

INCLUSION OF YOUTH WITH DISABILITIES – FACING THE CHALLENGES  
AND UTILIZING THE OPPORTUNITIES

The experiences of young people with physical disabilities in Thika, Kenya

Henna Elina Hasari

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Diaconia University of Applied Sciences

Järvenpää Unit

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*“In Kenya, even if you have the talent but no facilities, you can’t utilize your talent and use it in the future. So that’s why you find many of us begging in the streets. It’s not our wish, but the other way of finding money because we have the talent but there was nobody to tell us how we could improve our living style.”*

*Young person with disability, 17 years*

## ABSTRACT

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The aim of the study is to understand the everyday challenges Persons With Disabilities (PWD) face in the Kenyan society and to learn the possible opportunities and support networks which can be used more effectively when working towards the inclusion of PWD and the rights-based approach in the field of community development and social work with PWD. Special consideration was made in the fields of education and social participation.

The research is based on qualitative methods of data gathering which included individual interviews and focus group interviews with Young People with Physical Disabilities (YPPD). In addition, the study was made in cooperation with the native professionals in the Special Needs Education (SNE) field and with the actual professionals of the issue who are the PWD themselves.

The results of the research are categorized into the main challenges and opportunities based on the experiences of the interviewees. In addition, the paper also suggests ways for inclusion based on the earlier researches as well as the interview material gathered during the study. The main challenges discussed by the interviewees were attitudinal and economic barriers which were visible school life and in their social life which also included the leisure time activities such as going for shopping or participating in social events. In addition, the structural barriers such as poor infrastructure came up during the study. Furthermore, the opportunities and support factors found during the study were possible social support networks (instant family, peer support, faith in God) and support devices which eased the social participation of YPPD considerably.

Key words: Disability, Social participation, Special needs education, Inclusion, Young People with Physical Disabilities

## CONTENTS

ABSTRACT .....	3
Abbreviations .....	6
1 INTRODUCTION.....	7
2 BACKGROUND FOR THE RESEARCH .....	7
2.1 Motivation and the aim of the study.....	7
2.2 Significance of the research .....	8
2.3 The process of naming .....	9
3 CONCEPTUAL FRAMEWORK .....	10
3.1 Adolescence.....	11
3.2 Concept of disability .....	13
3.3 Human rights approach and other approaches on disability.....	15
3.4 Factors affecting the lives of PWD .....	18
3.4.1 Socio-cultural factors.....	19
3.4.2 Economic factors .....	20
3.4.3 Political factors .....	20
3.5 Inclusion and social participation.....	21
4 YOUTH WITH DISABILITIES IN KENYA.....	24
4.1 Qualities associated to adolescence and YPWD .....	24
4.2 Step towards inclusion – Young People with Physical Disabilities (YPPD).....	26
4.3 Every child has a right to education .....	28
4.4 YPPD and social participation .....	31
5 EARLIER RESEARCH .....	32
6 RESEARCH PROCESS.....	34
6.1 Research questions .....	34
6.2 Research environment .....	35
6.3 Ethical consideration .....	35
6.4 Methodology .....	36
6.4.1 Individual interviews .....	37
6.4.2 Focus groups.....	38
7 RESEARCH RESULTS.....	39
7.1 Factors affecting the lives of YPPD .....	39
7.2 Discussion in the field of education .....	43
7.2.1 Access to education .....	43
7.2.2 Economic situation .....	45
7.2.3 The strenghts and weaknesses of mixed and special education .....	46
7.2.4 Importance of education .....	49

7.3 Discussion in the field of social participation .....	50
7.3.1 Attitudinal challenges hindering participation.....	51
7.3.2 Accessibility and infrastructure .....	52
7.3.4 Accessibility and support devices.....	53
7.3.5 Support networks .....	54
8 DISCUSSION ON THE POSSIBILITIES FOR INCLUSION .....	57
8.1 Inclusive education.....	57
8.2 Education in overcoming negative attitudinal environment.....	58
8.3 Community education .....	58
8.4 Empowering the individual and important social networks.....	59
8.5 Collective actions for the youth.....	59
8.6 Political actions .....	59
9 CONCLUSION .....	60
REFERENCES.....	62
Appendix I INDIVIDUAL INTERVIEW CHART .....	67
Appendix II FOCUS GROUP DISCUSSION CHART.....	68

## Abbreviations

The following abbreviations will be used in the text.

FBO – Faith Based Organization

FPE – Free Primary Education

DAA – Disability Awareness in Action

DPO – Disabled People’s Organization

GoK – Government of Kenya

HIV – Human Immunodeficiency Virus

ICF – International Classification of Functioning, Disability and Health

MoE – Ministry of Education

MoEST – Ministry of Education, Science and Technology

MoYA – Ministry of Youth Affairs

NGO – Non Governmental Organization

PWD – Persons With Disabilities

SNE – Special Needs Education

UN – United Nations

WHO – World Health Organization

YWD – Youth with Disabilities

Abbreviations made for the document:

YPPD – Young People with Physical Disabilities

## 1 INTRODUCTION

Talent without facilities to harness it and to use it in practise is useless. This is what has happened to many people with disabilities in the past decades as their lives have been shaped by the notion of “DIS-ability”. Disability is a world-wide phenomenon which has its own history and definition based on its contextual environment. It is not only a medical condition, but a sum of factors that hinder the full-participation and application of the rights the PWD have. Thus this has made it an issue that involves the whole community and not only the individual as has been concluded in the past few decades after the evolvement of theories which understand disability as a social phenomenon and not as a personal tragedy.

In this study the current state of the Kenyan society and the facilities for PWD are discussed and reflected on from the point of view of young people with physical disabilities (YPPD) and the experiences they have had. The aim of the study is to discuss the challenges and opportunities in the Kenyan society for YWD and to create suggestions for further developments to improve the situation. The first part of the paper defines the concepts important for the research, and the part two aims to reflect the situation of YPPD in Kenya based on the earlier research and studies. After that the results of the research will be discussed in categories according to the experiences of the interviewees.

The study was carried out in autumn 2010. The two (2) focus group discussions and five (5) individual interviews were conducted in S.A. Joytown Secondary School, Thika, and two (2) individual interviews in separate universities in Nairobi. Total of 18 students participated in the discussions not to forget those who contributed in other ways and through informal discourse helping me to analyze the secondary data and phenomena connected to disability. In addition, I want to thank the deputy principal Evelyn K.Andolo for being a great encourager and a contact person during the whole research process, and other teachers of whom some have done their own research on the special needs education. At the end of the study I found myself holding in my hands experiences and knowledge that led me to have greater understanding of disability and what it is not – inability.

## 2 BACKGROUND FOR THE RESEARCH

Various factors contributed to the selection of the topic. The understanding of the importance of the study in the field of disability from young people's perspective was the main motivator for this study, as well as the alarming statistics on the educational opportunities of PWD. In this chapter I want to discuss the motivation and aims of the study as well as shed some light on the election of the terms and names that will be used throughout the paper.

### 2.1 Motivation and the aim of the study

According to a survey conducted by National Coordinating Agency for Population and Development (NCAPD), 4.6 percent of the whole population in Kenya is affected by disability of various forms (NCAPD 2008, 8). However, the estimation made by United Nations (UN) states that 10 per cent of the world's population live with disability and out of these even 80 per cent live in the developing countries (UN 2008, 2). According to Ministry of Education, in 2008 only 45 000 learners with special needs enrolled in special schools, units and integrated programs in Kenya (MoE 2009, 18) whereas another document by MoE states that the total number of students enrolled in special primary and secondary schools, primary units, integrated programs and special technical or vocational schools was as much as 221 995 students (Mugo & Oranga 2010, c.f. MoE 2007). However, despite of which prevalence statistics are applied, majority of the children with special needs do not have access to education in Kenya. Having had the opportunity to work in one of the schools offering special educational services for students with physical disabilities, the realization of this, and other challenges faced by children with special needs and their families, has become the main motivation for this research.

The aim of the study is to raise awareness of the alarming statistics and phenomena connected to disability in Kenya, as well as to bring in the views of the actual professionals who are the children, teenagers, university students, employees, home makers, grandmothers and grandfathers living with the disability. However, due to the varying needs different disability groups have and the diverse challenges they face, the study focuses only on the physical disability among the secondary school aged youth



(aged 15-22) and discusses the socio-cultural, economic and political elements and their impact on the lives of YPPD in Kenya. Special consideration will be made in the fields of education and social participation.

## 2.2 Significance of the research

The field of disability is connected with variety of challenges and contradictions in statistics, which seems to reflect the unfamiliarity of the issue in the society. To understand the different phenomena connected to disability it is important to notice also the occurring challenges in the field and the history of disability in the country.

Understanding the importance of rights based approach in the practice of delivering services for disability groups has started the transformation of attitudes and practices linked to disability earlier. By the rights based approach I refer to the service practice which has its roots in the human rights declaration which was introduced already back in 1948. This approach regards the equal treatment and equal provision of opportunities as a must in the lives of PWD, not connected to others' "good will" or "friendliness" in any way. In Kenya many good amendments and changes in the policies have been made for the good of PWD in the past decade, including the introduction of free primary education (FPE) and the Persons with Disabilities Act in 2003, signing of UN Convention of Rights of Persons with Disabilities in 2008 and approbation of the new draft of the constitution of Kenya in 2010. Kenya was also committed to provide more chances for education so that the enrolment rate of the children with disabilities would rise up to 10 percent by 2010 (WHO 2011, 214). However, the changes still tend to remain in the policy making level and have not been implemented successfully. Phrase "Education for all" is not visible in the lives of the children with disabilities and for majority of them the opportunities for education are not at reach at all.

Another challenge in the field is the considerable variations in the existing statistics (Mugo & Oranga 2010, 3; ILO 2004, 9). According to the report by Ministry of Education, Science and Technology in year 2004, out of 750,000 children with disabilities only 90,000 had been assessed and out of this number as little as 26,000 had signed up for school (MoEST 2004, 9). Still in the Education statistical booklet 2005

published by the same actor, the total number of students with special needs enrolled in school was 189,910 (MoEST 2005). The estimated prevalence of disability also varies; Kenya National Survey for Persons With Disabilities (KNSPWD) states 4.6 percent of disability prevalence and WHO applies the estimation of 10 percent in its research (which however is the most recognized and used in the policy documents by MoE and MoEST).

Though the enrolment rate of students with disabilities increased after the introduction of free primary education in 2003, still less than third of the school aged population with special needs have access to education. Public buildings and transportation means still tend to be inaccessible for the people with physical challenges in most parts of Kenya, including the mainstream school buildings and the infrastructure in the towns. This also holds back the idea of integration of the children with physical disabilities into regular schools, as class rooms are often small and inaccessible, as well as the integration of students with learning disabilities due to the attitudinal challenges and lack of trained teachers and modified teaching methods. Furthermore, even though a student with special needs is admitted to a regular school, discrimination may occur as happened in Khasoko where a girl with a minor learning disability was forced to return back to the special school because of other pupils who made fun of her for her disability (Kenya National Commission on Human Rights 2007, 33).

Hence, though a lot has been done, even more need to be done if the rights of the disability groups are to be implemented in practice in Kenya. For this reason this study aims to bring close the burning matter and discuss the meaning of the environment and the society in the lives of PWD. Through this I want to find out what could be done differently to guarantee the inclusion of YPPD in Kenyan society.

### 2.3 The process of naming

There has been discussion on the terms and names used when discussing disability matters. Different terms bring about different connotations and that is why one should be careful when choosing the names for matters. Naming process also brings about the power battle as has been visible in the history: the superior has the right to name other subjects; the first human being chose the names for the animals, the parents choose the

name for their child and the teachers choose how they are called and acted with in the class situation.

In the disability field, the terms noted with negative connotation are names such as ‘retard’, ‘crippled’, ‘handicapped’, ‘differently abled’ and ‘the disabled’ – however, these terms are still used in certain contexts. More preferable terms are ‘disabled people/persons (UK), people with disabilities (USA), people with learning disabilities (UK) and persons with an intellectual disability (USA). (Koistinen 9.5.2011).

There has been a debate on whether to place the ‘disability’ in front of the ‘person’ (disabled people) when the meaning refers to ‘people who have been disabled’ (social model) but still emphasises the disability before the person, or after ‘person’ (people with disabilities) when the disability is not seen as the identity or the first hand matter (but still the term refers to the medical understanding of disability).

