the use of condoms, and at the same time men probably see them as likely to be virgins and thus safe partners.”*¹⁹³

Above all because of high costs of medication for HIV positive children, there is often no treatment to help them to face this disease. Therefore the stigmatizations of these children force parents to keep it secret so that nobody is able to help them. It is really difficult to find out who is HIV positive. I got to know four children who were HIV positive but I do not know how many have not told us. *“They don’t tell it because in our society they believe a person who has HIV, they think it is an unmoral person, like prostitute, you see, because you can’t tell because people around they talk bad. They are even afraid of them.”*¹⁹⁴

In Kenya the negative health situation has at least some roots in colonization area because the Europeans brought in formerly unknown diseases (e.g. measles and tuberculosis). Furthermore unclean, infected water and a combination of unhygienic conditions contribute to the extension of cholera, typhoid, poliomyelitis, and trachoma.¹⁹⁵ However the last case of polio was recognized in 1993 and it seems under control for the next generations.¹⁹⁶

¹⁸⁸ cf. UNICEF d: <http://www.unicef.org...>

¹⁸⁹ cf. Interview Salome Kimata- UDEK 3.9.2007, Ingstad, Whyte 2007:240, 244f

¹⁹⁰ DK.org: <http://www.disabilitykenya.org...>

¹⁹¹ cf. Grut, Ingstad 2007:12 <http://siteresources.worldbank.org...>

¹⁹² cf. UNICEF d: <http://www.unicef.org...>

¹⁹³ Ingstad, Whyte 2007:245

¹⁹⁴ Interview Jeddidah Wairimu- CVO 29.8.2007

¹⁹⁵ cf. Guimbous 1993:7

¹⁹⁶ cf. Grut, Ingstad 2007:9,10 <http://siteresources.worldbank.org...>

In general there is a high appearance of diseases mainly caused by poverty. Compared to other African countries the health care system is relatively well developed but it cannot meet local needs sufficiently or uniformly. The quality of medical care is very different in urban and rural areas, and also between particular regions.

In 2003 634 health centers, 3351 clinics and dispensaries, and 514 hospitals were counted in Kenya. Mainly population growth hinders sufficient medical care and also access, which were not taken into account at planning.¹⁹⁷ If you compare these data with a developed country like Austria, which has 292 hospitals for eight million people, you realize that 514 hospitals in Kenya for 36 million people are not very much.¹⁹⁸

Health Institutions and Hospital Beds and Cots by Province, 2003*

Province	Health Institutions				Hospital Beds and Cots	
	Hospitals	Health Centres	Health Sub-Centres and Dispensaries	Total	No. of Beds and Cots	No. per 100,000 Population
Nairobi	58	54	381	493	5,011	21.6
Central	65	89	372	526	8,314	22.9
Coast	64	42	334	440	7,998	31.4
Eastern	65	80	692	837	7,822	15.4
North Eastern	8	12	68	88	1,914	14.2
Nyanza	98	117	333	548	12,545	23.2
Rift Valley	100	161	1,006	1,267	12,832	16.5
Western	68	94	196	358	6,971	19.4
Total 2003	526	649	3,382	4,557	63,407	19.5
Total 2002	514	634	3,351	4,499	60,657	19.2

Source: Health Information System, Ministry of Health (M.O.H)¹⁹⁹

This table shows a clear privilege of the capital province Nairobi, followed by a relatively good supply in the central and coast province, but in contrast extreme disadvantages for north eastern and western province. Shortage of hospitals and health centers leads to untreated illnesses, too late treatment, as well as sometimes no treatment at all if it is far from home or unaffordable. Inadequate roads and lack of money for transport hinder people to reach health institutions.²⁰⁰ In some cases parents of children with disabilities did not even know what exactly was going on with their child because they had never been to a doctor.

In my own research parents of 7 children (out of 24 disabled children), cannot afford any medical

¹⁹⁷ cf. KNBS e: <http://www.knbs.go.ke/>, Guimbous 1993:6

¹⁹⁸ cf. Netdokter: <http://www.netdokter.at...>

¹⁹⁹ cf. KNBS e: <http://www.knbs.go.ke/>

²⁰⁰ cf. Guimbous 1993: 7

treatment for their child.

K. is a 1 year and 8 month old girl who lives with her parents in Kagira. Her mother does the housework and the father works casual. She has one brother and a sister. They live in an iron sheet house and the chickens are running around everywhere. The girl is physically and mentally disabled 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 parents are not able to provide that because of their financial situation. This example illustrates how poverty influences access to health care. At the WHO Alliance for Patient Safety Conference on the 17th January 2005 in Nairobi, Hon charity K Ngilu, MP, Minister of Health pointed out that millions of African children, women and men endure prolonged ill- health, disability and death caused by medical errors, unsafe blood transfusion, counterfeit and substandard drugs, and unreliable practices because of poor work conditions.

Furthermore there is little information available from African countries to estimate the extent of adverse events in health care. There is a considerable concern about the issue of unsafe injections and blood borne pathogens because it is also reported by a WHO survey that at least half of all medical equipment in developing countries is unusable, at any given time, which results in neglect of patients or increased risk of harm.²⁰¹

23 percent of the population in Kenya live below the poverty line (living on less than 1.08 US Dollar a day)²⁰² and thus are not able to afford medical care at the point and time of treatment. That is why it is necessary to develop a social health insurance scheme that will ensure that every child has access to free immunization and every woman has access to free reproductive health services.²⁰³

Immunizations are not achievable for everyone. Although UNICEF has started vaccination programmes (3 million children were immunized against measles, polio, tetanus and other diseases), a large number of especially children cannot receive. 2006 92 percent of children aged one year are immunized against TB, 90 percent against DPT, 80 percent against Polio, 77 percent against measles, 80 percent against HepB and 74,1 percent against tetanus.

I did not find immunizations dates against meningitis but in my data I had contact with four

²⁰¹ cf. WHO g: 2005:1 <http://www.who.int...>

²⁰² cf. UNICEF d: <http://www.unicef.org...>

²⁰³ cf. WHO g: 2005:3 <http://www.who.int...>

children who were affected by the consequences of meningitis.

Furthermore 49 percent of children in Kenya, under five years with suspected pneumonia, are taken to an appropriate health- care provider, 33 percent under fives with pneumonia are receiving antibiotics, and only 27 percent under fives with fever receive anti-malaria drugs.²⁰⁴

In general infant mortality rate is high in Kenya (year 2000 under fives mortality per 1000: 105,4).²⁰⁵ Compared to a developed country like Austria (1000: 5 in 2006)²⁰⁶ the mortality rate in Kenya is very high. In Kenya causes of death among children fewer than 5 years of age are neonatal causes (24 percent), HIV/Aids (14, 6 percent), diarrhea diseases (16, 5 percent), measles (3, 2 percent), malaria (13, 6 percent), pneumonia (19, 9 percent), injuries (2, 7 percent), and others (5, 3 percent).²⁰⁷ In my research I met three children (4, 5, 9 years) who suffered from pneumonia and had no money for any treatment.

Disability in Kenya and in general in developing countries is very closely connected with the inadequate supply of goods and services for the majority of its population, caused by poverty. The poor health conditions constitute one of the most serious effects, and at the same time the primary cause of disabilities.²⁰⁸ Poverty is thus also linked to health because in all countries in the world the poor are sicker than the nonpoor. In general poor countries have higher rates of mortality, at all ages, as well as infant mortality and severe illness. Consequently therapies only aggravate the social inequalities because unequal access to these therapies leads to untreated poor people again.²⁰⁹ In Kenya as well as in other developing countries the health system is not accessible to the majority of people due to the fact that they are not able to afford insurances, treatments, and even the transport to a doctor.

²⁰⁴ cf. UNICEF d: <http://www.unicef.org...>

²⁰⁵ cf. KNBS e: <http://www.knbs.go.ke/>

²⁰⁶ cf. UNICEF e: <http://www.unicef.org...>

²⁰⁷ cf. WHO d: 2006 <http://www.afro.who.int...>

²⁰⁸ cf. Guimbous 1993:7

²⁰⁹ cf. Farmer 2001:12,14

3.4.1 Health care system for people with disabilities

“... not all groups and individuals suffer to the same extent. Certain social statuses (the poorest, the least powerful, the stigmatized, those experience systematic discrimination) place individuals at greater risk for human misery and its health consequences.”²¹⁰

Especially the poor and the disabled are limited in access to health care services due to lack of money to pay doctors and transport. Salome Kimata emphasized that, private hospitals are not affordable for the majority of people with disabilities only if they find a sponsor. That is why UDEK works closely with hospitals to ensure that patients are treated. The organization connects people with disabilities to hospitals and pays the difference of the amount.²¹¹ Even when people manage to see a doctor or medical clinic they often have to wait long times to be treated or they are sent away to come back at another time. To raise the money for transport to come back is often not possible.²¹²

According to the Kenyan national survey for persons with disabilities 2008 in urban areas 95, 2 percent and in rural areas 85, 6 percent are aware of health care services available. Although 79, 4 percent in urban and 71, 6 percent in rural areas are in need of any health services only 56, 8 percent in both rural and urban areas have ever received any treatment. Children aged 0- 14 years only 52, 4 percent and young people from 15- 24 years only 61, 4 percent received any health services although 77 percent of children aged 0-14 years and 79, 6 percent of young people aged 15- 24 years are in need of them. Men receive more treatment than women namely 58, 4 percent and women 55, 5 percent.²¹³

Because most people with disabilities have no socio- economic involvement to earn a living, they require some assistance like social security grants or other forms of financial support from institutions. Urban people with disabilities are more likely to have access to disability grants (16, 7 percent) compared to rural people where only 2, 9 percent receive any financial support. Financial support is very rare for people with disabilities although they need a lot of resources.

²¹⁰ Kleinman 1986:181 in 1995:12

²¹¹ cf. Interview Salome Kimata- UDEK 3.9.2007

²¹² cf. Grut, Ingstad 2007:35,36 <http://siteresources.worldbank.org...>

²¹³ cf. KNS for PWDs: 2008:16,17

Duncan Mwangi drew attention to this fact: *"I think it's very pathetic ... It's quite worrying because a person with disabilities needs a lot of resources. They need money, they need education, they need parents. They also need a vehicle for moving ... and you also need a therapy and psychological preparation and psychological encouragement and you also need property which is not very easy ... and again poverty it's much interplay."*²¹⁴

3.5 Political structures

Now I want to give a survey of the history of the country, from the beginning and ending of colonialism, development of political parties until today, the presidential election 2007 which has caused violence all over the country. It is very important to draw attention to the situation of disabled people in the time of elections and their political situation today. After doing so I will write about post independent initiatives and national policies and laws for people with disabilities in Kenya, especially about the disability act 2003. Furthermore it is important to mention the establishment of the National Council for Persons with Disabilities (NCPWD) and the implementation of the Continental Plan of Action on the African Decade for Persons with Disabilities.

3.5.1 History of the country

Time table²¹⁵

- 1887 Development of the British East Africa Company
- 1895 Establishment "East Africa Protectorate"
- 1902 enlargement by the East Uganda Province (Nyanza) (Kenya-Uganda railway)
- 1895- 1905 Development of a colonial administrated territory
- 1902 Crown Lands Ordinance
- 1906 Nairobi became the capital of the protectorate
- 1910 Africans paid 40 percent and settlers 20 percent taxes of their income
- 1900- 1925 Africans paid 5, 8 million £ taxes

²¹⁴ Interview Duncan Mwangi- APDK 10.09.2007

²¹⁵ cf. Schicho 2004:262,263, 265,268, Nohlen 2002:461

1915 Master and Servants Act → every worker aged over 15 years has to carry a pass (kipande) with information about employer and hours of work

1920 renamed into “Kenya”

1920, 21 Development of political activists against taxes and labor force

1922 excesses in Nairobi, 21 people died

1931 1.197.467 people had a pass (kipande)

1939, 42 strikes against the prohibition of unions

1944 Kenyan African Union was established

1952- 1960 Mau Mau rebellion

1963 Independency of Kenya

1978 D. arap Moi became president of Kenya

1982 constitutional amendment: abolition of the multiple party system under Moi

1991 abolition of the one-party system

1997 president Moi was elected again

2001 First time the KANU made a coalition

2002 Mwai Kibaki became president

2007 Mwai Kibaki was elected again followed by violence all over the country²¹⁶

After the Portuguese built trading posts in the 15th century, the Arabs ruled the east African coast until the 19th century when Britain started to colonize Kenya. The completion of the railway from Mombasa to the Victoria Lake stands for the beginning of belonging to the British east African protectorate which was established after several financial difficulties of the British East African Company in 1895. The fertile highlands were taken by white settlers and local farmers (Luo, Kikuyu) were dispossessed and conscripted to dependent wagedworkers (1902 the Crown Lands Ordinance).²¹⁷ The settlers destroyed their fields, stole their livestock, and even burned down whole villages. About three-quarters of the whole population lived in the highlands and were affected by dispossession. The conquest was marked by violence and oppression especially against those who resisted.

Kenya became a country of immigration because Charles Eliot called for workers from India to construct the Kenya-Uganda railway.²¹⁸ Until the end of the 1940ies, the British colonial administration controlled the economy of Kenya.

²¹⁶ cf. UNICEF f: <http://www.unicef.org...>

²¹⁷ cf. Nohlen 2002:461

²¹⁸ cf. Schicho 2004:262f

After the First World War H. Thukus founded the young Kikuyu Association to fight against land expropriation, pass control (1915 Master and Servants Act) and forced labor on the “white highlands”. 1944 this association was to become the Kenyan African Union (KAU), demanding access to white- owned land.²¹⁹

After the rebellion of the “Mau Mau” (1952- 1960), the KANU (Kenya African National Union) fought for decolonization. In addition to the KANU which was funded by Kikuyu, Luo and Kamba, the KADU (Kenyan African Democratic Union) was established by smaller ethnic groups. After 68 years of British colonization, 1964, under Kenyatta who came back from his studies in the London school of economics under Malinowski, Kenya became independent. After Jomo Kenyatta’s presidential term (1963- 1978), Arap Moi governed the country from 1978 until 2002 and he was the chairman of the only legal political party KANU (Kenya African National Union).²²⁰

Within the KANU powered by the forced self cancellation of the KADU 1964, the conservatives came to power under Kenyatta and Mboya with prowestern politics. After Kenyatta’s death in 1978 D. arap Moi became president and chairman of the KANU. Although he was representative of the Kalenjin minority, he was able to stabilize his position by promising the elimination of the grievances like corruption and land grant to his partisans in the country. Regional and ethnic power fights and economic difficulties influenced the domestic development. After an attempted coup of the air force in 1982, Moi authorized a constitutional amendment where he abolished the multiple party system.

In 1990 the governance under Moi became pressurized by the opposition (the FORD Party was founded under J.O. Odinga, the opposition of Kenyatta). Rebellions took place in various parts of the country. Under the pressure of donor countries in 1991 the one-party system was abolished. In 1992 under the pressure of the KANU multi party elections took place and Moi won the elections with 37, 2 percent. Although the government was changed into a multi party system it did not change the regime at all which was characterized by assembly ban, no freedom of expression, dubious trials and violent police operations against oppositional groups. Moi exploited ethnic conflicts to present his government as a national unity. In 1997 Moi was elected again; he won over parties like the Democratic Party (DP), the National Development Party (NDP), the Forum for the Restauration of Democracy (FORD) and others. In June 2001 president Moi appointed four members of the NDP minister.

²¹⁹ cf. Schicho 2004:268, Nohlen 2002:461

²²⁰ cf. Nohlen 2002:459, KNBS b: <http://www.knbs.go.ke...p.12>, Geiser 1986:13, Schicho 2004:261

It was the first time since 1963 that the KANU made a coalition. In December 2002 Mwai Kibaki became president of Kenya. He promised to fight in particular against corruption. The National Rainbow Coalition (NARC) got 132, the KANU 68, the Forum for the Restoration of Democracy people (FORD-P) got 15 and the rest which means small parties like e.g. the safina shared 4 seats in parliament.²²¹ On 27th of December 2007 Mwai Kibaki was elected again followed by violence all over the country.²²²

3.5.2 Presidential election 27th of December 2007

On 30th of December 2007 Mwai Kibaki was officially declared the winner of the elections of 27th of the same month. The elections were followed by violence countrywide between various communities. The consequences were deaths, injuries, looting, destruction of property, and displacement of thousands of people. The violence had its origins in ethnic rivalries mainly between the Kikuyu and Luo (Kibaki, the former president belongs to the Kikuyu and Odinga belongs to the Luo). UNICEF estimated more than 500, 000 people were in need of humanitarian assistance and more than 300 people died. Affected areas were Eldoret, Burnt Forest, Kisumu, Turbo, Timboroa, Kuresoi, Molo, Narok, Uasin Gishu, Kakamega, Bungoma, Mombasa and Mandera. Burning of houses, incidences of mass rape and other forms of violence took place. UNICEF estimated 100, 000 people suffering without food, shelter, water, fuel, essential medicines etc. Also in the largest slums of Nairobi, namely Kibera and Mathare people remain insecure because of lack of food due to destruction of local markets.²²³

But what happened to the people with disabilities during that time? The media did not give much attention to them, only few articles were put into the internet. 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”* which I will use to explain the situation of people with disabilities during that time. Furthermore I found an article on <http://www.lcd-enar.org/files/PEV.doc>, also by the Organization LCD *“Post- election violence in Kenya and the effect on disabled people”*.

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.

²²¹ cf. Nohlen 2002:461,462, Schicho 2004:261,270,284

²²² cf. UNICEF f: <http://www.unicef.org...>

²²³ cf. UNICEF f: <http://www.unicef.org...>

The Organization LCD and Phitalis Were Masakhwe visited various displaced persons camps and they realized that the situation for disabled people was very difficult. Disabled people 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 disabled are often not strong enough to queue and to find a way through the crowds to get support.²²⁴

Many people with disabilities had lost their assistive devices like crutches and wheelchairs in the flight from their homes. They are now dependent on family and relatives. LCD started to assess the situation on the ground to identify disabled people and find out what their needs are. The organization reported that a man with disabilities had gone without food for three days. Furthermore a girl was forced to sit on the floor in the dirt because she was not able to take her wheelchair with her. Moreover deaf people were not able to register until an IDP helped them to understand because he knew basic Kenyan sign language.²²⁵

In the flight, friends and relatives carried some people with disabilities but some were left behind at home or on the road. Some have reached the camps but the conditions there are poor for people with disabilities because the camps failed to respond to their needs²²⁶ because it is difficult to get health care services and specialized medicine. That is why people with disabilities such as diabetes and epilepsy remain untreated and children have even died because of lack of medicine. Not to forget the people who became disabled as a result of the violence. Conflicts, emergency situations always bring about disabled people through lack of medical care, increase rates of injury and disruption of medical health care services. Disabled people are mostly affected because they lose their assistive devices, family, friends, and, carers. Furthermore they are vulnerable, especially children and women to exploitation and sexual abuse.²²⁷

For the media people with disabilities seemed to be invisible. Fortunately LCD is working closely with local NGOs, the UN, and government bodies and they have already managed to support them. They have e.g. delivered a wheelchair to an 18-year-old boy.²²⁸

²²⁴ cf. Masakhwe 2008:2,3 <http://digitalcommons.ilr...>

²²⁵ cf. LCD b: <http://www.lcint.org...>

²²⁶ cf. LCD b: <http://www.lcint.org...>, Masakhwe 2008:2,3 <http://digitalcommons.ilr...>

²²⁷ cf. Masakhwe 2008:2,3 <http://digitalcommons.ilr...>

²²⁸ cf. LCD b: <http://www.lcint.org...>

3.5.3 Political situation for people with disabilities after the elections 2007

To summarize the situation after the elections I will also use an article by Masakhwe authored on the 28 of January 2008. Beside the violence, the elections have failed to send disabled people to parliament benches which means that millions of disabled 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. Phitalis Were Masakhwe who was in Mumias, his colleagues Salome Kimata in Gatundu South, Sammy Leshore in Samburu East and Dag Kimani in Lari were unsuccessful. In contrast Uganda has special constitutional mechanisms to ensure minority groups are represented in local and national politics.²²⁹ In Uganda, where five disabled MPs are representing people with disabilities and 50,000 disability politicians/councilors are in the entire local council system, who have influenced many decisions of government in their favor²³⁰, Kenya remains without any representation of disabled people. As Salome Kimata pointed out even before the elections: *“So when things are planned especially the ministry of primary they don’t have disability issues at hand.”*²³¹

Furthermore I saw a discussion on KTN on television on the second of August 2007 in Newline Life where people with disabilities were discussing the lack of representation at the political level. People with disabilities in Kenya want to be members of parliament, they need representatives, and they want to be politically involved. One reason why the system has failed to incorporate disabled people was money; candidates need a lot of financial support to afford the campaigns. Another issue is the accessibility to the election system. Some people with disabilities are not even able to access the building or the ballot paper is not available in Braille.²³²

The stigma of disability affects people with disabilities during their daily lives and also during political campaigns. Furthermore Masakhwe emphasized that many constituents believe that people with disabilities cannot 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 play a role and failed to encourage the presence of disabled people in politics. In addition, the Electoral Commission in Kenya (ECK) who receives nomination papers on first- come- first- served basis, meant that there were physical battles for candidates to present their papers.

²²⁹ cf. Masakhwe 2008: <http://www.independentliving.org...>

²³⁰ cf. Ndeezi in Munaizel et al. 2003: 99,100

²³¹ Interview Salome Kimata UDEK 19.9.2007

²³² cf. KTN discussion august 2007

In the chaos of violence after elections not many candidates with disabilities were able to get to the commission. The fight for representation of people with disabilities has gone to the courts. Hopefully there will be democracy soon!²³³

3.5.4 *Post independent initiatives*

The Ominde Commission was the first post independence education and manpower-training enquiry, which recognized the need for education for people with disabilities. It advocated arrangements to address the government's role in strategy building to support people with disabilities in their transition from school to the employment world. A vocational rehabilitation division in the department of social services was set up who established the Industrial Rehabilitation Centre in Nairobi in 1971. Furthermore vocational rehabilitation centers were founded countrywide with workshops for courses like carpentry, dressmaking and leatherwork. In 1980 the government declared the national year for persons with disabilities. Campaigns to raise the awareness on people with disabilities were launched and a national fund for people with disabilities was set up. In this time community based rehabilitation was introduced to involve the communities and change the attitudes among people with disabilities.²³⁴ CBR programmes have the potential to provide accessible rehabilitation to children with disabilities and involve the community in addressing barriers and participation.²³⁵

The Educational Assessment and Resource Services (EARS) were established in 1984 in conjunction with the Danish International Development Agency (DANIDA)²³⁶ and have improved the education service for children with disabilities. Different professionals such as teachers, social workers, and medical workers are involved to offer early identification, assessment, intervention, and advocacy in educational services. In addition it has offered integrated programmes to enroll children with disabilities in special schools, special units, and regular schools.²³⁷ The EARS consisted of 17 centers located throughout the country. The EARS project was started initially with support of the former Director of Education, Dr.G.Oluoch, a Senior Inspector, and Mrs. Catherine M. Abilla.²³⁸

²³³ cf. Masakhwe 2008: <http://www.independentliving.org...>

²³⁴ cf. Grut, Ingstad 2007:12 <http://siteresources.worldbank.org...>

²³⁵ cf. Philpott, Siat in Priestley 2001:164

²³⁶ cf. Anyango 1990:28

²³⁷ cf. Grut, Ingstad 2007:12 <http://siteresources.worldbank.org...>

²³⁸ cf. Kristensen 1991:5

3.5.5 National policies and laws for people with disabilities

All over the world many countries have adopted policies to promote the rights of people with disabilities to participate in society. Legislation and implementation strategies are essential tools to promote integration and social inclusion of people with disabilities. Although some countries have made progress in introducing disability- related legislation, many of these laws have not yet been implemented.

Social and political rights are as important as economic rights because they are closely linked to economic empowerment. Therefore it is important to improve the effectiveness of laws concerning disabled people in Kenya²³⁹ by e.g. giving a voice to disabled people when political decisions are made. While in developed countries special education programmes and various forms of rehabilitation have a long history, in developing countries they had to start their efforts to improve the lives of disabled people. Characterized by a shortage of resources, and problems of getting political support because of people with disabilities mainly rely on foreign donor agencies and NGOs.²⁴⁰ When I talked to Salome Kimata, she stressed that things are planned in the ministry without considering people with disabilities and thus the implementation of the disability act is missed. *“So when things are planned especially the ministry of primary they don’t have disability issues at hand. And you know when you miss at the primary level you also miss at the implementation.”*²⁴¹

Furthermore Duncan Mwangi explained that: *“I’m happy that in Kenya there is the will but I think the implementation is taking a little bit long. ... But I think of a president putting things in place ... he leaves it and then think the implementation has been done not very good.”*²⁴²

Salome Kimata argued that: *“From the government we not need two things just one- to implement the disability act 2003. Let us not just have a document which is acquiring dust right because all these things I’m telling you they are profited for. I give one example they say every child has the right to access education. Why this disabled child is still at home? And the other children without disabilities are in school because the education is free.”*²⁴³

²³⁹ cf. KCP 2004:1 <http://www.ilo.org...>

²⁴⁰ cf. Ingstad in Ingstad, Whyte 1995:246

²⁴¹ Interview Salome Kimata- UDEK 19.9.2007

²⁴² Interview Duncan Mwangi- APDK 10.09.2007

²⁴³ Interview Salome Kimata- UDEK 19.9.2007

3.5.6 Disability Act 2003

In 1997 a taskforce was founded by the task group of the government, including Kenyan disabled persons' organizations, which was followed by a lobbying campaign by disabled people in Kenya. After a bill about all Kenyans with disabilities had been discussed in parliament, in April 2003 the bill was finally enacted as the "Persons with Disabilities Act 2003" on 31 of December 2003.²⁴⁴ The act 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.*"²⁴⁵

This definition shows that in Kenya they see disability also as a social, economic, and environmental factor on the national level. Therefore it is recognized that disability is not only an individual but also a social phenomenon.

