See me, and do not forget me
People with disabilities in Kenya

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Map of Kenya

(http://en.wikipedia.org/wiki/Image:Kenya, 2006)

TABLE OF CONTENTS

Abbreviations

APDK -   Association of Physically Disabled in Kenya
CBR -   Community Based Rehabilitation
DPO -   Disabled People's Organisation
EARS -   Educational Assessment and Resource Services
ICF -   International Classification of Functioning
KDHS -   Kenya Demographic and health Survey
KNAD -   Kenya National Association of the Deaf
KSPH -   Kenya Society of the Physically Handicapped
KUB -   Kenya Union of the Blind
MDG -   Millennium Development Goals
NCPWD -   National Council for People with Disabilities
NGO -   Non Governmental Organisation
PWD -   People with disabilities
SDO -   Social Development Officers
TB -   Tuberculosis
UDPK -   The United Disabled Persons of Kenya
UN -   United Nations
UNESCO -   United Nations Educational, Scientific and Cultural Organization
WHO -   World Health Organisation

1 Background

The WHO estimates that about six hundred million people live with disabilities of various types in the world, and the number is increasing due to the rise of chronic diseases, injuries, car crashes, falls, violence and other causes such as ageing. Of this total, 80% live in low-income countries; most are poor and have limited or no access to basic services, including rehabilitation facilities. (www.who.int Oct. 2006)

Kenya acknowledges disability as a phenomenon that cuts across all spheres of society and which requires support from all sectors. Despite the lack of accurate data on the number of Persons with Disabilities in Kenya, it is noted that persons with disabilities are not a homogeneous group but are varied in terms of the nature of their disability and their mental, physical and social needs. Persons with disability in Kenya represent a critical segment. Like in most developing countries people with disabilities in Kenya are a marginalised population and face problems as a result of their disability. Most have no access to education, health, employment or rehabilitation.

Despite the absence of accurate data, the Government and other stakeholders have continued to offer a wide range of services to Persons with Disabilities. It is however acknowledged that these services have reached only a small percentage of Persons with Disabilities and are unequally distributed between and among various disabilities. The majority of persons with disabilities live in extreme poverty. Therefore, there is a need to develop strategies to empower persons with disabilities, reduce their poverty levels, and make them self-reliant and able to participate in national development.

This report is a contribution towards describing the lives of people with disabilities in Kenya. The report presents results from two field works conducted during two weeks of May/June 2005 and two weeks of October 2006. The work was done on behalf of the World Bank. We hope that work will be useful for actors in Kenya, whether governmental authorities or NGOs working for the benefit of people with disabilities, and that it will contribute to the improvement of the living conditions for people with disabilities in Kenya.

1.1 The contributors to the study

The field work was carried out by:
- Dr. Benedicte Ingstad, Professor of Medical Anthropology at the University of Oslo and a Senior Researcher at SINTEF Health Research
- Lisbet Grut sociologist and Senior Researcher at SINTEF Health Research
- Dr. Joyce Olenja, Associate Professor in Medical Anthropology, Department of Community Health, University of Nairobi. Dr. Olenja has also given valuable comments on the report.

Many people have contributed to this study:
- Ms. Cecilia Mbaka at the Ministry of Gender, Sports, Culture and Social Service, and Acting Director of the National Council For Persons with Disability, Kenya, took care

of the facilitation of the field work and is a major contributor to heading 1.5 Kenya and disability issues.

- The district officers at the districts visited had prepared a sample of informants according to our requests, for which we are thankful. Without this preparation we would not have managed to visit as many places and people as we did.
- We are also grateful to the representatives of the local DPOs in the areas visited. Because of their outreach actions, mobilisations and awareness building activities they knew most of the people with disabilities in the areas and they did their utmost to supply us with information and contacts. In this way their contribution has enriched the data material.
- But most of all we would like to express our thankfulness to the informants, the people themselves, who opened their homes to us and with an open mind gave us the opportunity to delve into their everyday life. We consider ourselves privileged to have had the opportunity to interact closely with people living with disability and we sincerely hope our work will contribute to the improvement of the lives of people with disabilities in Kenya.

1.2 Country background

The Republic of Kenya in Eastern Africa is bordered by Ethiopia to the north, Somalia to the east, Tanzania to the south, Uganda to the west, and Sudan to the northwest, with the Indian Ocean running along the southeast border. Kenya comprises eight provinces, divided into several districts each headed by a centrally-appointed Provincial Commissioner and District Commissioner respectively. The Capital city Nairobi enjoys the status of a full administrative province. The government supervises administration of districts and provinces. (www.Wikipedia.org, Oct. 2006)

From the coast on the Indian Ocean the Low plains rise to central highlands. The highlands are bisected by the Great Rift Valley; with a fertile plateau in west. The Kenyan Highlands comprise one of the most successful agricultural production regions in Africa. The highlands are the site of the highest point in Kenya: Mount Kenya (5199 meters). The climate is tropical, hot and humid at the coast, temperate inland and very dry in the north and northeast parts of the country.