Another trend in the naming process is the disability groups’ own definitions and names on themselves; some communities of people with hearing impairments prefer to be called “The Deaf” with capital letters to show the value and equal status.

After careful consideration on the terms used in Kenyan context in the fields of education and inclusion, this study adopts the terms Persons with Disabilities (PWD), Youth With Disabilities (YWD) and the Young People with Physical Disabilities (YPPD).

### 3 CONCEPTUAL FRAMEWORK

In this study I lay the basis on the rights approach on disability and thus approve the issues, results of the study and solutions from the rights’ perspective. I study the contextual understanding of disability from three standpoints; socio-cultural, economic and political, and study what kind of impact these factors have on the lives of YPPD. In addition, the meaning of exclusion and inclusion will be discussed to understand the context and to pit the current situation against the ideal state of the community.

I also chose to apply in this study N. Singal's three dimensional model he developed for his study on the transition of the youth with disabilities in India (Singal 2008). In his research, Singal studies areas of education, employment and social participation from YWD's point of view. However, this study is narrowed only to the areas of education and social participation for the limited age group which is the secondary school aged students who are already in the education system, as only these two areas were considered to be current issues in their lives as no experiences of employment/unemployment came up during the interviews.

The definitions may vary depending on the context and the source, and that is why it is important to define the concepts central in the research. Due to the nature of the study, the differences between common definitions will be discussed and regarded from the contextual basis. Examples from various countries have been taken to realise how the definitions vary from context to another and to get slightly more international perspective on the issues dealt with in the study.

In the coming chapters the following concepts and issues will be characterized: adolescence, disability from the perspective of an individual and social phenomenon, physical disability, factors of reasoning disability i.e. socio-cultural, economical and political factors, education and social participation, rights approach and the meaning of exclusion and inclusion.

### 3.1 Adolescence

The definitions for term 'adolescence' and age frame for 'the youth' can change considerably from one country to another. This time period is defined to start roughly after the age of 10 and end at the age of 30. It is a phase described as a stepping stone from childhood into adulthood. American Academy of Child and Adolescence Psychiatry (AACAP) shares the time of adolescence into three parts; early adolescence (10-14 years), middle adolescence (15-16 years) and late adolescence (17-21 years) (Spano 2004), ending the time of adolescence to as an early age as 21 years. However, the time of adolescence concerns various matters with different emphasis depending on the culture of the society. Erikson described the time of adolescence and puberty to be the time of

questioning due to the changed social roles and expectations as well as due to the sexual maturity that is new compared to the time of childhood (Erikson 1950, 235).

Depending on the document, the definition of ‘the youth’ varies; in Kenya 2007 National Youth Policy by GoK ‘the youth’ are defined as “anyone aged between 15 and 30 years” (NPI-A 2009, 4) whereas ‘the youthful population’ is defined with the age group of 15-24 years in the National Statistics of Kenya (KNBS 2009, 4).

As a comparison, in the same way some differences are found in the British Youth Policy in which the services are aimed at ‘the youth’: England 11-19 years, Scotland 11-24 years, Wales 11-24 years and Northern Ireland 4-24 years, and in which the statistics of youthful population consist of the youth aged between 13-30 years (Youth partnership 2010, 4-5).

In England, support for accessing education and leisure time activities have to be secured for young people aged 13-19 years, with separate note for the youth with learning disabilities who are obliged to these services up to age 24 (Youth partnership 2010, 11). In Kenya, the distinction between the youth with disabilities was made in the Youth policy (2006) but not in Disability act (2003) or in the strategic plan for Youth affairs (2007). However, no instructions on how to implement the policies with special groups have been given, and this raises the question if the rights of the YWD are fully considered in these documents and especially if these documents make any practical difference in the actual lives of YWD.

After these considerations, it might not be possible to refuse Jane Kroger’s suggestion of adolescence as a purely cultural phenomenon. In her book she comments;

adolescence does seem to be a time, at least in contemporary, technologically advanced western cultures, when one is confronted with the task of self-determination, (Kroger 1996, 16).

However, she also cites the experience of a Samoan-born youth in New Zealand, who states that

As a Samoan-born I had never heard of it (adolescence) until I came to New Zealand. I don’t think it was part of my life because it is a Western concept, (Kroger 1996, 20; cf. Subject no.3 in Tupuola 1993, 308).

The notions of rebellious and responsibility free youthful years are not matters of fact but only reflections of the adolescence in a particular context, was the context then the country, region or even family. The youth in Samoa do not necessarily carry the same image but the image of responsible teenage years when it is time to start supporting the family and to become one of the important actors in the family and in the surrounding community.

Another example of the various definitions of “young” and “youthful” is the trend which allows to describe even a forty year old person as “young”. In Kenya this group of “young people” may cover the population up to 40 years, which reflects different culture and idea of young age than when compared with the Western definitions of youthful age. In Western countries adulthood is widely connected to gained physical maturity, which is often gained by the age of 21 whereas, in this case, Kenyan view connects the adulthood to the gained respect and stable status in the society.

As adolescence means slightly or even tremendously different matters in different countries, it is important to acknowledge these differences when working with the youth from various cultural backgrounds. Understanding the role of the youth and the responsibilities and tasks connected to it affect the behavioural model and hence also the understanding of adulthood and maturity. It is also important to keep in mind the UN definition of a child, which covers all the human beings under 18 years (UN 1989). Thus the youth in the early stage of adolescence are in the position of a child until they turn to the age of young adulthood or adulthood in the age of 18 years. In this document I apply the definition by KNBS of the youthful population which covers young persons from 15-24 years (KNBS 2009, 4).

### 3.2 Concept of disability

According to the early definitions of disability by WHO, disability is

any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (WHO 1980).

In the same document, International Classification of Impairments, Disabilities and Handicaps (ICIDH), WHO defines impairment as;

any loss or abnormality of psychological, physiological or anatomical structure or function  
(WHO 1980)

and handicap as;

a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual  
(WHO 1980).

Even in the first definitions of World Health Organization, disability is referred to as a negative phenomenon. It uses words as ‘restriction’ and ‘lack’, and is contradicted with ‘normal activities of a human being’. Impairment is defined as ‘abnormality’ and handicap as a disadvantage position due to the impairment or disability. This supports what C.Barnes and G.Mercer have to say about the status of PWD in the society: due to the social values, the PWD have had to adjust to their identity being somehow ‘not normal’ or ‘defective’ (Barnes & Mercer 2006, 21). However, in 2001 WHO set up a new set of definitions in “International Classification of Functioning, Disability and Health” (ICF) which turned out to switch the negative connotations into broader ideas of the disability as both medical and contextual phenomenon:

Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)  
(WHO 2011, 4).

But, however good definitions are made, there still seems to be different understanding of disability between the people defined as disabled and the people with the status of non-disabled which was also indicated in the research process. Even today the thoughts of disability are still connected with challenges; monetary, educational and social challenges, and challenges in employment sector and challenges in the ability to have any political influence in the society. On the other hand, PWD rarely view life with disability as a challenge but as usual life. Disability is not weakness or hindrance but another matter in life which indeed does not mean suffering.

However, due to insufficient support by the society, PWD and their families often face multiple oppressions. Family caring for the child with disabilities may encounter economic challenges, limited chances for work, worsened health conditions and relations

in the family (Barnes & Mercer 2006, 18). Barnes and Mercer also take examples of women with disabilities who do not have equal access to services compared to men with disabilities, and disabled people with ethnic minority background who do not need services as much the people with disabilities from the mainstream society because of the greater family support they get due to their culture (Barnes & Mercer 2006, 39, cf. Rae 1993 and Begum 1993, 1994).

### 3.3 Human rights approach and other approaches on disability

In the field there have been three dominant approaches on disability that cover other sub branches of approaches. Depending on the context, these approaches can be seen as separate but most often they are linked and overlap each other. The approaches discussed in this chapter are the traditional approaches, charity approach and human rights approach. The latter has been applied in this study.

The traditional approaches on disability are adopted in many original cultures where religion is the main element of the society. It is based on a moral system and moral judgements, on the ideas of right and wrong and price and punishment that follow the deeds done. In some societies the disability is viewed as a shameful result of ‘sin’, or ‘bad deed’ done in the past. It is a ‘punishment’ for the family or individual. On one hand, disability can be seen also as a supernatural phenomenon as is among the Suba in Western Kenya where people with intellectual disabilities are believed to be reincarnation of deity and hence are respected in the community (Mugo & Oranga 2010, 6). On the other hand, also acquired disabilities may be treated with awe for example in the case of an amputee acquired in war. However, if disability is seen as a punishment and shame in the community, PWD are easily excluded and their rights neglected.

The charity approach visualizes PWD as the objects of help in the society. Disability is not any more a ‘punishment’, but a phenomenon affecting fellow human beings who need help them to fulfil their basic needs such as sufficient feeding, place to stay, opportunity for cleanliness and personal hygiene. The service history in the field was characterized by this approach at the beginning of the disability services and was obtained by various non-governmental organizations (NGOs), churches and assisting groups. However, often this approach still considers disability as ‘abnormality’ and PWD as objects of pity and



caring; not as individuals who are obliged to the same rights as people without any stated medical disability. Interesting enough, in many countries the values of voluntary sector and public sector conflict as there is no legislation covering all the services provided by various service providers (public, private and the third sector) and thus great differences in the actual services and the way of delivering them exist. In Kenya this approach is common and according to J. Mugo and K. Oranga even the Persons with Disabilities Act enacted in 2003 is based on charity approach as they explain;

instead of addressing education as an issue of human rights (as attempted in the Children Act), the Persons with Disabilities Act (GoK 2003, 290) takes a charity approach by stating that the government should: ‘make provisions for assistance to students with disabilities in the form of scholarships, loan programs, fee subsidies and other similar forms of support in both public and private institutions (section 7:1) (Mugo&Oranga 2010, 5).

This approach does not support the rights based approach which aims to recognize PWD as citizens with an equal status who are obliged to services and play the role of ‘the subject’ in advocating for themselves, not the role of ‘the object’. Another difference between the charity approach and human rights approach is the focus of action; charity model focuses on the fulfilment of occurring individual needs but does not deal with the structural constrains as the human rights approach aims to do (Katsui 2008, 15).

Human rights approach is based on the UN Convention on Human Rights which was declared in 1948 after the Second World War. It emphasises non-discriminatory practice and equal treatment of all human beings. The Convention consist of 30 separate articles declared as human rights for all people despite of “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status” (The Universal Declaration of Human Rights 1948, article 2). According to the Convention, among others, every human being is obliged to right to life, liberty and security, right to standard living, free education, non-discriminatory treatment, own property, political activity, and right to work and be protected from unemployment (The Universal Declaration of Human Rights 1948). No human being is to be object but subject of their own life. As The Declaration of Human Rights is an international concept, it unites various countries that have ratified it. By 2006 “all countries have ratified at least one of the seven core UN human rights treaties -- and 80 % of states have ratified four or more” (Office of the UN High Commissioner for Human Rights 2006, 5).

In addition to the original convention on basic human rights, UN declared a convention on the rights of PWD in 2006. Meanwhile the convention aims at “emphasizing the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development”, it has been highly criticized by PWD and the representatives of disability issues. In Don MacKay’s words on UN Convention of Rights of Persons with Disabilities, the chairman of the Ad Hoc committee, “this treaty should not have been necessary, as persons with disabilities have same rights as all other persons”. This criticism is based on the debate “whether the disability issues should be mainstreamed in the policy documents or not”. On one hand, the separate documents for PWD’s rights should be abolished as their rights should be covered already in the broader human rights declaration, but on the other hand, the separate declarations seem to secure the notion and implementation of the rights to a greater extent. However, meanwhile the specification ensures the notion of the challenging matters the disability groups face, it also excludes and segregates them from others.