A national council for persons with disabilities should be established to formulate and develop measures and policies designed to implement the rights of persons with disabilities with the aim to *"achieve equal opportunities for persons with disabilities in areas of education, employment and participate in sporting recreational and cultural activities and are afforded full access to community and social services."*²⁴⁶

The persons with disabilities act, 2003 includes areas as e.g. employment, access to education, health services, and public buildings, prohibition of discrimination against disabled people, to participate in sports recreational activities, and to ensure assistance in voting presidential, parliamentary, and civic elections. Furthermore the act says that a fund should be established, and television accessibility should be ensured through sign language or sub- titles in all newscasts and educational programmes, and in all programmes covering events of national significance. The telephone service should ensure that persons with hearing or visual disabilities can communicate through the telephone system.

In addition the act prohibits that doctors neglect their patients. Finally the act includes the exclusion from paying tax and income from jobs. 5 percent of jobs in both public and private sectors should be reserved for disabled people. Therefore it is important to achieve projects which are able to implement that and will promote sheltered employment, regular or self- employment opportunities for people with disabilities.

²⁴⁴ cf. KCP 2004:5 <http://www.ilo.org...>

²⁴⁵ The PWDs Act 2003:No.14

²⁴⁶ The PWDs Act 2003:No.14

The act says that the national council for people with disabilities (NCPWD) membership should not exceed 27 persons, with a minimum of at least twenty members with disabilities²⁴⁷ from organizations of and for people with disabilities, government ministries Attorney General's office, and office of the president. Their functions will be the implementation of the disability act 2003, to take a census of people with disabilities, to manage the national fund for people with disabilities, to register all groups who deal with disability, and to give certificates for tax exemptions.²⁴⁸

Discrimination by employers is prohibited in relation to *"the advertisement of employment; the recruitment for employment; the creation, classification or abolition of posts; the determination or allocation of wages, salaries, pensions, accommodation, leave or other such benefits; the choice of persons for posts, training, advancement, apprenticeships, transfer, promotion or retrenchment; the provision of facilities related to or connected with employment; or any other matter related to employment."*²⁴⁹

Although the disability act has existed since 2003 not much has changed and people with disabilities are waiting for the implementation in areas of employment, education, barrier free society, and participation in various fields of life. Duncan Mwangi pointed out that it is one of the biggest challenges of Kenya to implement the disability act which was passed in 2003.²⁵⁰

He was talking about success in fields of education, that now children in slum areas can go to school but children with disabilities are still not able to afford special schools and do not fit in well in regular schools. He believes in integration and participation of children and young people with disabilities in the education system. Furthermore in his opinion it is very important to sensitize the teachers that integration would be successful.²⁵¹

²⁴⁷ cf. The PWDs Act 2003:No.14

²⁴⁸ cf. Wanjama 2004:1

²⁴⁹ The PWDs Act 2003:No.14

²⁵⁰ cf. Interview Duncan Mwangi- APDK 10.09.2007

²⁵¹ cf. Interview Duncan Mwangi- APDK 10.09.2007

3.5.7 Establishment of the National Council for Persons with Disabilities (NCPWD)

In 2004 the NCPWD was established and it is run by a board of directors. The activities which are run by a secretary focus on the following functions: *“to formulate policies and develop measures for the establishment of systems and structures, to mobilize resources for council activities, research, to advocate public awareness, a registration service, to enhance capacity of DPO (Disabled People’s Organization) institutions and individual PWDs (People with disabilities), operationalization of National Development Fund for PWDs and issue adjustment orders.”*²⁵²

The strategic issues are: *“to formulate, design and develop policies and measures that will guide the operations of the Council for the next three years, to mobilize and generate adequate resources for council activities, to support research and provide accurate information on disability to the public, to develop mechanisms to facilitate the registration of individuals, groups and organizations; as well as places and institutions providing services to PWDs, to strengthen capacity of DPOs, institutions and individual PWDs to influence and monitor the implementation of service delivery, to constitute a Board of Trustees to manage the NDF for PWDs as per the Act, to promote and facilitate the mainstreaming of PWDs in social and economic development through financing viable IG projects and to work towards bringing into force Section 24 of the Act, regarding Adjustment orders.”*²⁵³

The strategy issues of NCPWD are well developed but the way to implement them is not given. It does not provide how these services will reach the people and if and how the individual benefits.

²⁵² Grut, Ingstad 2007:16 <http://siteresources.worldbank.org...>

²⁵³ Grut, Ingstad 2007:16 <http://siteresources.worldbank.org...>

3.5.8 Implementation of the Continental Plan of Action on the African Decade for Persons with Disabilities

During the 37th summit of heads of states in Lome, Togo in 1999, the African decade of disabled persons 1999- 2009 was declared. The objectives of the decade are to achieve full participation, equality, and empowerment of persons with disabilities in Africa.

Kenya has established a national plan of action concerning the following issues: *“Policy and Legislation, participation and self representation, quality service provision, special groups; children, youth, women and universal design, preventive measures, capacity building, resource mobilization, advocacy and Awareness; and coordination monitoring and evaluation.”*²⁵⁴

In January 2004 the Ministry of Gender, Sports, Culture, and Social Services organized a national conference on the African decade of persons with disabilities. During that conference it was recommended that the government should establish a secretariat with resources to appoint a national standing committee to coordinate the implementation of the action plan. A draft session paper 2001 on national employment policy and strategy was set up which includes a clause concerning the promotion of training and employment opportunities for people with disabilities. The draft suggests that the government should establish specialized programmes to support the integration of persons with disabilities in regular employment and training programmes.

The vocational rehabilitation division of the department of social services (DSS) is responsible for 12 rural vocational rehabilitation centers and for the Nairobi’s industrial rehabilitation center (ICR). This center trains people with disabilities in areas of carpentry, metalwork, leatherwork, tailoring, traditional crafts, printing, jewellery, textile manufacture, agriculture, commercial studies, telephone operations, and computer courses. These activities are part of the national rehabilitation programme which was founded to offer an opportunity to acquire employment skills for people with disabilities. Furthermore they are responsible to advise the government on policy for people with disabilities, to ensure that more awareness is given to prevention of disability, to coordinate the work of government and voluntary organizations who care and rehabilitate persons with disabilities, to offer vocational rehabilitation and skill training programmes which include assessment, training, vocational guidance, follow- up and social services and to offer selective placement/resettlement.

²⁵⁴ Grut, Ingstad 2007:16 <http://siteresources.worldbank.org...>

So far, according to reports of delegates to the International Labor Office (ILO) Technical Consultation, the government of Kenya has improved access to rehabilitation, education, training, and employment of people with disabilities. Policies were established to ensure girls and boys with disabilities have access to education, in particular those from rural areas, the training of youth, women and men with disabilities relevant to marketable skills, the promotion of vocational rehabilitation, education and training programmes, and the development of strategies to promote employment of people with disabilities.²⁵⁵

4. Disability in the context of socio- cultural structures in Kenya

The understanding of and responses to difference vary between cultures and over the time. Traditional attitudes, perceptions of specific impairments, lack of public knowledge, and misconceptions about disability may invite specific interventions (e.g. acceptance, abandonment, celebration, extermination, ridicule, rehabilitation, or healing).²⁵⁶ According to Neubert and Cloerkes who analyzed reactions, valuations and constructions of differentness and disabilities in various ethnic groups, with the use of the Human Relations Areas Files (HRAF), there are different reactions towards disabled people. There are extreme ones where children are killed or exposed, reactions of protection and help, forms of isolation which means that they are excluded from social life, restricted participation, modification of participation which means they achieve their own roles in social life (especially mental differentness is often basis for shaman roles and can lead to reactions of dread or deference²⁵⁷) and *laissez- faire* reactions which means no special reactions, no special protection or any disadvantages.²⁵⁸ They found out that infanticide of children with severe and/or multiple disabilities are widely-used, *laissez- fair* reactions, are very rare, isolation is also rare, only if the group hide them to protect them from foreigners or the isolation of mentally disabled who were aggressive. Killing of older children and adults with disabilities took only place in exceptional emergency cases. Modification of participation is most common. That means disabled people were allowed to participate in social life. Shamans, healers, priests, and seers had special roles but they were not seen as disabled. In some societies also physically disabled, blind people, twins, intersexual and transsexual people could get such roles

²⁵⁵ cf. KCP 2004:9,10,11 <http://www.ilo.org...>

²⁵⁶ cf. Stone in Priestley 2001:54, Kikkas in Priestley 2001:121

²⁵⁷ cf. Neubert, Cloerkes 2001:50

²⁵⁸ cf. Neubert, Cloerkes 2001:53,54

depending on their religious competence.

Therefore reactions to the same disability and social roles/positions of disabled people can even vary within cultures because culture specific constructions and reactions are different in the analyzes of individual biographies. In some cultures infanticide is forbidden and isolation does not take place whereas in others it is common.²⁵⁹

Children with disabilities often suffer more from social attitudes and social barriers than from their disability. Usually the family especially mothers are held responsible for the impairment, which may be viewed as punishment, curse or wrong behavior during pregnancy.²⁶⁰

In the KISE Bulletin of 1989 I found traditional beliefs about albinism. Some people believe that a pregnant woman who cuts the holy bible into pieces is likely to get punished by god by giving her a baby who is neither African nor European. Others believe that albinism occurs if the mother has sexual contact with a “mzungu” (white people). At the coast people believe albinism is a result of “shetani” (evil spirit).²⁶¹

Such perceptions and stigmatization are linked to specific beliefs and practices which lead to exclusion and marginalization of disabled people in society and it is limiting the integration and participation in the family and community as a whole.²⁶² *“To be excluded is to be treated unequally and thus disadvantaged. Excluded people usually belong to stigmatised minority groups, and their exclusion amounts to an unacceptable denial of full citizenship rights.”*²⁶³

In general, the disabled or their parents may be held partly responsible for their condition or the condition of the child through different reproaches, such as neglecting of therapy, driving too fast, and behaving wrong during pregnancy. However concerning their difference to other marginalized groups, there is one important issue that should be emphasized. With respect to female and racial exploitation, sexism and racism have important exploitative social and economic functions that have their origins in the male hierarchy and slavery, whereas negative attitudes towards the disabled seem to lack, if not totally, the social or economic roots. Therefore the devaluation of the disabled has no economic purpose or political interest of great moment. The disabled are victims without a cause.²⁶⁴

There is a need to sensitize people in order to change their perceptions on disability issues. It is not possible to work efficiently as a therapist with the disabled if they are not accepted by society.

²⁵⁹ cf. Neubert, Cloerkes 2001:75,76

²⁶⁰ cf. Kwa Yalo 1989:9

²⁶¹ cf. Neubert, Cloerkes 2001:77,78

²⁶² cf. Philpott, Sait in Priestley 2001:157

²⁶³ Thomas 2007:11

²⁶⁴ cf. Murphy et al. 1988:236

The acceptance is achieved by raising the awareness on disability issues.²⁶⁵ Negative opinions about disability draw upon cultural stereotypes and images.²⁶⁶

For a long time people with disabilities in East Africa were seen as incapable of gainful employment and it was embedded in the original Kiswahili term “wasiojiweza” which means “those incapable of performing”. Social and family attitudes depend on cultural practices and beliefs of various ethnic communities.²⁶⁷

That is why in Kenya there are different beliefs what can cause disabilities. For example disability is sometimes seen as a result of witchcraft and sorcery. That is why some parents feel ashamed and therefore hide their disabled child in the house so that they cannot be associated with witchcraft.²⁶⁸ *“Oh you see that child you see such a thing maybe those people practice witchcraft.”*²⁶⁹

Also in Uganda, if parents and/or the disabled family member practices witchcraft it could be the cause of a disability.²⁷⁰ Neubert and Cloerkes found out that in most cultures common beliefs about causes of disability are witchcraft, magic, spirits, and gods. Furthermore cultures believe in causes like destiny, bad omens, disharmony between body and soul and loss of soul. Furthermore these causes, illnesses, and diseases in general can lead to social conflicts and are embedded in the social environment.²⁷¹

The main problem is lack of awareness of people with disabilities by service providers, policy makers and the community at large. There are low levels of advocacy for the rights of persons with disabilities, especially children with special needs in education. It resulted in maintenance of negative attitudes, low expectations, and abuse of rights of persons with disabilities. Only a few people address issues on disability in public meetings or in the media. There is no priority given and stigma is associated with special needs and disability. It is even a mystery for many Kenyans. A disabled woman who was affected by the consequences of polio commented that: *“They feel ashamed to have such a child and they don’t understand that even you are helpful to the patient and what ever and then this child has been brought up if it is educated ... The people they don’t understand they don’t know.”*²⁷²

²⁶⁵ cf. Albrecht, Weigt 1993:2

²⁶⁶ cf. Thomas 2007:21

²⁶⁷ cf. Ndurumo 1993:2

²⁶⁸ cf. Interview Salome Kimata- UDEK 19.9.2007

²⁶⁹ Interview Salome Kimata- UDEK 19.9.2007

²⁷⁰ cf. Sentumbwe in Ingstad, Whyte 1995:163

²⁷¹ cf. Neubert, Cloerkes 2001:80,82

²⁷² Interview W. W. 5.9.2007

Also cultural beliefs and practices against learners with special needs exist in Kenya although special education has been implemented for over half a century. Sometimes local communities are not aware of services for people with disabilities as e.g. the Educational Assessment and Resource Services (EARS) which assess children with disabilities. This includes early identification, intervention, assessment, referral, and educational placement of children with special needs aged between 0 and 18 years. Although it was observed that there is a lack of awareness and sensitization it is remarkable that the Kenyans elected a president who was at that time, because of an accident in a wheelchair!²⁷³

Another issue is, as Murphy in Ingstad and Whyte²⁷⁴ mentioned, some people believe that disability can only happen to the poor and not to any “respectable people” as Simon Gichuhi from CVO observed: *“... people expect that these things only happen to the poor but it is quite funny because even if it once happens to “respective persons” they hide these cases. They don’t want anybody to know and it is very hard for even the poor members of society to know that “respectable people” have got these children because they try every way possible to hide these cases ... they also think that all the society will take them ... as weak or ... it is not taken in a positive way.”*²⁷⁵

The Kenyan national survey for persons with disabilities found out how people with disabilities cope with attitudes towards them at home. The survey figured out that seven out of ten did not see people’s attitudes towards them as a problem at home. Of those who see these attitudes as a problem, 36, 9 percent see it as a minor problem, compared to 57 percent who see it as a major problem (10, 1 percent in rural areas and 6, 7 percent in urban areas reported that it has always been a daily problem at home). In general more males (62, 3 percent) than females (57, 9 percent) see people’s attitudes towards them at home as a major problem. Children and young people responded that it is a major problem for 59, 4 percent of children aged 0- 14 years and for 58, 4 percent young people aged 15- 24 years.²⁷⁶ These numbers show that the majority of people with disabilities do not see social attitudes as a problem at home. The majority of those who see it as a problem regard it as a major problem. The Kenyan national survey for persons with disabilities did not figure out in how far social attitudes from outside home influence their life situation which would be an interesting issue.

²⁷³ cf. MOEST a 2003:62,67,68

²⁷⁴ cf. Murphy in Ingstad, Whyte 1995:152

²⁷⁵ Interview Simon Gichuhi- CVO 30.8.2007

²⁷⁶ cf. KNS for PWDs: 2008:18f

In my research I talked to a young disabled woman about reactions of people in daily life and she commented that people were imitating her and laughing about her hump but she never replied anything to them,²⁷⁷ whereas at home and in her family she gets support and they stand by her and do not discriminate her in any way.

Because I have not studied one ethnic group in particular and because of ethnic diversity in urban areas, I do not want to generalize what people think about disability. I just want to give a survey of different beliefs which can influence the status of people with disabilities in Kenyan society.

Therefore I cannot talk about discrimination outside home, only what people have told me. I have also talked to parents who do not suffer from discrimination in their community or neighborhood. S. is a seven-year-old boy who lives in Muthure with his parents and his brother. He has mental problems and suffers from epilepsy. He has learning disabilities and goes to nursery school although he is too old. The parents explained that there is no discrimination in the neighborhood and in the community on the whole because people know what epilepsy is and they do not fear it. S. participates in all games with his peers and the children know that they should call for his mother if there are symptoms.

I also met a mother who said that after overcoming the first shock she had come to see her child (with mental disability) as a challenge and she knows god wants her to bring that baby up, in the way she is. She is a gift to her and she appreciates the baby.²⁷⁸ The same I have read in Ingstads research in Botswana that some people believe to give birth to a disabled child is a positive challenge and a gift from God.²⁷⁹

²⁷⁷ cf. Interview J. W. 5.9.2007

²⁷⁸ cf. Interview mother of B. 13.8.2007

²⁷⁹ cf. Ingstad in Ingstad, Whyte 1995:256

4.1 Social attitudes towards disability

In Kenya things have changed in terminologies in the last years. The mentally challenged were in the past called “wajinga” (fools, idiots), but now are called “waliopungukiwa na akili” (those with low intellectual ability), the hearing impaired were in the past called “bubu” (deaf and dumb) and later on “viziwi” (deaf), but are now referred to as “wasiosikia” (those who cannot hear), the physically disabled were in the past called “viwete” (cripple, lame) but are now called “walemavu” (disabled person). The term “waliolemaa” (diseased, deformed people) is now used for the whole disabled population instead of “wasiojiweza” (people who are ill, sick, and not able to (it is used negative)).²⁸⁰

Although terms have changed and the government made steps in changing the image of people with disabilities through campaigns in the media, social attitudes and discrimination still remain in Kenyan society because there is still limited coverage of disability issues by both print and electronic media. Compared to issues of HIV/Aids and gender, very little publicity has been given to issues related to people with disabilities.²⁸¹

Abusive remarks are used as Salome Kimata argued: *“There are times children have been called “jinja”. I don’t know if you know what is a jinja a Swahili name for an idiot. You know? A teacher told this to a child you see? How does this child feel? It’s like I’m a jinja and I’m an idiot. So we need someone to sensitize teachers.”*²⁸²

Duncan Mwangi commented that for some people in the country disability is still a taboo. *“There are people who still feel that disability is a taboo. It could only happen to the others and never to them. The others don’t want to be associated with that kind of disability ...”*²⁸³

Negative social attitudes lead a person with disability to isolation and consequently to disadvantages for the person in different social- cultural or social- economic contexts. Even if a person is as qualified as on good as an able bodied one, he or she will not get the job because of negative social attitudes.²⁸⁴

²⁸⁰ cf. Ndurumo 1993:3

²⁸¹ cf. MOEST a 2003:69

²⁸² Interview Salome Kimata- UDEK 3.9.2007

²⁸³ Interview Duncan Mwangi- APDK 10.09.2007

²⁸⁴ cf. Interview Salome Kimata- UDEK 29.9.2007

Disabled people have things in common with the situation of other socially devalued people in every country. They are recipients of unfavorable identities and therefore objects of prejudice.²⁸⁵ Furthermore the disabled are seen as a threat, as a danger to the vulnerability of the human body. They represent a fearsome possibility.²⁸⁶ That is why ... *“a lot of education should be done to let the public know that people with disabilities are human beings, at least there need to be some representation for people with disabilities in all media decision making if possible.”*²⁸⁷

At the website www.disabilitykenya.org I have found that: *“Stigma and prejudice are also key issues as in many communities a child with a disability is viewed as being born as the result of a curse, or misbehavior of earlier generations. This can lead to neglect (being shackled, held in small rooms with little interaction) and lack of participation in the community.”*²⁸⁸

The term “stigma” was introduced by the sociologist Goffman and describes an attribute of a person, which is denigrative. The main point is the negative definition of the attribute. Stigmata affect prejudices and attitudes and exist 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.²⁸⁹ 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. Physical deformities are visible and make a disabled person immediately discredited, versus those “blemishes of individual character” and “tribal stigmas” that are less easy to perceive.²⁹⁰

Neubert and Cloerkes found out that in most cultures they have analyzed, reactions and care are dependent on the severity and visibility of disabilities and how they limit the individuals in their functions in a community or in a society as a whole. There exist no cultures where privileges or benefits for people with disabilities are reported.²⁹¹

²⁸⁵ cf. Murphy et al. 1988:235

²⁸⁶ cf. Murphy et al. 1988:237, Murphy in Ingstad, Whyte 1995:143

²⁸⁷ Interview Duncan Mwangi- APDK 10.09.2007

²⁸⁸ DK.org: <http://www.disabilitykenya.org...>

²⁸⁹ cf. Cloerkes 2000: <http://bidok.uibk.ac.at...>

²⁹⁰ cf. Ingstad, Whyte 2007:85, Thomas 2007:23

²⁹¹ cf. Neubert, Cloerkes 2001:102,103

In Kenya, disability, among some ethnic communities, is seen in terms of relationship between family members of one lineage and family members of another lineage what a Kenyan author Ndurumo is calling the dowry system.²⁹² The child's disability in this context is seen as the father's inability to pay the marriage payment for his wife. Marriage payment among many ethnic groups in Africa was traditionally given in the form of cattle, sheep, and goats. It is expected that the father fulfils his obligation. If the father fails to give this payment it was deemed to be the cause of the misfortune.²⁹³

As the mother of a disabled child explained: *"Here we believe in dowry, maybe I gave my father in law not enough dowries and this is why my child is suffering."*²⁹⁴

Another significant issue is that disability is sometimes regarded in Kenya as a consequence of witchcraft and sorcery due to the problematic social relations. There are also other cultural aspects that are related to the beliefs about the causes of disability, such as the violating of the eating taboos and the disrespect for the ancestors by ignoring their needs.²⁹⁵

Moreover, disability in Kenya could be seen to be caused by the relationship between family and god. If a child is born with a disability, it was killed and sent back to god, so that god might send another child. In general some people in different cultures regard a disabled child as a punishment by god. Therefore these children were killed, exposed, or treated with traditional healing methods.²⁹⁶ According to Neubert and Cloerkes, in many cultures, children with severe and/or multiple disabilities were killed or exposed directly after birth. The severity code of the disability influences the reactions of people. In some cultures infanticide became rare influenced by colonization and by unwillingness to provide information. Furthermore there are also cultures where children with multiple disabilities were taken care of.²⁹⁷

Simon Gichuhi commented that things have, however, changed in Kenya, especially in urban areas. Education made people understand that it is not a curse to have a disabled child and that it has nothing to do with the relationship to ancestors.

²⁹² I will call it marriage payment because dowry is no payment of the other family it is from the Bride to the groom's family

²⁹³ cf. Ndurumo 1993:2

²⁹⁴ Interview mother of B. 13.8.2007

²⁹⁵ cf. Talle in Ingstad, Whyte 1995:62

²⁹⁶ cf. Furrer in Albrecht, Weigt 1993:88

²⁹⁷ cf. Neubert, Cloerkes 2001:50,57

He recalled that: " ... long time they used to associate themselves maybe the ancestors and the image of the family but when studies have been done by scientists it is the education has taught them that the cause is not about the ancestors or traditions but the cause could be maybe during birth, maybe during when the child is in the womb ... this has helped people to understand that it is not about the tradition that has led to disability."²⁹⁸

Kenneth Ndua, a social worker from an organization who started to care for disabled street children pointed out that: "In fact there are places, ... where they have traditional beliefs. They think if you are disabled even in my community, the Kikuyu community, they go and throw you away into the forest ... I'm surprised even some places just very near around here. You become an outcast they throw you into the forest." When I asked why people do this he answered: "Because you are going to bring a bad omen to that community."²⁹⁹

Salome Kimata remarked that: "And also a point which leads to marginalization is lack of understanding from the community of what disability is all about. There are people who think that we are either curse or maybe there is witchcraft... you see a person with disability the people think they can be affected."³⁰⁰

Obviously, these myths and beliefs about the causes of disabilities strengthen the negative attitudes towards people with disabilities. Negative attitudes lead to stigmatization of people with disabilities and how they are perceived and treated.

When I talked to a disabled woman who suffered the consequences of polio, she explained that her neighbors do not like her and her family and that "... they do not understand anything about disability. They don't help us." Furthermore she reported that people expect that disabled people are begging. Therefore she is proud to have the possibility to make a computer course at UDEK where she can show that she can do something productive. She stated that: "I think people they have seen a lot of disabled here. Like now when we are working here it's better than to sit down and beg you see? Those who have shown that they do something very productive. Give them work or somewhere to work you can show them that you can do it and rather than sitting down and beg which they expect. You see?"³⁰¹

²⁹⁸ Interview Simon Gichuhi- CVO 30.8.2007

²⁹⁹ Short interview Kenneth Ndua- Food for the Hungry 8.9.2007

³⁰⁰ Interview Salome Kimata- UDEK 3.9.2007

³⁰¹ Interview W. W. 5.9.2007

In all my interviews people commented that some people in Kenya believe that a child with disabilities is a curse but I have not met anyone who believed that him/ herself like a friend of mine, social worker himself argued when he was joining the interview with Kenneth Ndua:” *It is like somebody let a path behind that in the line of this family somebody will get some disability and so what happens is that people don’t want to come out because then people go around and say this is a curse family. They have a child with disability.*” Furthermore the social worker continued:”*You know there is something about that family if someone sees a disabled child nobody wants to marry someone from that family because you fear that your children will also become disabled. Actually there are a lot of needs around here.*”³⁰²

According to Guimbous, a Kenyan author called Mbithi argued that the system of relations is like a large network including each member of the local group. In many cases a child belongs not only to the parents but also to the whole community. It is expected that children co-operate in the task of the community, and in view of economic maintenance. In rural areas children who are physically strong and e.g. children and young people with intellectual disabilities are often fit into life and work without special notice of the family and community.³⁰³ That is why e.g. the hearing impaired children are often kept at home to work on the fields instead of educating them in a school.³⁰⁴ They are not seen as disabled because they fulfill their obligations in a community as Shakespeare commented:”*The visibility and salience of impairment depend on the expectations and arrangements in a particular society: for example dyslexia may not become a problem until society demands literacy of its citizens.*”³⁰⁵

It is also important to bear in mind that children are seen as a sort of insurance for the future of their parents because most Kenyans cannot afford any health insurance. That is why families with more than two children are very common in Kenyan society.³⁰⁶

In my fieldwork from all 48 children I visited through home visits I figured out that most of these children have at least one sibling. The majority of them have four siblings (12 children). 8 children have one sibling as well as two siblings, 7 children have three siblings, 5 children have 5 siblings, 4 children have 6 siblings, and one child has even 8 siblings. I have visited only two single children. This shows that until today families have had a high number of children.