The population is estimated to be 34.7 million. The estimates listed in the table below take into account the effects of excess mortality due to AIDS that result in lower life expectancy, higher infant mortality and death rates, lower population growth rates, and changes in the distribution of population by age and sex than would otherwise be expected (CIA - the World Factbook): July 2006 est.)

Population distribution by age and density:

Total population	34,255,720
Urban population	41.6 %
Population above 60	4.1 %
Population under 15	42.8 %
Density*	56

* People per km2

Kenya is a country of great ethnic diversity with many different cultures represented, (more than 42 ethnic communities). Notable cultures include the Swahili on the coast, pastoralist communities in the north, and several different communities in the central and western regions.

The predominant religion is Christianity (Protestant 35%, Roman Catholic 33%, Seventh-day Adventist: 10.0%). Estimates for the percentage of the population that adheres to Islam or indigenous beliefs vary widely but the Muslim religion accounts for about 10%, mostly along the coastal areas and in the north, and Traditional Religions account for 10%. Other religious groups include Hinduism, Jainism & the Bahá'í Faith. Tension between the various ethnic groups accounts for many of Kenya's problems. During the early 1990s, politically instigated tribal clashes killed thousands and left tens of thousands homeless.

About 75% of the work force is engaged in agriculture, mainly as subsistence farmers. The standard of living in major cities, once relatively high compared to much of Sub-Saharan Africa, has been declining in recent years. Most city workers retain links with their rural, extended families and leave the city periodically to help work on the family farm.

Poverty:

Unemployment rate:	40% (2001 est.)
Population below poverty line:	50% (2000 est.)
Population living in the slums in the cities*	70.7 %
Poor people's part of country's consumption	6.0 %
People living in extreme poverty	22.8 %
Average poverty gap	5.9 %

* Percent of the city population

Education[1]

Education is a fundamental human right, set forth in the Universal Declaration of Human Rights and the International Human Rights Covenants. The Right to Education is essential and indispensable for the exercise of all other human rights and for development. Education is considered the primary vehicle by which economically and socially marginalized adults and children can lift themselves out of poverty. UNESCO declares that no civil, political, economic and social right can be exercised by individuals unless they have received a certain minimum education. However, millions of children still remain deprived of educational opportunities, many of them on account of poverty. People with disabilities face particular challenges in education and training. Many are denied access to basic literacy and numeracy skills: It is estimated that 98% of children with physical or mental impairments in developing countries do not attend school and that less than 10 % of all disabled children go to school.

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[1] Information on education is mainly from www.unesco.no oct 2006

Education in Kenya has been based on an 8-4-4 system since the late 1980s, with eight years of primary education followed by four years of secondary school and four years of college or university. Primary education in government schools became free and compulsory in January, 2003 40 years after it was first promised in 1963. Now that education is free, schools have become overcrowded and there are not enough teachers to cope with the demand. Children are not getting the attention needed from their teachers due to the overcrowding of classrooms.

Education (%):

Illiteracy	15
Illiteracy adult women	20
Illiteracy adult men	9
Children in primary school	76
Children completing primary school	75
Public expenditure education (percent of GNP)	6

Health[2]

Together with HIV/AIDS and TB malaria is one of the major public health challenges undermining development in the poorest countries in the world. UN estimates that malaria kills an African child every 30 seconds and many children who survive an episode of severe malaria may suffer from learning impairments or brain damage. Pregnant women and their unborn children are also particularly vulnerable to malaria, which is a major cause of perinatal mortality, low birth weight and maternal anaemia.

According to the WHO (The World Malaria report 2005), malaria is a major public health problem in Kenya, with malaria burden and transmission patterns varying across the country. The areas near Lake Victoria and at the coast - among the chosen areas for this field work - are particularly exposed. A national malaria strategy was launched in 2001 and the malaria control programme was upgraded to a full division with its own budget line. October 2006 there was a ministerial declaration that all those suffering from malaria should receive free treatment at health facilities.

Malaria :

Children treated with anti-malaria (%)	26
Children protected with anti-malaria net (%)	4
Malaria related deaths (individuals per 100,000 deaths)	63
Malaria related deaths (individuals per 100,000 deaths) Children 0-4 years	334
Malaria incidents (per 100,000)	546

The first AIDS cases in Kenya were recognized in 1984 (1987 in Kisii district), but it is now believed that 1 in every 18 adults is infected with HIV in all areas. Over 70% of AIDS cases are among the most economically active age group and also the best educated and skilled.