In addition, the whole rights approach has been criticised for cultural biases, challenging implementation process and possible negative consequences after the implementation (Katsui 2008, 8-11). Though, on one hand the Convention allows countries to make specified plans on implementation depending on the cultural context and earlier background of practice (the convention is easily adapted and feasible), it does not support countries in implementing the declarations in practice. The human rights approach may also turn the human rights declaration to be the end but not the means (Katsui 2008, 11) if the right to health becomes more important than the health itself (Kennedy 2004, 61). However, each of the approaches in the field have both strengths and weaknesses; how we use them, makes the difference. All the theories are made to serve the service practice and help to realize and analyse the phenomena connected to the issue, and the aim is to take the best out of each approach and make use of it in the practise. I wanted to build my research on the human rights approach firstly for the fact that the approach already has been adopted quite prominently in the research and practice in the disability field. Furthermore, it has brought out some good results in the practise such as transition from the charity approach which used to be (and still is to some extent) quite common in the disability field in Kenya and even in other countries. Secondly, I find it important to build on the past researches and the strengths of the human rights approach as it can bring about some cohesion in the field which can be made to be another stepping stone

forward. In this research the human rights approach is visible throughout the study having emphasising on the reflection of the results to the ideal situation and in the suggestions for further action on how the matters for YPPD could be improved.

### 3.4 Factors affecting the lives of PWD

There are various factors that shape our image of disability in our lives. Even though the phenomenon is the same, it carries different ways of manifestation depending on the context we are in. Cultural values, social environment, political situation and even economical factors modify our understanding of different concepts and even our concept of disability. A young woman in a wheelchair does not face the same situations in two different countries in as much as the countries are separate from each other in the cultural or social basis. In a country where individualism and public welfare system takes place, moving around and sustaining oneself might not be a problem as the society takes care of that. However, due to the growing trend of individualism, social challenges such as loneliness, social exclusion and distant family relations may become the disabling factor in her life. On the other hand, the same woman might not experience such challenges in a society based on social networks and third sector but might have to live under the poverty line because of other challenges such as unemployment, non-existing welfare benefits and insufficient access to rehabilitation services. In another context someone with the same medical condition might not feel themselves disabled at all.

To understand these factors and find the connection between them and the service sector, the research has to arise from the actual life experiences of PWD. These factors can be approached from various aspects of life, but in this research I want to approach them from the point of view of education and social participation. As mentioned before, N.Singal introduced the idea of looking into the transitions of young people with disabilities in the areas of education, employment and social participation (Singal 2008). Due to the focus and the view point of the study, I want to concentrate on the fields of education and social participation which are the most current topics for YWD who already are in the education system. The aim of connecting the fields of education and social participation with the factors explained in these chapters is to concretize the phenomena and view the socio-cultural, economic and political factors from the point of view of education and social participation in the lives of YPPD.

In this chapter we discuss these various socio-cultural, economic and political factors that are also used in the analysing phase of the research.

### 3.4.1 Socio-cultural factors

Culture does not stay the same over the years but it continually transforms and develops (Ife 2008, 79). It mixes with other cultures, adopts new habits and creates new traditions. Oxford dictionary defines culture as

The ideas, customs and social behaviour of a particular people or society – the attitudes and behavioural characteristics of a particular social group (Oxford dictionary 2011).

Culture is closely connected with the history of the country or social group and is highly connected to the values and the religious, ethical and moral principles of the community. In one culture it is polite to empty the plate when eating whereas in another culture emptying the place means the food was not enough. As mentioned earlier, in some cultures disability is connected with morally bad decisions and deeds and is defined as a consequence of sin whereas in another culture disability is seen as a godly interference.

Socio-cultural factors consist of the attitudes, expectations and social roles and group norms in the society that can be reflected either in micro (family, first hand contacts and surrounding community) or macro level (municipalities/cities, society) and they reflect both the conscious and unconscious behavioural habits and traditions. Edgard Schein divides culture into three categories; artifacts, espoused values and basic underlying consumptions (Schein 1992). Artifacts refer to the visible reflections of culture such as dressing codes, language, music and arts, whereas espoused values are the conscious strategies, goals and philosophies reflected in the behaviour. Behaviour is also affected by unconscious, taken-by-granted thoughts, perceptions, values and feelings that modify the way we see our reality. These learnt values and behavioural models affect the understanding of disability and is reflected in the lives of PWD. Especially the cultural factors in the close environment can affect the lives of children with disabilities tremendously and determine their future to better or worse. The children may lack the education due to the low interest of the parents in education, lack of knowledge or sufficient information on the education for students with disabilities. On the other hand they might get discriminated in the social sphere as in cases when the children are hid from the rest of the community because of the “shame” they are considered to bring

along or they do not have access to social places as they are denied entry due to the disability.

### 3.4.2 Economic factors

The economic situation in the micro and macro level has various effects on the wellbeing in the different layers of the society. In the field of disability the discussion of economic situation is mostly connected to poverty and lack of resources as it often seems to be the most prominent view: “disability brings along poverty”. But it has to be remembered that economic factors also refer to the stable financial situation and abundance.

According to Khandaker Jahurul, the chairperson of National Forum of Organizations with the Disabled (NFOWD), the economic challenges in the society do not bring about only financial challenges but also affect “the enjoyment and realization of human rights” (Khandaker 2008). In his words, the economic crises always affect the poorest in the communities, and according to WHO, PWD are in greater threat to live under the poverty line if compared with non-disabled people (WHO 2011, 39). Khandaker also claims that even as much as the majority of PWD live under the poverty line (Khandaker 2008). They also have worse educational outcomes and job opportunities than the non-disabled people (WHO 2011, 39). As discussed earlier in this paper, poverty and disability many times go hand in hand and whereas poverty is a consequence of disability, it is also a cause of disability, which makes the connection between the poor and disability more evitable.

In addition, Khandaker states that in the time of economic crisis, PWD confront great challenges due to insufficient access to work and amounting seclusion, segregation and discrimination in the society (Khandaker 2008).

In the research I studied how the occurring economical situation in the close community and family affected the lives of YPPD in the fields of education (especially: access to education) and social participation.

### 3.4.3 Political factors

The communities together build up the society and the society builds up the communities. Politics is a combination of commonly made decisions that in the ideal case reflect the will and interests of the whole nation. Political factors affect all the matters in the society

and bring in either positive or negative effects in the lives of the individuals. Political factors cover areas such as legislation and policies, discriminatory laws, lack of implementation and political instability.

In New Zealand the challenges due to the political environment arose in the field of educating a disabled child. Despite of the strategies, legislation and plans that secured the rights for non-discriminatory and inclusive education for the child with disabilities, a family had to complain to the Human Rights Commission when they were required extra fees for educating the child in the school environment and in addition were asked to pick the child from the school before the actual ending time (Purdue et al 2011).

In the research the political factors and their effects on the lives of the interviewees will be studied and discussed. The positive effects of political action often start from the structural changes in the society and from there slowly become visible in the near environment of PWD. The political actions often aim to make the change in the infrastructural level and create more accessible environment for PWD. However, in most of the cases these changes tend to be more of “integrative” by nature than “inclusive”, meaning that the changes tend to remain in the structures and not necessarily get into the attitudinal level. The differences between these two approaches are discussed more in the following chapter.

### 3.5 Inclusion and social participation

Inclusion is a broad concept often connected to the ideal picture of a society where everyone is accepted, appreciated, valued, loved; everyone is given a chance to be an active participant and an equal member in the community. Frederickson and Cline describe the inclusion of the students with special needs in the mainstream school environment with the statement:

Inclusion implies the introduction of a more radical set of changes through which schools restructure themselves so as to be able to embrace all children (Frederickson & Cline 2009, 71).

Inclusion tends to have a more radical stand than the integrated model which often has been the easier way to organize Special Needs Education (SNE). Whereas inclusive approach urges the community and for instance: the mainstream schools, to challenge the

culture and history of previous working methods, at the same time it brings about the challenge of practicalities and need for new ideas and extra resources. In addition, according to Kathie Snow, does not mean only the adaptation of physical environment but is a state of mind:

Being included is not a privilege to be earned, nor a right that is given to individuals. Inclusion is—first and foremost—a state of mind. Do you *feel* you belong: in your home, at work, in a classroom, at church, in the PTA, or at a T-ball game?”  
(Snow 2001, 391).

For these reasons the integration of the students with special needs in separate class rooms seems to be the easier option, however not necessarily the best for the student as being in a separate section in school might be a ”shameful” issue for the child. On the other hand, it is important to keep in mind the right for the child for quality education and non-discriminatory environment. This is not always automatic if the students are collected together in the mixed school without realizing the possible, already existing attitudinal barriers which may bring about tension between the regular and special students.

In addition to school life, inclusion is a concept which can be used in all spheres of life. It contains the break down of attitudinal barriers, behavioural barriers, social barriers and environmental barriers, and is often defined through its antonym: exclusion. Without recognition of exclusion, inclusion can not be identified or understood. According to Levitas et al, social exclusion

is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in society, whether in economic, social, cultural or political areas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.  
(Levitas et al 2007, 9).

However, social exclusion is a term used only when the situation brings about negative effects in the individual’s life, whether he is willingly or unwillingly in the situation. In circumstances when people who are in the exploiting situation willingly but not understanding their unequal position (eg. in case of accepted, discriminating social statuses and predicted social roles) social exclusion is the term to be used, but if the individual willingly removes himself from the contact with the mainstream it is not ‘social exclusion’.

Social exclusion is not necessarily a matter for minority groups in the society but can also affect the majority as happened during the Apartheid in South-Africa and in case of the land owners and peasants at the beginning of the 20<sup>th</sup> century in Finland. In both cases the countries went through civil wars.

In their paper on the multidimensional character of social exclusion, Levitas et al introduce the indicators of social exclusion approved by EU in 2001. The list names 18 primary and secondary indicators of social exclusion, of which thirteen (13) were connected to low income and unemployment and two (2) to insufficient access to education (Levitas et al 2007, 33). Exclusion is a structural phenomenon which places individuals in a vulnerable position on the basis of background or changed, temporary life situation. In Kenya National Youth Policy 2002, the vulnerable youth groups were named to be

- youth with disabilities
- street youth
- youth infected with HIV/AIDS
- female youth
- the unemployed youth and
- out of school youth

(Ministry of Home Affairs, Heritage and Sports 2002).

In the same document issues such as unemployment and underemployment, health related problems (HIV/AIDS, STI, drug and substance abuse, poor access to health services), school dropout, crime and deviant behaviour, limited sports and recreational facilities, abuse and exploitation (sexual, physical, mental abuse, child labour), limited participation and lack of opportunities, limited and poor housing and limited access to information and communication technology were listed as matters affecting the youth in Kenya (MoHAHS 2002). To ensure the inclusion in these areas it is important to ensure the accessibility of services and the correct information for all. This starts with actions such as organizing health related education, reducing the expenses of education and discussing the importance of schooling (especially in case of children with special needs), offering places for social gatherings and events for youth and offering help in housing issues.



Enhancing the social participation and the access to leisure time activities and safety are vital elements when moving towards inclusion in the society. In this study social participation will be considered in relation to the leisure time activities, accessibility and quality of social interaction of YPD.

#### 4 YOUTH WITH DISABILITIES IN KENYA

The youth have been given considerable responsibility to become the actors who will take their place to build the nation, to “be fruitful and multiply; fill the earth and subdue it; have dominion over the fish of the sea, over the birds of the air, and over every living thing that moves on the earth” as it is put even in the first pages of the Bible (Gen.1:28).

In Kenya the young people aged 15-24 years constitute about 21 per cent of the population (KNBS 2009, 4). However, at the same time the youth confront challenges that may lead to exclusion from the society, challenges such as poverty and insufficient education, unemployment, HIV and AIDS, street life, teenage motherhood, disabilities. As John Mugo and Josephine Oranga also state, a great number of studies have been targeted on the young people and especially on issues as HIV and AIDS infections and education, but only a little has been done to study the youth with disabilities. (Mugo & Oranga 2010, 3). Supporting their statement, I find it important also to focus on the youth with disabilities and search and spread information about the issues they face in the society.

The following chapters study the situation of YWD in Kenya and discuss the fields which should be considered when aiming to include YPPD in the society. Furthermore their role in the society and the current access to education and social participation will be discussed.

##### 4.1 Qualities associated to adolescence and YPWD

Adolescence includes the ideas of future prospects and aim to reach the set goals or so to say dreams which are considered as important matters in life. There are qualities set by

the individual (dreams) and qualities set by the surrounding community (expectations). Citing J.Mugo and J.Oranga, these qualities of transition into adulthood consist of

Gaining access to employment, maintaining a home, becoming appropriately involved in the community and experiencing satisfactory personal and social relationships, (Mugo & Oranga 2010, 6).