³⁰² Short interview Kenneth Ndua- Food for the Hungry 8.9.2007

³⁰³ cf. Werner 2003:A6

³⁰⁴ cf. Guimbous 1993:25

³⁰⁵ Shakespeare 2006:35

³⁰⁶ cf. Gaab 2001:17

Family planning programmes in Kenya have not been able to reduce the birth rate to the desired extent because of traditional attitudes that children are identical with prestige, prosperity and, security. Moreover a refusal of contraceptive contributes to a high birth rate.

The Kenyan national survey for persons with disabilities figured out that the use of family planning among women with disabilities was found to be 15, 6 percent. 14, 4 percent use pills, 27, 9 percent use injections and 18, 6 percent use surgical methods. In urban areas the use of Norplant (18, 1 percent) and condoms (55, 1 percent) was high, whereas in rural areas female sterilization (23, 7 percent) and periodic abstinence (10, 7 percent) were more common.³⁰⁷

Because of high school fees for special needs education parents often give priority to their able-bodied children.³⁰⁸ Another point is that parents with children with disabilities made the experience that not even their able bodied children got any employment. That is why they are investing in their children without disabilities.³⁰⁹

Therefore parents see no advantages to educate their disabled children. Besides that they are often not able to care for the child, if it needs fulltime attention because they have to look for their daily income. Moreover they often fear abuse or violence if the children are not at home. That is why some of these parents hide their children³¹⁰ to protect them from discrimination.

As Lock pointed out: *“For parents of children with disabilities the acceptance or rejection of disability by the medical world and by the public at large is understood as a matter of politics and societal attitudes. Many mothers and fathers are conflicted, because no matter how much they believe that society must change they do not want their own children to suffer prejudice and discrimination.”*³¹¹

In education and employment the situation of children and young people with disabilities is very much influenced by social attitudes because employers often underestimate the potential of these people. Besides that teachers in public schools are not sensitized on children with disabilities they are often overstrained by the high numbers of pupils in a class. That is why it is nearly impossible to care for a child who has special needs. Therefore the only way to earn money is begging on the streets where tourists are met frequently. Since the 80s the government has tried to inform the population about disability to change the attitudes among them.³¹²

³⁰⁷ cf. KNS for PWDs: 2008:17

³⁰⁸ cf. Grut, Ingstad 2007:38 <http://siteresources.worldbank.org...>

³⁰⁹ cf. Interview Salome Kimata- UDEK 29.9.2007

³¹⁰ cf. Interview Duncan Mwangi- APDK 10.09.2007

³¹¹ Lock in Ingstad, Whyte 2007:191

³¹² cf. Gaab 2001:20

4.2 Discrimination and marginalization of people with disabilities

Discrimination and marginalization of people with disabilities has its 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. Besides it is important that the perspectives of persons concerned are³¹³ included; namely perspectives of disabled people themselves, their family members, and also people who work in organizations of disabled people.

Neubert und Cloerkes maintained that in many societies disabled people are stigmatized and often discriminated and marginalized. Special roles would be a chance to escape from the force of normality. It would be an advance if people with disabilities achieved acceptance. Differentness does not mean being of little value. People with disabilities do not have to compare themselves with normality; they can achieve and develop their own identity which would be the right way to emancipation.³¹⁴

However, disabled people's lives have been widely devalued on many levels- as biologically inferior, as psychologically damaged, as culturally "others" and as an economic burden to society.³¹⁵ Therefore they are stigmatized and it is important to analyze the dominant culture on how the concept of normality is seen. Disability, especially in industrial countries is seen as deviance, damage and dependency which postulates stereotypes and stigmatize, marginalize, and disempower people with disabilities.

It is obvious, however, that these stereotypes might be different in different cultural and social circumstances.³¹⁶ That is to say, the perceptions of disability vary across cultures. It follows that a person who is regarded somewhere as disabled would not be regarded as such everywhere. Therefore universal attitudes towards disability and differentness do not exist.³¹⁷

Shakespeare confirmed that: *"The meaning of impairment is a cultural issue, related to values, and attitudes of the wider society."*³¹⁸

³¹³ cf. Wülser in Albrecht, Weigt 1993:51

³¹⁴ cf. Neubert, Cloerkes 2001:108

³¹⁵ cf. Priestley 2003:38

³¹⁶ cf. Corker 1998:27,33,42

³¹⁷ cf. Neubert, Cloerkes 2001:85,88,89

³¹⁸ Shakespeare 2006:35

Sterilization of mentally disabled people, negligence, and abortion of disabled children show that also in industrial countries extreme reactions towards disabled people do exist. Separation in special institutions to protect them from mainstream society can lead to isolation, especially after school age. Disabled people in industrial countries have no special roles like healers or priests. Help and support also vary in different cultures and within cultures. To improve the situation of disabled people, participation in decision-making, barrier removal and accessibility are key words to achieve equity.³¹⁹

People with disabilities in Kenya face many challenges. Salome Kimata just listed a few. She was talking about the deaf and dumb who face high illiteracy levels because of communication barriers. The physically disabled are challenged by inaccessibility to buildings and in transport and locomotion. The albinos because of poor vision have problems in the access to information. Furthermore it is difficult for them to work outside when the weather is hot because their skin is very sensitive. The blind cannot move alone and need everywhere they go a guide to assist them. The mentally challenged need protection and a safe working place because they are easily mistreated and abused,³²⁰ especially children with mental challenges. They are vulnerable to be lured with gifts and to be sexually abused. That is why some of them are already mothers and fathers at a tender age and many of them are HIV positive. Lacks of life skills and vocation have made them more vulnerable to sexual abuse.³²¹

4.2.1 Information structures

Information like electronic and print media is for most people with disabilities inaccessible and prevents them from participation or profit 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.³²² As Salome Kimata observed: " *You will find there is a lot of information at the market but unfortunately it is inaccessible to the disability fraternity.*"³²³

³¹⁹ cf. Neubert, Cloerkes 2001:96,107

³²⁰ cf. Interview Salome Kimata- UDEK 19.9.2007

³²¹ cf. Mitambo 2007:1,2

³²² cf. Grut, Ingstad 2007:15 <http://siteresources.worldbank.org...>

³²³ Interview Salome Kimata- UDEK 3.9.2007

UDEK developed a governors' programme with specific education on nationhood and constitution of democracy, governance and on human rights. All the materials are disability friendly and should support people with disabilities, their parents, guardians, and caregivers. It should ensure that people with disabilities, especially during the elections, make decisions from an informed position. In addition UDEK wants to start a programme where they assess the level of involvement of people with disabilities within the elections because they realized that police stations are disability unfriendly and further the vote, if someone e.g. is blind could be manipulated depending on the workers' attitude there.³²⁴

The Kenya national survey for persons with disabilities figured out that regarding the disabled Kenyans information devices (like hearing aids, magnifying glasses, Braille) are used by 20,1 percent (male 16,1 and female 14,4 percent), communication devices (like sign language interpreter, portable writer) are used by 0,3 percent (male 0,4 and female 0,1 percent), mobility technologies (like wheelchairs, crutches, walking sticks/frames and guide) are used by 11,8 percent (male 17, 6 percent and female 11, 3), household items (like flashing light on doorbell, amplified telephone) are used by 0,1 percent (0,2 male and 0,1 female), personal care and protection devices (like special fasteners, bath and shower seats, toilet seat raiser) are used by 0,4 percent (0,5 male and 0,3 female), handling goods and products (like gripping tongs, aids for opening containers) are used by 0,1 percent and computer assisted technology (like keyboard for the blind) are used by 0,0 percent. All together this means devices are used by 31, 5 percent of the people with disabilities in Kenya. It seems to be much but only information devices are used by 20,1 percent and mobility devices by 11, 8 percent. All other devices are rarely used. This shows a clear privilege for men because all devices are more used by men. Totally this means all devices are used by 33, 1 percent male and 25, 6 percent female.

Number of children and young people using assistance devices/ support services (in percentage)

age	supportive device	Information device	communication device	personal mobility device	Household items	personal care and protection device	handling products and goods device	computer assistance device
0-14	20, 4	0	0	20, 4	0	0	0	0
15-24	15	12,3	0, 3	2, 6	0, 3	0, 3	0	0

³²⁵

Children until they are 14 years old use only personal mobility devices but nothing else. Young people between 15 and 24 years mostly use information devices but other devices are rarely used.

³²⁴ cf. Interview Salome Kimata- UDEK 3.9.2007

³²⁵ cf. KNS for PWDs: 2008:9

Therefore many people with disabilities have inadequate access to various technologies, especially in rural areas where only 25, 9 percent use an assistive device or support service while in urban areas 41, 2 percent. The same in information technology- only 11, 2 percent in rural areas and 30, 3 percent in urban areas.³²⁶ That is why institutions like UDEK provide computer technologies for persons with disabilities.

In other words there is a major missing of assistive devices and especially individual devices. E.g. wheelchairs are often too heavy, not affordable, and often not usable on Kenyan roads.

Furthermore there is often no person available who pushes the wheelchair.³²⁷ In my own research I met six children who are in need of a wheelchair and the parents cannot afford it.

4.2.2 *Infrastructural disadvantages*

To show to what extent people with disabilities suffer from infrastructural circumstances I want to give a survey of their challenges and problems in daily life. In general persons with disabilities in Kenya are challenged by a poor infrastructure and the Kenyan national survey for persons with disabilities figured out that 93 percent in rural areas and 87 percent 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 percent are affected on a daily basis and 3, 4 percent on weekly basis). Three out of five of those who are affected find the immediate surroundings a major problem in their daily life.³²⁸

Environmental factors such as temperature, terrain, accessibility of transport, climate, noise etc. can improve or hinder a person in various activities like working, going to school, taking care of one's home, and being involved with family and friends in social, recreational, and civic activities in the community. According to the Kenyan national survey for persons with disabilities nearly one in five disabled Kenyans (17, 6 percent) is affected on a daily basis and 4, 5 percent are affected on a weekly basis by environmental factors. 64, 8 percent of people with disabilities told that environment is a major problem in their daily activities (68, 4 percent in rural areas are affected by natural environment while 64, 5 percent in urban areas). The majority of children and young people see environmental factors as a major problem too (0- 14 years 67, 2 percent and 15- 24 years 64, 6 percent).³²⁹

³²⁶ cf. KNS for PWDs: 2008:9

³²⁷ cf. Grut, Ingstad 2007:36 <http://siteresources.worldbank.org...>

³²⁸ cf. KNS for PWDs: 2008:10, 12

³²⁹ cf. KNS for PWDs: 2008:14

That is why many people with disabilities have no access to various activities in life. To drive a wheelchair in e.g. Nairobi is nearly impossible. Duncan Mwangi argued that the infrastructure is unsuitable for the disabled, not only for the disabled but also for old people and mothers with children. Furthermore people with disabilities have no access to buildings as e.g. shopping centers; it is not possible to access with a wheelchair.³³⁰ He reported that: "... *It's a hustle, it's actually a nightmare - moving around in town being in a wheelchair. It's even a nightmare to move when you are blind ... What we need is that we remember that the environment is for all of us...*"³³¹

Therefore public transport is not accessible for people with disabilities and most of the time it is overcrowded.³³² A friend of mine 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 ... some are not strong ...*"³³³

Moreover for some people with disabilities it is even impossible to move independently in the cities. Duncan Mwangi mentioned a friend of him who is blind and somebody has to guide him. Furthermore he was talking about his wife who was worn out because she was waiting at the bus terminal in the mornings to make sure that they get on the bus.³³⁴

A disabled woman affected by the consequences of polio argued that she has problems in public traffic and cars just stop sometimes to let her go. In addition she is affected by the high pavements. She reported that: "... *You see there are these pavements which are very high and you can't walk through that ... Sometimes they have arranged something where you can walk and they keep a tag for disabled places like ... some are very high. You can't go.*"³³⁵

In other words access to public buildings, a disability friendly infrastructure would be very important so that every person with a disability can go to school or work if he/ she is in a wheelchair³³⁶ 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.³³⁷

³³⁰ cf. Interview Duncan Mwangi- APDK 10.09.2007

³³¹ Interview Duncan Mwangi- APDK 10.09.2007

³³² cf. Gaab 2001:30

³³³ Interview Duncan Mwangi- APDK 10.09.2007

³³⁴ cf. Interview Duncan Mwangi- APDK 10.09.2007

³³⁵ Interview W. W. 5.9.2007

³³⁶ cf. Interview Duncan Mwangi- APDK 10.09.2007, Grut, Ingstad 2007:14 <http://siteresources.worldbank.org...>

³³⁷ cf. Interview Salome Kimata- UDEK 19.9.2007

4.2.3 Accessibility to schools

Going to school is not only a question of being able to afford school fees it is also a matter of accessibility, because many regular schools in Kenya are not accessible to many children with physical disabilities.³³⁸ Lacking of assistive devices like Braille transcribers, audiologist speech therapists, interpreters, physiotherapists, occupational therapists, teacher aid producers, hearing aids etc. as well as inaccessible buildings lead to inequality within the learners.³³⁹

Therefore the MOEST recommends that all schools should enable the children to access the school curriculum because children with special needs in education cannot all be expected to access the same curriculum as their peers. Appallingly there is no sign language curriculum developed by the Kenya Institute of Education.³⁴⁰

Therefore accessibility is often not given as I will show in the following table with my own data.

Accessibility to education of children and young people with disabilities

stay at home (5-12)		stay at home unemployed (21-24)		special school (8-12)		primary school (7-10 years)		nursery school (6,7 years)		0- 3 years		No data		Total
7		4		4		4		2		1		2		24
boys	girls	boys	girls	boys	girls	boys	girls	boys	girls	boys	girls	boys	girls	
4	3	3	1	3	1	2	2	1	1	0	1	1	1	

These data show that seven children under 12 years stay at home and four young people are unemployed and stay at home too which means 11 children and young people have no access neither to education nor employment. Just four children go to special and four to primary schools. Only one family of them is able to pay the special school fees. Two of them go for free and one child has an arrangement that the mother should pay as much as she is able to. Two kids go to nursery school although they are too old. All together this means just 10 children go to school and none of the young people have an employment. Many children stay at home because they never went to school, they were expelled from school or they cannot afford further education. The children are excluded by a system where they fail and have to live with the stigma of “failures”. Sometimes they are even ignored and left to survive on their own. There is no other way as to drop out because they are seen by teachers and schools as “unteachable”.³⁴¹

³³⁸ cf. Grut, Ingstad 2007:40 <http://siteresources.worldbank.org...>

³³⁹ cf. UNESCO c: <http://www.unesco.org...>

³⁴⁰ cf. MOEST a 2003:xi,54,59

³⁴¹ cf. Bernard 2000:8,9 <http://unesdoc.unesco.org...>

11 (0- 24 years) children and young people with disabilities who stay at home (unemployed)

never go to school (both 12 years)	expelled from school (5,11)	went to primary (14-24)	went to special school	no data	Total
2	2	3	0	4	11

Two boys had never even gone to school and thus stay at home. Two children were expelled from regular schools because they could not follow the other children and therefore stay at home too. Three young people with disabilities went to primary school which shows that some have been enrolled in regular schools. Not even one child went to a special school.

Another issue is that society is not barrier free or disability friendly like the learning environment in regular schools and units, public facilities such as churches, mosques, cinemas, halls, and other public amenities, public transport such as matatus and buses, public facilities like toilets, telephone, and lifts. In schools there are often inaccessible toilets, doorways, desks, chairs, tables, writing and reading materials and lighting systems etc.³⁴²

4.2.4 Gender Issues and vulnerability

Article 6 “Women with Disabilities” of the UN Convention on the rights of persons with disabilities from December 2006 says that: *“States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. Furthermore the article says “States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”*³⁴³

Therefore also the UN recognize that women and girls with disabilities suffer from double discrimination for being female and disabled as Salome Kimata pointed out: *“For women it is double because like e.g. I’m a disabled. I come to apply for a job in a place you know it comes the time maybe tomorrow I will become pregnant and of course you will have to ask for permission or maybe I’m not pregnant but I have children so I will be on and off duty. So they are very very resistant to employ women with disabilities if you compare with our male combatant.”*³⁴⁴

³⁴² cf. MOEST a 2003:41

³⁴³ UN a: <http://www.un.org...>

³⁴⁴ Interview Salome Kimata- UDEK 19.9.2007

That is why the UN demand to eliminate gender- based stereotypes.³⁴⁵ Another important aspect is that women in Kenya have a lower esteem. Salome Kimata pointed out that 80 percent of women with disabilities are single mothers because of lower esteem. Furthermore most of these single mothers are street dwellers. Salome herself as a disabled woman and director of an office, when she comes home she is a wife and runs the home.³⁴⁶

Worldwide disabled boys often receive better attention than disabled girls and a better treatment, more food and more opportunities. It is the same with non- disabled boys, they often are favored over non- disabled girls.³⁴⁷

The risk of abuse and mistreatment is present for children with disabilities, especially for girls. Globally the most frequently excluded children are girls. Gender is the major factor of being left out of school. Failures to make school safe and secure leads to an insecure position for girls who want to attend school. „*In and around schools, between teachers and students and among students themselves, psychological and physical threats, abuse, and actual violence are globally becoming matters of serious, sometimes tragic, concern. Girls are especially vulnerable in schools that fail to serve as “safe havens” from sexual harassment, physical attack, or abusive corporal punishment, often by teachers.*“³⁴⁸

Girls and women have to take the role of domestic chores, caring for siblings or drop out when they become pregnant. Therefore girls and women with disabilities are very vulnerable because there is lack of rights and they do not have good chances to find an employment. In my own research I met a disabled girl aged 24. She was not able to follow education and further employment because on the one hand she could not afford any training and on the other hand she had to take care of her siblings because her mother had died of HIV/ Aids.

As I have already mentioned in Kenya it is very difficult to get an employment as a disabled person, especially for women with disabilities. The Kenyan national survey for persons with disabilities stated that males are more likely to be employed than females (17, 7 percent and females only 7, 5 percent).³⁴⁹

Globally two thirds of the 130 million primary school aged children who do not attend school are girls. In Africa almost 26 million girls are out of school.³⁵⁰

³⁴⁵ cf. UN c: <http://www.unescap.org...>

³⁴⁶ cf. Interview Salome Kimata- UDEK 19.9.2007

³⁴⁷ cf. Werner 2003:12

³⁴⁸ Bernard 2000:5 <http://unesdoc.unesco.org...>

³⁴⁹ cf. KNS for PWDs: 2008:15

³⁵⁰ cf. Bernard 2000:12 <http://unesdoc.unesco.org...>

In a report of the taskforce on special needs education the MOEST found out that in Kenya 26, 885 children with special needs were enrolled in schools in the year 2003 (15, 129 boys and 11,756 girls). These numbers show that more boys are included in the education system than girls.³⁵¹

Another important issue is that in Kenya men receive more medical treatment than women (men 58, 4 percent and women 55, 5 percent receive medical treatment.)³⁵² Therefore access to resources is highly gendered, and the life experiences of disabled women require specific attention³⁵³, which could be a thesis on its own.

HIV/Aids affects especially disabled children and girls³⁵⁴ because some tend to see them as “clean”. Some people believe that disabled women are not sexually active. That is why they do not expect to be infected.³⁵⁵

Ingstad talked about girls with disabilities being raped in Botswana. The same I talked about with Salome Kimata who explained that these girls and women with disabilities are highly vulnerable when it comes to possibilities for sexual abuse by casual sex partners and these girls are even more at risk for HIV/AIDS.³⁵⁶ *“Think of even a deaf woman ... she cannot scream. Think of a blind woman she cannot even identify the rapist. Think of a woman in a wheel chair she is defenseless ... they are highly vulnerable.”*³⁵⁷

Furthermore she confirmed that the mentally disabled are easily abused and at risk of HIV/Aids too.³⁵⁸ I also found this information on www.disabilitykenya.org *“Children with disabilities are subject to a range of risks including that of being abused and more vulnerable to HIV.”*³⁵⁹

That is another reason why parents hide their children because they fear mistreatment and abuse. This is even much harder if the mother is a single mother and has to care for the children without any male support or protection.³⁶⁰ Moreover as in most parts of the world the women care for the children and in some cases the father leaves the family if the child is born with a disability.³⁶¹

³⁵¹ cf. MOEST a 2003:17,18

³⁵² cf. KNS for PWDs: 2008:16,17

³⁵³ cf. Priestley 2001:4

³⁵⁴ cf. Philpott, Sait in Priestley 2001:155

³⁵⁵ cf. Grut, Ingstad 2007:12 <http://siteresources.worldbank.org...>

³⁵⁶ cf. Interview Salome Kimata- UDEK 3.9.2007, Ingstad, Whyte 2007:240,244f

³⁵⁷ Interview Salome Kimata- UDEK 3.9.2007

³⁵⁸ cf. Interview Salome Kimata- UDEK 19.9.2007

³⁵⁹ DK.org: <http://www.disabilitykenya.org...>

³⁶⁰ cf. Grut, Ingstad 2007:46 <http://siteresources.worldbank.org...>

³⁶¹ cf. Interview Jeddidah Wairimu- CVO 29.8.2007

4.3 The situation of families of children and young people with special needs in Nairobi area

Children with special needs are those from slums and around the communities in Kinoo, Uthiru and other regions of Kikuyu Area. Most of the children are Kikuyus but other ethnicities who live around the Kikuyu community as well. Most of these children come from very poor families with unemployed parents who work for example in the mines at Jua-kali Industries (people from Shauri Yako), which means that accidents and death of one parent is very common.

Others are squatters and live below the poverty line. That is why for most of the children with disabilities the family is very important because they support and protect each other. Some of the children I have seen in my fieldwork were treated according to the circumstances in a way that parents tried their best to give them a good life which means clean housing, food, sometimes an occupation and contact to other children. Nevertheless I saw mistreatment as well but it is difficult to estimate in how far parents are able to give any support, even for their able bodied children. Therefore it is more important to focus on the treatment of the individual disabled person by the community, the family, and institutions.³⁶²

According to Neubert und Cloerkes in some cultures family and guardians are important to care for a disabled family member, whereas in industrial countries most of the times institutions (state aid, churches, organizations, welfare organizations) support or care for disabled people.³⁶³

In other words mistreatment is maybe the wrong word because I felt that most of the parents do their best to give their children support. Furthermore the parents were searching for help by visiting parents' seminars to inform themselves about disabilities, causes and consequences, and how to handle their children. Mobilization and sensitization will also help to reduce stigma. The parents are also informed e.g. that all children have the right to access education. They also wanted their children to be educated and to interact with other children. Because of lack of resources and financial support some parents have no other possibility but to leave their child at home alone. Therefore the children are neglected because the parents have no other chance when they work.

³⁶² cf. Ingstad in Ingstad, Whyte 1995:260

³⁶³ cf. Neubert, Cloerkes 2001:101

4.3.1 *Socio- economic and socio- cultural situation of the target group*

The families I visited had children with mental and/or physical disabilities. Some families live under extremely poor circumstances which mean the houses and shelters are made of iron sheets and only some have a foundation. The houses are often not fixed which means there are holes and the rain comes inside which makes the walls humid. Because of cooking inside the windowless houses are filled with smoke and walls are damaged by soot. The children sleep under such circumstances because most of the houses have only two rooms, which are not really separated (only with a torn piece of material), which influences their health situation. Therefore environmental factors like no sanitation facilities, pollution inside and outside the house, no access to clean water and health services lead to various illnesses.

Nearly all children I visited wore old and dirty clothes because parents cannot afford to buy new ones and washing is not easy without access to water. Most of the children sleep in dirty and humid beds, especially those with physical disabilities who urinate in beds because they cannot go outside to the toilet. The project members of CVO recommend plastic sheets because to sleep under such circumstances makes children vulnerable to infections.

Because of high school fees, the parents cannot afford to take these children to special schools; that is why it is up to them to give them education and the independency they need in life. Especially the mentally disabled need full time attention, which is very difficult for parents who have to earn their daily income. That is why the only way is to lock these children up at home because they are not able to stay alone and help themselves. Furthermore these families do not receive counseling how to deal with such a child. They often struggle on their own and do their best to take care of their child.³⁶⁴

In general disabled people are socialized, as regards their behavior, by their parents, who might have no knowledge of the social and physical problems disabled people face. Disabled people were not brought up by disabled parents, nor did they grow up among disabled people. Therefore in most cases the family is not able to give the child the special training he/she needs, the child has to leave the home.³⁶⁵

³⁶⁴ cf. Grut, Ingstad 2007:42 <http://siteresources.worldbank.org...>

³⁶⁵ cf. Murphy et al. 1988:241

As Simon Gichuhi the programme coordinator from CVO claimed: “... *they don’t know how to deal with some of these situations, some of the parents are illiterate, they have not been to school, they don’t know where to go to look for such kind of help, that’s why they have been locking up their children. They don’t know with whom to leave the children, maybe the others go to work and they need to go and look for daily bread. So the only alternative for some of them is to lock their children in the houses and leave them there ...*”³⁶⁶

The physically impaired have to face a poor infrastructure and often cannot afford wheelchairs or walking assistance. Therefore they are not able to move alone at all and the reality is to stay at home doing nothing. To live in such circumstances does not allow them to develop their full potential. Lack or no attention at all from parents and teachers from (special) schools force these children to become depressed, aggressive, loud, or angry. When they grow older it will become very difficult to handle them and to help them living a respectable life. Moreover it is easy to abuse them by paying them less or discriminate against them in different fields of life. It is very important to meet the needs of these children because for most of them it will be very hard or even impossible to live an independent life.