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[2] Information on health is mainly from www.undp.org 2006

Indicators related to health (www.globalis.no):

	Total	*Male*	*Female*
Infant mortality rate (2006 est.):	59.26 deaths/1,000 live births	61.92 deaths/1,000 live births	56.54 deaths/1,000 live births
Life expectancy at birth (years, 2006 est.):	49	50	48
Under nourished population	31.0 %	not available	not available
Underweight children	19.9 %	not available	not available
Fertility**	5.0		
HIV/AIDS adult prevalence (KDHS 2004):	6.7%		
AIDS-related deaths (individuals)	150,000		
HIV-knowledge 15-24 years(%)		47	34
Children measles vaccination rate (%)	73		
Use of contraception (%)	39		
Young mothers (Live-born per 1000 woman 15-19) (%)	78		
Births with qualified attendants (%)	42		
Health expenditures per individual (US dollar per individual/year)	19		
Health expenditures in public sector (percent of GNP)	2.2		
Mortality related to pregnancy (per 100.000 live-born)	1,000		
Doctors per 1000 individual	0.04		
Literacy:(age 15 and over that can read and write) (2003 est.)	85.1%	90.6%	79.7%

** Average children per woman

Last polio case in Kenya was reported in 1993 (WHO 2006). A case was found in Daadab refugee camp in October 2006 suspected to have come in from Somalia.

1.3 Kenya and disability issues[3]

Persons with disability in Kenya represent a critical segment. According to the current health and demographic survey, done by the Ministry of Planning and National Development, Kenya is expected to have a population of over 3 million (10% of total population) disabled persons.

Disabled persons in Kenya like in most developing countries are a marginalised population and face problems as a result of their disability. Most have no access to education, health, employment or rehabilitation. The majority experience hardships as a result of inbuilt social, cultural and economic prejudices, stigmatization and more often, abuse and violence. Additionally, disabled women are more disadvantaged due to their gender and their disability.

Kenya acknowledges disability as a phenomenon that cuts across all spheres of society and which requires support from all sectors. Kenya's earliest recorded initiative for organized care and provision of services to persons with disabilities goes back to the missionary era. In 1946, the Salvation Army Church established a programme to rehabilitate men blinded during the Second World War. The programme later became the country's first school for the blind marking the commencement of provision of formal education for blind children in Kenya and East Africa. The mainstream churches; Catholic, Presbyterian, Anglican and Methodist followed this example by establishing schools and institutions for children with visual, hearing and physical disabilities in various parts of the country where they had their missions. With the departure of missionaries, the Government started providing teachers and financial grants to these service providers eventually taking over the management of the various institutions which they had initiated.

Among other service providers who have contributed to the betterment of people with disabilities alongside the government over time are; the Kenya Society for the Blind, the Association for the Physically Disabled of Kenya, the Kenya society for the Mentally Handicapped and the Kenya Society for Deaf Children.

Other players in this sector are the Disabled People's Organizations (DPO). These are national associations and community based groups formed and managed by persons with disabilities to advocate and to pressurize for services and participation in national development. They create awareness, act as representatives of persons with disabilities and press for service provisions.

The oldest among them is the Kenya Union of the Blind (KUB) established in 1959. Others who have been in operation for some time include; The Kenya National Association of the Deaf (KNAD) (1987) and the Kenya Society of the Physically Handicapped (KSPH) (1986). In 1989, these National organizations alongside other smaller district and community ones came together to form The United Disabled Persons of Kenya (UDPK). UDPK became an umbrella body with a stronger voice and negotiation capacity to champion disability advocacy work. It has worked very closely with the Government in raising awareness, identifying needs and services for disabled persons, and organizing such events as the UN International Day for persons with disabilities. Parent associations and support groups have

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[3] Contributor to this head is Ms. Cecilia Mbaka

also in the recent past made useful contribution in respect to children and adults with intellectual disabilities.

1.3.1 Post independent initiatives

The first post independence education and manpower-training enquiry, the Ominde Commission of 1964, recognized the need for education and training in the disability sector. It recommended measures to address the Government's role in the coordination and improvement of service quality and delivery strategies and transition from school to employment world. The recommendations resulted in the Parliamentary Sessional Paper number 5 of 1968 which set the pace for Government leadership in provision and coordination of services for persons with disabilities. It also established the Vocational Rehabilitation Division in the Department of Social services. The first initiative from this effort was the establishment of the Industrial Rehabilitation Centre in Nairobi in 1971. Ten rural vocational rehabilitation centres were subsequently established countrywide to offer artisan courses such as carpentry, dress making and leatherwork.