In the Youth policy document, areas as employment, health, education and training, sports and recreational activities are covered. However, as mentioned before, consideration for the YWD is in Kenya Youth policy but no specific implementation plan has been made except the statement that 10 per cent of the programmes are to be in favour of the youth with special needs, who are

unemployed youth, out of school youth, female youth, youth infected and affected by HIV/Aids, street youth, physically and mentally challenged youth and youth in difficult circumstances (PoK 2007, 19).

The uncomfortable part is that the lack of implementation is prevalent in the society. Legislation on the adjustment of public buildings and the requirements on non-discriminatory practice in accessing schools or employment have been made but without visible changes in the practice. For this reason the youth with disabilities may fall “through the cracks”, to use the term by Mugo and Oranga. Even though the aim is to mainstream the special sub groups to be included in the main group (in this case: the youth), with no special consideration these groups may drop out from the whole implementation process.

There are numerous cases when a mentally challenged child has been left home without schooling or even a hint of possible, satisfactory work place, or grown-ups who stay in the dormitories and have not been allowed to have intimate relationships, or women with disabilities who have been made infertile by force. Unfortunately, these have been and even still are the reality for some PWD. Young people with disabilities have the same expectations and dreams in life as non-disabled youth, not to talk about the rights. This has to be remembered when planning the programmes and services.

#### 4.2 Step towards inclusion – Young People with Physical Disabilities (YPPD)

Youth with disabilities is one of the vulnerable groups in the society. Due to the economic and socio-cultural tensions, they face challenges such as unemployment and ill-health. They may be abused physically, sexually, mentally or in economic terms, and may drop out from school or have no access to education at all. YPPD and their closest care-takers may face economic challenges due to the expenses resulting from the disability; hospital treatment, recommended diet and support devices or possible need for boarding school environment if there is no chance to commute from home to the free primary day school. As it is discussed in UN document, there is “strong bidirectional link between poverty and disability” (UN 2008, 2) and as combined with the issues mentioned above, the poverty vice versa may cause disability in cases such as undernourishment (*during pregnancy/childhood*), insufficient access to health care services (*in case of illness/accidents*) and unsafe living environments (UN 2008, 2, italics added by author). For these reasons it is vital to find ways to include the children with disabilities and their families right from the beginning into the social system by raising awareness both in the community and among the families of children with disabilities, and by building up a society that offers equal chances for all and applies the non-discriminatory practice in the service sector.

In the 56<sup>th</sup> session for ESCAP, UN Economic and Social Commission for Asia and Pacific, several areas and issues were considered as the inclusion of disabled persons was discussed in the development process. The session served as a “new millennium impetus to equalization of opportunities for disabled persons in the ESCAP region” (UN 2000), and considered the following matters in the discussion; national coordination, legislation, information, public awareness, accessibility and communication, education, training/employment, prevention of causes of disability, assistive devices and self-help organizations. Even more than a decade afterwards the same matters are still under hot debates in the field of disability rights and inclusion. As was noticed in the millennium, inclusion is a phenomenon that has to be acknowledged and acted upon in various areas of interest both in the society and the individual’s life. To enhance the inclusion of YWD, the following areas and matters have to be considered:

- National Coordination  
One way to move towards inclusion and more harmonized society is to control the national coordination of services to ensure the application of disability policies in community level. This should ensure the provision of various services supported by the law, such as rehabilitation services and education.
- Legislation  
As working towards inclusion, it is important to ensure the equal treatment by law and recognition of equal rights of PWD. The legislation should be based on the rights of PWD and not on charity. The recognition of special groups in Youth and Disability policies is vital to avoid the drop outs in the system.
- Information and public awareness  
Providing correct information and support to access information through internet, peer support groups, special equipment/means eg. Braille, reading machine is vital in empowering YWD. This includes also the campaigns for awareness raising and introducing the disability topics and issues to public.
- Accessibility and Communication  
This covers areas such as the accessibility of public transportation, buildings and the neighbourhoods as well as introducing applicable methods to enhance communication eg. Braille, sign language.
- Education  
In the field of education, the inclusive/integrative education has a great role in including the YWD. This means also that the public schools have to be made accessible for students with special needs. In addition it is important to provide information on the importance of educating children with disabilities in the community, support for the families with low-income and building/renovating accessible school environments in the neighbourhood of the child.
- Training/Employment  
This includes possible training periods and work placements for PWD, the ensuring of the non-discriminatory practice in the fields of employment and the provision of equal access to employment for all.
- Prevention of disabilities, Rehabilitation and Assistive devices  
Support for pregnant women and the families with children with disabilities is a vital element in preventing disabilities as well as an eased access to health care for

all. This also includes the provision of free or low-price rehabilitation services and assistive devices by the state/municipality.

- International and National Cooperation and Self-help organizations

One of the most effective ways to harmonize the service sector is to enhance the cooperation between various actors in the field and providing space for effective discourse between the governmental and the non-governmental service providers. This includes also international cooperation for the interchange of resources and knowledge. It is also vital to support the DPOs and other organizations working for the inclusion of PWD.

(UN 2000).

In addition to the issues mentioned above, Tomson Dube et al provide ideas about good practice in the research by Disability Awareness in Action (DAA) in 2005. They discuss the promotion of inclusion in the field of disability, legislation and public policy, and draw their conclusion from the research carried out in several countries and reflected to earlier researches by DAA. A few matters considered as vital for the change were

collection of experiences from PWD and the use of the material for campaigning, enforceable and applicable legislation with, when necessary, penalties if not followed, clear definition of social model of disability and especially disability groups, concept of reasonable accommodation or adjustment and inclusion of PWD in the policy making level  
(Dube et al 2005, 20).

#### 4.3 Every child has a right to education

In 2003, Free Primary Education (FPE) was declared as a political commitment in the country. After that the primary schools have had to plead with the Ministry of Education, Science and Technology (MoEST) for a separate permission to collect funds (Sifuna, Daniel N). After the declaration, the enrolment rate of the students with disabilities increased significantly; in 2003 there were 23, 459 students with disabilities in primary and secondary school whereas in 2006 the number had increased up to 36, 239 (MoE 2009, 23). Kenya is also committed to achieve universal free primary education and gender equality by year 2015 (MoE 2011).

In 2003 20.1 per cent of the total expenditure of the government was used to education purposes whereas before in 2000 it was only 16.5 per cent (Sawamura & Sifuna 2008, 105, c.f. Oxfam & ANCEFA 2004, 30). Even if the primary education is often defined as ‘free’ for the students and their families, many schools still collect various fees and require certain costs to be covered by the family. Nobuhide Sawamura and Daniel Sifuna collected a table visualising the average costs for school items often required to be covered by the family, and the estimated amount of money reached up to 10,000 ksh per year per student (Sawamura & Sifuna 2008, 108). In addition, the boarding schools collect additional fees to cover the living expenses for the students. These facts set the children from humble background to a vulnerable position and question the equal opportunities and the whole concept of free primary education. Furthermore, the government has not been able to provide YWD schools near their location, which compels the students to move out from their neighbourhood to attend the far-located boarding schools with extra expenses. Families with children with disabilities face multiple challenges and additional costs due to the unequal provision of opportunities in the whole education system, and the education of the children is dependent on the family’s income, charity, “harambe” (money-collection) or possible sponsors. As discussed earlier, disability is often connected to poverty and the extra expenses on education make families unable to provide their children with quality schooling if schooling at all. Sawamura and Sifuna also mention the unequal position of schools with large and small number of students as the government pays the schools 1,020 ksh per students per year (Sawamura & Sifuna 2008, 105): this affects the quality of teaching when the schools aim to increase the number of the students to gain better income that is compounded of both the provision from the state and smaller additional fees collected from the care-takers of the students.

According to MoE, in 2008 there were

1342 special units and 114 public special schools which include vocational and technical institutions, that cater for students with special needs and disabilities (MoE 2009, 18).

As neither inclusive nor integrated education is at its strongest at the moment in Kenya, this means that majority of the children with disabilities do not have access to education. In addition to the insufficient provision of special educational services, the challenge is namely segregated education services. Children with disabilities often have to travel long

distances to attend schools suitable for their condition and due to the circumstances are forced to attend boarding schools. This also means additional fees, which no more reflects the main core of 'free education'. As Umesh Sharma states in his article discussing the inclusive education in India, it is for the special learner to adapt to the system before the system tries to fulfil the educational needs of the child. He continues that the system provides education for the children with mild disabilities, but omits the students with severe disabilities as they do not fit in the regular education system. These children rarely have access to schooling and if they do, it is in the realms of special schools. (Sharma 2005.) In his article, Sharma also discusses the challenges that occur when trying to oppose segregated educational services and replace them with the integrated education. He states challenges such as

- poverty
- negative existing attitudes
- dissemination
- insufficient training to stake holders
- insufficient resources

(Sharma 2005).

As discussed earlier, disability in many cases causes poverty and vice versa. Thus disability is often connected to poverty and in some societies the first idea of a disabled person is someone begging in the street (which however should not be the case). Poverty combined with the negative existing attitudes and dissemination leads the families and communities to reason that educating of a child with disabilities is not possible, sustainable or even necessary. The negative attitudes also refer to the religious attitudes which reflect the values of the society, and these attitudes namely are one example of the negative socio-cultural factors in the lives of PWD. In countries such as India and still to some extent, Kenya, disability is connected with something bad done in the past and punishment from gods, which contributes to the unequal status of PWD and to the fact that the children with disabilities are not taken to school. Furthermore, introducing education for children with disabilities in such environment requires perseverance and lots of informative training and collective actions with the whole community. Insufficient resources from the state and other sectors are another challenge that hinders the embracing of special education. The special needs education requires more resources

compared to the mainstream education, resources such as training of the staff, bigger number of staff, special equipment and conformed environment with for example slides, special toilets and extra space. Another challenge is the varying approaches in the field. Throughout the history the disability services have been based on the charity approach and in most cases the religious communities have been the first ones to “show God’s love to the weakest in the community”. When the rights-based approach came up and the rights of PWD were noticed, the governments started to work on the equal provision of services which, however, has not gained its full potential until now. The public services are supported by NGOs and FBOs that are not necessarily based on same values as the services provided by the state, and this might create tension in the service sector as many NGOs still practice the charity approach. This hinders the disability development as the charity approach still tends to reinforce the roles that keep PWD in unequal position.

Despite the challenges, a positive change has already been started and the situation has improved significantly in the last decade. The introduction of FPE alleviated the access to education for children from humble backgrounds and it was visible in the increased number of students with disabilities enrolling in schools right after 2003. Already in 1970, the integrated units and programmes for students with disabilities were introduced, and the education was not anymore provided only in separate schools (MoE 2009, 17). In addition, Kenya has approved the declaration “education for all”, and was also committed to provide more chances for education so that the enrolment rate of the children with disabilities would raise up to 10 percent by 2010 (WHO 2011, 214).

#### 4.4 YPPD and social participation

According to Ho et al, participation in leisure time activities during the adolescence is vital

in developing skills and experience for successful transition to adulthood  
(Ho et al 2008, 2).

However, as the majority of the interviewees attended boarding school (16 out of 18), the reality of decreased opportunities to interact with the outside community was considered. The discussions on leisure time activities and social participation were based on the



earlier experiences, the experiences gained during the holiday times and the occasions when the student had been in contact with the community for one reason or another.

In the life of a student, school has a great role in providing a safe environment with co- and extra-curricular activities, peer support and educational services, and in this way it supports the students in their growth to maturity. However, the inclusion in the surrounding community is visible only in the leisure time when the safety net of a boarding school has been taken away. The interaction with the surrounding community, peers and other support networks plays an important role in the inclusion process of YPPD. A special boarding school provides a safe environment for the child, but how well does it prepare the students to face the surrounding society after schooling? This is one reason why integrated schools are preferred to be better options to educate students with special needs as also Dr Mani stated already in 1998;

the true objectives of integrated education are to - - Provide a natural basis for adult life experiences so that blind students may take their proper places as contributing members in all sectors of society.  
(Mani 1998).

In the research we limited social participation into two main areas that were social relationships (family, friends, surrounding community) and access to voluntary leisure time activities.