4.3.2 Evaluation home visits

I have visited 38 families with 48 vulnerable children and young people with special needs (20 girls and 28 boys). When I talk about special needs I mean children and young people who are challenged by disabilities, HIV/Aids or who lost both parents. In my research I work however, only with the topic disability. That is why I want to describe the situation of children and young people with disabilities. But before I want to give a survey of my whole fieldwork of all 48 children I visited. After doing so I will work more detailed with the data on 24 disabled children and young people aged from 2 to 24 years.

Data of all 48 children with special needs

38 children were aged under 17 (22 boys, 16 girls) and 10 ranged from 18- 31 years (6 male, 4 female). These families were already registered at the project³⁶⁷ and the project members went on home visits to estimate the needs according to the families’ living conditions. Most of the families expected that something would be done to assist them.

³⁶⁶ Interview Simon Gichuhi- CVO 30.8.2007

³⁶⁷ see registration service of CVO see appendix

In some cases it was possible to donate basic things like food, clothes, and school books and to link them to other organizations who care for disabled people's needs. First of all a data collection is very important to have an overview of the needs of these families and their children.

All 48 children sex and age

children	years	boys	girls
9	0-5	4	5
19	6-11	11	8
9	12-17	6	3
10	18-31	6	4
48 children		28 boys	20 girls

Orphans and HIV/ Aids cases

Four children were HIV positive (all of them under 17 years; 1 girl, 3 boys) and 11 children were orphans; 9 under 17 years and two ranged from 18-31 (6 girls, 5 boys). 7 of these children live with their grandmother, one girl with her grandparents and one boy with his great grandmother. About the other orphans I have no information. This data indicate that HIV/Aids is a major problem in Kenya on various levels for many children who lose their parents due to the virus. As a consequence of the epidemic I met five children who had lost their mother because of HIV/Aids. When I talk about orphans I mean children who have lost both of their parents due to different circumstances in life and they need special attention to show them that somebody cares for their needs. Sometimes relatives cannot give them the care and attention they need depending also on their financial situation. Total 11 orphans out of 48 children is a high number. I do not know all the causes of the deaths, only due to HIV/Aids and because of mines at Jua-kali industries in Shauri Yako where accidents and deaths are common because of insufficient safety precautions.

Other vulnerable children and their needs

There were nine children who could not be categorized under the issues of HIV, disability or who were not orphans but nearly all of them had health problems. Three siblings were faced by land clashes and are settling down and all children lived at very low living standards. When I talk about health problems I mean problems like lack of protein and vitamins (2 cases: one four and one 11-year-old child), an one year-old girl had skin problems, three children (4,5 and 9 years) had pneumonia, one child (10 years) had an eye problem and a two-year-old child did not take food well. As I have already mentioned these children have health problems because of the socio-economic conditions in which they live.

Children and young people with disabilities

For the rest of my thesis I would like to concentrate on the data on disabled children and young people we visited during my fieldwork.

Children and young people with disabilities (2-24 years)

age ³⁶⁸	boys	girls	Total
0-2 before school age	0	1	1
3-5 preschool age	0	1	1
6-14 primary school age	7	11	18
15- 18 secondary school age	0	0	0
19- 24 after school age	3	1	4
Total	14	10	24

We met total 24 children and young people with disabilities (14 boys and 10 girls) ranging from the age of 2 until 24 years. Most of the children are in primary school age which means from 6-12 years old.

4.3.3 Differences in disabilities

Some of the children and young people with disabilities have multiple disabilities, namely 6 children (2-12 years) (4 boys 2 girls). They have more than one condition of disability like one boy aged 7 is mentally challenged, suffers epilepsy, and has learning disabilities. One girl, 9- years- old, has intellectual disabilities and has speech problems due to a heavy tongue. I saw four children who suffer the consequences of meningitis which means they are both physically and mentally disabled. One girl, nine- years- old is hemiplegic, she has disturbance of equilibrium and weak bones. Just in one case of meningitis I saw a wheelchair in the house but it was difficult to use because of bad streets.

³⁶⁸ cf. KIE: <http://www.kie.go.ke...>

It is difficult to categorize these 24 children and young people with disabilities. One child has a hump, one has cerebral palsy, 4 children suffer from the consequences of meningitis and are therefore physically and mentally challenged, 3 children have muscular dystrophy, 5 children have various forms of mental problems and have therefore also learning problems, two children (of them) have down syndrome, 3 cases have epilepsy, one child suffers disturbance of equilibrium and one child has a brain damage due to little oxygen at birth, 2 children are hemiplegic, one child has speech problems because of a heavy tongue and one is an aggressive and mentally challenged child.

One child is HIV positive, disabled and an orphan; one child is HIV positive and an orphan and one child is HIV positive and disabled. In some cases the parents did not even know what exactly was going on with their child because they had not been to any assessment nor to a doctor. The Kenyan national survey for persons with disabilities figured out that although 79, 4 percent disabled Kenyans in urban and 71, 6 percent in rural areas are in need of health services only 56, 8 percent in both rural and urban areas have ever received any treatment. Of children with disabilities aged 0- 14 years only 52, 4 percent and young people with disabilities from 15- 24 years only 61, 4 percent received any health services although 77 percent of children aged 0-14 years and 79, 6 percent of young people aged 15- 24 years are in need of them.³⁶⁹ This data agrees more or less with my data, that the major problem is lack of basic health and rehabilitation services.³⁷⁰

The project members developed a form to document their data and the circumstances in which the children and their families live. I took pictures to illustrate the situation. Different variables such as names of the child and his/her parents, age, sex, health status, family status, household members, siblings, parents occupation, location, expectations, report from doctor, child ability, communication skills, talents etc. were our interview guide and some further questions which I developed on my own. Because the project members had to assess as many children as possible, the visits were often carried out in a short time. That is why I have the information differences within the children.

³⁶⁹ cf. KNS for PWDs: 2008:16f

³⁷⁰ cf. Werner 2003:13

Guardian/parent id photocopy

41 NO-20

P.C.E.A UTHIRU PARISH CHRISTIAN ED
ORPHANED AND VULNERABLE C

CHILD ASSESSMENT FORM

1. Name of the child RETH WOMAN

2. Name of Parents EDITH MW

3. Age 9 yrs

4. Location KIMBO

5. Sub- Location KIMBO

6. Area of Residence MUTIGA CHCH 07 JAN 2007

7. Sex FEMALE

8. Health Status Good health status
has no other health co
has no children

9. Family Status (Are they working or not) NO NOT

10. No. of siblings:- Brothers 2
 Sisters 1

11. Are parents:- Single Both V
 Orphan (If Guardian include guardian detail)

12. Physical address 252 KIRIA
 Tel:- 011 68 53 11

13. Parents/Guardian Expectations He is a school for special
needs should be put in the army it would be

14. Medical Report from the Doctor Child has
physical disabilities needs special school
for the child

Official use only. (Remarks on)

Child ability Good slow preparing

Communication skills Good

Talents very hard working good

Listening Good

Personal judgement (assessor)

Child skill	How to develop it
<u>He is not</u>	<u>should be</u>
<u>not very hard</u>	<u>take to special</u>
<u>hard working</u>	<u>school</u>
<u>not</u>	

Comments

Name Thuy Nhat

Signature NEW Date 21/01/07

4.3.4 Parents of children with disabilities

Employment parents of 24 children and young people with disabilities

	mothers	fathers	Total
casual	7	7	14
cares for housework	13	0	13
farming	0	1	1
driver	0	3	3
business	1	3	4
no data	1	1	2
			37

In my research I figured out that 15 children and young people with disabilities have both parents, 7 children live with their single mothers, and two orphans live with their grandmothers. The mother of one of these orphans had died of HIV Aids some years ago.

Most of these parents work casually (7 fathers and 7 mothers); 13 mothers I visited stay at home doing the housework. In Kenya casual work is the most common possibility to get some income.³⁷¹

One mother and three fathers run a business which means selling products and goods (like soft drinks, cigarettes, sweets, salt, cooking fat etc.) private or in a shop and three fathers work as drivers. Only four parents have a regular income and one mother is a care-taker. One father works as a farmer. Lack of jobs lead to an increasing importance of the informal sector as the data says that the number of employees in the informal sector has increased in the years 2001 to 2005 (Informal sector: 4, 668 700 people (2001) to 6, 407 200 people (2005) which means 1, 738 500 people in four years.)³⁷²

Nearly all parents I visited through home visits have no regular income which means that they have to look every day how to earn their daily bread with casual work. For the parents it is very difficult to care for their disabled children because it is hard to meet medical expenses, provide special nutrition, employ care givers, and afford assistive devices. Therefore many children cannot access education.³⁷³

³⁷¹ cf. Guimbous 1993:2

³⁷² cf. KNBS a: <http://www.knbs.go.ke/>

³⁷³ cf. MOEST a 2003:27

Children are often suffering from poor nutrition and health care, from inadequate water, sanitation,³⁷⁴ and shelter and live in families with an unstable income and limited opportunities to participate.³⁷⁵ 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.³⁷⁶

Sometimes parents lose, what Ingstad and Grut 2007³⁷⁷ are calling the “fighting spirit” which means that they give up. Faced by socio- economic challenges and many losses that poverty creates, to care for a disabled family member sometimes becomes a burden and therefore too much because resources are missing and labor capacity is not enough. Negligence or abuse could be the consequences of desperation over the situation where parents and family members are no longer able to care for a child with disabilities.³⁷⁸ In my own research I have seen cases where parents were hiding their children because they did not know what to do with them. Others could not send their child to school or any assessment. Moreover if a child is expelled from school parents do not know how to handle the situation as a colleague from UDEK who joined the interview stated: *“They know the case but when they throw them out you know for the parents okay they think for my child there is no help because where should we go? So many parents give up ...”*³⁷⁹

Simon Gichuhi argued similar things: *“Let me say it is a little bit hard and tricky for these parents to acquire such institutions because before they come there they are forced to pay money and maybe they cannot afford this money and when they cannot afford it, they forget about such institutions. That’s why they get back ... their children and their needs have not been met, their problems have not been met. That’s why if the government expand more institutions and offer free help to these parents the problem would be cupped and it would not go beyond the limits.”*³⁸⁰

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 been to a doctor ... *“some of them are not up to date they have not understood what disability is all about ... like lack of exposition. I have a mother of a child in the village who does not even understand the disability of her child. Another thing is lack of knowing what to do with this child.*

³⁷⁴ cf. Werner 2003:13

³⁷⁵ cf. Bernard 2000:2 <http://unesdoc.unesco.org...>

³⁷⁶ cf. Bernard 2000:2 <http://unesdoc.unesco.org...>

³⁷⁷ cf. Grut, Ingstad 2007:38 <http://siteresources.worldbank.org...>

³⁷⁸ cf. Grut, Ingstad 2007:39 <http://siteresources.worldbank.org...>

³⁷⁹ Interview Salome Kimata- UDEK 3.9.2007

³⁸⁰ Interview Simon Gichuhi- CVO 30.8.2007

*You don't understand the needs of disability you don't know which school you have to take this child or bad contribution so what are you left with? The bad one is poverty. Even if I know this child can be taken to Nairobi or whatever do I even have money for the transport or a therapy or whatever.*³⁸¹

Transport costs are a major challenge in Kenya because it is unaffordable for many people. Just a few are able to use the transport system frequently, the majority is walking.

4.4 Children with disabilities in Nairobi suburbs

Sometimes I cannot exactly tell what has caused the disability of some families because some children have never been to any doctor or assessment. Most of the assessment centers charge money which is not affordable for most of the parents. That is why UDEK offers advocacy service to find an assessment center that can make it for free or UDEK pays for the child.³⁸² In general in developing countries people often do not know their diagnoses because they have no access to health care services.³⁸³ Like one mother of a disabled child she had no idea which illness her child has. Although she went to a doctor, he had never mentioned the cause of the disability.³⁸⁴

With the description of some families and children living in the suburbs of Nairobi, I want to make links between the individual lived experience of disability and the social context in which disabled people live. The use of life stories helps to understand how they are embedded within societies, and influenced by periods of social change.³⁸⁵

Another important point is how socio-economic circumstances limit their participation in society and what parents do to bring out the best in their children.

³⁸¹ Interview Salome Kimata- UDEK 19.9.2007

³⁸² cf. Interview Salome Kimata- UDEK 3.9.2007

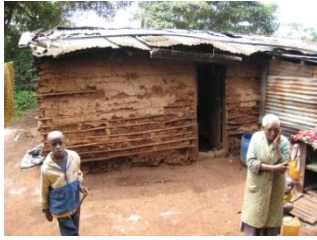
³⁸³ cf. Braithwaite, Mont 2008 <http://siteresources.worldbank.org...>

³⁸⁴ cf. Interview mother of B. 13.8.2007

³⁸⁵ cf. Priestley 2001:245

4.4.1 Family from Gichecheni

Their mud house³⁸⁶



After identifying a very desperate case in the sub location

Gichecheni the CVO project decided with the help from the church and donations of our (Stefan and my) families and friends to build a house for a 71- year- old grandmother (widow) who cares for her five orphaned grandchildren. Their mother died of HIV and the

father left the family. One boy is HIV positive and the oldest girl is physically disabled. She has a hump and therefore she cannot walk long distances. Furthermore it is very difficult for her to find a job because on the one hand she broke up school and on the other hand she has to care for her younger sister. That is why children and young people, especially girls, can often not continue education because they have to care for their siblings or work at home.³⁸⁷

The house in which they use to live is a mud house with a grass roof. There are holes in the thatch. When it rains parts of the wall subsides. They have no electricity and access to clean water. There are no sanitation facilities and their chickens live directly next to the house. Above all the family is cooking with coal inside the house. That is why the walls are damaged by smoke and soot. Maybe it is the reason why the small girl has skin problems. Furthermore the medications for her and her brother who suffers HIV/Aids are not affordable. The family has no access to health care services. Because of free primary education since 2003 the boys are able to go to school. Although they live under extreme low circumstances they have survived with the help of the community and well wishers by receiving donations like food, clothes etc.

The children sleep with their grandmother in one bed. They have two rooms but they are not really separated. Therefore they live in an overcrowded housing situation. They have no access to clean water, and cooking pots and charcoal burners are near the sleeping quarters. All these factors can cause diseases as well as skin infections. The clothes of the small girl are wet because she is not frequently swaddled. The children wear old clothes and some of them have no shoes. When we visited them we realized that these circumstances are really dangerous for the children's health. The grandmother is not able to cook and do the housework; she is tired because of old age. That is why the project decided to help them in constructing a new house.

³⁸⁶ © (Pictures taken by Katharina Bittner)

³⁸⁷ cf. Bernard 2000:10 <http://unesdoc.unesco.org...>

The construction started on the 14th of August and the house was opened on the 8th of September 2007. All the members from the project and the community volunteered and worked very hard to give the family a better quality of life. Furthermore the project integrates young people with special needs in giving them skills by participating in these activities.

4.4.2 Girl from Gitaru

room where she sleeps³⁸⁸



The girl I want to describe is five-years- old and lives in a sub location called Gitaru. She seems to be mentally challenged but the parents do not know because the girl has never been taken to any assessment. She has mood swings, maybe it is bipolar disorder but I do not know. In one moment she is behaving according to culturally accepted norms and at the other moment she becomes aggressive and hits and bites people and other children. That is why the parents do not know how to treat her. She went to Kanjeru special school for two weeks but she was expelled because she was too peculiarly behaving and the teacher said that she was in need of a therapy. Since that time she has not gone to school because the parents cannot afford a special school. Except for the lessons from the CVO project she gets no education.

Like many girls all over the world her elder sister takes care of her after school. In the morning she stays alone, locked in the house. Inside her room there is only a bed with a piece of foam and no pencils, toys, etc. Being locked for many hours a day makes her situation worse.

The parents are overstrained and have to work many hours a day because they have no other chance besides treating her that way. When we talked to them I tried to motivate them in giving her some skills and avoid locking her in the room. Hopefully they will find a way to improve her behaving.

Their house is an iron sheet house without foundation but the iron sheets fall apart and rain comes inside. There is no electricity which means when she is locked in, it is dark in her room.

This girl is an example of children with a disability who fail to utilize the mainstream school system to its full extent. Having the motivation and the ability, but lacking of economic resources and no social support, her parents gave up and she stays at home. With some extra help she could go for further education.

³⁸⁸ © (Pictures taken by Katharina Bittner)

These are two examples of families who live under extremely poor circumstances. Both girls have no access to health care and assessment services, education and employment. The older sisters are taking care of their younger siblings. Both families have no access to clean water or sanitation facilities. The neighbors are donating food and sometimes look at the girl when parents are at work. Also the neighbors of the family in Gichecheni look after the children and donate things like food etc. what is missing. Furthermore in constructing the house neighbors and friends came to volunteer.

4.4.3 Two boys with meningitis

All together I have seen four children within the home visits who suffer from the consequences of meningitis. According to the World Health Organization “*Bacterial meningitis infection by *Neisseria meningitis* (Nm), is a contagious disease that causes inflammation of the membranes enveloping the brain and the spinal cord.*”³⁸⁹

The WHO estimates, across the African meningitis belt, from December 2006 to May 2007 there were 53,000 cases of meningitis, 4,000 people died. It is a disease which should be treated immediately. Furthermore there is a vaccine which prevents the disease but many African countries are not sensitized to its importance due to lack of information.³⁹⁰

Meningitis can lead to brain damage which causes permanent neurological and psychopathological disorders. This can further cause impairments as hearing- impairments, visual impairments, epilepsy, speech impairments, behavioral difficulties, learning disabilities, cramps, etc.³⁹¹

The children we visited, suffer from the consequences of meningitis and have both mental and physical disabilities. All of them do not talk and it seems that they are deaf and dumb but the parents cannot tell exactly.

The first boy I want to describe is 12 years old. I will call him S. and he lives in Gitaru also in an iron sheet house. The mother told us he suffered meningitis when he was a small boy. Since he goes to therapy to strengthen his bones, his condition has improved but he has never been to a school. That is why he is only partly able to use sign language which he has learned from his family.

³⁸⁹ WHO c: 2007 <http://www.afro.who.int...>

³⁹⁰ cf. WHO c: 2007 <http://www.afro.who.int...>

³⁹¹ cf. Meli et al. 2002: <http://www.medicalforum.ch...>

S. is not able to talk or hear and he communicates by showing his feelings. He shakes his head and moves around like dancing when he is happy and gets angry if he needs something. S. creeps on his bottom to move around because the family is not able to afford a wheelchair. Furthermore it is difficult to afford medication. He has five siblings and the family lives only from the father's income who is a driver. S.'s mother does not know how to handle him and what exercises she could give him.

The second case of meningitis is Z. from Muthure and he is eleven years old. When he was five years old he suffered from meningitis. He has six siblings which means that they are a large family and therefore difficult to subsist. Because of an arrangement, the mother should pay when she is able to; he attends the "Waithaka special school for mentally handicapped". Anyway she is afraid that sooner or later they will throw her son out because she cannot pay. His father left the family and the single mother works casually to support the family. Z. is not able to talk and hear but I do not know if he is dumb or deaf. He is mentally challenged and communicates through his feelings. He makes loud noises and moves his body all the time by shaking his head. When he is unsatisfied he starts crying. The state of their house is poor because the walls are damaged and the roof is leaking.

These are two examples of children whose parents cannot or hardly afford a special school. Both of them have no access to health care services and therefore to medication. Both boys have a big family and one mother is a single mother and it is admirable how she is able to manage seven children without a partner.

The main challenge is that the parents cannot afford any assistance like education and health services, in a way that they can understand the condition of their children. 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. For me personally it is admirable to handle a disabled child without any professional support and that these two boys creep around on the floor because they cannot afford a wheelchair.

4.4.4 *Two girls with a hump*

When I saw this girl, from the family in Gichecheni, aged 24 with a hump on her back I really did not know what had happened to her. I talked to the project members to ask about her condition but they could only tell me that it started growing when she was a child and now it starts to cause problems. According to Werner who has written a book about how to work with disabled village children in developing countries, it could be kyphosis which causes a rounded back. This condition may result from weak back muscles or from poor posture.³⁹² She is a very small girl and looks like she is 15. She is very thin and shy. She cannot speak English that is why I got all my information translated by the project members. She has never been employed and she has not finished secondary school. That is why it is very difficult to find an employment. She has to care for her smaller sister. Her dream is to become a hairdresser but she needs to be trained.

The second girl I talked to is J. and she is 24 years old, too. She is able to talk in English because of secondary education but her voice was really low. That is why it was often hard to understand her. I got to know her at UDEK where she is doing a computer course for free to improve her chances of getting a job. Because of high transport costs of 20-50 Kenyan Shillings (~ 20-50cents for a one way ticket) it is difficult for her to attend the course frequently. She finished secondary school with the hope to make the IT course. When we talked about discrimination she pointed out that people imitate her and laugh about her hump but she never replies anything to them. When I asked her about her dream she replied that she would finish this course to earn money to support her family because her family with six siblings needs her.

In general J. seemed to behave and talk in a very devout way. I was really concerned because she had so much hope for herself and her family.

These are again two examples which show that girls often take care of their families. The first girl cannot keep a job because of her sister and the other girl wants to earn money to support her family. Both families are very large and therefore not easy to support. Both of them have no access to employment although one has finished secondary school. They have problems with transportation costs and they cannot walk long distances because of their condition. One of them has problems with discrimination but her family stands by her.

³⁹² cf. Werner 2003:161

4.4.5 Two boys with muscular dystrophy

Within the home visits I saw three cases of muscular dystrophy and all these cases were boys because the disease affects boys mainly. I want to describe two brothers who live in Gachui. Jo. is 12 and W. is 8- years- old. Both of them suffer muscular dystrophy at a different stage which means that this disease is getting worse when the child gets older.

The older brother cannot walk anymore and he needs a wheelchair to move around which his mother told us is not affordable. W. is a little bit better because he can walk small distances. Both of them go to Dagoretti Children's Center for free where they go to school, get food, rehabilitation services like therapies etc. Their mother stays at home, doing the housework and their father works casually. They have two sisters.

Muscular dystrophies are conditions of genetic disorders which means that the muscles do not get stronger. It causes muscle weakness and/or wasting. There is no medicine to cure this disease and to boost the muscles. Therefore I have to add that they need therapies and if necessary surgeries. They are not affected mentally. That is why they do their school work very well but things like writing becomes a problem because of weak muscles. Muscle weakness first affects the feet, the fronts of thighs, the hips, the belly, the shoulders, and the elbows. Later, it affects the hands, the face, and the neck muscles.³⁹³ The physical therapist from Dagoretti children's center explained two forms which are common in Kenya. The two forms are called Becker muscular dystrophy and Duchene muscular dystrophy.

Becker muscular dystrophy generally affects only males and it is caused by errors in the gene. The disease affects mainly the shoulder, upper arm, pelvic and thigh muscles. The symptoms start in the early teens or twenties and are recognized by the limitation of walking fast, running, climbing stairs etc. It is very important to be aware because the condition can affect the heart and breathing muscles.

Duchene muscular dystrophy is also a genetic disorder which causes progressive muscle weakness and the muscle cells break down and die. This condition affects mainly boys but with very rare exceptions also girls. The symptoms start when the child is aged between one and three when it is no longer able to run or jump or gets difficulties climbing stairs. At the age of 11 the children are wheelchair bound.³⁹⁴ Therefore muscular dystrophy is a disease where children need a lot of resources and therapy. It is also dangerous because as I have mentioned it can affect the heart and breathing.

³⁹³ cf. Werner 2003:109

³⁹⁴ cf. Muscular Dystrophy Campaign: <http://www.muscular-dystrophy.org/>

That is why in developing countries where people often cannot afford any treatment these children may die very early. Thankfully W. and Jo. can go to Dagoretti Children's Center where they get the best treatment until they are 18 years old but what will happen when they finish school?

Jo.'s symptoms started when he was nine years old. Before that time everything was normal. He started to feel weak by walking and his bones also got weak. His left arm followed until he could not walk at all. Most children become unable to walk by age 10.³⁹⁵ The Living Standards in which the family lives are very low. They have no money for food and the mother is carrying the boys to school on her back. On the same day, when we saw the two boys, we visited Dagoretti Children's Center to talk to the Organization "Feed the Children" to get some support for the project. After being successful with that, we met a physical therapist who gave us an interview. He knows W. and Jo. because he treats them as a therapist. He told us that beside rehabilitation there is a lot that can be done for them so that they can improve their condition. W. is getting depressed at times and his brother follows him. Beside feeding them they give them some easy work as e.g. giving them a plastic cup and not a heavy one. The PT also told us that when they are sleeping they should be given a light blanket because even a heavier one can invite some problems.³⁹⁶

We talked to the PT about the projects feeding programme and that the family of W. and Jo. told us that they are going hungry some days because they go without food. The PT told us that there are many families without food and that these are the challenges they face handling cases of disability. The center has given food for the holidays to the family and the PT told us that they were not honest to us. The center gave beans, some kilos of rice, cooking fat and some packages of maize flour. In the PT's opinion enough for the whole holidays; even more than for two kids. Furthermore he told us that they had already donated them a wheelchair and they probably covered or sold it when we were there.