In 1975, the special education section was set up within the ministry of education to coordinate education for children with special needs. Independent sections with specialised staff responsible for every disability category were later established within the inspectorate and curriculum development arms of the Ministry of Education.

The Government declared 1980 the National year for persons with disabilities ahead of the 1981 United Nations International year of the Disabled persons. Aggressive awareness campaigns on disabilities and need for collaborative efforts were launched during that year. These efforts continued during the UN International Year, 1981. This is when the National Fund for the Disabled was also set up as a Trust. By according direct assistance to both individuals and institutions, the Fund continues to supplement efforts by the Government and other service providers.

Community based rehabilitation (CBR) strategy was introduced during this period of great awareness drive. It was considered a suitable approach to actively involve communities in the change of attitudes and acceptance of persons with disabilities. The existing institutionalized rehabilitation services were inadequate in meeting the growing needs and CBR proved a solution to the expansion of service provision. Early initiatives for this strategy were through the Ministry of Health, but the idea was taken up by other service providers and remains an important feature of service delivery to persons with disabilities.

In 1984, the Ministry of Education introduced the Educational Assessment and Resource Services (EARS) which has greatly improved the growth and quality of educational services for children with special educational needs. EARS centres were initially opened in 22 districts and were closely linked to District Education Offices. EARS embraced a multi-sectoral approach by different professionals such as teachers, social workers and medical workers. It involved the community in the early identification, assessment, intervention and placement in educational services. EARS have enhanced the inclusive education delivery strategy which promotes placing of children with disabilities in integrated programmes. This has increased educational placements for children with special needs beyond the capacity of residential schools and opened the special educational residential schools to slow learners or those with multiple disabilities.

In the early days, training of special needs teachers was conducted on the job within respective institutions for either the blind or the deaf. The first specialized training was that of the deaf at Kamwenja Teachers Training College in the early 1970's. Teachers for the blind and the mentally handicapped were later trained in Highridge Teachers College in early 1980's. In 1987, all special education teachers training were consolidated at the Kenya Institute of Special Education. In addition to the three special areas of the visually impaired, hearing impaired and the mentally handicapped, the education for the physically handicapped was introduced. The Kenya Institute of Special Education provides specialized training at Diploma level to teachers already trained to teach ordinary schools but with interest in special education. It also introduced short-term certificate courses for teachers in special schools, units and integrated programmes. It has recently introduced Distant-learning programmes with a current enrolment of more than seven thousand. Special education is also now offered in two public universities.

Another remarkable progress in addressing the disability concerns came in 1993 when the Attorney General appointed a Task Force to review laws relating to persons with disabilities. The Task Force went round the country collecting views from the public and persons with disabilities. It completed its assignment within three years, and presented a report and a draft Bill to the Attorney General in 1997. The draft Bill was signed into law in December 2003.

The Persons with Disabilities Act of 2003 was brought into effect in June 2004. Its key provision was the establishment of a National Council for Persons with Disability whose mandate is to implement the rest of the Act on the rights, privileges and protection of persons with disabilities. The Minister responsible has appointed the Council, which coordinates provision of services and advises the Minister accordingly.

1.3.2 Issues of critical concern

There are critical issues that Kenya needs to address in order to provide services to Persons with disabilities. There is no accurate data on the number of Persons with Disabilities in Kenya. Although a disability module was included in the 1989 National Population and Housing Census, little information was collected on disability due to poor targeting. The information obtained was inadequate for policy formulation or national planning. It is not possible therefore to indicate with certainty the level of prevalence of disability in Kenya. The National Council for Persons with Disabilities (NCPWD) is in the process of registering all persons with Disabilities in Kenya. A policy guideline has been developed by the council and pretested. The prevalence rate as per the pre test is 2.3% of the total population. The Council is lobbying for funds to roll out the registration exercise. The Government through the NCPWD is also in the process of carrying out a national survey to establish the actual number of Persons with Disabilities, types of disabilities, their prevalence, geographical coverage and age distribution.

UN estimates indicate that Persons with Disabilities represent between six and 10 percent of the population of any country with varying proportions within segments of the population as well as between countries.

WHO and the Kenya Demographic and Health Survey (KDHS), estimate that about 10% of the country's total population have a form of disability. With a population estimated at 32.2 million in 2003 (Economic Survey, 2003), approximately 3.2 million persons in Kenya

have a disability. The statistics vary from District to District due to the diverse socio-economic status.