## 5 EARLIER RESEARCH

A lot of developmental research and studies have been made on the SNE in the developing countries. These papers include studies, research and informative articles on education for children with special needs and mainly concentrate on the education system and the structural challenges in the society. These are for example the research by Kenya National Commission on Human Rights; “Objects of pity or individuals with rights: the right to education for children with disabilities” (KNCHR 2007), publication “Children with disabilities” by UNESCO (UNESCO 2006) and paper by Ture Jonsson and Ronald Wiman “Education, poverty and disability in developing countries” (Jonsson&Wiman

2001). Furthermore, 'Education For All' has become one of the most celebrated goals for international organizations as UN, WHO, UNESCO, World Vision and Save the Children, which has also contributed to the increased worldwide interest in education systems.

Conversely, much smaller number of qualitative research on the lives of children with disabilities has been made, and even in these studies the tendency to interview only professionals and parents instead of the children is visible. However, the research by Ingstad and Grut "See me, and do not forget me – People With Disabilities in Kenya" (SINTEF Health Research 2007) studied the experiences of PWD in Kenya and the link between disability and poverty in the context through a great number of personal interviews from PWD themselves. In the study the challenges as well as opportunities of PWD were discussed. In the interviews, challenges such as diminished access to education or employment, mistreatment by care-takers and neighbours, stolen rights for ownership and inheritance, increased physical and sexual violence came up as well as opportunities that were namely the supporting family of the person with disabilities, possible sponsorship and peer support.

In Kenya quite a few related studies have been made in Thika where a good number of schools and nurseries for children with disabilities are located. One of these was the research conducted in Thika Highschool for The Blind by Mugo and Oranga (the research has been referred to even earlier in this report). In the study John K. Mugo and Josephine Oranga tested the youth transitions in Kenya and in particular the youth transition for the youth with disabilities (Mugo & Oranga 2010). In the paper Mugo and Oranga discuss the vulnerable position of YWD in the transition phase from school to employment or further studies, and conclude that the YWD in Kenya are not taken into consideration enough in the policies, they lack the sufficient access to education and for further studies after primary school, and have almost no chances to gain employment.

Other research that were considered during the study were the research conducted in Ireland in 2004 for National Disability Authority (NDA 2004), and another research conducted by Beth Wambugu and published in 2010 (Wambugu 2010). Both of the researches studied the participation of PWD and raised the concern of diminished social and political interaction. "Survey on Social Participation and Disability" published by NDA concluded that PWD move around less and socialize less outside of their home

compared to the mainstream population, and that over 40 per cent of PWD could not access the public transportation. However, the study also noted a few positive remarks that were the accessible homes (two third of the respondents), good health and the opportunity to manage their own money. In her study, Beth Wambugu studied the political participation of YWD in Kenya especially in the 2007-2008, and found out that all of the interviewed were politically active and even as big percentage as 90 per cent had voted in 2007 general election. However, at the same time YWD were excluded from the political processes in Kenya as no opportunities for them to attend voting or political activities were provided.

According to the earlier researches and studies, PWD confront variety of challenges in the various fields in their lives, but at the same time have opportunities which may help them to tackle the hardships and exclusion. In Kenya the major challenges in the field are the structural and attitudinal challenges.

## 6 RESEARCH PROCESS

The research was conducted in autumn 2010 in Thika and partly in Nairobi, Kenya. The methodology for the research was chosen on the basis of its applicability and suitability for qualitative research. The ethicality and the reliability of the research and the research methods were considered throughout the study process.

### 6.1 Research questions

The aim of the research is to study the current, contextual situation of YPPD in Kenya in the fields of education and social participation and the research aims to answer the question:

- What kind of challenges and opportunities do young persons with physical disabilities have in Kenya in the areas of education and social participation?

The question above is divided into three sub questions;

- What kind of socio-cultural challenges and opportunities are there for YPPD in Kenyan society?

- What kind of economic challenges and opportunities do YPPD have?
- How do the political factors affect the lives of YPPD?

Each country has its own realization of disability and thus also special behavioural habits connected to it. In this study I want to study how the cultural and social values and economical and political ideas affect the lives of YPPD in Kenya and what kind of challenges and opportunities they face. In further discourse we aim to discuss the possible ways to better the situation in Kenya and suggest ways to create more inclusive community and society.

## 6.2 Research environment

The majority of the interviews were conducted in Thika in S.A. Joytown Secondary School whereas two (2) of the interviews were conducted in two separate universities in Nairobi. Thika is a market town with a number of special schools and nurseries for children with disabilities. S.A. Joytown Secondary School is a mixed school for physically challenged youth with various physical disabilities, such as poliomyelitis, spinal bifida, cerebral palsy, amputees, muscular dystrophy, stunted growth and dwarfism. In 2010, total of 174 students enrolled in Joytown Secondary School at the beginning of the school year. Ten per cent of the places are reserved for regular students and all the classes are mixed; both for boys and girls, for regular and physically challenged and for students with severe and with mild disabilities.

The school started in 1980 with only 20 students and a few class rooms but has expanded enormously both in the number of the students and the environment and school buildings during past 30 years.

## 6.3 Ethical consideration

The interviewees were guaranteed the confidentiality of their identity and no detailed information about the research was given out to others than the relevant persons within the study. All of the interviewees were considered to be well capable of deciding themselves about whether they wanted to be interviewed or not despite of the varying ages of the attendants (15-22 years). Out of 18 students six (6) were under 18 years old. In these cases the same consideration was applied as contact with the parents was not

accessible because of the far location, boarding school environment or personal issues. Before the interviews the interview process was explained in detail and permission to use the material for research purposes was asked only after the interview when the interviewees were given final opportunity to withdraw from the research. In case of individual interviews, the interviewees were given written form of the interview and asked to give permission only after reading through the interview. Interviewees' names are not mentioned in the following discussion and neither coding was used as it was considered important in securing the identity of the interviewees.

#### 6.4 Methodology

In the research the qualitative approach was applied as the aim of the research was bound to human behaviour and phenomena described by the PWD themselves. J.C. Glen (2010) describes the use of qualitative research methods as use of questioning words “why” and “how” instead of the words asking for quantities, places or time periods. It was a popular approach already in the beginning of the research history but was overrun by the fame of quantitative research approaches in the 1950s and 1960s. However in 1970s the qualitative researches started to come out again and the method gained interest from the researchers again. (Glen 2010, 95).

In the research both the individual and group interview methods were used as the combination of the methods was considered necessary and effective for the material collection. The individual interviews were chosen to be unstructured to give the interviewees space to discuss the matters that were most important for them. However, in such interviews the challenges may be data hardly comparable with each other, difficulties in analysing the data and time-consuming interview sessions or analysing phase (Kothari 2004, 98). To avoid too broad topics in the interviews, an idea chart for the discussions was drafted to keep the topic in between certain limits (see appendix 1).

When comparing with the individual interviews, the group discussions focused more on the discussion over topics picked from the individual interviews and finding solutions on the situation in Kenya from the point of view of the students. The focused interviews are often used to develop the hypothesis (Kothari 2004, 98) and in this case they also served as a tool for analysing phase.

In the research I chose to use both individual and group interview methods. The research consisted of two (2) focus group interviews with a total of eleven (11) students and of seven (7) unstructured, individual interviews. The age of the interviewees varied from 15 years up to 22 years. Two of the interviewees had completed high school and transferred to universities. In addition to the interviews, secondary data was collected through the everyday observation and informal discussions with the professionals.

The interviews were recorded and later transcribed into written form for the data analysis

#### 6.4.1 Individual interviews

According to Gillham, the interviews are

Inherently more flexible, what ever the level of structure, ranging as they do for ‘listening in’ and asking questions in a real life setting to the standardized recording schedules used by market researchers (Gillham 2005, 3).

This gives the data a deeper taste of humanity as the experiences and situations are discussed in detail instead of sharing the phenomena into list without deeper personal contact. For this reason and the aim of the study I decided to use interview method instead of questionnaires, which however, is another quite used way of collecting data.

The individual interviews were conducted by using open ended questions and giving the main role to the interviewee to tell his/her story in their own way. Certain framework for the interview was sketched before hand to ensure the acquisition of information and ideas needed to answer the research questions. The interviews were divided into four parts in a relatively narrative manner, starting from the birth and early childhood. The second area was possible schooling opportunities and the socio-economical situation of the family, and the third area consisted of questions about free time and social relationships. Fourth area dealt with students’ ideas about the past and the future. In the beginning of the interview, short introduction to the interview theme was given. However, if some area did not come up naturally during the interview, it was not picked up anymore by the interviewer to maintain the freedom of talk for the interviewed about the issues they found most important in accordance to the topic. For the interview chart see appendix 1.

As Kothari explains, the interview process should be made easy for the interviewee to access and to relate in easily (Kothari 2004, 99). For this reason the interviews were organized in a familiar place for the interviewee and the interviews were conducted in informal manner without using too much formal language or terms which could have hindered the bonding and creation of trust between the interviewer and the interviewee. The gender ratio for the interviews was 3:4 (female-male). The time for interviews varied from 45 up to 90 minutes.

#### 6.4.2 Focus groups

In addition to the personal interviews, focus groups were organized to discuss the social and educational challenges in the field of disability and to raise up the issue of dealing with the matter and what could be done with the challenges in Kenya. For the group interview chart see appendix 2. A focus group method was chosen to collect information and to explain the personal experiences through brainstorming in the group, as well as to develop the hypothesis already drafted after the individual interviews (Kothari 2004, 98).

There were two focus group discussions; one for girls and one for boys. Girls' group attendants totalled of five (5) and Boys' group total of six (6). The group sizes were intended to be kept relatively small to ensure the workability of the group and to give enough space for everyone to attend actively.

Focus groups have generally two dimensions which specifically define it: the focus on specific topic and the special set of interviewees which has been defined before hand (Gillham 2005, 60). In this research both the group (YPPD) and the content (Challenges in different layers in the society for PWD and coping with them) were defined before hand. The benefits of the group interview method are many, and Gaskell summarised the benefits in three points: the synergy in the group when the group together becomes more effective than it would be if the same elements were separate, possibility to observe the group dynamics during the interview and possibility to observe emotional effects of the topics and discussion which are not always as visible during the individual interviews (Gillham 2005, 63, c.f. Gaskell 2000, 47). These elements were visible during the focus group interviews and gave the view of the interviewees into the understanding of the phenomena discussed.

The groups were organized in S.A. Joytown Secondary School, Thika and the interviewees differed from the students in individual interviewees. The group sessions took approximately 90 minutes each.

## 7 RESEARCH RESULTS

Analysis of the data aims to answer the question of “from which elements was the data made”. The qualitative analysis can be done on the basis of categorising the data or using narrative method to understand the phenomena studied. (Gillham 2005, 126). In this study I chose to apply the categorical analysis which is common method as analysing qualitative data. The phenomena occurred in the interviews were categorised into topics which seemed to be most common for the interviewees. Majority of the experiences discussed were connected to either the social or economic spheres of life.

In the first chapter I discuss shortly the various socio-cultural, economic and political factors that rose up during the interviews and which seemed to have emerged also in the fields of education and social participation of the interviewees. After that, in the following chapters some of these factors are picked up and discussed in detail, and the experiences on the various challenges and opportunities they had brought about are studied. These challenges and opportunities the interviewees had faced in the fields of education and social participation will be analysed in categories and with the help of the references from interviews.

### 7.1 Factors affecting the lives of YPPD

In the data analysis the challenges and opportunities the interviewees had faced were divided into three groups: socio-cultural factors, economic factors and political factors. In the interviews, the socio-cultural and the economic factors got more attention from the interviewees than the political factor. In this chapter I want to discuss shortly the various socio-cultural, economic and political factors that rose up during the interviews. After this, the core findings of the positive and negative experiences of the interviewees will be discussed in the following chapters to answer the research question in detail.



Table 1. figures the factors found in the research and shows the effects of these factors on the lives of the interviewees; how they became visible in practise. Various challenges had similar effects, and as an example, the insufficient access was both the result of attitudinal and economic challenges.

Table 1. The findings of the research and the effects of socio-cultural, economic and political factors in the interviewees' lives.