The PT saw Jo. walking the last time in 2005. That is why they offered the family a wheelchair because the center knew the condition of Jo. They gave them even two wheelchairs; one for home use and one the center keeps there.

But when we arrived at their house there was no wheelchair and the boys told us that they were hungry because there was no food for them. In the Dagoretti Children's Center they give all their treatments for free because it is the mission of this organization to help all that are very needy true care nutrition and social services.

³⁹⁵ cf. Werner 2003:109

³⁹⁶ cf. Interview Josephat Gichana- DCC 4.9.2007

The PT told us people sometimes change the truth about the circumstances in which they live. It also happens when the members of the center make home visits. Some families even change their house and transform it to another neighborhood. They hide their things to show that there is nothing like when the project members and I visited W. and Jo. there was no food, no wheelchair and the house was very poor. I do not know if it was their house but the wheelchair and the food were gone or hidden. Those are the challenges some projects face and networking within different institutions could improve the situation.

The center has also seminars for parents to understand the condition of their child. The main challenge is transport costs because many parents cannot afford to visit the center. For some parents the center pays the costs of transport or gives them vehicles to move around.³⁹⁷

I should like to repeat once again that we realized that networking is very important within all institutions, that support services can be shared. When we saw the house of W. and Jo. we realized that it was in need to be fixed and that the family needed to buy some clothes and sheets for the boys. They are in need of that because they are not able to stand up on their own, often pee in bed at night. Especially this family does everything to get help, also by changing the truth about the circumstances in which they live. The two boys can go to the center until they are 18 and hopefully after this they will find some other institutions which are able to support them.

Fortunately these two boys are treated and protected in a center where they receive all resources. I went to Dagoretti Children's Center and I was really impressed by the working conditions of the therapists. Furthermore the boys make progress in school and they like to study. They enjoy school and moreover their mother showed me their school report with good marks. Maybe she changed the truth to save money for them because she fears the future when they are out of school. The situation of these boys is really desperate because after school they may not receive therapy any longer. It is desperate due to the fact that heart and breathing muscles also get weak which means that a child usually dies before age 20 from heart failure or pneumonia.³⁹⁸

³⁹⁷ cf. Interview Josephat Gichana- DCC 4.9.2007

³⁹⁸ cf. Werner 2003:109

4.4.6 *Two boys with down syndrome*

D.T. is 11 years old and seems to be a happy boy because of his openness and laughing. He likes singing and is able to go alone to the shop. When he went to school he loved writing. Fortunately the family told us that there is no discrimination in the neighborhood and the community. His parents work casually, which means that they have no regular income. He has four siblings and lives in an iron sheet house with the whole family. D.T. was to nursery school until they expelled him when he was 5. He was not able to qualify for primary school because he could not follow the curriculum of the other kids. High school fees force his parents to keep him at home. So what happens is that he cannot achieve education. When we talked to the family they told us that they were so tired of projects and they only let us in because the mother knew one of the project members personally. She told us that she had always gone in search of help for many years. Snaps were taken out of her child but nothing happened. I remembered the beginning of our stay when the chairman made money with the poorest by taking snaps and trying to find some well wishers who donate without questioning it.

The second case with down syndrome is D. He is 27 years old and lives in a sub location called Rukubi. His parents are farmers and they have their own land. With his eight siblings D. lives in a small house. He finished class 4 primary school when he was ten but he could not continue because he was not able to follow the other kids. For D.'s parents it is neither affordable to send him to a special school nor to vocational training. That is why he stays at home and takes care of the sheep.

I would like to state that D.T. and D. have several things in common. Both were expelled from school and cannot follow a special school. They stay at home and do their best. Although the parents cannot take care of them the whole day (because of work) both boys have to be able to cope with being left alone. As well as many other children in Kenya the boys have many siblings (D.T. 4, D. 8) which means a large family is very important for survival.

These families with children with disabilities have one thing in common- all of them cannot afford a special school. Although the government of Kenya is giving some additional grants to special schools and units, it is not provided to children with disabilities who are in regular schools. Besides there is a discrepancy of giving funds to some schools because some are given more than others and some go without any funding.

The government does not realize that children with special needs education need more than other children which includes a barrier free environment, health care involving mandatory medication, treatment and surgery, special nutrition, support services such as interpretation, readers, teacher aides, therapy and assessment services, guidance, social services and public awareness etc. Often parents cannot afford therapies and it is difficult to reach the centers. That is why it happens that children with e.g. cerebral palsy receive physical therapy only once a month which is definitely not enough.³⁹⁹

In my fieldwork I figured out that families with disabled children have various needs as for example the following:

Needs (all 24 children and young people with disabilities (0-24 years))

assistance in basic needs ⁴⁰⁰	need a wheelchair	need physical therapy	need medication
11	6	4	11

11 children need assistance in basic needs which means they live at very low living standards. They have not enough food for their families and they wear dirty and old clothes. Above all they have no access to clean water and the children have no school equipment. Six children we visited need a wheelchair which means that it is not possible to buy one because of lack of money.

Simon Gichuhi explained the problems parents face if they are in need of a wheelchair: “*Parents know where they can buy wheelchairs but they cannot afford to acquire the wheelchairs because first they are too expensive for them, they don’t have enough money, some of them are casual workers and laborers, they work for their own daily living, for their daily bread but they are not able to raise funds to buy a wheelchair. They need connections to have these wheelchairs; they need organizations which fight for them. We will help them acquire these wheelchairs and even if they acquire a wheelchair, they need servicing. They cannot meet money for the servicing of these vehicles. And also when the children are growing up, the wheelchairs are becoming worn out day by day. They need replacement...*”⁴⁰¹

In addition 11 children require medical care and four are in need of physical therapy but the parents are not able to pay.

³⁹⁹ cf. Interview Josephat Gichana- DCC 4.9.2007

⁴⁰⁰ basic needs: food, clothes, shelter, school equipment) very low living standards

⁴⁰¹ Interview Simon Gichuhi- CVO 30.8.2007

This data shows that families with disabled children have various needs which the parents cannot meet. Although many associations like the Association of the parents of Hearing Impaired, Autism Society of Kenya, Cerebral Palsy, and Down syndrome are very aware and active; their activities are limited because of lack of funds, physical facilities and human capacity.

Furthermore local organizations for and of people with disabilities as KSDC (Kenyan Society for Deaf Children), KSB (Kenyan Society for the Blind), UDPK (United Disabled Persons of Kenya), KNAD (Kenyan National Association of the Deaf), KUB (Kenyan Union of the Blind), APDK (Association for the Physical Disabled Persons of Kenya), KSMH (Kenya Society for the Mentally Handicapped), KAWE (Kenya Association for the Welfare of Epileptics) and international NGOs like Sight Savers, DANIDA (Danish International Development Agency), VSO (Volunteer Service Organization), CBM (Christoffel Blinden Mission), UNICEF, and UNESCO play a key role in supporting the governments effort in service provision like assisting the affected children and their parents.⁴⁰²

5. Special needs education for children and young people in Kenya

Education is a human right as the UN Convention of the Rights of the Child article 28 informs:” 1. *States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:*

(a) Make primary education compulsory and available free to all;

(b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;

(c) Make higher education accessible to all on the basis of capacity by every appropriate means;

(d) Make educational and vocational information and guidance available and accessible to all children;

(e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.”⁴⁰³

⁴⁰² cf. MOEST a 2003:27,28

⁴⁰³ UN Convention Article 28: <http://www2.ohchr.org...>

The UN Convention confirms that education should be accessible for every child which is not given in Kenyan society and in developing countries in general. Furthermore secondary education is for most people in Kenya not an option because they cannot afford to pay school fees. Thus education is the primary vehicle to lift economically and socially marginalized children and young people out of poverty.⁴⁰⁴

Nevertheless millions of children still remain without education, especially vulnerable ones as children with disabilities who ironically have the greatest need of education.⁴⁰⁵ Although the UN Convention suggests an own article number 23 for children with disabilities, *“... that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community and that ... States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child”*⁴⁰⁶ it is not fulfilled because many children with disabilities remain in deep seated poverty without access to education⁴⁰⁷, health and rehabilitation care.

As I have already mentioned it has been estimated that 140 million children are out of school, a majority being girls and children with disabilities. 80 percent of these children live in Africa⁴⁰⁸ and 98 percent of children with disabilities in developing countries do not go to school.⁴⁰⁹

Now I want to give a survey of the situation of special needs education in Kenya. My main source is “a report of the taskforce on special needs education” from the MOEST from the year 2003. I want to include my own data on special needs education issues because I have met various parents whose children have no access to compulsory education. Therefore organizations of and for disabled people appeal to make education for children with special needs for free so that they can equally participate in the education system.

⁴⁰⁴ cf. UNESCO d: <http://www.education.nairobi-unesco.org...>

⁴⁰⁵ cf. Anupam in Hegarty, Mithu 2002:77

⁴⁰⁶ UN Convention Article 23: <http://www2.ohchr.org...>

⁴⁰⁷ cf. Odoyo 2005:14

⁴⁰⁸ cf. UNESCO a: <http://unesdoc.unesco.org...>

⁴⁰⁹ cf. UNESCO b: <http://www.unesco.org...>

Salome Kimata stressed that: “... government was able to make some contribution to the special schools but it is not a hundred percent free. So even that disposal the government is not paying ... you find these children at home. So that is a very hard situation for us because we expected the funding and we don’t have that money to give... So when they made primary education for free they never had in mind that we have children with special needs who cannot go to public schools.”⁴¹⁰

In Kenya since January 2003, primary education has been for free. The number of children who are enrolled in school has increased, classes are overcrowded, pupil teacher ratios in densely populated areas are high, costs of equipment for special needs education is expensive, numbers of orphans due to HIV/Aids increase, and therefore there are not enough teachers to care for the children especially for those with disabilities.⁴¹¹

Education and further special education is for children with disabilities in an unsecured position. When primary education was declared for free, 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.⁴¹²

In 1991 the KISE Bulletin wrote about the same problems like lack of specialized facilities, trained personnel and big classes with very little or no support. It was also recognized that class sizes have to be reduced to a manageable size which can be handled effectively to achieve successful integration.⁴¹³ Until today there are the same problems in schools, overcrowded classes and little support. Therefore children with disabilities are not able to make progress in such learning environments.

As Simon Gichuhi recalled, parents complain because in integration classes they do not see any improvement of their children. They are often not sure if it is better to put their child in a regular school or to keep him/her at home.⁴¹⁴

⁴¹⁰ Interview Salome Kimata- UDEK 19.9.2007

⁴¹¹ cf. Odoyo 2005:14

⁴¹² cf. MOEST a 2003:24,26, UNESCO c: <http://www.unesco.org...>

⁴¹³ cf. Ogonda 1991:31

⁴¹⁴ cf. Interview Simon Gichuhi- CVO 30.8.2007

Exclusion is an interactive process where factors like non- enrollment, passivity, absenteeism, repetition and drop outs are factors of becoming excluded. It is an interaction between individual, community and situational factors which lead to exclusion.⁴¹⁵ Before I analyze the situation of special needs education in Kenya I want to define terms which describe children with special needs in education by quoting the report on Special education of the MOEST of Kenya.

5.1 Definitions of children with special needs in education from the Ministry of Education, Science and Technology (MOEST)

Disability, the *“term refers to physical, sensory, mental or other impairments, which have substantial long term or adverse affects on a person’s ability to carry out normal day to day activities.”*⁴¹⁶

Handicap *“is a disadvantage or a restriction of activity, which results from a disability or form society’s attitudes towards a disability.”*⁴¹⁷

Special needs *“refers to conditions, barriers or factors that hinder normal learning and development of individuals. These conditions may include disabilities, social, emotional, health or political conditions.”* special needs education *“is education, which provides appropriate modifications in curricula, teaching methods, educational resources, medium of communication or the learning environment in order to cater for individual differences in learning.”* Special school *“refers to a school that is organized to exclusively provide educational services to learners with disabilities today.”*⁴¹⁸

Autism is *“a lifelong disability that primarily affects communication and social interaction. Such children relate to people, objects and events in abnormal ways such as insisting on structured environments and by displaying many self stimulated behaviors.”* Cerebral Palsy ... *“is a disorder of the brain, which occurs as a result of brain damage, or lack of development in the part of the brain controlling movement and posture in early life.”*⁴¹⁹

⁴¹⁵ cf. Bernard 2000:4,5 <http://unesdoc.unesco.org...>

⁴¹⁶ MOEST a 2003:xix

⁴¹⁷ MOEST a 2003:xx

⁴¹⁸ MOEST a 2003:xxii

⁴¹⁹ MOEST a 2003:xviii

Communication difficulty *“is a condition, which either interferes with the smooth flow of one’s speech and language or hinders the acquisition and development of a language.”* Deafness *“is profound hearing loss resulting in inability to perceive speech and spoken language.”* Deaf-Blind *“is a condition where a person has impairments in both vision and hearing.”* Emotional and behavioral difficulties *“is a term to describe the deviation from appropriate behavior for a given age, which significantly interferes with one’s own learning and development or that of others.”*⁴²⁰

Epilepsy *“is a brain problem, which is characterized by a fit or sudden loss of consciousness, convulsion or seizures. Epilepsy is not contagious or caused by witchcraft.”* Hard of hearing *“refers to persons with mild to moderate hearing loss but still can hear and use spoken language.”* Hearing Impaired *“is a condition of hearing loss ranging from mild to profound.”*⁴²¹

*“Multiple handicaps is a term used to describe a combination of two or more handicaps in a child.”*⁴²²

5.2 Major problems and consequences of special needs education

Worldwide men and women with disabilities continue to be unemployed, underemployed and underpaid which results in extreme poverty. The International Labor Organization (ILO) adopted a convention of international standards to ensure equal opportunities and treatment for disabled people in relation to employment and social integration especially in the labor market. Access to education becomes more important especially for children and young people to develop knowledge and skills to have better opportunities to find an employment. Many children with disabilities are excluded from education caused by lack of money, negative attitudes and social barriers.⁴²³

Therefore children from poor families have fewer chances to receive education and to go beyond elementary schooling, even more so for children with disabilities.⁴²⁴ Although primary education has been for free in Kenya since 2003 and many children with special needs have been enrolled in special schools, special units and in regular schools, it does not guarantee education for the poorest ones because special education is still not for free.

⁴²⁰ MOEST a 2003:xix

⁴²¹ MOEST a 2003:xx

⁴²² MOEST a 2003:xii

⁴²³ cf. Priestley 2001:8,9

⁴²⁴ cf. Grut, Ingstad 2007:37 <http://siteresources.worldbank.org...>

The government was only contributed a very small amount and the costs of special education is expensive.⁴²⁵ Money for books, uniform, shoes, and transport is often not affordable and sometimes the children have to pay for lunch.

Children with special needs are placed in regular classes but it is not integration as it is known in European countries where there is a special teacher who cares for the ones with special needs. The opposite is happening these children in Kenya can only do their best to follow the standard curriculum. Unfortunately it is far from integration or inclusive education which could be an option in education as people from disability organizations stress that integration would be really important because it is very difficult to reintegrate in society after being in a special institution where children are protected. Furthermore children with disabilities who are integrated in regular schools, do not have to leave their homes to move to special institutions which are often far away and not affordable.⁴²⁶

If parents in Kenya can afford it, they prefer to enroll their children with disabilities in special schools because they fear there are not enough resources in regular schools as Salome Kimata emphasized: *“So what the government has done, is there are some special units like a class within the same center, but look at the facilities, they are very scarce... parents of children with disabilities are still taking their children to special schools not a special unit within a public school. So that you ensure if my child is deaf I’m taking him or her to a school for the deaf where we know all the facilities are there.”*⁴²⁷

In general it depends on the disability the child has which school is the most profitable. An important model is the one of inclusive education⁴²⁸ where individuals with differences are seen as opportunities for enriching learning and not as a problem.⁴²⁹ To implement integration or inclusive education teachers have to be trained about forms of disabilities, prevention, and early diagnosis. Teachers have to be competent to share the knowledge with other primary teachers and he/ she has to be open for team work. In developed countries these competences are shared between parents, primary teachers, special pedagogy, special education teachers and school counselors.⁴³⁰

⁴²⁵ cf. Interview Salome Kimata- UDEK 3.9.2007

⁴²⁶ cf. Interview Duncan Mwangi- APDK 10.09.2007

⁴²⁷ Interview Salome Kimata- UDEK 19.9.2007

⁴²⁸ Inclusive education and integration see my thesis chapter 5.2.1

⁴²⁹ cf. UNESCO a: <http://unesdoc.unesco.org...>

⁴³⁰ cf. Albrecht in Albrecht, Weigt 1993:33

Inclusive education can only be possible when children with disabilities have all resources to meet their needs, but as I have already mentioned in Kenya most of the teachers are not able to advance these children because they do not know how to implement inclusive education. That is why many of them dropped out of school because the school environment was not beneficial for them. Therefore to implement integration or inclusive education is very difficult as Simon Gichuhi reported: *“I think the teachers cannot give this child special attention. There is no need of such a child in that school because the teacher will always give the attention to the normal children but he is not giving the right attention to these special kids. That’s why many of them are dropped out of school. Many of them are felt marginalized and they feel that they don’t belong to that category. They have gone back to their homes and they have not acquired education. That’s why when we talk about special, they need special attention; they need to be taken care of in a special way so that they can acquire their skills.”*⁴³¹

Moreover a number of factors might negatively effect the implementation of inclusive education as e.g. the public, teachers and participants who do not understand the philosophy and attitudes on the part of teachers who still view the learner with special needs in education as a problem. Communities and parents are ill prepared to support their children with disabilities. Other factors as lack of trained teachers, no curriculum which is accessible to all, lack of barrier free facilities etc. make inclusive education difficult.⁴³²

Therefore learning unfriendly environments when resources are missing in schools, like the inability to provide competent teaching methods, relevant curriculum and health facilities exclude children with disabilities from education.⁴³³ School buildings are not barrier free; in particular toilets are not accessible. Furthermore the learning environment is not adequate, learning resources, specialized equipment like Brailers are not available. Teachers are not able to give attention and do not know how to handle those children with disabilities including those who are hyper-active and dyslexic.⁴³⁴ Physiotherapists, occupational therapists, sign language interpreters, Braille transcribers and psychologists are required but not available.⁴³⁵

⁴³¹ Interview Simon Gichuhi- CVO 30.8.2007

⁴³² cf. MOEST a 2003:ix,2,81,82

⁴³³ cf. Bernard 2000: 5 <http://unesdoc.unesco.org...>

⁴³⁴ cf. UNESCO e: <http://unesdoc.unesco.org...>p.10,74

⁴³⁵ cf. MOEST a 2003:ix,2

Therefore an assessment report from UNESCO Nairobi office in collaboration with Kenya's MOEST recommends raising awareness on disability issues, especially to make infrastructure barrier free, to train more teachers on special needs education and to sensitize parents and communities on the issue of disability.⁴³⁶

Another issue is that the MOEST recommends that special needs education should be included in the Ministry. There is a lack of appropriate and adequate facilities, funding and personnel for special needs education. Furthermore lack of awareness, advocacy and sensitization and inadequate priority characterize the development of special needs education. It is important to sensitize the public through media and provincial administration.⁴³⁷

In general there is lack of data on children with special needs who do not attend school. The taskforce counted 26, 885 learners who are in special education programmes. The majority are learners with mental disabilities followed by children with hearing impairments. That is why a population census for all types of schools should be created. Most of the children with special needs come from poor families and are challenged by economic, socio- cultural and environmental barriers.⁴³⁸ Therefore the UNESCO recommends that is an obligation of a society to ensure that socio-economic, cultural and political barriers can be removed.⁴³⁹

The unit costs of educating a child with special needs in a day school is 17, 000.00 Ksh, (17, 000€)⁴⁴⁰ and for a child in a boarding school it is 32, 000.00 Ksh (32, 000€). These costs include assistive devices such as hearing aids, wheelchairs and crutches, learning resources such as Braille machines, low vision devices, support services such as occupational therapy and physiotherapy, mandatory medication such as drugs for epileptic, hyperactive and autistic children, environmental adaptations such as construction of ramps and adapted toilets.⁴⁴¹ In other words children with disabilities need a lot of resources.

⁴³⁶ cf. UNESCO e: <http://unesdoc.unesco.org...p.10,74>

⁴³⁷ cf. MOEST a 2003:xiif

⁴³⁸ cf. MOEST a 2003:x,3

⁴³⁹ cf. Bernard 2000:6,11 <http://unesdoc.unesco.org...>

⁴⁴⁰ cf. Außenministerium für Österreich: <http://www.bmeia.gv.at...>

⁴⁴¹ cf. MOEST a 2003:32

Children and young people with disabilities at home (unemployed) 11 children (0-24 years)

cannot afford special school	need assessment	need vocational training	need employment or further education	no data	Total
5	1	2	2	1	11

This table shows that out of 24 children and young people with disabilities 11 are at home because they do not go to school or do not have any employment. In my research I got to know five children with disabilities between 6 and 14 years who cannot afford a special school and have to stay at home; one child needs an assessment service and two need vocational training. Furthermore two young people need an employment and/or fees for secondary school or college. In Kenya 90 percent of disabled children are at home or in regular schools. The enrollment on the tertiary level is low. All in all 70 percent of children with disabilities are at home⁴⁴² which is, compared to my data where I found 50 percent at home, even higher.

Children and young people need help in education; school fees are not affordable for:

special school	secondary school	college	No data for further education	Total
10	1	1	12	24

This table shows how many families need support in areas of education. The number of the children who need special education differs from the other table because I have included the children who go for free or are enrolled in regular schools. Three children go to special schools, two for free and the mother of one child has an arrangement that she should pay when she is able to. One child with cerebral palsy is enrolled in a primary school but the parents want her to go to a special school which they cannot afford. One child is in a special unit within a regular school but her mother wants her to go to a special school because she believes that her child does not make any progress in this unit. This means that the parents of 10 children could not afford a special school. Young people with disabilities who are out of school need vocational training to find an employment which is also difficult to afford.

Although many children have already been assessed there is a high demand in local communities in terms of parents' training, sensitization, follow- up services and home- based programmes. These services cannot be met because of lack of transport, facilities, personnel, and insufficient funding. That is why many children with special needs in education have not been reached and identified. Some are still hidden at home and are not placed in any programme.

⁴⁴² cf. UNESCO f: <http://www.ibe.unesco.org...p.6,9>

In addition most of the screening tools and equipment used from Educational Assessment and Resource Services (EARCs) are inadequate and need revision because the EARCS should provide early identification, intervention, assessment, referral and educational placement of children with special needs aged between 0 and 18 years. There are no tools for children with learning difficulties, giftedness, talentedness, and behavioral difficulties.⁴⁴³ Even if the child is assessed transport to schools is often not affordable, if it exists at all.⁴⁴⁴

Organizations for and of people with disabilities appeal for resources for special institutions and for pre- school units which should be established as apart of special schools⁴⁴⁵ to prepare children before they are enrolled in primary education. As Duncan Mwangi commented: *“But my honest pray is that we need a lot of support to pre- schools. Pre- schools and care givers, pre- schools and professions. So my appeal again to the government to give a lot of resources to these special institutions.”*⁴⁴⁶

A Physical therapist from Dagoretti children’s center stated that it would be very important to introduce pre-schools. He argued that children should be enrolled as early as possible to avoid that they are staying at home until they are ten years.⁴⁴⁷ He pointed out that: *“like kids of this kind they are still scribbling, they are not very good at reading, just know a few special skills ... in a special unit people still help them on the toilet etc. So it could be a solution to train them in some activities that a higher number of kids can be sent to pre- schools.”*⁴⁴⁸

5.2.1 Integration and inclusive education

Integration and later Inclusion are seen in both economically richer and poorer countries as a major strand in education development. The successes of the concepts are highly dependent on the equipment of schools, as well as on the availability of professionals who can assist mainstream teachers.⁴⁴⁹

⁴⁴³ cf. MOEST a 2003:61,62,65

⁴⁴⁴ cf. Grut, Ingstad 2007:40 <http://siteresources.worldbank.org...>

⁴⁴⁵ cf. MOEST a 2003:48

⁴⁴⁶ Interview Duncan Mwangi- APDK 10.09.2007

⁴⁴⁷ cf. Interview Josephat Gichana - DCC 4.9.2007

⁴⁴⁸ Interview Josephat Gichana- DCC 4.9.2007

⁴⁴⁹ Dyson in Munaizel et al. 2003:37

Since the 70s in German speaking areas 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 disabled people and to avoid separation and segregation in the educational system. The deficiency perspective was the past and the child's competences came to the fore.⁴⁵⁰ 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. The Salamanca Statement and Framework for Action on special needs education (UNESCO 2004), is a document which advocates for Inclusion of students with special educational needs to be taught in the regular school system, with a specific focus on those who are vulnerable to marginalization and exclusion.⁴⁵¹ The statement advocates that Inclusive education means to welcome all children without discrimination into the regular school and it is according to the Salamanca Declaration from 1994 a human right.⁴⁵²

Integration challenged the view of special needs pedagogy which was near to medicine and psychiatry, reclined on the view of defects of disabled people, as the medical model of disability.⁴⁵³ An essential point is that learning problems as Westwood pointed out arise from a complex interaction of circumstances such as *"curriculum content, learners' prior knowledge and experience, learners' cognitive ability and task- approach strategies, teachers' instructional methods, complexity of teachers' language, suitability of resource materials, learners' confidence and expectation of success, and the perceived relevance value of the learning task."*⁴⁵⁴

Therefore it is often the learning environment which can cause learning disabilities and not the child who has a deficiency. The deficiency paradigm which suggests learning problems due to e.g. below average intelligence, poor concentration, problem with visual and auditory perception, difficulties in understanding complex language and limited vocabulary, low motivation etc.⁴⁵⁵, has legitimated differentiated school models. Schools were introduced for the blind, the visual impaired, the hearing impaired, the physically disabled, the mentally disabled, children with learning difficulties and behavioral challenges.