With these varying estimates, it is therefore necessary to confirm the magnitude of the population with disabilities and to determine the actual extent of each disability for purposes of planning and service provision. This calls for commitment from various stakeholders to a national survey to identify the numbers through the national census exercises.

It is noted that Persons with Disabilities are not a homogeneous group but are varied in terms of the nature of their disability and their mental, physical and social needs. Despite the absence of accurate data, the Government and other stakeholders have continued to offer a wide range of services to Persons with Disabilities. It is however acknowledged that these services have reached only a small percentage of Persons with Disabilities and are unequally distributed between and among various disabilities.

1.3.3 Disability, a cross cutting issue

Disability impacts on all aspects of society and national development. The following challenges are recognised:
- The combined effect of disability and HIV/AIDS.
- Challenges to economic development.
- Limitation in attainment of education for all goals.
- Omission of disability concerns in the millennium development goals.

The extent to which HIV/AIDS has infected or affected Persons with Disabilities has not been determined yet. It is expected they suffer same level of prevalence as the rest of the population. The combined effects of HIV/AIDS and Disability on a person or group of persons, present the Government with a situation of extreme need.

Different types of Persons with Disabilities must be assisted to achieve skills that would enable them participate in gainful employment. Otherwise persons with disabilities will be a drain on family and national resources. Unemployed Persons with Disabilities are unable to contribute to family income and welfare and may strain limited resources as their families attempt to provide special care. Thus, education is the most important tool for participation of Persons with Disabilities in the socio-economic life. It helps develop positive attitudes towards the importance of work and self-reliance while sharpening skills necessary for integration into social and national affairs. It is imperative that access to education of Persons with Disabilities is given due attention.

It is noted that Millennium Development Goals (MDG) do not specifically address disability concerns, deliberate efforts will therefore need to be made to integrate disability issues in its MDG implementation programmes.

1.3.4 Barriers

Various barriers ranging from environmental, communication, social to economic, prevent persons with disabilities from attaining acceptable quality of life.

The construction and building environments pose many difficulties in physically accessing public buildings, roads and other infrastructure to persons with physical impairments. Building codes, physical planning laws and standards are unresponsive to the needs of the disabled. Public transport laws do not facilitate modification of public vehicles

and they are inaccessible to persons with physical impairments. Building codes, physical planning and transport laws need amendments.

Electronic and print media are generally inaccessible to people with visual, hearing or intellectual disabilities. This prevents them from participating or benefiting from information in these channels. To overcome these communication barriers, it is imperative to introduce forms accessible by persons with impairments. These include; brailing of printed information, sign language interpretation, eye-catching simplified messages, well illustrated and easily repeatable information. These should be delivered in accessible public settings.

Attitudes and practices embedded in cultural beliefs, taboos, rites of passage, and religion create near insurmountable obstacles to the participation of persons with disabilities in social and cultural activities. It is necessary therefore to overcome these barriers through aggressive and effective public education and rehabilitation programmes.

Economic barriers prevent persons with disabilities from fully participating in employment, commerce and credit. Poverty alleviation programmes normally fail to specifically identify persons with disabilities as a target group and even when identified, such persons still face many obstacles. Many are condemned to live in extreme poverty. These barriers can be overcome by turning persons with disabilities into economically productive members of society through adequate training and credit support programmes.

1.3.5 Disability and development

Disability is a development issue and there is need to acknowledge the rights of persons with disabilities to development and the need to address factors that push them into absolute poverty.

Disability and poverty are often intertwined. The Ministry of Planning and National Development's MDG Progress Report for Kenya 2003, indicates that the level of poverty in Kenya now stands at 56% against a target of 21.7% by the year 2015. The majority of persons with disabilities live in extreme poverty. Therefore, there is a need to develop strategies to empower persons with disabilities, reduce their poverty levels, and make them self-reliant and able to participate in national development. This would call for development of disability sensitive programmes at the national and local levels. Additionally it would require participation of non-state actors in this endeavour.

1.3.6 Key achievements on issues of persons with disabilities

A. Enactment of the Person with Disability Act, 2003

The Persons with Disabilities Act concerns the Rights for persons with disabilities. It aims at restoring their citizenship and their humanity as well as dealing with issues of discrimination, equal opportunity and neglect. The Persons with Disabilities Act 2003 provides a legislative framework through which issues of access will be addressed. It provides a framework for the acceptance of people with disabilities into the Kenyan society, it tries to remove the stigma of disability, and it drives the point home that persons with disability are very normal and able. The Act was approved in 2003, with some amendments, and enforced in June 2004.