FACTORS	OPPORTUNITIES	CHALLENGES	EFFECTS
socio-cultural	<ul style="list-style-type: none"> <li>* relationship with God</li> <li>* supportive instant family</li> <li>* peer support</li> </ul>	<ul style="list-style-type: none"> <li>* negative attitudes and beliefs in the community: neighbourhood, school, family</li> <li>* verbal and mental abuse</li> </ul>	<ul style="list-style-type: none"> <li>+ self-confidence</li> <li>+ motivation</li> <li>+ positive self-esteem</li> <li>- shame</li> <li>- fear</li> <li>- low self-esteem</li> <li>- no access to education</li> </ul>
Economic	<ul style="list-style-type: none"> <li>* access to support devices</li> <li>* Sponsor</li> <li>* lower school fees in some of the schools</li> </ul>	<ul style="list-style-type: none"> <li>* lack of monetary support</li> <li>* poverty due to the disability</li> <li>* humble background</li> <li>* lack of support devices</li> </ul>	<ul style="list-style-type: none"> <li>+ independence</li> <li>+ accessibility</li> <li>+ access to education</li> <li>- no access to education</li> <li>- dependence</li> <li>- lack of good health</li> </ul>
political	<ul style="list-style-type: none"> <li>* Persons With Disabilities Act 2003</li> <li>* new draft of constitution 2010</li> <li>* right to compensation in cases of somebody causing the disability</li> </ul>	<ul style="list-style-type: none"> <li>* no legal welfare benefits for PWD</li> <li>*lack of proper implementation and follow-up</li> </ul>	<ul style="list-style-type: none"> <li>+ legal right for quality life</li> <li>+ notion of the issue in the society</li> <li>- deprivation due to the disability and extra expenses caused by disability</li> <li>- lack of implementation of rights in the everyday life</li> </ul>

The socio-cultural factors included various factors that the interviewees saw either as challenges or opportunities. The opportunities included elements in their lives that had given the interviewees support and encourage, and among others helped them to overcome difficult situations and other challenges they had faced. These elements were faith in God, supportive instant family and peer support from the other students with disabilities. The faith in God and His support came up mostly when the acquisition of the disability, reflections on the own identity and overcoming challenges were discussed.

The issue of family relations had two dimensions which the interviewees pointed out: supportive and encouraging family environment and rejecting instant family or relatives. According to the interviewees, the supportive family had had effect on the positive identity building, accepting of disability and the whole process of finding ways to cope with the disability in the everyday challenges.

Importance of peer support was not discussed as much as the effect of the family and faith, but it mostly it came up when the interviewees described the differences between the mainstream and special schools, and the benefits of special schools. However, for many it had also been the key to accepting the disability.

The challenges mentioned in the interviews were the rejection and discrimination in the neighbourhood and even in the family due to negative attitudes and beliefs. Some of the situations which the interviewees connected to negative attitudes and behaviour were situations when

- the interviewees got extra attention in the streets in forms of staring or verbal or mental abuse,
- they had not been allowed to fulfil the social roles which otherwise they thought would have been theirs had there not been the disability (eg. Cooking and other household tasks, role of student: this is: education) and
- they were not treated equally compared to non-disabled counterparts.

The positive effects of social and cultural factors discussed in the interviews were gained self-confidence, motivation and positive self-esteem whereas the negative factors brought about shame, fear, low self-esteem and even inability to access education in cases when the parents did not find it important for the child to join school but kept him/her home. All of these topics will be discussed in detail with the extracts from the interviews in the following chapters.

The economic factors in the interviewees' lives were multiple and they got great interest as it was seen as one of the most current and greatest challenge in their lives. Some positive elements that had helped them were possible sponsor or other sector who took care of the school fees for them, lower school fees in certain schools for YWD and access to support devices which was also clearly connected to the economical situation in the student's and their family's life. The challenges that hindered their participation and independence were lack of monetary support or humble background (mainly had effect on school fees or access to support devices), lack of support devices and poverty generated by the disability as a result of high hospital fees or other expenses due to disability. These factors affected the independence or dependence of the students, accessibility in the fields of education and infrastructural and social environment (mainly when the support devices were not at hand or the humble background created social barriers). In addition, the factors affected the health condition of the students in cases when, due to the economic situation, they were not able to pay for the fees to attend hospital in the time of acquiring disability, treating the disability or trying to get support devices such as wheelchair or crutches.

The political factors did not gain as much interest from the interviewees as the previous two factors discussed due to the fact that the research had emphasis on the challenging experiences the interviewees had faced and support networks they got. For this reason the political elements will not be discussed in detail in the following chapters which aim to discuss the experiences and phenomena that the interviewees had found challenging or encouraging in their lives. The changes in the political sphere came up only when the ideas on the improvement of the situation of PWD in Kenya were discussed. According to the interviews as well as the discussions with the professionals, the good elements in the recent history of Kenya in disability development were the Persons with Disabilities Act released in 2003 and the new draft of constitution in 2010 which consider PWD better than the previous constitution. In addition, the legislation on compensation received in case of acquiring disability as the result of disability caused by somebody else came up in the interviews as this had helped one of the students in the cases of covering the expenses caused by the acquisition of disability. However, most of the students had not got any benefits from the state but had had to deal with the expenses on their own. In addition, another negative factor stated by the interviewees was the missing implementation of existing legislation in cases such as modifying the public buildings

(especially: schools) and transportation means accessible for PWD. The existing legislation had positive effect as it gives PWD legal right to services, but at the same time the lack of proper follow-up of the implementation process makes the changes in legislation invisible in the practical life.

## 7.2 Discussion in the field of education

All of the interviewees had attended both primary and secondary school. However, some of the interviewees had not been able to join school in due age for various reasons connected to the disability: the parents did not find it necessary in the beginning, the family lacked the money for the school fees or the child was signed in school later along with younger siblings. In addition, the challenges in the economic situation and the challenges and the opportunities of the mixed and special schools came up in the interviews. Altogether the experiences the interviewees had had reflect some of the great challenges YWD are facing in the fields of education and schooling in Kenya. However, despite of the challenges, also the opportunities in the school life came up, which were the peer support in special schools and integrated education in cases when it was not discriminating the students with disabilities. However as a conclusion, many changes have to be made to create more adaptable education system for PWD and to allow the students with disabilities to practise their right to education.

### 7.2.1 Access to education

Access to education was closely connected to the economic situation and the either positive or negative attitudes on educating a disabled child in the family. One third of the interviewees had experiences in their schooling history on belayed entrance/interrupted education that had been consequence of the disability. In the group discussion one of the students experienced this discussed his case;

The days I was born, the society, including our biological parents, had not realized the essence of educating a disabled child. For example from my personal point of view, my mother persuaded my father to take me to school. - - But what was my father's stand, he had a hypothesis that educating a disabled child was wasted time and wasted money. He saw no importance in educating child like me, so I was around for two years before a close relative of mine took action. And because of him I am in school today.

Another young woman recalled;

We were not supposed to be in the same class with my little sister but I don't know what went wrong, we found ourselves being in the same class that day.

Kenya National Council on Human Rights (KNCHR) research on the rights of PWD reflected the same issues as discussed in the interviewees in this study. KNCHR interviewed SNE teachers, of whom many had given witness for situations when the child with disabilities had been shut into the house by the family as there was seen to be “no value in educating a child with disability”. For many of the parents the children were the inefficient part of the community or victims for whom the parents went to fight to find the basic necessities of life. (KNCHR 2007, 33)

For some of the interviewees acquired disability had also interrupted the studies and for the reason they were able to join the classes only later on;

After the accident I was admitted to hospital for two and a half years. There I was trained to use my leg for various tasks and such. - - After that I was taken to children's home where I could stay and study.

For most of the students the disability, whether acquired or congenital, had had a negative effect in their education as discussed above. However, one of the interviewees considered the disability as a great help for him as the disability had given him access to education. In his case, he was able to get a sponsor from abroad due to the disability and the humble background, and he became the only member in the family to study up to high school level. His siblings were not able to transfer even to secondary school after they had completed primary school. He stated:

I am lucky because I was born as disabled person. If I was not disabled person, maybe I couldn't have studied up to this level. So it is a blessing. I don't see it as a failure or disadvantage, for me it was an advantage, and I appreciate it.

Such an approach is unique compared to the earlier studies which mainly reflect the disadvantaged position of PWD and the challenges they face. However, as working towards the inclusion of PWD in the society, it is important to find also the opportunities which could be used to gain the results aimed at.

### 7.2.2 Economic situation

In the interviews also the economic situation and monetary challenges were closely connected to schooling and issues related to it. In addition, poverty generated by the disability came up in the discussions as stated by one of the interviewees:

My mom took me to hospitals to be operated, and all those operations cost a lot of money. So when it came to schooling, there was a challenge in terms of funding. That's why we try to look for scholarships and stuff.

Reasons for economic challenges derived from the policy level and family background. These reasons were lack of welfare benefits for PWD, single-parent families and occupation of the family (mainly low-income jobs/entrepreneurships). In a majority of the cases the families led by one parent were led by the mother of the house, or in cases when no parents were around, by other care-taker such as other siblings or the grandparents. The occupations of the families were mainly low-income jobs and entrepreneurships, and the families had had humble background for longer time period. However, also interviewees from middle or high income families reported economic challenges. Lack of welfare benefits contributed to the poverty generated by the disability mainly in cases where accidents, hospital visits and medication occurred. In addition, the FPE introduced in Kenya in 2003 has showed its contradictory and discriminatory practices especially in the lives of children with disabilities. Though the day scholars benefitted from the introduction of FPE and the number of both students with disabilities and regular students rose up significantly after 2003, it still made only small or no difference at all in the lives of the students who were not able to join the day schools because of the disability and insufficient facilities in the regular schools.

Ingstad and Grut (2007) discuss the same phenomenon after conducting a research on the connection between disability and poverty. Compared to the education of non-disabled child, educating a child with disabilities easily surpasses in the expenses (Ingstad&Grut 2007, 37-38). This might be another issue which takes the parents from taking their child with disabilities to school, as well as the low level of education and esteem in many of the families. In many cases they do not even know where to go for help and information (Ingstad&Grut 2007, 38).

Economic challenges were visible in the students' lives as a lack of support devices, hardships in funding the schooling, inability to join the school for the whole semester and

the fear of the future in terms of education and employment opportunities. The school fees for the students were provided by a relative or the instant family, with the help of harambe (money collection) or a sponsor. Another interviewee staying with her grandmother after the loss of her both parents enlightened her situation;

She is paying for the school fees though she is a widow. She works in the local markets. It's a great struggle, but she is strong.

Another interviewee told;

When I came here for the first time, my sister and brother had harambe, a fundraiser for me. They have done that up to now every year.

On the other hand, some schools for students with disabilities collect lower school fees compared to the regular schools because of the previous experiences that had proved the idea that the majority of the students come from humble background. However, when the solutions for insufficient access for education for students with special needs were discussed, the need for community education in terms of accepting the children with disabilities and emphasizing the need for educating the child came up stronger than the need for the government to provide monetary support for the families with children with disabilities. The cultural barrier was seen to be a bigger challenge than the monetary challenge in the society.

### 7.2.3 The strenghts and weaknesses of mixed and special education

The matter of education rose up in both the focus group discussions, and both opinions for and against separate schools for special needs education were discussed. The special schools got the approbation from the majority of the attendants in both of the groups. Mixed schools were seen as a challenge when the education and gaining good marks were numbered as the main aim for the schooling, whereas the special schools were discussed to be challenge for the life after the school as no special institutions would be there to support them afterwards. Many of the interviewees mentioned the fear of harassment in regular schools. This fear and acknowledgement of the disability has become an issue for many PWD across the world as concluded also Shakespeare (2005) after conducting a research which included interviews and participatory observation in 14 different schools. In comparison with the results of his study, also many of the interviewees had experiences on being abused verbally, mentally or even physically.

Furthermore, even if the respondents had never experienced such harassment, the knowledge of the matter had shaped their self-image and behaviour in the social networks. (Frederickson & Cline 2009, 527, cf. Shakespeare 2005, 17). This shows that the already existing, deep rooted social ideas and second-hand experiences create also a barrier for the PWD to mingle with the mainstream society as they have learned that they will be 'picked on'. For this reason PWD, as well as any other minority group, sometimes find it easier to spend time with their peer group and not with the mainstream. However, the support of the peer group should not be undervalued as almost all of the interviewees emphasized the peer support and acceptance they had received when they shifted from a regular school to a special school;

It was very hard to accept myself after the accident until I came here. Then I accepted myself.