⁴⁵⁰ cf. Deppe-Wolfinger 2008: <http://bidok.uibk.ac.at...>

⁴⁵¹ cf. Westwood 2007:3

⁴⁵² cf. Banerjee in Hegarty, Mithu 2002:112

⁴⁵³ cf. Deppe-Wolfinger 2008: <http://bidok.uibk.ac.at...>

⁴⁵⁴ Westwood 2007:7

⁴⁵⁵ cf. Westwood 2007:7

Integration is an educational category which addresses social, educational and institutional terms under which children learn or if it is not implemented the right way it can even prevent children from learning. 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.⁴⁵⁶ 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.⁴⁵⁷ 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.⁴⁵⁸ The main question is how a school can be restructured in order to respond positively to all pupils as individuals.⁴⁵⁹ The point is not just putting disabled children in regular schools, it is much more the question how all children fare 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.⁴⁶⁰ Although until today progressive education and integration pedagogic have developed successful models like the open learning concept, project working and so on, both primary and secondary education have difficulties in educating all children together. The two- group theory of children with and without disabilities focuses on the education of children with disabilities, whereas the education for children without disabilities remains the same. Furthermore there is a lack of understanding the heterogeneity of children in areas of gender issues, ethnicity, nationality, social classes, and religion. To achieve the participation of all children the term Inclusion was developed which is a renunciation of the two- group theory.⁴⁶¹

Inclusion is *"a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities and reducing exclusion within and from education."*⁴⁶²

The MOEST defines inclusive education as *"... it addresses the learners' needs within the mainstream school and advocates for all children, regardless of their disability, to access quality education in their neighborhood schools, together with their brothers and sisters."*⁴⁶³

⁴⁵⁶ cf. Deppe-Wolfinger 2008: <http://bidok.uibk.ac.at...>

⁴⁵⁷ cf. Pumm 1996: <http://bidok.uibk.ac.at...>

⁴⁵⁸ Dyson in Munaizel et al. 2003:40

⁴⁵⁹ cf. Anupam in Hegarty, Mithu 2002:80

⁴⁶⁰ Dyson in Munaizel et al. 2003:38,39

⁴⁶¹ cf. Deppe-Wolfinger 2008: <http://bidok.uibk.ac.at...>

⁴⁶² UNESCO a: <http://unesdoc.unesco.org...p.13>

⁴⁶³ MOEST b 2003:3

Therefore the aim is no longer only integration of one group, rather a school for all where every individual child is also encouraged to avoid selection of children who come from deprived families. To achieve the goal of inclusiveness schools are supported by specialists like psychologists, social pedagogues, nurses and occupational counselors. As I have mentioned in Scandinavia as well as in Austria and German there exist successful implementations of inclusive education where all children participate in learning processes. Thus the main aim is that inclusive education becomes the norm in educational systems to avoid segregation of children in different kinds of schools⁴⁶⁴ where parents feel eliminated from education as a mother of a hearing impaired child in Austria recalled that the first time she felt rejected was when the disability was diagnosed and she was told that her child will never speak like a “normal” child, that her child will never be able to go to a “normal” kindergarten or “normal” school.⁴⁶⁵

In German speaking areas parents of children with disabilities can choose between special schools and integration classes within regular schools. According to Pitschmann who made an empirical study about attitudes of parents towards special schools and integration classes in Austria, the choice of the school is highly dependent on the type of disability, the age of the child and on experiences which parents have already made in any school type.⁴⁶⁶

As far as I know integration and inclusive education could be successful models if it is implemented with enough resources which means enough teachers, individual working materials, individual psychological care which are very costly⁴⁶⁷ and therefore not available in all schools. Very important is the knowledge concerning creativity strategies that children interact with each other by having fun together. Especially in developing countries Werner recommends to build playgrounds made of local resources which can be helpful to develop skills. Role games are important for children to put themselves in the position of other children with different needs, and toys can be produced of local resources, etc.⁴⁶⁸ Another way to help children gain appreciation of the disabled child and learn ways to be helpful is through child-to-child activities which means that children learn ways to protect the health and well being of other children- especially younger ones and those with special needs. The children learn simple preventive and curative measures appropriate to their life situation in their community. They pass what they learn to other children and families. This programme was developed in 1979 during the international year of the child.⁴⁶⁹

⁴⁶⁴ cf. Deppe-Wolfinger 2008: <http://bidok.uibk.ac.at...>

⁴⁶⁵ cf. Pumm 1996: <http://bidok.uibk.ac.at...>

⁴⁶⁶ cf. Pitschmann 2003:8,10

⁴⁶⁷ cf. Inclusive education a 2003:4 <http://www.european-agency.org...>, Pitschmann 2003:53f

⁴⁶⁸ cf. Werner 2003:455,467

⁴⁶⁹ cf. Werner 2003:427

5.2.2 *Integration and inclusive education in Austria*

In Austria there are many different models of how to implement integration or inclusive education and not all are suitable. Nevertheless although I can only talk about my training periods in special schools and integration classes, I saw successful as well as disputable implementations of integration or inclusive education. This success depends on the cooperation and communication between teachers who are working together in a class. That is why in primary schools, where children have the same teachers the whole day, it is much easier to work as a team and discuss the whole class.

In secondary school the situation differs from primary education because children are educated by various teachers depending on how many subjects they are taught. In integration classes at secondary level there are usually special education teachers who care in all subjects for the children with special needs but he/she is also responsible for the other kids. The main challenge is in fact that all other teachers who are responsible for the non disabled children, are changing every lesson. In other words to communicate and cooperate within teachers becomes a major problem. Nevertheless there are secondary classes where teachers work as a team successfully and meet frequently to discuss and develop the curriculums for the individual child. Sometimes it is necessary that teachers meet in their free time which is not easy to organize and they are not paid for it.

I should like to repeat once again that the type of disability of the child influences the attitudes of parents towards integration because there are classes in Austria where teachers achieved great progress concerning e.g. cognitive and social aspects in the field of inclusion of children with behavioral challenges such as aggressive behavior against classmates.⁴⁷⁰ On the one hand there is a general acceptance that the children with mild disabilities should be integrated in regular classrooms whereas the inclusion of all students with disabilities is not without critics.

There can be practical problems of everyday routines because severe and multiple disabilities or children with challenging behavior require a high degree of physical care and management, compared to children with milder disabilities like learning disabilities who present fewer problems.⁴⁷¹

⁴⁷⁰ cf. Inclusive education a 2003:6 <http://www.european-agency.org...>

⁴⁷¹ cf. Westwood 2007:4

Pitschmann stated that the majority of parents of children with disabilities see integration as not only important for the social, emotional and personality development but also for the learning progress. These parents think that children with all forms of disabilities should be integrated in regular classes whereas parents from non disabled children mentioned that only children with slight impairments should be integrated or it should be free to choose in which school parents want to enroll their child. Another reason why parents enroll their child in a special school might be that they do not want to accept that their child is disabled. Therefore they may prefer to send their child to a regular school.

There are various advantages and disadvantages of integration or inclusive education. The benefits are that parents of children with disabilities can see success if they recognize that their child can learn in a regular school environment. It is a possibility to raise self perception because of contacts to non- disabled peers. But on the other hand parents also fear not enough advancement and therapies for their children with disabilities in an integration class or the daily remembering that the child is disabled; they fear that their children could be stigmatized or rejected.⁴⁷² In general across many countries, recent reviews of the research literature on integration and inclusive education have demonstrated that children with disabilities can achieve higher academic standards in integrated settings although there is also the question if the self-concept of the child may suffer. This idea challenges the practices in the field of inclusive education.⁴⁷³

In my training period in Vienna I only saw one disputable implementation of integration at secondary level where the special needs education teacher claimed that other teachers do not communicate and cooperate with her. The children with disabilities were taken out of the class in subjects as Mathematics, German and English. In principle it is sometimes necessary but it is difficult to handle these children in a way that they do not realize that they cannot follow the curriculum of the other kids.

To include children with disabilities in regular schools is important because to have the chance to finish at secondary level avoids the stigma of special school graduation when they are searching for an employment in the future.⁴⁷⁴

⁴⁷² cf. Pitschmann 2003:16,36

⁴⁷³ cf. Anupam in Hegarty, Mithu 2002:79

⁴⁷⁴ cf. Inclusive education a 2003:6 <http://www.european-agency.org...>, Pitschmann 2003:16f, Dyson in Munaizel et al. 2003:39

Another significant point is that parents of children with disabilities could believe that the child could try to compare his/her school performance with the non- disabled and that they become frustrated. Although some parents worry about these circumstances and therefore prefer to send their children to special schools, there are also some who maintain that the child can benefit from heterogeneity in classes because they see it as a possibility to cope with mainstream society in the future. Moreover participation in youth culture involves the maintenance of friendships, networks and relationships with peers.⁴⁷⁵ Most probably the non- disabled children can benefit from the environment as well because their attitudes to children with disabilities can develop in a positive way. Therefore most of the parents with non- disabled children, in the study of Pitschmann, have positive attitudes to integration classes in regular schools. Nevertheless there are also parents who fear that children with disabilities could stress their non disabled peers, especially children with behavioral challenges.⁴⁷⁶

To avoid that children start to compete and stress each other general factors for successful inclusion are the following: *“Strong leadership on the part of the school principal; development of a whole-school policy supportive of inclusion; positive attitudes in staff, parents and children towards students with disabilities; commitment on the part of all staff to work collaboratively and to share expertise; development of mutual support networks among staff; regular assistance from paraprofessionals (classroom aides and assistants); adaptation of curriculum and teaching methods (differentiation); effective links with outside agencies and services; adequate resourcing in terms of materials and personnel; ongoing training and professional development for staff; close liaison with parents; direct parental involvement in a child’s educational programme, where possible.”*⁴⁷⁷

Moreover it is important that there are not too many children with special needs in an integration class, because to achieve the best, children need space and teachers who are not overstrained. The opposite is happening in some classes in Vienna where 10 children with special needs out of circa 28 children can be the norm. Nevertheless there are other experiences too as I read in the country report of inclusive education at secondary level in Austria that there also exist classes with 5 children with special needs out of 25 children.⁴⁷⁸

⁴⁷⁵ cf. Priestley 2003:91

⁴⁷⁶ cf. Pitschmann 2003:19,21,25,26,30,31,72

⁴⁷⁷ Westwood 2007:5

⁴⁷⁸ cf. Inclusive education b 2003:9 <http://www.european-agency.org...>

In general there is a higher acceptance on children with physical impairments compared to children with behavioral challenges. The minority of parents of disabled and non-disabled children and also teachers believe that children with multiple disabilities are not integrable. Parents and teachers who have experiences with integration of children with multiple disabilities feel it is challenging but the children benefit. In other words attitudes lead to insecurity and decline which could be reduced.

In general to find out if a child could be integrated or not is also dependent on personal and behavioral characteristics and on how much time the child needs. Another aspect is that even if the child is cognitive appropriate to his/her age but his/her behavior is conspicuous and bothersome, some people might think it is maybe not integrable. According to my opinion, I think all children are integrable if teachers and their supporters are convinced of what they are doing. Another aspect is school achievement which becomes more important when children are getting older because deficits become more visible.⁴⁷⁹

In developing countries, where children in special institutions stay there for months, often without any contact to their family, they may become isolated from social life and therefore find it difficult to adjust to life in their communities when they go back there.⁴⁸⁰ Therefore schools which are far from home do weaken the link between the school and its local community.⁴⁸¹ The same happens in developed countries when children with disabilities who are brought in special schools, separated from their families, friends and community, experience a separation from society that has almost become as permanent as their physical condition. Rehabilitation services or other institutions, they usually move from one kind of separation to another and remain therefore liminal.⁴⁸² *"It is then that they learn that disability refers less to a condition of their bodies than to an imposition by society"*⁴⁸³ ... *an arrestment in life history that is dramatized in a rite of passage frozen in its liminal stage.*⁴⁸⁴

To counter such effects, in Kenya they offer special education in regular schools and started to implement the model of inclusive education.

The success of integration is dependent on the attitudes the teachers have and how they are communicate. It is the key for acceptance in a group. In general the following factors are important to implement integration namely attitudes, resources and curriculum requirements whereas teachers and parents have different preferences.

⁴⁷⁹ cf. Pitschmann 2003:34,35,39,107

⁴⁸⁰ cf. Ingstad, Whyte 1995:22

⁴⁸¹ cf. Dyson in Munaizel et al. 2003:42

⁴⁸² cf. Murphy et al. 1988:240

⁴⁸³ Murphy et al. 1988:240f

⁴⁸⁴ Murphy et al. 1988:241

In Austria there are also parents whose children started in integration classes and later continued in special schools. As I have mentioned, children can become depressed when they start to compete with their non-disabled counterparts. It can be said that most parents from both disabled and non-disabled children do not complain about the idea of integration, rather about implementations, certain aspects and circumstances of the individual school. It is important that teachers are available to talk to parents, to help them to understand their fears and to reduce them because sometimes parents feel left alone. Parents of disabled children often wish for more profitable discussions. They ask for further training of teachers in special needs education whereas others ask for more flexibility, open-heartedness, empathy and communication.⁴⁸⁵

Lack of awareness of disability issues can lead to fear of the unknown. Therefore it is important that teachers are aware of the diversity of learners in their personal characteristics, behavior, interests and learning aptitudes because assumptions that they are all the same can lead to negative stereotyping of particular groups of children with disabilities.⁴⁸⁶

As I have mentioned at primary level it is easier to implement integration because teachers work together the whole day. They have the opportunity to care and look after one class.

In Austria there exist different learning models developed by e.g. Montessori and Freinet. I want to mention the “open learning techniques” developed by Freinet which offers an education environment where children can choose what they want to learn, they can take the time they need, choose their place where they want to learn and have the choice to work alone or in a group. Therefore if they feel uncomfortable in their learning environment they can change the place if it is e.g. too noisy. In such an atmosphere children learn from each other in an equal learning environment. There is a sort of time frame and exercises which the children should fulfill, developed by teachers on the knowledge of the individual strengths of the child.

I cannot say if it is the best model for all children but in my training period I saw integration as well as special classes where this model was implemented and the children helped and supported each other in learning processes in a way which was really impressing. Their social behavior was well developed and the non-disabled took care of the disabled children. Moreover children can make friends with their disabled classmates and vice versa.⁴⁸⁷

⁴⁸⁵ cf. Pitschmann 2003:47,48,49

⁴⁸⁶ cf. Westwood 2007:17

⁴⁸⁷ cf. Inclusive education a 2003:7 <http://www.european-agency.org...>

Both reports on inclusive education in Austria show that parents of all children are satisfied that their children interact and support each other in different ways as e.g. one girl *“assists a disabled boy to board the bus every day, which would teach her to become reliable.”*⁴⁸⁸

Pitschmann comes to the conclusion that parents of children in integrated classes as well as those of special schools think that to find non disabled friends could be possible in regular classes. In general parents are more concerned about the social aspect rather than on learning progress. Another very important point is that if parents put their child in an integration class, they expect advantages for the whole family⁴⁸⁹ and they noticed the impact on advances in independence at home because in an open learning environment the children with special needs learn how to work alone and how to use a time frame.⁴⁹⁰ In my own experience I had the impression that nearly all children benefited from this model of “open learning” because they do not feel under pressure to achieve learning goals. There is no competition between the children because they know that all learners are different and individual and have their own exercises to fulfill. The majorities of parents with children with disabilities who are in an integration class do not compare their children with the non- disabled and furthermore do not see the school environment as competing.⁴⁹¹

The children learn to be considerate of all others and they get to know children who have different needs. Assumptions are playing, working and learning should be planned with all children in mind and that all children can participate. Teachers are working together and develop strategies which include all children in every subject.

In some classes educational psychologist are supporting the children, especially those with emotional and social behavioral challenges. These are specialists who work on the basis of psychotherapeutic knowledge and talk with the children and their guardians as well as with teachers.⁴⁹² Nevertheless parents fear as I have already mentioned that their children with disabilities receive not enough attention from teachers and experts in integration classes. Another aspect is that in both primary and secondary level teachers encounter difficulties in the financial situation for their classes. That is why schools often raise financial support from parents⁴⁹³ which could be very problematic if the children come from lower income families.

⁴⁸⁸ Inclusive education b 2003:6 <http://www.european-agency.org...>

⁴⁸⁹ cf. Pitschmann 2003:18,48

⁴⁹⁰ cf. Inclusive education a 2003:9 <http://www.european-agency.org...>

⁴⁹¹ cf. Pitschmann 2003:18

⁴⁹² cf. Inclusive education a 2003:3 <http://www.european-agency.org...>

⁴⁹³ cf. Inclusive education b 2003:4,9 <http://www.european-agency.org...>

In some families parents of children with special needs do not take care of them at all, which means that these children have to be taught without the support of the parents.

Mostly it affects children from low income families where parents have not enough time to come to school and talk to teachers or support their children at home.

These circumstances are really challenging because cooperation between parents and teachers and naturally with the child is essential. It is necessary to provide the best information to the parents about the school and the models which are taught.⁴⁹⁴

According to my beliefs integration and inclusive education are very precious models of learning but there are also many challenges because not all schools have enough resources. Too many children with disabilities in a class, not enough teachers and materials etc. can make the situation even worse. In such cases I can understand why parents prefer to enroll their child in a special school. Nevertheless there are also successful models where children with and without disabilities benefit from the learning environment and from each other.

Another issue is how to meet the basic needs of children with e.g. intellectual disabilities for training in self-care, daily living skills and communication when they are placed in an environment where standard curriculum prevails. Although there are benefits in mainstream schools for them, these children are taught issues which are maybe not very relevant to them. Functional skills sometimes receive limited attention. Therefore for some children special schools may offer the best environment to meet their needs⁴⁹⁵ but it depends on the type of the school. On the one hand there are "Allgemeine Sonderschulen"⁴⁹⁶ where children with learning disabilities as well as children with behavioral challenges are enrolled. I made one of my training periods in a school of that kind and I made the experience that the children come from different social backgrounds. They were enrolled due to different reasons- some because of their mental and/or behavioral problems and some because they could not speak German. Most of the children were aware of being in a special school and of their future perspectives. They knew that they had not reached the same aims as their peers in regular schools. To avoid the stigma of special school graduation when they are searching for an employment in the future⁴⁹⁷, these children could have been enrolled in an integration class. I have to state that I have neither experience with special schools for children with physical disabilities or multiple disabilities nor with their integration in regular classes.

⁴⁹⁴ cf. Pitschmann 2003:24

⁴⁹⁵ cf. Westwood 2007:19

⁴⁹⁶ „general special school“

⁴⁹⁷ cf. Pitschmann 2003:16

Therefore I have not seen myself which school form will achieve the best for a disabled child, but I think parents should have the right (which allows them) to choose between both- integration classes or special schools.

The situation in developing countries is much more difficult because there are not enough resources to fulfill the implementation of inclusive learning. Parents of children with disabilities in developing countries who are not able to afford special schools, can only try to put their children in regular classes and hope that they do not drop out or are expelled from school. Teachers in regular schools in Kenya are not able to take care of these children because on the one hand they have no time because of high pupil numbers and on the other hand they are not specialized and thus do not know how to handle them. That is why parents with children with disabilities in Kenya, when they get the chance, put their child in a special school because there they are definitely better cared for than in a regular school or special unit. Whereas in an inclusive school, even in developing countries, if the school has resources, works together with parents and guardians, if teachers are sensitive on the issue disability, I assume that it would be a model for a sustainable inclusive environment.

In my own experience in two special schools in Nairobi (Jacaranda Special School and Dagoretti Children's center) I realized that the children are treated very professionally. They receive all kind of therapies, the schools care for alimentation, lessons are planned especially for the child's disability and teachers are able to concentrate on a small number of children. Therefore if parents are able to afford a special school or if they get the chance to enroll their child for free, it is definitely the better option. But the situation differs in rural areas because special schools are far away and parents do not want to take their children many kilometers far from home where it is often not possible to visit them. The same I realized in Austria, especially parents from rural areas see an advantage in integration classes because of shorter ways to schools.⁴⁹⁸

Beside the fact that special schools in Kenya are not affordable for the majority of parents with children with disabilities, inclusive education would be an option to avoid children out of school. In Kenya if children with disabilities drop out or are expelled from regular schools, there is often no school where these children can be enrolled.

These factors lead to exclusion because regular schools are unable to address the diversity of learners. Nevertheless to avoid children out of schools an option is inclusive education where children can stay in their community and interact with their non disabled peers.

⁴⁹⁸ cf. Pitschmann 2003:19

But I should like to repeat once again that the participation is limited by factors like attitudes and values, lack of understanding, lack of necessary skills, limited resources and inappropriate organization. Therefore elements like clarity of purpose, realistic goals, motivation, support, resources, accessibility and evaluations are very important. The following steps should be taken to achieve inclusive education: All pupils should take part in all subjects and activities, teaching and learning should be planned with all pupils in mind, a curriculum should be developed which understands and respects differences as well as other cultures, pupils should experience success in learning processes, especially together, and difficulties should be seen as opportunities.⁴⁹⁹ This new perspective on special needs education is based upon the view that the way forward has to be to *“reform schools in ways that will make them respond positively to pupil diversity, seeking individual differences as something to be nurtured and celebrated.”*⁵⁰⁰

There are many training approaches developed by pedagogues for students with different educational needs. Children with intellectual disabilities e.g. need a reality based curriculum and the concept of “learning by doing” may be the best for this group of learners. Students with physical disabilities are not necessarily intellectually disabled. Therefore this group of learners can participate in the regular curriculum if the lessons are planned with assistive devices in mind as e.g. visual or hearing aids. Therefore it is important that these children have the same opportunities to access the same range of experiences as those students without disabilities. Assistive technology (AT) plays a major role for children with disabilities to participate and communicate and to facilitate access to the curriculum.⁵⁰¹ To implement successful inclusive education there are different strategies for mainstream teachers to avoid segregation, frustration, exclusion, and overstrained and under challenged children. Just to mention some points for teachers: the hearing impaired should always be supported by visual aids and the teacher should never talk in a position where the child cannot see him/her. The visual impaired need to be taught mobility skills for orientation. Therefore it is important not to change the class situation or to place the child near noises (like window place). In general it is important to train other students to assist the children with disabilities as e.g. to support the students with impaired vision by note taking, repeating and explanations.⁵⁰²

⁴⁹⁹ cf. UNESCO a: <http://unesdoc.unesco.org...p.20,30>

⁵⁰⁰ Anupam in Hegarty, Mithu 2002:81

⁵⁰¹ cf. Westwood 2007:23,34,35

⁵⁰² cf. Westwood 2007:40,41,44

Another important issue is to improve social skills in peer group acceptance because integration and inclusive education will not automatically lead to social integration into a peer group. Due to observation it is important that teachers are able to identify as soon as possible if any child in the class appears to be without friends and to identify children with problems in social interactions.⁵⁰³ Furthermore it is important to influence the attitudes children have by building a climate of respect for individual differences. The following activities may be beneficial for children to improve their attitudes: *“viewing videos depicting children and adults with disabilities coping well and doing everyday things, reading and discussing stories about disabled persons and their achievements, conducting factual lessons and discussions about particular disabilities”*⁵⁰⁴, etc. Another important strategy is the one of “circle of friends” where a group of children supports the child with disability to solve problems that may arise. Five or six students volunteer as a group and have to fulfill activities like to greet the child, to be friendly and helpful at all times and to assist with routines at lunch and break times. The members meet frequently to set goals and devise possible strategies. They should also report the progress in a week to the teacher and discuss the problems that may arise.⁵⁰⁵

5.2.3 Integration and inclusive education in Kenya

In Kenya there is an inclusive education programme and it is the first of its kind. This programme is called Oriang Cheshire Inclusive Education Project (OCIEP) and it is supported by Leonard Cheshire International (LCI) an organization which cares for disabled people around the world. The programme is offered in five schools in Oriang, Western Kenya and includes 2568 children from whom 565 are disabled. Although this programme has changed the lives of many Kenyan children in a positive way, there is a lack of teaching/learning resources. The programme is based on a community based participatory approach and their aim is an inclusive environment. They provide aids and devices, change the attitudes among children with disabilities, and uplift the communities in socio- economic areas.⁵⁰⁶ With the help of community members and teachers, the Otondo primary school was made accessible for physically challenged children by building an accessible toilet, painting the walls, building ramps, flattening floors and level paths, which makes the access easier for children with mobility impairments. The walls were painted white to introduce more light for the visually disabled. Trees in the grounds were used to build more classroom furniture.