The act also provides for the following:
- Rights of Persons with Disabilities
- Rehabilitation of persons with disabilities
- Equalization of opportunities

- Establishment of the National Council for persons with disabilities.

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

The NCPWD was founded in November, 2004. It is run by a board of directors consisting of 20 people. The day to day activities are run by a secretariat . The following are the core functions of the secretariat:

- Formulate policies and develop measures for the establishment of systems and structures
- Mobilize resources for council activities
- Research, advocacy and public awareness
- Registration
- Enhance capacity of DPO institutions and individual PWDs
- Operationalization of National Development Fund for PWDs
- Issue adjustment orders.

STRATEGIC ISSUES : 2005 – 2008:

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

C. Implementation of the Continental Plan of Action on the African Decade for Persons with Disabilities (1999 – 2009)

The African Decade of disabled persons 1999-2009 was declared during the 37th Summit of Heads of States in Lome, Togo in 1999. The goal of the decade is full participation, equality and empowerment of people with Disabilities in Africa. Kenya domesticated the continental plan of action and came up with a Kenya National plan of Action on the African Decade of People with Disabilities. The Plan focuses itself on ten broad issues:

1. Policy and Legislation
2. Participation and Self representation
3. Quality Service Provision
4. Special groups; Children, youth, women and elderly with disabilities
5. Universal design
6. Preventive Measures
7. Capacity Building
8. Resource mobilization
9. Advocacy and Awareness; and
10. Coordination Monitoring and Evaluation

Efforts have been made to roll out the plan of action to the district level by disseminating the plan and the Act and coming up with district specific plans of action. Various stakeholders are also implementing the plan and plans are underway to monitor the impact of decade activities.

Disability Day

The UN day for disabled persons has been celebrated in Kenya on 3rd of December for the last 12 years. It is the day that persons with disabilities create awareness of the recognition of their rights and consideration for full participation in all sectors of the economy and at all levels of decision making.

Specifically, the UN Day aims at achieving the following objectives:
- Give persons with disabilities an opportunity to focus on their rights and responsibilities.
- Create awareness to the general public of the plight of persons with disability. The sensitization is geared toward creating an accommodating environment for persons with disabilities. Thus enabling persons with disabilities and able-bodied persons to complement each other in making the world a better place for all.
- Enable various stakeholder to take stock of their achievements and challenges to enable them focus on the way forward.

2 The study of disability and poverty

2.1 The Problem

The overall objective of this study as formulated by the World Bank is to gain more knowledge on how human functioning affects people's living conditions and vice versa. People's functioning levels vary significantly, whether in relation to physical or intellectual capabilities, sensory abilities (hearing and vision), or the impact of mental health. The effects of disability go beyond those with functional impairments themselves, as this report will demonstrate. Family members must often absorb extra responsibilities that inhibit their participation in the economic and social life of their communities.

Unfortunately, due to limited research in this area, we do not have good knowledge of the relationship between poverty and disability. At present, there is a growing effort to obtain quantitative data that can provide prevalence estimates and general links between poverty and disability. However, there is scant information on the dynamics between the presence of impairments and the economic and social life of disabled people in developing countries. A qualitative study could thus provide us with important information on the daily reality of the lives led by disabled people, and how their functional status interacts with the physical and policy environments they face.

Based on this background, the purpose of this study has been to uncover in Kenya how cultural factors, inaccessible infrastructure and lack of resources prevent people with various mental, physical, and sensory impairments from participating in the economic and social lives of their communities, as well as how the living conditions and social barriers affects the presence of disabilities.

2.2 Understanding disability in the context of poverty

The concepts of disability and poverty are core concepts to this study. These concepts are open to interpretation and can be perceived in different ways. It is important to be aware that the understanding and application of these concepts can vary from one socio-cultural context to another (Whyte and Ingstad 1998).

2.2.1 Disability as limitation of functioning and participation

The concept of disability has in the past twenty years developed from a medical model focusing on the individual's impairment to a social model of functioning and participation, focusing on limitations in activities and restrictions in social participation. One has seen a shift in terminology and an increasing tendency towards viewing disability as a complex process involving a number of different elements at individual and societal level.

A recent model of disability is WHO's Classification of Functioning, Disability and Health: ICF - The Model of Functioning. According to ICF disability arises when an individual's ability to do daily activities, carry out social roles and participate in communal

activities that are considered normal or common by the individual and the community, is limited or hindered because of a bodily, sensory, mental and/or intellectual reduced function and environmental barriers.