What gave me motivation was time when I was taken to the children's home. - - There were some people who were more challenged than me - - even some of them were born without hands, they had two legs but no hands, and still I could see them writing... that motivated me.

Before I despised myself, I hid myself in our house. When I came to this place I became free.

In comparison to the peer support in special schools, the negative sides of the mixed education were mentioned to be the negative form of comparisons between "the abled" and "the disabled", exclusion or abuse and experiences of being alone. Two of the students explained:

If you are alone in a regular school, you will just be thinking "I can't run like them, I cannot do this and that". If you want to go somewhere you feel like you are burden to them if they should push your wheelchair for you to get somewhere.

I think it's good to be in a special school where we cannot be looked down upon and where we cannot be mocked by other people.

This support, or lack of it as was mentioned to be in mixed schools, was relevant feature considered to contribute to the success in the schooling as one of the interviewees compiled;

So there (in mixed schools) we face many challenges. - - they keep on asking what happened to you, why are you like this.... they laugh at you, and when such things happen they affect your mental capacity and your performance in school.



Another interviewees continued by stating:

The problem there (in mixed schools) is with the academics, they will be affected. It (harassment) is ok when you are outside doing nothing, but when we are learning, you need right environment. Like those schools, they don't have facilities. I don't think we could make it. In addition some students maybe write slowly, so when it comes to exams, these people will face some challenges.

My education in mixed school was affected because I didn't get any friend to interact with and the teachers in the school used to beat me.

However, also comments for integrated education were made in the discussions. The current trend of integration and insufficient resources by the government to provide special schools for all children with disabilities came up in the discussions, as well as the practical benefits of regular schools:

Being in a special school without regular students is bad because maybe those who are in a wheelchair don't have the strength to push themselves, and neither have the other students, so it becomes difficult.

Being in a separate school is not good because out there you meet all kinds of people. After all, you won't live in that school for the whole of you life. - - it becomes difficult to cope with the outside world after completion of school life.

In the boys discussion group another interviewee also stated the current, impractical situation in his comment for integrated schools:

Here we have three national secondary schools for physically challenged. These schools are in three of the provinces. Is there reason for someone to move from one province to another because of schooling? And how many get in? So I think the government should do something. Even if it could be quite hard, let it be in those regular schools if they provide proper facilities so that all the disabled students can join them.

Both of the groups preferred the special school in the discussions but also noticed the need for mainstreaming of the special education. The major challenges for the inclusion at the time being were seen to be improper facilities, insufficient training of the teachers and harassment by regular students. In addition, all of these challenges were seen to affect the student's success in academics which is the main core of the education.

Inclusive education is not easy in practise as it is quite new concept and urges the schools to do more than up to now. Sue Stubbs (2002) discusses the inclusive education in the context of developing countries and gives out a list of challenges and opportunities of which some came up also during this research. Some of the challenges for inclusive

education were namely culture and the existing values resisting diversity, lack of cooperation from various sectors and the fact that the possible resources were connected to already existing, segregated education. The related opportunities she discussed were, among others, existing human rights approach and elements of it, and the active participation of PWD and their families in the field. (Stubbs 2002, 42). These challenges and opportunities are visible even in Kenya even though the main challenge was not the existing legislation and policies which would not support inclusive education, but the actual implementation of the policies.

However, if all PWD were to be educated, the special schools could not provide schooling for all. Because of the expenses due to the far distances and special environment, inclusive education was seen as the only solution in the future though not necessary the most wanted.

#### 7.2.4 Importance of education

As described earlier, the challenges in the mixed schools and their effects on the success in education were considered as big challenges. This is because for the students with disabilities, education plays a great role and for the interviewees the good grades seemed to be the only way up. Another interviewee expressed her fear of the future and seriousness of studies in her life:

Every time lesson goes and I get nothing, I feel like my chances are getting fewer and fewer. I am not like another person who can go and try somewhere else, me I am limited. I have to put more importance on studies so that I will get somewhere as I cannot move from place to place or do some extra like keeping chicken or farming.

Singal, Jeffery, Jain and Sood (2009) researched the importance of education for PWD in India. The topic of the research includes an extract from one of the interviewees and reflects the same idea as the comment above: “With education you can do anything; without education there’s nothing you can do” (Singal et al 2009, 1).

For these matter the issue has to be realized as the education indeed plays a vital role in the lives of the children with disabilities. Mainstreaming should never take place at the expense of YWD. However, when discussing the strengths and the weaknesses of included or integrated education, it is vital to talk about the issues with their right names. Integration and inclusion are often referred to as synonyms which also Thomas et al

noted already a decade ago (Thomas et al 1998), and this sometimes seems to be the case even in today's society. However, it is important to notice the difference between physical inclusion or integration and overall inclusion. As Snow described, inclusion is not only made of the physical deeds (same class room, same teachers, same school compound) but "a set of mind" ("do I feel I belong to the group?") (Snow 2001, 391). We have many ways to measure inclusion with physical indicators but if we are to reach even satisfactory level of inclusion, in addition to the physical inclusion we have to consider the inclusion in the attitudinal environment and social life, and work on the improvement of the inclusive atmosphere. None of the interviewees reported to have such experiences in the mixed schools they had attended.

### 7.3 Discussion in the field of social participation

The interviewees had various experiences on the participation in the surrounding community and fulfilling the developed social roles in the home environment. Some of the students had been able to attend the everyday life activities to the extent they themselves had wanted, and been able to be an equal member of the family, student, or participant in some other activities such as church, sports clubs or NGOs. However, three quarters of the interviewees reported exclusion from certain social activities due to disability. Both of the challenges and the factors that had supported the students in their life will be discussed in detail in the following chapters.

However, due to the challenges the interviewees had faced, many of them reported that they were at the time being, or wanted to be in the future, active in the organizations for PWD. Even though at the moment YWD face various challenges that hinder their participation in the social activities in their family or community, they want the situation to change and also be part of the change in their communities. Nonetheless, the interviewees also brought out the opportunities of support networks and support devices. Another good way to take a step towards inclusion is to notice these factors and ensure the sufficient community education and provision of support devices to PWD. PWD are eligible to the freedom of social participation and that right should be noticed and applied in the society.

### 7.3.1 Attitudinal challenges hindering participation

A few of the interviewees reported exclusion in the family as they were not allowed to fulfil the specified roles in the family. In many of the Kenyan families the women are still taking care of the household work and cooking, and in a few cases the girl children with disability were not allowed to cook or join in for the household tasks. One interviewee recalled:

There was time when I was not allowed to touch anything; I was just there like a small baby. Like baby is there and she can't do anything but has to wait someone to come and help her.

Other challenges occurred when the interviewees wanted to attend social activities outside of their home such as church service or concerts, or visit their friends. One of the interviewees was not allowed to get out of the house alone even after turning to the adult age of 18 years. Other interviewee described situations, when he had not been allowed to get into public places such as concert places or restaurants due to the wheelchair he was using. In addition, many of the interviewees, who used wheelchairs, had had challenges in getting into the public vehicles as the conductors had denied their access.

The study by Ingstad & Grut (2007) resulted in finding similar challenges for PWD in Kenya as the interviewees in this study discussed. They claimed that the deep rooted beliefs and negative attitudes the communities had created even “insurmountable obstacles to participation” of PWD (Ingstad&Grut 2007, 15). According to the interviewees, this was true and in the discussions it was included in the topic of accessibility. Accessibility concerns both the physical and attitudinal environment in the matters such as physical infrastructure of the public buildings as schools, shops, banks, transportation and streets, as well as in the issues connected with social decisions; rejection in the family, denial of a work place and abuse due to the disability. The students discussed how various forms of negative thoughts and deep rooted assumptions about disability had been visible in their lives. Many of the interviewees had had experiences on verbal or mental abuse when they had gone out:

When you are treated as taboo, a disabled person, and there are no other disabled there, you find some people imitating how they walk and that's very bad, you don't feel comfortable when you are alone.

Other students described their experiences:

They stop and it is like the president is passing, what ever they are doing they stop and watch there. The kids come and touch your wheelchair and make fun of you.

I think in town it is when the nightmare falls. - - People see like you are struggling a lot, and they come and want to help you, and I think this is the sign of pity, sign of sympathy, but what we don't need is sympathy, what we need is empathy.

Some of the students had also been denied access to public places due to the disability:

I was really nicely dressed but the watchmen there, just because I was in a wheelchair, told me "we don't allow beggars to come inside, so don't come and beg because you disturb all the people here."

Many of the interviewees mentioned that "they see us as beggars". It seems that in Kenya many still connect begging with disability whereas it used to be that begging was connected with poverty (Albrech et al 2001, 19). Inasmuch as the poverty has become one of the major challenges for PWD in Kenya, the disability has been connected directly with poverty and thus also with begging. This shows how false picture generalization can create with time. This also affects the self image of PWD and their families as mentioned by Ingstad and Grut (Ingstad&Grut 2007, 38). During the interviews, some of the interviewees mentioned this by stating that they themselves did not want to go to public places because of the disability. One interviewee explained why she did not go back to the previous school she used to go to:

The way we used to be, we used to dance and all. I used to be the chaplain for dance, you see, and now I can't even walk properly. The other students are pitying you. That's why I didn't go back.

Many of the interviewees with acquired disability mentioned that they were not able to return to the school they used to go before acquiring the disability either due to attitudinal or physical reasons.

### 7.3.2 Accessibility and infrastructure

The issue of accessibility and transportation occurred in all of the interviews in one way or another. In the group discussions it was considered as one of the most important issues to be worked on by the government along with the negative attitudes in the community

and the accessibility to education for children with special needs. One interviewee commented:

I think the biggest challenge is the accessibility. Meaning access to the posts and education, and the infrastructure, like access to buildings. Sometimes you cannot go to the university because it does not have something that you need to go to the class upstairs.

Moving around in the towns without personal help was impossible according to some of the students. The majority of the interviewees who used a wheelchair found it very challenging to move around alone, whereas the students using crutches mentioned it as a mild challenge. Students without support devices found it possible, though in some cases hard, to move around alone. However, these challenges were not always due to the physical infrastructure but result of social ignorance as well. One student using a wheelchair commented:

The problem I have is with the ones who collect money in public vehicles, most of them don't allow us to enter into the vehicle because of the wheelchair. - - So you wait for long to get a good vehicle where the wheelchair can be carried.

The challenges with the infrastructure were also mentioned to be current at homes, and a few of the students had moved to relative's place as they could not stay at home because of the inappropriate facilities. One specific challenge mentioned by a number of students was the latrine toilets which are the most popular form of a toilet in Kenya.

According to the interviewees, the improvements in the infrastructure and facilities should be done both in the towns and the public buildings as well as at the homes of PWD.

#### 7.3.4 Accessibility and support devices

Access to support devices was one of the issues that was the challenge as well as the opportunity for the students. It was a challenge in cases when the appropriate support devices were not provided for the student. However, it also was opportunity when the devices were at reach, and according to the interviewers the support devices helped their lives to a great extent. Many of the interviewees had experiences on time when they had not been provided the support devices in appropriate time:

After the accident I didn't have a wheelchair, so they used to carry me. Only in the children's home I got one.

When I was child I used to move around crawling. When I was taken to the hospital, they made me some shoes that fit my legs. And I started walking. My mother taught me to walk when I was 10 years old.

I could not control my bladder which was a problem. I went to primary school and sacrificed myself not to drink anything so that I wouldn't urinate on myself in school. When I did my national exams, the responsible teacher taught me to use catheter. I started using it and now I can control, I can drink anything I want, now I am ok.

Many of the interviewees found it challenging to be dependent on other people around them. Another interviewee stated;

I was walking before but people used to hold my hands or carry me around. Then I sort of gave up and just decided to sit in a wheelchair not to distract other people.

Another interviewee discussed the insufficient access to the support devices and the economic challenges connected to it:

You still find wheelchairs that cost up to thousands of Kenyan shillings, what about that other person who comes from a humble background and cannot afford? He has to crawl.

In addition, the students had various experiences on the use of support devices and their applicability. Some of the challenges mentioned were the heavy structure of wheelchairs and unsuitable artificial limbs.