⁵⁰³ cf. Westwood 2007:80,81

⁵⁰⁴ Westwood 2007:84

⁵⁰⁵ cf. Westwood 2007:83f,84f

⁵⁰⁶ cf. LCD a: <http://www.lcint.org...>

Not all children sit on chairs but only a few remain sitting on the mud floor. All these activities were carried out with the help of the members at Otondo primary school, which has a ten-member committee made up of community workers, health workers, parents of children with disabilities, and members of the school management committee. In addition they go to villages to identify disabled children and recommend to parents to send them to school. Another issue is child- to- child support because the children recognized the importance of supporting each other. For example when a boy with epilepsy starts to have a seizure , the other children remove any potentially dangerous objects, like furniture or stones. The children stand by the boy until the seizure stops. Besides, the learning environment is very comfortable for the children because they sit and work in groups rather than rows, shops were built to learn about using money and assembling miniature gardens were set up to learn about environment.⁵⁰⁷

Although just a few children with disabilities from neighboring districts are living in a home attending Oriang primary school, and although teachers and materials are lacking to support the children, the project has already included a few children and they have ideas how to implement inclusive education in Kenya.⁵⁰⁸

5.2.4 Lack of teachers in special needs education

In Kenya there is a lack of resources in special needs education, especially of available teachers. Only 20 percent of teachers have necessary training in special needs education. In consequence there is a shortage of trained teachers in all special schools and special programmes.⁵⁰⁹ The same stated Simon Gichuhi: *"What people think; or what the government has done in our normal schools is that teachers have not been trained to handle these special children."*⁵¹⁰

The average number of pupils in a class is 55 instead of 10. That is why it is nearly impossible to distinguish between the individual. Furthermore in regular schools there is no second teacher and thus no professional who is able to care for children with disabilities.⁵¹¹ In some regular schools some children stay in one class without making progress, in particular in units for learners with mental and hearing impairments.⁵¹²

⁵⁰⁷ cf. Leonard Cheshire's quarterly Magazine Issue 20.2004

⁵⁰⁸ cf. Orpa Ogot 2008:5 www.lcint.org...

⁵⁰⁹ cf. UNESCO c: <http://www.unesco.org...>

⁵¹⁰ Interview Simon Gichuhi- CVO 30.8.2007

⁵¹¹ cf. HDI: <http://www.afdb.org...p.19>

⁵¹² cf. MOEST a 2003:53

A mother of a child who has intellectual disabilities and speech problems due to a heavy tongue pointed out, that she put her child in a special unit because the doctor had recommended that to her. However, this special unit is far from home and the girl cannot make any progress because she still remains in one class. The girl will stay in this class until she feels tired or until she is getting too old.⁵¹³

In Kenya more teachers should be trained and integration classes need a teacher aide for learners with mental challenges. It would be important to support such teachers by readers and sign language interpreters in regular classes. In Nairobi Province there are only five special schools and 15 special units. Although there are only these 20 institutions the teacher- learner ratio is 1:9 which is very effectual compared to Malindi at the coast which has a ratio of 1:195! Teachers for special needs education are trained mainly at the KISE, Kenyatta and Maseno Universities. Since they were established, they have trained 4255 teachers in special needs education and 5700 in a distance learning programme from KISE which is weighed against 1.8 million learners with special needs. That is why the demand of teachers trained in special needs education is very high.⁵¹⁴ Distance education was introduced to reach teachers all over the country. It is characterized by students receiving written and sometimes recorded self-instructional study materials with aids for revision and exercises for self checking.⁵¹⁵

When schools fail to provide trained teachers, moral support and learning advancement, the education system segregates children who cannot follow the mainstream. Diversity has to be addressed, but teachers cannot be prepared for all possibilities they find in schools, in particular when there are just a few materials and when children come to school malnourished, abused and without any experience of intellectual stimulation. This can lead to a teacher's burn out. Devaluation of teaching and teachers takes place. In other words there is a high demand of creativity strategies because it is difficult to interact with children who are vulnerable, culturally and linguistically different and especially when they do not come frequently because of helping at home.⁵¹⁶

Moreover the number of persons with disabilities who can act as role models in a teaching profession is very small because trained teachers with disabilities are not preferred in employment just like their non- disabled counterparts.⁵¹⁷

⁵¹³ cf. Interview mother of B. 13.8.2007

⁵¹⁴ cf. MOEST a 2003:2,36,37

⁵¹⁵ cf. Kwa Yalo 1992:6

⁵¹⁶ cf. Bernard 2000:7,9 <http://unesdoc.unesco.org...>

⁵¹⁷ cf. MOEST a 2003:39,51

5.3 History of special education in Kenya

Special schools and programmes were pioneered by churches and voluntary and charitable organizations including the Catholic church, the Salvation army, the Presbyterian church of East Africa, the Methodist church of Kenya, the African inland church and the church of the province of Kenya. The churches sometimes worked together with independent organizations as the Kenya Society for the Blind, the Kenya Society for the Deaf children, the Association for the disabled people in Kenya, and the Kenyan society for the mentally handicapped. Civic organizations like the Round Tables, Rotary International, and the Lions Club also contributed to the building of special schools.⁵¹⁸ Before Kenya became independent in 1963 the first one Thika school for the blind was developed which was founded in 1946, followed by St. Nicholas special school for the mentally handicapped in 1948 (today Jacaranda special school), Aga Khan unit for deaf children in Mombasa and Egoji school for the blind (today St. Lucy) in 1958⁵¹⁹, for the physically disabled in Dagoretti in 1961 and Joytown Thika in 1962. Kenya offers both segregated and integrated special needs education.

In 1964 the Kenya Education Commission was founded to investigate the formulation and implementation of national policies regarding the needs of children with special needs. Although the commission first addressed the importance of special education in 1964, the government did not take an active role until the mid 1970s. Special education was pioneered by NGOs, with the education of visually impaired which were the first schools to receive attention from the Salvation army. The second area was the education of mentally handicapped followed by education of the hearing and physically impaired.⁵²⁰

Integration was introduced in the 1970s mainly for learners with mental disabilities and hearing impairments. Children with physical disabilities came to small homes which cater for disabled children who live in these homes near their community and near schools to access education and to become integrated in the community. The children live with a foster mother and parents should cooperate and support the children and take them home in the holidays.⁵²¹ The Kenya integrated education programme (KIEP) for learners with visual impairments was emulated by Lutheran and Catholic churches.⁵²²

⁵¹⁸ cf. Ndurumo 1993:14

⁵¹⁹ cf. Thoneick 1984:56, MOEST a 2003:10

⁵²⁰ cf. Ndurumo 1993:31

⁵²¹ cf. Geiser 1986:122,124

⁵²² cf. MOEST a 2003:10f

Rehabilitation programmes are mostly connected with rehabilitation schools and with community based programmes. Centers exist such as Nyabondo, Bombolulu, and Mbagathi.⁵²³

Many problems were experienced like lack of preparation by schools, lack of resources, and lack of adapted curriculum. Even today the regular curriculum is insensitive to the needs of children with special needs.⁵²⁴ The communities were not informed of what their roles would be and the children did not understand why they were being moved from their special schools to regular ones.

Traditionally in Kenya, the government in collaboration with churches and NGOs has provided special education. Today special needs education services are now offered by programmes such as special schools, special units, integrated, small homes programmes, KISE, rehabilitation, vocational, teacher's training colleges, universities and through support services.⁵²⁵ In 1975 the special education section was established in the MOEST; categories were set up later.⁵²⁶

5.4 Categorization of children with special needs in education

Four categories of education of children with special needs are offered by the Kenyan government in special schools, special units, integrated programmes and regular schools. These are the following categories of learners in special schools namely children with hearing impairments, visual impairments, mentally disabled children, physically disabled children, deaf and blind children. The physical environment and educational resources are modified to meet the needs of these specific groups of learners.

Special units are classrooms located in regular schools but for a specific type of disability namely learners with mental disabilities and those with hearing impairments. Integrated programmes are for learners with visual impairments and to some extent for those with physical disabilities. The Kenya Educational Integrated Programme (KIEP) facilitated these programmes for visually impaired children.

Children with disabilities may receive rehabilitation services in rehabilitation centers and rehabilitation schools like Nyabondo, Bombolulu, and Mbagathi. Rehabilitation schools were known as borstal schools and include institutions like Kabete and Kirigiti.

⁵²³ cf. MOEST a 2003:10f

⁵²⁴ cf. UNESCO c: <http://www.unesco.org...>

⁵²⁵ cf. MOEST a 2003:8,9

⁵²⁶ cf. Grut, Ingstad 2007:12 <http://siteresources.worldbank.org...>

These programmes are under the Ministry of Home Affairs and their emphasis is more on corrective and behavioral reforms rather than educational services. Community based rehabilitation is offered in homes by community based organizations. These programmes are facilitated by Volunteer Service Organization (VSO) through Educational Assessment and Resource Services (EARSs). CBR is an alternative to institutions which are not achievable for the majority because of transport costs.

The concept of CBR is based on low costs for people who are affected, simple technology, use of local resources and community participation. Rehabilitation aids should be made of local materials, family members should train their disabled children in activities in daily living, and schools, workplaces, and neighborhoods should be sensitized to include their disabled community members.⁵²⁷ The model of CBR was introduced to leave disabled children and young people with disabilities in their families and communities, to avoid exclusion by enrolling them in special institutions which are most of the time far away and lead to cultural isolation.⁵²⁸ CBR includes preventative arrangements like hygiene, balanced diets, preventive medical checkups, immunizations, sensitization of the community and initiation and accomplishment of activities where people with disabilities can participate. It includes assessment, counseling, communication skills, skills which are needed for daily life, physiotherapy, appropriation and creation of assistive devices, training mobility, inclusive education, vocational training, support in searching for an employment, governmental support, seminars and information about disability causes and consequences, and medical attendance.⁵²⁹

In Kenya there are 15 CBR programmes funded by various local and international organizations. Oriang inclusive education project is one of the 15⁵³⁰ which I have already described. For example APDK offers CBR through mobile clinics which assess and treat persons with disabilities, their parents, and guardians.⁵³¹ A team of rehabilitation workers visits the families and assesses the situation to come up with home based rehabilitation programmes. The families learn how to handle a disabled family member through an individual rehabilitation programme. APDK mainly caters for physically disabled people but they refer other cases to collaborate institutions.⁵³²

⁵²⁷ cf. Ingstad, Whyte 1995:22f

⁵²⁸ cf. Vespermann in Albrecht, Weigt 1993:229

⁵²⁹ cf. Ostermeier in Albrecht, Weigt 1993:119,122,124,125,126,127

⁵³⁰ cf. CAN 2006:10,11 <http://www.afri-can.org>

⁵³¹ cf. APDK Folder

⁵³² cf. Interview Duncan Mwangi- APDK 10.09.2007

Vocational programmes are offered for children and young people with visual impairments, hearing impairments, mental and physical disabilities as e.g. sheltered workshops like Jacaranda and Variety Village, vocational schools like Mumias and Nyand'oma, technical schools such as Karen Technical school for the deaf and Machakos institute for the blind. The KISE and primary teachers' colleges offer courses in special needs education for primary school teachers. Kenyatta, Nairobi, and Maseno University offer courses in special needs education in both secondary and primary schools.⁵³³

Children with hearing difficulties, communication difficulties, emotional and behavioral difficulties are left out. Furthermore orphaned children, children infected by HIV/Aids, street children, abandoned children, refugees, working children and gifted children are left out too. The demand for special needs education for all these children has increased. That is why the MOEST is in the process of implementing inclusive education to make education accessible to all children in Kenya.⁵³⁴ Exclusion has to be addressed by the creation of integrated learning systems, where all children can participate.⁵³⁵

5.5 Children with special needs in education

The National Development plan estimated that about 1, 3 million children aged between 0-15 years and 1, 8 million children aged 0-19 years have disabilities. There are no statistics according to age, sex or geographical distribution or degree of disability. The taskforce collected data from special schools, units, integrated programmes, district education officer(s), MOEST headquarters and EARS. It was found out that 26, 885 children with special needs were enrolled in the year 2003 (15, 129 boys and 11,756 girls).⁵³⁶

In Nairobi Province there are 968 children with disabilities enrolled in school: 176 hearing impaired, 129 visually impaired, 225 physically disabled, and 440 mentally disabled children. If you compare girls and boys, more boys are in school than girls in every type of disabilities. Compared to other provinces Nairobi has the least enrolment while Nyanza has the highest. From estimated 1, 8 million children with disabilities as I have mentioned only 26, 885 have a place in a school. Therefore 1, 75 million children are at home or in regular schools.

⁵³³ cf. MOEST a 2003:10,11f

⁵³⁴ cf. MOEST a 2003:1

⁵³⁵ cf. Bernard 2000:10 <http://unesdoc.unesco.org...>

⁵³⁶ cf. MOEST a 2003:17,18

Statistics from ordinary/regular schools found out that 10-15 percent of the children in regular classes are those with special needs in education. 7, 5 million children are in primary schools and it is estimated that between 800,000 and 1.9 million children with special needs education who are in regular classes have no necessary support.⁵³⁷ This data shows that in Kenya there are not enough special schools and special- units as a physical therapist from Dagoretti children's center commented: " *There are so many special schools but not enough.*"⁵³⁸

In addition Simon Gichuhi pointed out that: " *... we need more institutions because the one we have, the facilities becoming limited so that they can no longer meet the needs of these children. So we need to expand more institutions so that these children can learn without shortage of resources, without shortage of materials, without shortage of their time being affected ...*"⁵³⁹

5.6 Non- formal educational programmes

Non- formal educational programmes mainly cater for children who are not in school or those who are too old to join class one. They are run by individuals, faith-led organizations and local CBOs and NGOs. In most cases there is no educational curriculum. Therefore the aim of such programmes is to occupy the children by play activities, games, and sports to prevent them from being involved in criminal activities and to protect them from abuse. Like one social worker from an organization who started to care for disabled street children commented, it is very important to support these children to prevent abuse and mistreatment. He himself started a project where the social workers teach these children some skills by showing them e.g. songs that the children understand where their private parts are and that it is not okay when people touch them. They call it prevention and further they form prevention groups to bring the mentally challenged children together to share experiences.⁵⁴⁰

The main challenge is related to low quality education and the programmes are not linked to the formal education system. There is also a lack of adequate teaching and learning resources, poor physical facilities, and low prioritization by government in terms of financial support.⁵⁴¹

⁵³⁷ cf. MOEST a 2003:19,20

⁵³⁸ cf. Interview Josephat Gichana- DCC 4.9.2007

⁵³⁹ Interview Simon Gichuhi- CVO 30.8.2007

⁵⁴⁰ cf. Short Interview Kenneth Ndua- Food for the Hungry 8.9.2007

⁵⁴¹ cf. UNESCO f: <http://www.ibe.unesco.org...p.10>

Above all these organizations sometimes provide identification, counseling and community mobilization and sensitization.⁵⁴² The community based organization CVO which I have worked with provides education for children with special needs. Although teachers are not trained as special needs teachers or as teachers at all, they try to give their best to offer these children education. The activities range from singing, teaching subjects like mathematics and english to playing soccer and games on the field of the church.

The education, which CVO offers, faces many challenges because not all social workers are trained as teachers. Moreover sometimes 70 children (depending on the weather) come to class with various special needs, which is difficult to handle. Furthermore they talk different languages and mix their mother tongue with Kiswahili. The children do not come punctually which means that there is a lot of unrest in class. Therefore it is difficult for the children to concentrate. The major problem is that there are just a few tables and seats and children have to learn on the floor.

⁵⁴² cf. MOEST a 2003:22,69

6. Conclusion

In this MA- Thesis I have analyzed the situation of children and young people with disabilities in Kenya, especially in a small area in the suburbs of Nairobi. In order to understand the complexity of the situation I have focused on factors which limit 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 areas.

There are of course underrepresented voices in this thesis because as I have mentioned above I only talked to a small number of people. The chapters illustrate biographical influences: impairment, family, advocacy, experiences of inaccessibility and discrimination, barriers, social, and political issues concerning a vulnerable group in a country in the developing world. In the first chapter I focused on how disability is defined internationally to understand classification systems which are given by the WHO, and the arguments offered by scholars and activists working in the field of disability studies. 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. 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 present a catastrophe, a condition to be hidden, like in some families I have described, as well as a symbol of self- identity and self worth as e.g. Salome from UDEK who founded an organization to empower people with disabilities in Kenya.

Furthermore I have analyzed the international policy agenda to give an overview of political activism among the disabled, in general, during the last years. The history of disability studies made me understand which models exist and who pioneered the field. The disability movement swung 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. According to Oliver, 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.

Therefore the social model explains how social barriers limit the participation of disabled people in all cultures but it does not explain what it means to be a disabled person in modern society, how people experience their impairments, and furthermore, it does not say anything about the differences among the disabled themselves. It could be asked what kind of impact these differences might have on the identity. According to the social model disability leads to social exclusion because of barriers which oppress them. It replaced the medical model, which stands for the dominance of professionals. Anyway although the social model can explain how social barriers and inaccessibility lead to exclusion from society, however the number of disabled people becomes irrelevant if disability is just seen as a product of structural exclusion. Furthermore if disabled people share a common experience of oppression, regardless of their impairment, as black people share a common experience of racism, the forms of therapy could be regarded with skepticism. And, as indicated, it conceals the heterogeneity of disabled people in general and as a result, the distinction between disability and impairment within the social model hinders the explanation of psychological and physical consequences of the individual which are as important as social barriers.

Personally I see disability as a combination of both models- the individual and the social model because on the one hand the situation of a person with disability depends on the individual life situation as well as it relies on social circumstances. Therefore in my opinion people with disabilities are disabled by society and by their bodies; e.g. a person with hearing impairment who work on the field may not feel disabled by society when he/she is able to fulfill his/her requirements as a farmer.

Nevertheless the social model is a good theoretical framework to analyze the situation especially in a developing country like Kenya because nearly all resources are inaccessible, and the life of the majority of disabled people is limited by social barriers as well as by a wide range of factors such as poverty, cultural attitudes, and socio- economic conditions and so on. The Kenyan national survey for persons with disabilities figured out that environmental factors such as temperature, terrain, inaccessibility of transport, climate, noise, etc. can hinder a person in various activities like working, going to school, taking care of one's home, and being involved in social, recreational and civic activities in the community. 64, 8 percent of people with disabilities said that environment is a major problem in their daily activities. In addition the majority of children and young people see environmental factors as a major problem (0-14years 67, 2 percent and 15-24 years 64, 6 percent).

Therefore people with disabilities face a lot of challenges due to communication barriers, inaccessibility to buildings, transport and locomotion, no access to information because of computers which are inaccessible to people with vision impairments, no independent mobility for blind people because they cannot move in the traffic alone, and so on.

It will take a long time to achieve participation of disabled people in mainstream society and to achieve an inclusive environment, because people with disabilities in Kenya still remain invisible in all fields of life.

The concept of “liminality” as well as “the social model” may help to understand that disability is partly socially constructed, 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. In many non western countries puberty rites mark the transition from childhood to adulthood and thus children come back as adults whereas after rehabilitation service or other institutions like special schools, they usually move from one kind of separation to another and remain therefore liminal. Disability refers therefore less to a condition of the bodies than to an imposition by society. In other words disabled people are frozen in a liminal stage.

80 percent of the disabled people in the world live in developing countries caused by different factors, such as diseases, inhumane work conditions, war, accidents, lack of prenatal care, inaccessibility to the health care system, environmental factors such as pollution, the consequences of malnutrition and also by birth so on.

Disabled children and young people in developing countries are the most excluded group in all societies. Without future perspectives they suffer silently, mostly at home marked by the lack of nutrition, health care and education as well as negative attitudes and the lack of pleasure and fun with their peers – issues that would be important for children and young people in general. Inaccessibility to schools exclude them from the education system and therefore from their peers. 150 million children with disabilities live worldwide and 98 percent of them in developing countries do not go to school. The results of no education are far- reaching when children with disabilities become young people without employment and future perspectives. They are depressed and overrepresented in the ranks of the poor. Therefore the linkage between poverty and disability is bi- directional because poverty causes disability and disability causes poverty. Women and girls with disabilities suffer from double discrimination for being female and disabled. In Kenya women have a lower esteem and 80 percent of disabled women are single mothers due to the fact that fathers leave the families or disabled women got pregnant because of abuse.

In general worldwide disabled boys receive better attention than disabled girls and a better treatment and more opportunities. Globally the most frequently excluded children are girls. Gender is the major factor of being left out. Failures to make school safe and secure leads to an unsecure position for girls and children with disabilities who want to attend school. Because of domestic chores, caring for siblings or drop outs because of pregnancy, girls often cannot attend school. Two thirds of the 130 million primary aged children who do not attend school are girls. Also in Kenya more boys with special needs are enrolled in schools than girls (2003 15,129 boys, 11,756 girls).

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 mentioned above in developing countries 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 like blindness, leukemia, and epilepsy. In developing countries 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 countries.

Kenya is a country of 36 million people and it is estimated that 10 percent of the population is living with disabilities. Although this number is high these people remain underrepresented, not only in economy, employment, education and, health care but also at the political level.

One of the gravest socio- economic problems in Kenya is the labor market situation because 54 percent of the population is unemployed. Even much worse for people with disabilities of those who are employed the majority work in specific areas like traditional work as tailors, carpenters, recorders, car mechanics, farmers, artisans etc. and they have no good chances to advance or to cross industry lines. UDEK is an organization who fights against poverty to empower disabled people by providing computer courses. Salome, the director, pointed out that discrimination of employees also influences the unemployment rates of disabled people.

Furthermore girls and children with disabilities are vulnerable when it comes to possibilities of sexual abuse from casual sex partners and these girls and children are at risk of HIV/Aids. Above all because of high costs of medical treatment and medication for HIV/Aids and other diseases there is often no treatment at all to cure illnesses or diseases.

That is why not all groups suffer to the same extent because the low social status puts people at greater risk of health consequences. Social security grants like assistive devices or other forms of financial support are not available for the majority of people living with disabilities in Kenya. The Kenyan national survey for persons with disabilities figured out that 93 percent in rural areas and 87 percent in urban areas found it a major problem to survive without assistive devices. To escape from poverty is therefore often impossible.

Although there are many movements within the disabled and many institutions have been set up in the last years, at the political level they remain invisible. Therefore nobody can stand up for their rights in parliament where decisions are made. Although the Persons with Disability Act was founded in the year 2003, people with disabilities remain excluded from various fields of life and remain unrepresented at the political level.

Cultural, social, and family attitudes influence the life of children with disability. According to my informants in some areas in Kenya they are even killed or exposed, as well as abused, mistreated and neglected. However the majority of parents, to whom I have talked, are aware of the vulnerability of their children. They are searching for help and try to protect their children, even by hiding them to avoid discrimination and abuse. Parents often fear negative attitudes and do not know how to cope with that. Therefore they try to support their child in the best way possible and work hard to afford any assistance the child needs. I have made the experience that although parents have to handle their children without any resources and social support, they give their best to show love to their child and to develop their potential. Although most of the houses, which I have seen, were very poor, I had the impression that parents care for hygienic living standards, good nutrition and a little bit education as far as they know how to do. I have also met parents who see their disabled child as a gift because they argue that god wants them to raise this special child. They know that there is a potential in their children and that people can benefit from their sensibility and especially from how these children see the world. Therefore families are very important in Kenyan society, although fathers seem to abandon often their families. The family is often the only social security people, especially children, have, and on the other hand they share love, and friendship. To show how the individual family is dealing with a child with disabilities I have given some examples of families which I visited. I was concerned about their destiny and how they handle their situation. Although all of them live a really challenging life it seems that they make the best out of the situation to give the child a respectable life as far as they are able to. Although I have realized that most families take care of their disabled children social attitudes, discrimination and cultural beliefs influence the status of disabled people in Kenya.

Families often fear to be associated with witchcraft, bad omens, sorcery, myths, and beliefs about causes of disabilities which can bring negative attitudes and can lead to fear, insecurity and isolation from social life. Prejudices and discrimination are socially and culturally constructed and institutionalized and based on oppressive power relations. It is important to reconstruct these factors to understand the origins by including the perspectives of persons with disabilities themselves, their family members, and people who empower them.

In Kenya nearly all resources are unavailable for people with disabilities, like schools, health-care institutions, employment, NGOs, and training schools. Especially special schools are not affordable for the majority of parents of children with disabilities. Although the UN convention of the rights of the child from 1989 informs that all children have the right to education, millions of children still remain without, especially vulnerable ones as children with disabilities. Although primary education has been for free in Kenya since 2003 and many children with special needs have been enrolled in special schools, special units, and in regular schools, it does not guarantee education for the poorest ones because special education is still not for free. That is why many children with disabilities remain at home without any education. Integration and inclusive education could be models to offer education in regular schools in a way that disabled children can participate in various activities. For many children with disabilities in Kenya, especially in rural areas it is the only possibility to achieve education at all because special schools are expensive or often too far away. However the success of inclusive education is highly dependent on creativity strategies and attitudes of teachers, parents and the community as a whole. Moreover accessibility depends on available resources and the willingness of the participants to integrate disabled children. Because of lack of money, inaccessible curriculums, negative attitudes and a high teacher-pupils ratio, children with disabilities often drop-out of regular schools and have no other opportunity but to stay at home. That is one reason why I have identified a need of programmes to reach these families and improve their situations.

In general there is a serious limitation of access to basic needs. Even if parents of disabled children are willing to support their child they have often no opportunity to achieve any services to improve their situation. What can they do when the child is not able to walk to school, when the transport is not affordable, when you cannot reach the school building because of inaccessibility, when you are afraid that other children will tease your child and when there is no other option offered by society? And how should parents know how to deal with a disabled child in order to help the child to develop her/his abilities? Lack of counseling and information provided leads to hidden children and desperate parents.

CBR and inclusive education are models which can improve their situation when they reach people all over the country and when parents know that they can come out with their children in need. Moreover information about disability issues has to be provided through the media (radio, TV, newspaper) because people should be informed about health services like vaccinations and were to get them. Health care and rehabilitation are fundamental to improve the lives of people with disabilities and even if they are provided for free people have to be able to get to know about it and most important they have to reach the places where it is provided.