Within this model, understanding disability is to understand both the individual and the social consequences of the impairment. The interaction between the individual and his/her environment in the wide sense of the word is in focus, taking physical, personal, social and environmental aspects into consideration. Thus, to understand disability it is necessary to focus not only on the individual but also on the family and/or the social group within which the individual co-exists, and how the individual, the family and the society functions and copes within their particular social and cultural setting. Within the Model of Functioning both the individual and the environment are in focus.

However, the ICF-model is sometimes criticised for being too individualistic and for placing too heavy a focus on the individual's limitations (Oliver 1993, Yeo and Moore 2003 among others); the ICF-model does not direct the focus of understanding towards the society's exclusion mechanisms against people with certain bodily, sensory, mental and/or intellectual qualifications (Barnes 1999). To understand the full consequences of a disability one should consider that both the medical model (which focuses on the impairment) and the social model which focuses on the barriers are relevant.

The ICF-model is designed to be culturally neutral and applicable in cross-cultural connections. The question is, is such neutrality possible or does this make the model too general? Disability, and thus the perception of 'normality' and 'disability', must be understood as social and cultural constructs. The personal, practical and social consequences of impairment will differ depending on factors such as gender, economic and social class, culture, caste and remoteness. Different kinds of impairments are understood differently and will have different consequences in different cultures. The perception of and the society's response to, for example, blindness or whether the impairment is congenital or acquired later in life, will vary according to different cultural circumstances.

2.2.2 Poverty - a multidimensional concept

The understanding of poverty as well as international policy for alleviating poverty has broadened during the last decades. Development thinking has moved toward a new paradigm characterized by broader and better integrated understanding of development (Wolfensohn & Bourguignon 2004). The understanding of poverty has changed from a narrow focus on income and consumption to cover education, health, social and political participation, security and freedom, environmental quality, and lately also social justice and human rights (Wolfensohn & Bourguignon 2004). Clearly this has led to increased interest in micro-level decisions and instruments and measures intended to improve poor peoples' access to food, shelter, education, and health care. Furthermore, focus has been directed towards improving service delivery to poor people and to ensure increased influence on important decisions affecting their lives.

Understanding poverty requires a focus on peoples' living conditions in a comprehensive way. The concept of poverty as well as the concept of living conditions is complex and multi-dimensional. The understanding of living conditions has developed from a relatively narrow economic and material definition to a concern with human capabilities and how individuals utilise their capabilities. An individual's level of living is defined not so much by his or her economic possessions, as by the ability to exercise choice and to affect the

course of his or her life (Loeb and Eide 2004). Similarly, the perspective on poverty has developed from a focus on the economy and material welfare in a narrow sense, to include human capabilities and how individuals utilize these capabilities. The World Bank Report *Attacking Poverty* (2000) focuses on opportunity, empowerment and security as key words in understanding poverty. Poverty arises when the individual is being deprived of the necessities of material well-being and the denial of the opportunities for living a tolerable life.

Poverty is affected by many aspects in the individual's life:
- Lack of income/subsistence and material welfare.
- Lack of basic needs such as food, clothing and housing.
- Lack of health and access to health services.
- Lack of education and occupational training.
- Lack of capability - seen as the opportunity to achieve acceptable levels of basic functioning.
- Lack of opportunity to participate and/or decide in organisational and political matters.
- Lack of knowledge about civil rights
- Lack of participation in leisure and community activities.
- Lack of experience of respect and self-respect.

In other words poverty arises when the individual is deprived of the opportunity to lead a healthy life, does not enjoy a decent standard of living, is not able to participate in social and political life and/or lacks respect and self-respect. Connecting poverty to deprivation involves comparing living conditions to a defined standard or way of living. It will be necessary to consider both global standards (for instance standards set by the UN: 'people surviving on less than one US dollar a day') and local standards held by the individual's community and society to understand how the different conditions influence people's lives.

2.2.3 The relationship between disability and poverty

When individuals with different levels of functioning encounter barriers to health services, education, employment, public services, and infrastructure, they are disabled. That is, disabled in the sense that their ability to participate in economic activities and lift themselves from poverty suffers. Disability is thus to be understood as an interaction between human functioning and an environment which does not account for different levels of functioning. In other words, people with physical or mental limitations are often disabled not so much because of their functioning level, but because they do not have access to education, labour markets, and public services. This exclusion leads to poverty, and in a vicious circle, poverty can lead to more disability by making people more vulnerable to malnutrition, disease, and unsafe living and working conditions.