### 7.3.5 Support networks

Based on the individual interviews, there were three main social support networks. These networks are discussed in this chapter starting from the spiritual support network. The notion of peer support emerged in every interview but according to the interviewees, it was not considered to be the most important actor in their lives. After the comparisons between the interviews and the analysing of the data, three main social networks were found and prioritized according to the interviews.

In five out of seven individual interviews God had a major role as a motivator and supporter in the lives of the interviewees, and this relationship was described as the most important for the interviewees. Throughout the interview process, the questions did not put forward the issue of religion or faith, but the interviewees picked up the topic of a

relationship with God when discussing the self-esteem, time after acquiring disability, process of building one's own identity and the future. When asked the questions about social relationships, some of the students referred to their relationship with God as did another student:

First I say it's God, the first person in the hierarchy. Because He has brought me very far, He has helped me to stay alive, when I was desperate, He gave me hope.

In many interviews, the relationship with God also came up when asked a question about the future and the students' future plans, dreams and fears:

In future I would like to be in the best place God has planned for me.

I believe in God and I believe that God is my Father and He will take me there, to the promised land.

After five years I would be in school, and maybe God helps me so I go to a good university or college.

Many of the interviewees acknowledged that their relationship with God had deepened due to the acquired disability. For the respondents with congenital disability, God had helped them in the process of building own identity and getting answers to questions about own self and own future. Two of the interviewees with acquired disability said:

I didn't know God much before, maybe I went to church and sang, but when I got the disability I can see God has brought me very far. There were many in the accident who died, but for me, I am still alive.

So as for me I accepted it (acquired disability) and said 'maybe God had this thing for me, this happened to me for His glory'. That time I accepted it and actually from that time I really saw God Himself revealing Himself to me widely. From that time, I don't care! I can't allow somebody to tell me this or that or misuse me because I am somebody, there is no difference between us. - - He knows everything and before He knew it would happen. - - It really pushed me to God.

In many cases God was also seen as the supporter and encourager in challenging situations.

In addition to the faith in God and His support, the family's and especially the mother's role in the family came up strongly, and her support was mentioned to be relevant in the process of building own self-esteem and confidence. The interviewees recalled:



She has tried to build my self-confidence a lot, and that is why I can talk even to you right now, openly. She built my self-confidence by taking me to hospitals that have other people with disabilities so that I can see that I am not the only one with the disability.

She was somebody to me by the way. I liked her so much, but God liked her more than I. - - When I was in the hospital she could take care of me and make sure that before I ever got to the theatre, I had seen her and she had prayed with me.

Other important members in the family were the father in the cases he was still present, and other siblings. However, the interviewees had both negative and positive thoughts about other family members as there had been both the experiences of rejection and encouragement. Many of the interviewees came from a single-parent (in majority of the cases: single-mother) families, and in these cases the parents had separated earlier on, the other parent had died, or left the family when the disability had occurred. The interviewees had mostly good experiences of the relationship with their siblings and only in a few cases the rejection and shame caused by the siblings was raised up. In addition, for some the access to education had changed their position in the family as the family had realized the importance and effect of education.

The third support network for the students was created by the peers as was already shortly mentioned in the discussion on the benefits of special schools. Other peers in the same situation helped the interviewees to get motivated, to accept themselves and the disability and to develop positive self-esteem. The importance of peer support emerged in six (6) out of seven (7) interviews. One of the interviewees stated:

Before I didn't know there were people like me. Before I started to despise myself and I hid myself in our house but when I went to that place I became free.

The interviewees mentioned that the peer support had helped them to understand the whole matter of disability clearer and to see the situation around them and to find that they were not alone. In addition, it had helped them to gain confidence and motivation to go forward and find ways to target higher in their lives.

## 8 DISCUSSION ON THE POSSIBILITIES FOR INCLUSION

Inclusion is a manifold phenomenon which concerns various fields in the person's life. Arising from the results of the research and as an outcome from the interviews, the ways to improve the inclusive practices in Kenya were several and many issues should be acknowledged to gain reasonable and meaningful results in the inclusion process. The issues emerged from the interviews concerned current practices in the fields of inclusive education, education of PWD, community education, community and youth empowerment and political actions.

### 8.1 Inclusive education

In the interviews both the fears and the hope for better future prospects were visible. In the service sector the situation of PWD has been analysed but to which extent is the question. Growing trend in the fields of education and schooling is inclusive and integrative approach which in as much is considered to be one of the main prospects in the field of inclusion as well has been also found out to be economically the best option. However, as was discussed before, both of the schooling systems have both challenges and benefits. Integrative schooling should not be done at the expense of the students with disabilities. Inclusion is the ideal when discussing the inclusion of the students with disabilities but it is important that it is done in the way which benefits everyone. In Kenya the aims of the primary and especially secondary education are clearly connected to the future and access to future studies in universities or colleges. This means that the students should be provided the best opportunities to learn and study to make it to the universities. At the moment majority of the schools in Kenya are not ready to accommodate the students with disabilities in the realms of infrastructure and attitudinal environment. Often harassment in the school environment affects the child's or youth's success in the studies and thus is not beneficial for the child though thought to be good for inclusion. The environment, both physical and attitudinal, should be prepared accessible for the students with disabilities in the regular schools, and this is done also through community education and broadened views and information on the matter in the schools.

## 8.2 Education in overcoming negative attitudinal environment

In Kenya the education of children with disabilities has been discussed by various sectors working for the rights of PWD and the importance of educating PWD came up also during this research process. The main tool for inclusion of PWD in the society is namely education. In as much it fulfils the right of the person with disabilities and provides them the opportunities to act in the society and get reasonable source of income, it also changes the surrounding environment and has meaningful impact on the attitudinal atmosphere. One of the interviewees stated in the interview: “they should educate us to avoid others to look down upon us”. Nidhi Singal (2007) states the bi-directional, positive effect of education claiming that the education

Has an important role not only in shaping the lives of people with disabilities, but also in shaping the perception of those around them  
(Singal 2007, 29).

The government of Kenya has done great improvements in the process of allowing the PWD to practise their rights to the fullest but still a lot has to be done and one of the next steps should be the follow-up of the implementation process of the legal rights of PWD in the municipal and regional level.

## 8.3 Community education

In addition, community education is one of the important tools in the process of inclusion of PWD in the education system. The families of the child should be provided with sufficient information and support right in the beginning as the child is born. Alternative ways to support the family such as networking with other families with children with disabilities are good ways to give the families space to grow up together with the children and discuss the matters with others in the same situation. Despite the fact that many of the families with children with disabilities come from humble background and sometimes the most effective support is considered to be monetary support, alternative ways tend to have more longitudinal effects. To support the families in becoming independent and active actors in the society gives a great substrate for the child in the family.

#### 8.4 Empowering the individual and important social networks

As came out in the research, in addition to God, the instant family and other students with disabilities were the major actors in the supportive networks of the interviewees. This should be considered when planning forward the ways to include PWD in the society. We believe that in the inclusion process the family oriented approaches have more effective results compared to the client based approaches. In as much the empowerment of the individual plays an important role in his /her life, the empowerment of the family starts off the change also in the surrounding community. Inclusion requires cooperation by all the actors in person's life if ideal results are sought. However, sometimes the monetary resources are not enough to fulfil all the desired aims and that is why it is important to find out alternative ways as utilizing the power of the group.

#### 8.5 Collective actions for the youth

In addition to the family relations, the peer support has also important role in supporting the individual. As testified before, the group has many benefits which empower all who are included in it. That's why PWD should be provided opportunities to get together and decide on issues concerning them and advocate for themselves. Furthermore, despite of the noted segregation between the regular students and students with disabilities, the youth as a group should be provided opportunities to act together to work on the issues concerning them. This can happen for example through youth groups acting against HIV infections among the youth, various sports clubs or, as mentioned before, education.

#### 8.6 Political actions

In as much there should be change in the political and communal spheres to make a change, majority of the students emphasised the visibility of PWD in the community. The change should not come only from outside but start from the inside. "PWD should come out for people to see them", as one of the interviewees stated. One interviewee emphasised that disability is not an issue that was invented yesterday but has been around for longer time than we let others to understand. PWD should be encouraged to act and advocate for themselves and to come out in the community and become visible elements of the society. The organizations for PWD should take firmer stand on matters that

exclude PWD in their everyday environment. Various actors should start to act on the matters, was it in the grassroots level or in the political sphere. In the interviews it was visible that neither one can make the change alone but both methods are needed. One practical requirement based on the interviews was to get more PWD in the parliament and active in the politics.

## 9 CONCLUSION

Challenges in life can never be removed totally but are part of human life in the same way as all the things that lead to happiness. However, we can provide everyone the same rights and opportunities in the society and community and support each other to live the life in the best way for them, and provide support to overcome the challenges in one way or another. This study was to provide an outlook on the current situation YPPD are facing in Kenya and to find out challenges with what they have to deal with in their everyday life and opportunities which should be noted and realized when working towards the inclusion of PWD.

To develop the services in cooperation with PWD and their families, it is important to find out what the families find out to be the challenges they face and what kind of help they feel they would need. In addition, the already existing cooperation between various sectors working with the matters concerning PWD in Kenya should be studied and the results should be employed to find out new ways to create links and networks between these organizations and PWD themselves.

As compared to other researches, the study had limitations which are important to be noted when reflecting with the results. The study was conducted with students who already had accessed the education system. Totally another view point could have been got if the interviewees had been the youth with disabilities outside of the education system. However, due to the foreign background of the researcher (me), the interviewees' knowledge of English was necessary for completing the research without the third actor in the interviews, this is, the translator. In addition, to maintain the fluency in the data collection and analysis, the study process was made in close interaction with

professionals and colleagues with Kenyan origin. This also was to gain as objective focus in the study which however, is never totally possible due to the various cultural and social backgrounds of the researchers. Observation took place during the three months stay in Kenyan setting whereas the discussions and interaction with professionals, colleagues and students with disabilities with Kenyan and Finnish origin continued throughout the research process. This was to create a clearer picture of the phenomenon as the understanding of the issues was to rise up from the context and from the students themselves.

The study helped me to develop professionally in the fields of disability studies and research methods. Through the process I learned to conduct meaningful and effective group discussion sessions as well as individual interviews which I found to be an important skill in the field of social work. In addition, the personal contact with the issue gave me greater interest towards it and the rights of PWD. However, in the future I still want to develop in the fields of social research and find ways to use the research results in the service sector and in my personal work.

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## Appendix I INDIVIDUAL INTERVIEW CHART

### FIRST PART: CHILDHOOD AND DISABILITY

How was your childhood in the environment you lived?

How did the disability take place? How did it affect you? What did you think or feel about future then? How did you cope with the situation? What did you find challenging, if anything?

### SECOND PART: EDUCATION AND ECONOMIC SITUATION

How has been your schooling time? Tell me about your primary school and your time there. What about secondary school? How did you finance the studies? What is the economic situation in your family and neighbourhood from your point of view?

### THIRD PART: SOCIAL RELATIONSHIPS

Did disability affect your family relationships, if yes, how? If no, how do you find it? Who do you think has been the closest person to you? Why? How were the other students in the regular school/special school?

### FOURTH PART: FUTURE AND PAST

Where would you like to be after 10 years? What are your dreams? Do you think you can achieve them? If yes, how? If no, why? What would you like to be differently, if anything?

## Appendix II FOCUS GROUP DISCUSSION CHART

The group discussions were divided into three sections; challenges, education system and coping with the challenges.

### CHALLENGES

1) Societal level – infrastructure, legislation, registered services; How did the society structures affect the everyday life with disability?

2) Community level:

Cultural elements – taboos, habits, beliefs of surrounding community; What kinds of challenges did the respondents confront related to cultural backgrounds?

Construction of social relationship – family, friends, neighbours, relatives; What kinds of relationships did respondents have? How did the social community affect the everyday life with disability?

3) Services – implementation; How were the services distributed? Access to services? Possible barriers in access to services?

### EDUCATION SYSTEM

What factors affect access to schooling system? How? Segregated or integrated model preferred? Opportunities and challenges with the segregated model?

### COPING WITH CHALLENGES

How did the respondents cope with the challenges they confronted in societal, communal or social dimension? What could still be done?