The awareness of disability issues can only rise if governments 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!**

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9. Interviews

Experts

Salome Kimata (Executive Director United Disability Empowerment in Kenya UDEK) 03.09.2007 and 19.9.2007

Duncan Mwangi Ndegwa (Executive Officer Association for the Physically Disabled of Kenya APDK) 10.09.2007

Kenneth Ndua Mitambo (Social Worker- Food for the Hungry) 8.9.2007 (Short Interview)

Josephat Gichana (Physical Therapist Dagoretti Childrens Centre DCC) 4.9.2007

Head of Assessment Department (HAD)- KISE 25.9.2007 (Short interview)

Worker Christian Vision Organization

Simon Gichuhi Kinyi (Project Co-Ordinator) 30.8.2007

Jedidah Wairimu (24 years) (Childrens Departement) 29.8.2007

Disabled themselves or their guardians

J.W.(24 years) (girl)(Physically challenged- hump) 5.9.2007

W. W.(female) (physically challenged- polio started with 3 years) 5.9.2007

A. N.(physically challenged- polio) 5.9.2007

Mother of B. (9 years) 13.8.2007

10. Appendix

NGO's institutions and projects to empower people with disabilities in Kenya

NGOs, CBOs and DPOs play an important role in supporting people with disabilities in Kenya and they have different priorities in their support. However, there is an asymmetry of giving and receiving in the way they work which maintain "*a structure of inequality that reduces the status of the recipients.*"⁵⁴³ Therefore the act of giving is "*not a gesture of oneness with the donee, but a symbol of separation and superiority.*"⁵⁴⁴

Some are specialized on a specific disability and some take care especially of children, young people, and women etc. To get in contact with such organizations is not easy for people with disabilities because they are often not informed about the existence and if they are they can often not reach the institutions because of lack of money for transport or they cannot join transport at all, if it is not possible to take the child into any bus or matatu. Some children I met had the luck to be sponsored by institutions like Dagoretti Children's Center where the children do not have to pay anything. On the other hand I saw children who were expelled from school because they could not follow the others and some parents do not even think about sending their child to a special school because of high costs.

⁵⁴³ Murphy et al. 1988:236

⁵⁴⁴ Murphy et al. 1988:236

That is why special education programmes are very important and international development agencies or NGOs fund them.⁵⁴⁵

All organizations which I have visited are funded by various organizations from foreign countries, often with support from sister organizations in Europe and North America. These institutions are most of the time expected that they will eventually be sustained locally through fund- raising and/ or government support. In recent years NGOs as APDK as well as others have reached a large population through community- based programmes. Basically Scandinavian countries like Norway, Sweden and Denmark are the pioneers in establishing special institutions in developing countries and in establishing the principles of integration and normalization⁵⁴⁶ as in Kenya, e.g. DANIDA has established the KISE.

There exist also organizations which find it hard to survive, because to be dependent on fund- raising gets institutions into an unsecured position.

The aim of these organizations is to support children and young people with disabilities by empowering them in giving education and health services and furthermore by raising the awareness on disability issues in the country. Because there are so many programmes, which support children and young people with disabilities, I am not able to mention all of them. That is why I decided to describe only the one I have visited myself.

Other very important institutions are self-help groups where people with disabilities come together to discuss their challenges and exchange information. Moreover they organize income generating activities to support each other as a disabled woman told us who went to a group every Wednesday to make handicrafts, fireworks, and tablecloths. Another aspect is that since she is in that group she has not felt alone anymore, before she even hated herself.⁵⁴⁷ Also at UDEK a woman who gave me an interview stated that it is important to exchange issues with other disabled people to support and advise each other.⁵⁴⁸

UDEK (United Disability Empowerment in Kenya)

UDEK is a non-profit making, non-political NGO whose main goal is to assist persons with disabilities in areas of empowerment. It is a disability organization who aspires to unite groups, associations, and organizations for and of persons with disabilities. The institution recognizes that persons with disabilities are a part of society and therefore need equal opportunities as every other able bodied person to participate in development in society. A Board of governors

⁵⁴⁵ cf. Oloo 2006: <http://www.ossrea.net...>

⁵⁴⁶ cf. Ingstad, Whyte 1995:16,174,175

⁵⁴⁷ cf. Interview W. W. 5.9.2007

⁵⁴⁸ cf. Interview A. N. 5.9.2007

nominated by its stakeholders runs UDEK.

Salome Kimata, the executive director of UDEK founded the organization in 2003 when she came back from Japan where she got an idea of how to empower people with disabilities. She wanted to start an initiative to work and empower people with disabilities. Because computer technology was what she had learned, she started with two computers and a printer which were donated by a Baptist church from Japan. The organization was registered in 2004 and she got money from the embassy of Finland to buy computer electronic equipment and a Braille embosser. In the same year she managed to have other organizations on board like UNDP who gave her some IT equipment. This continued with organizations like: GTsept from Germany, the embassy of Poland, the National Funds for People with Disabilities (NFDK), National bank, NIC bank, and UNDP. With her chairman, who is blind and an advice chair who was a banker and physically disabled she started as a team and pressured treatability and accountability.⁵⁴⁹

UDEK is the first of its kind in Kenya, having realized the potential of persons with disabilities in information technology and business management skills. A lot of empowerment is highly required for the disabled on human rights education because information is power. UDEK would like to incorporate different organizations and well wishers who appreciate their sincere efforts in advocating for the importance of these training facilities and their impact on the growth and well being of the society, country and the economy as a whole.⁵⁵⁰

UDEK offers courses mostly for free or people should pay what they can afford. That is why it is quite challenging to maintain all resources to give quality education.⁵⁵¹

The vision of the organization is a barrier free society for people with disabilities. Their mission is to empower them in many spheres of life, especially in education programmes. The objective of the organization is social, economic and information technology empowerment for people with disabilities. In addition UDEK advocates for their rights and tries to influence the policy and decision making organs to promote equality of all persons with disabilities.

I should like to repeat once again the activities of UDEK: computer technology training (CTT), sign language training, preparation of ITC materials like brailing materials, advocacy and action programme (advocating for the rights of persons with disabilities e.g. right to education, accessibility, health etc.; HIV campaigns), and a referral system to help persons with disabilities with various challenges like the correction of deformed limbs etc. depending on the nature of his/her disability. If the parents cannot afford the whole surgery, UDEK pays the difference.⁵⁵²

The direct beneficiaries of the organization are people with disabilities, especially those with

⁵⁴⁹ cf. Interview Salome Kimata- UDEK 19.9.2007

⁵⁵⁰ cf. UDEK Proposal 2007:2f

⁵⁵¹ cf. Interview Salome Kimata- UDEK 3.9.2007

⁵⁵² cf. UDEK Proposal 2007:3f

physical disabilities by offering them assistive devices.⁵⁵³ The organization wants to establish data and information on the number, types, and causes of disabilities. To collect these data they will carry out a survey in two districts in every province to give a good representation and to establish the average number. They want to document how many disabled children are attending school and how they experience it. The survey will also shed light on the percentage of children with disabilities who are receiving basic education and which facilities are available for them. The outcome of this survey will be used to put pressure on the education authorities to achieve the project goal: education for all.

One of the main challenges of the project is that many people with disabilities who live outside Nairobi find it difficult to access the services due to high transport and accommodation costs. UDEK provides in some instances bus fare to students because otherwise they cannot manage to come to class.

Jacaranda School for the Mentally Handicapped - Nairobi (Kileleshwa Area)

In 1946 Jacaranda School was a day care centre for war veterans. It was turned into a school with the support of Aga Khan, sponsorships by churches, by children's homes, from orphanages and banks. The government pays schoolbooks and education equipment whereas therapies, food, and supervision are not. The children have to pay for transport, therapy fees and food per year 22000Ksh (~ 220€). Some can pay less because the school does not send people away. There are three types of transport for the children: Matatu (travel alone), school bus, or hire transport vans. All of these possibilities are very expensive and often not affordable for the parents. That is why every day a different number of children come to school. Inside the school there is a large playground where the children move.

When I visited the school, a very nice director assistant showed us (Stefan, me and two other visitors) the school. Jacaranda School for mentally handicapped is based in Nairobi, Kileleshwa Area and caters for children with mental disabilities. 170 children are enrolled in the school and their homes are visited to assess the situation in which they live. Next to the school there is a sheltered workshop for young people with mental challenges to produce soup and necklaces. These products are exported to various countries in shops as e.g. the Body Shop in England and Canada.

A day in the school starts with music and dancing to warm up. After this the children go to physiotherapy which means massage, correct food, trampoline, bike, a chest pull, power ring, stepper for balance and also activities for fun like hoola hoop, pull reducer, hand grip, home trainers, and weight training etc. The same room is used for physical education. Physiotherapy is

⁵⁵³ cf. UDEK Proposal 2007:6f

45 minutes per lesson and takes place once in a week. Two occupational therapists care for ten children. In the school there are two nursery classes caring for 11 children. They are taught in eating, moving and going to the toilet alone. Once in a week teachers give progress reports and discuss their cases. In the development class where all children have speech problems, a hearing impaired teacher is training the children in sign language. Two times a day there are physical activities, namely physical education and dancing.

In primary class (9-15 years) they learn arithmetic, English, and how to follow the teachers' instructions. They work independently. These children have coordination problems and difficulties to balance. Two teachers care for them. In another class the children are trained in vocational training and learn how to make necklaces, baskets and carpets by weaving, knitting and sewing. Occupational therapy is a kind of evaluation and assessment. Especially for autistic children who have concentration deficits it is very important to achieve self-help skills. The balance beam should help the children to walk. Furthermore there are two workshops where the children repair and paint school equipment like tables and chairs. But these children are also taught in mathematics, arts and other subjects.

APDK (Association for the Physically Disabled of Kenya)

APDK is an NGO which empowers physically disabled people in Kenya. Four projects in Coast Province are run by APDK; the APDK Rehabilitation Clinic, the Bombolulu Cultural Center, the Likoni Furniture Workshop and the Faida (benefit) Microfinance Project.⁵⁵⁴

The Association was established in 1958 and is a non- profit making, charitable NGO with the objective to offer rehabilitation services to people with disabilities. These rehabilitation services are promoted through medical rehabilitation, social rehabilitation, and economic empowerment. They develop supportive devices like wheelchairs, walking sticks, and orthopedic aids, to meet the needs of people with physical disabilities.⁵⁵⁵ They provide occupational therapy, physiotherapy, and orthopedic rehabilitation services with special attention being paid to children with physical disabilities.⁵⁵⁶ Through mobile clinics they offer community based rehabilitation by assessing and treating persons with disabilities, their parents, and guardians. They develop income generating activities which are micro financed. APDK provides surgeries and follow after care operations.⁵⁵⁷ Duncan Mwangi Ndegwa started to work there in 2001. Disabled himself he had always dreamed of being employed within an organization for people with disabilities. When he was a child and his leg was paralyzed he came to this organization which helped him through many years of

⁵⁵⁴ cf. USAID: <http://www.equip123.net...>

⁵⁵⁵ cf. APDK Folder

⁵⁵⁶ cf. Kahara Agatha. APDK

⁵⁵⁷ cf. APDK Folder

rehabilitation services for free. This support helped him to accept himself as a disabled person. The mobile clinic visits families with disabled family members and social workers, and occupational therapists assess the situation and come up with home based rehabilitation programmes. *“And then we talk to the mothers because we have to work with her to access the child. And even for cases with operation they can come here.”*⁵⁵⁸

The families learn how to handle a disabled family member through an individual rehabilitation programme. The organization mainly caters for physically disabled people but they refer other cases to collaborate institutions. APDK also supports children in paying their school fees, not a hundred percent, but 75 percent. This programme is funded by the Netherlands and they give funds for education for 60 disabled children. Furthermore they offer transport for free to take the children to school.

APDK runs successful programmes in Nairobi namely the Jacaranda School for the Mentally Handicapped and the Bombolulu programme in Mombasa where they employ 300 people with disabilities. The organization cooperates with various institutions like “Safaricom” a Telephone Company, which has served 70 people with disabilities and also supports APDK with money, Barclays Bank and various others.⁵⁵⁹ However although they have made success in employing people with disabilities they still worry about the number of unemployment within the disabled. *“Where they start something like Safaricom and you see the statistic from people who are still in the business is quite worrying.”*⁵⁶⁰

In particular APDK produces the following supportive devices: crutches, kneecaps, surgical boots, therapeutic devices like rollers, therapy steps, cerebral palsy chairs, parallel bars, adjustable walking aids, walking canes, various wheelchairs, and tricycles etc. to provide mobility at minimum or no costs.⁵⁶¹ All these products are prepared by people with disabilities for people with disabilities. The recent programme of Barclays Bank and APDK provides over 600 tricycles and wheelchairs to persons with disabilities in Nairobi. The organization wants to produce motorized ones with minimum costs because it will improve the comfort and speed of people with disabilities.⁵⁶²

⁵⁵⁸ Interview Duncan Mwangi- APDK 10.09.2007

⁵⁵⁹ cf. Interview Duncan Mwangi- APDK 10.09.2007

⁵⁶⁰ Interview Duncan Mwangi- APDK 10.09.2007

⁵⁶¹ cf. APDK Product catalogue

⁵⁶² cf. Wanjama 2004:1

KISE (Kenya Institute of Special Education)

The need to establish an institute of special education in Kenya has come up in the early 60s. It received no serious attention until president Daniel T. arap Moi officially declared the National Year of the Disabled in 1980. This even created an increased public awareness of people with disabilities.⁵⁶³ The KISE which is run by a council appointed by the Minister for Education, Science and Technology was established in 1986⁵⁶⁴ with the assistance of the Danish Development Agency (DANIDA) to meet educational needs of children, young people, and adults with disabilities. The Institute is training teachers on special needs education⁵⁶⁵ and has a distance learning programme to reach students, outside Nairobi Province. Unfortunately this programme lacks equipment like Brailers, sign language manuals, computers and relevant books and publications on children with special needs in education in the centers. 5700 students are enrolled in the programme but it has not reached all districts.⁵⁶⁶

The two years diploma courses and the three months certificate courses in special needs education cover four areas of specialty, namely education of persons with hearing impairments, visual impairments, physical, and health problems and persons who are mentally challenged.⁵⁶⁷ External bodies control some of the activities of KISE. That is why KISE made slight impact on issues like development of assistive devices, learning resources, research, assessment, information services, training experts for e.g. speech therapists, sign language interpreters etc., and creation of awareness and sensitization of children with special needs in education. When I visited KISE, the head of the assessment department pointed out that there are no data on children with disabilities in Nairobi. KISE assesses only children who come to the institute and they do this by hand without a computer. They register the children in a book per name, age, disability, and parents. The KISE Council does not include representation of persons with disabilities, students, parents, and professionals. However organizations for and of people with disabilities, the MOEST are over represented.⁵⁶⁸

KISE offers two different diplomas on special needs education; one in inclusive education and the other follows the specialization model. Unfortunately KISE has no courses for professionals in special needs education such as counselors, audiologists, clinical and educational psychologists, sign language interpreters, speech and language therapists, Braille and hearing aid technicians and special needs education rehabilitation officers etc.⁵⁶⁹ Since 1986 the institute has already trained

⁵⁶³ cf. Abilla 1987:3

⁵⁶⁴ cf. Netsey-Afedo 1987:2

⁵⁶⁵ cf. KCP 2004:9 <http://www.ilo.org...>

⁵⁶⁶ cf. MOEST a 2003:71,76,77

⁵⁶⁷ cf. KISE Folder p.2,5

⁵⁶⁸ cf. MOEST a 2003:71,72

⁵⁶⁹ cf. KCP 2004:9 <http://www.ilo.org...>

741 teachers at diploma and 3214 teachers at certificate level to handle children in special schools, units and integrated programmes.

KISE has offered special needs education training to professionals from different countries like Uganda, Malawi, Zambia, Tanzania, Ghana, Somali, Ethiopia and others. The institute is networking with the Uganda National Institute for Special education and the University of Oslo. The institute was funded by DANIDA between the years 1986 and 2000. Since they left, the institute has serious financial challenges for the implementation of its programmes. The government has also been given support and some funds are raised through fee payment.⁵⁷⁰

Dagoretti Children's Centre and Special School

Feed the children an organization from the United Kingdom regulates the Center and gives a home to 80 boys and girls with disabilities. They provide a community based rehabilitation programme for over 100 families of children with special needs. There is an abandoned baby center for 70 babies and a special school for 230 children both with and without disabilities.⁵⁷¹

Dagoretti Children's Center is based in Dagoretti, a slum within Nairobi area. The center offers speech therapy, physiotherapy and mobility aids like wheelchairs. Because many parents are overstrained and sometimes embarrassed to have a disabled child it happens that they prefer to leave their child in the centre. The centre tries their best to prepare the children and young people for the life outside, that they are able to reintegrate in society after leaving. That is why the centre offers vocational skills and also helps them to stay independent when they go back to their community. At the centre there is also a special school which is managed as a city council school. They care for children who physically disabled, health- impaired, hearing impaired and mentally disabled. The children are from all over the country and do not pay any fees. That is why the center depends on donations. 20 teachers are employed and they are trained on special needs education.⁵⁷² The center also cares for orphans, abandoned children including newborn babies.⁵⁷³

Bombolulu Workshops and Cultural Centre Mombasa

The workshop which is located in Mombasa was founded in 1968 and it is a project of APDK. 250 persons with disabilities are trained and employed by the project in handicraft production and business skills. All products are in a showroom and visitors can buy at a fair price which allows the project to continue their work. In the workshop mainly persons with physical disabilities are employed and live in the center which provides education for their children. The people are

⁵⁷⁰ cf. MOEST a 2003:75,80

⁵⁷¹ cf. Kimisitu: <http://www.kimisitusacco.or.ke...>

⁵⁷² cf. Globe Tree: <http://www.globetree.org...>, Feed the children United Kingdom <http://www.feedthechildren.org...>

⁵⁷³ cf. Project Albert 2001: <http://www.projectalbert.co...>

accommodated on the land of the organization for free.⁵⁷⁴

Bombolulu is based in Mombasa and their products are made of materials ranging from soapstone, brass, seeds, copper, wood, semi precious stones to recycled materials etc. In 1989 they started with woodcarving made of woods like neem, mango coconut, prosopis julifloar and casuarina. They produce various things like animal figures, masks, salad spoons, belts, buckles, wooden buttons, and nativity seats. In 1987 a tailoring workshop was established where textiles like printed fashion wear, table clothes, napkins, carpets based on traditional motifs are produced. In 1990 a leather workshop was set up with products as belts, sandals, handbags, brief cases, tablemats, backpacks, canvas etc.

The organization has collaborations with the following partners: Polio Hilfe Kenia from Germany, SERV International from USA, Traidcraft from United Kingdom, CTM from Italy, Solidar Monde from France, Dritte Welt from Germany, Akzente Germany, Oxfam, Fair Trade Company Japan from Netherlands, Ten Thousand Villages from USA and Barbara Wilson.⁵⁷⁵

I visited the organization when I went to Mombasa. Although the people who work there can earn a living and educate their children, there is no possibility to work one's way up because the people working there are not qualified for any other employment.

Christian Vision Organization (CVO)

CVO is a community based non profit and non political organization which assists vulnerable children in areas of basic needs, education and information services. The organization was initiated by the Christian board in conjunction with the Board of social responsibility BSR from PCEA UTHIRU PARISH. The project started on 9th June 2007 after the group members (volunteers and social workers) had visited the area and the surrounding areas and discovered that there were so many neglected children living with disabilities both physical and mental, orphans and HIV positive children. They searched for a way to help these children by coming up with this project, which is based at PCEA Gichecheni church grounds. Their main intention is to improve the living standards of these children by building up an institution which includes a (special) school to offer them education, medical care, therapy and medical facilities like assistive devices, and basic needs support. The project is based in Kinoo Location in Kikuyu Division and has been registered since 2008 at the Ministry of Gender, Sports, Culture and Social Services which is responsible for formulating policies concerning persons with disabilities and for monitoring the implementation of the Disability Act 2003, as well as the National Action Plan for the Decade of Persons with

⁵⁷⁴ cf. Fairer Handel von dwp: <http://www.dwp-rv.de...>

⁵⁷⁵ cf. Bombolulu Workshop: <http://www.apdkbombolulu.com...>

Disabilities.⁵⁷⁶ CVO is a very new project but it has already realized how to meet the needs of children with special needs. The activities are carried out at the PCEA Gichecheni church grounds. The cooperation with various organizations as for example “Feed the Children” made it possible to cover basic needs like food. The organization “faulu- Kenya” provided blankets, food, materials, which the project passes onto the parents of children with special needs. Beside that the project started a poultry project which is funded by Basic Needs U.K. They bought 500 chickens to raise and sell them. In addition the project bought shares for the group IPO (Initial public offering) for Safaricom (a telephone company) worth 10, 000 Kenyan Shillings.

The project has already identified a large number of children with special needs and disabilities to face their needs and support them in all fields of life. The registration service started in June and they advertised it through media like newspaper and radio. Parents came with their children from far distances in Kikuyu division and communities around, to find some help and to be assisted with their children who need a special treatment which they often cannot afford. So far they have registered over 300 hundred children and have grouped them into four categories: children with disabilities (the mentally disabled, the physical disabled, the hearing impaired, the speech impaired, and children with down syndrome and learning disabilities), neglected children who need to be assisted in basic needs (shelter, food, education and clothes), orphans, and HIV positive children. Some families have to face every category which means to take care of an orphan, having a disabled child and a HIV positive one. These cases the project describes as very needy and desperate, which means they obtain priority by giving them food, education for their children and information service for free. The project members are organizing to go on home visits to identify the circumstances in which the registered families with children with special needs live and to collect data on the issues of disability, HIV, and orphaned children. Their main intention is to assess the situation to develop strategies of financing.

As I have already mentioned the project has a feeding programme. Three times a week these children and their parents come and take lunch at the church ground, which is prepared by the people from the kitchen department. If somebody is not able to come, the project provides food to carry home. Because of the cooperation with Feed the Children, the project has been able to continue supporting these families. Feed the children has donated 50 bags of rice each 50 kg. After identifying a very desperate case in the sub location Baraniki the project decided to build a house for a 71-year- old grandmother (widow) who lives with her six orphaned grandchildren. One boy is HIV positive and the oldest girl is physically disabled. The house in which they used to live was a mud house. The construction started on the 14th of August and the house was opened on the 8th of September 2007. It was the first time of constructing a house and the volunteers did not

⁵⁷⁶ cf. KCP 2004:9 <http://www.ilo.org...>

have much experience. Nevertheless they worked very hard to give the family a better quality of life. Another significant point is that they integrate young people with special needs in giving them skills and integrate them in activities like building this house for a very needy family.

The project has started to offer seminars to the parents to explain to them the causes and effects of disability in their society. The seminars are held in Kiswahili and Kikuyu depending on the languages of the parents. Beside that it is very reasonable that these parents can meet and exchange their challenges and problems in daily life. The seminars take place every Monday and Wednesday. The main aim is to change negative attitudes among disabled people and their families. The project has already invited scholars who talk about disability and HIV. They are also taught about how disabilities occur, how diseases can be prevented and how to care for a disabled child. They call in “parents’ seminars” where all people can listen and study for free.

To help these parents to become financially independent the project started with activities like producing necklaces, bracelets and baskets to sell on local and as soon as possible on foreign markets. We supported the project with cooking fat, salt, and materials (pearls and accessories) to start generating income activities. The project has already sold all necklaces and bracelets, the parents of children with special needs have made. With the money of 7730 Kenyan Shillings the project opened a bank account and registered the project at the Ministry.

In Addition the project offers an education programme to the children to study basic school knowledge and to carry out physical activities. Although the volunteers are not educated as teachers they try to give their best to teach them. Between three and four social workers are teaching the children and the day starts with singing and dancing. Depending on the weather almost 70 children come to the church. But the large number of children makes it difficult to teach them individually because they are all of different ages and have different educational needs. Furthermore they do not have enough equipment, neither desks nor a blackboard. The outdoor activities like playing soccer and other games take place in the garden of the church ground.

Departments

The project has several departments to organize themselves in different areas. Every department has its own field of activity and the representatives meet continuously to discuss aims, problems and future perspectives.

The project coordinator is appointed to manage and administer all affairs of the project. He/she is entrusted with responsibility of executing policies, planning and regulating activities and finances of the project.

The children department volunteers to teach the children to acquire skills and knowledge on basic school education depending on the abilities of the child. With the support of well wishers, the

project has received crayons for coloring, pictures for reading, puzzles, markers, and puppets. Moreover the children's department organizes excursion for the children because for some it is the only possibility to leave their quarter. The main challenge is that the social workers are not trained as teachers. Moreover sometimes 70 children come to class with various special needs which is difficult to handle. The children do not come punctually which means that there is unrest in class. Therefore it is difficult for the children to concentrate. The major problem is that there are just a few tables and seats and children have to learn on the floor.

The kitchen department caters for food and drinks for the children and their parents. It has representatives in charge that ensure that there is enough food for everyone. Three times a week after class the children take lunch together. Depending on the financial situation of the project they give ugali (mush), Sukumaviki (similar to spinach), rice, meat, cabbage, and beans.

The social work department is responsible for assessing and registering the children and keeps the records of every child. When conducting home visits the social worker assess the homes to identify the needs of the children and to see in which circumstances they live. Furthermore they visit their homes to verify what parents said when they registered their children at the project. It also monitors and evaluates the distribution of food, clothes or any other donations that comes along.

The parents' department coordinates the parents of the children with special needs and involves them in every discussion about the project. It is very important to listen to their opinions to go further. The representatives who have been elected by the parents join the meetings of all departments. These representatives pass all information to the parents and organize their income generating activities.

The project seeks to strengthen the economic position of poor families to reach initiatives which have the potential for wealth creation and poverty eradication. They want to establish more income generating activities which are profitable to be shared among the members as dividends as e.g. farming, setting businesses, setting clinics to cater for the sick. There are many resources missing for this project because they depend on well wishers, companies and private people. The most important things are to buy desks, chairs, and a blackboard and furthermore to get some money for transport to continue with the home visits. The main aim is to establish their own institution which means buying a piece of land and constructing a building where the children can get all the resources they need.