Although there is a close linkage between poverty and disability, little research has been carried out into analysing the mechanisms behind this relationship (Elwan 1999). An abundance of literature has shown living conditions among individuals with disabilities in high-income countries to be low compared with non-disabled. While less focus has been placed on this relationship in low-income countries, a few recent studies and reviews have documented the same pattern. (Eide, van Rooy & Loeb 2003; Loeb & Eide 2004).
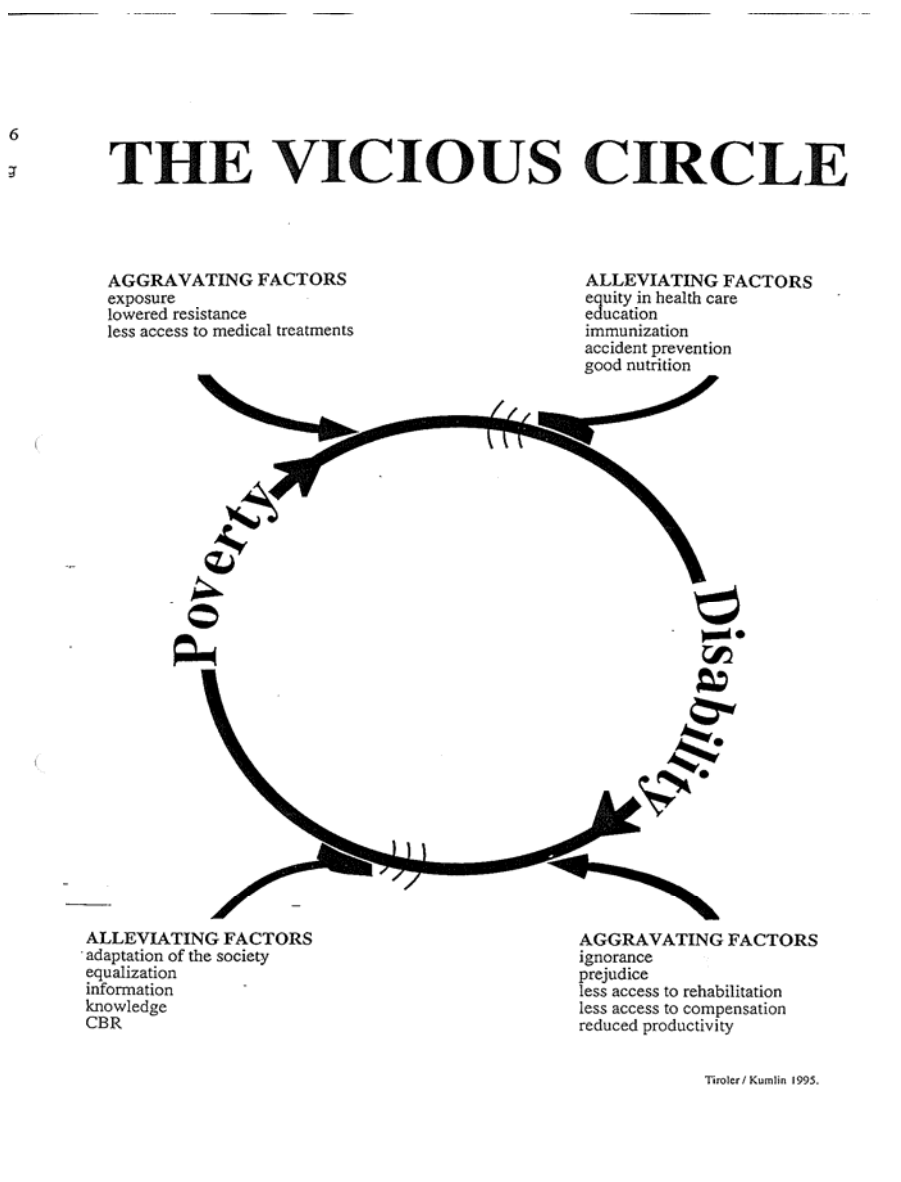
The relationship between disability and poverty is bi-directional as poverty often leads to disability and disability often leads to poverty (Yeo and Moore 2003, Yeo 2005). Even though disability does not necessarily cause poverty, and poverty does not necessarily cause disability, the relationship is strong. There is scant information on the dynamics of how the

presence of impairments affects the economic and social life of people as well as how poverty affects the occurrence of disability in developing countries; however, there is sufficient knowledge to conclude that people with disabilities are at risk of being and remaining among the poorest. At an individual level the relationship depends on the social and economic circumstances under which the individual is living. Among the most prevailing exclusion mechanisms are low education or illiteracy; unemployment and limitation in social contacts; exclusion from political and legal processes; low priority for access to limited resources such as food, clean water and land; lack of support for high costs associated with the impairment. (Elwan 1999, Yeo and Moore 2003)

Lack of bodily and/or mental functioning may deprive the individual of access to income and subsistence, education and social participation. In this way, people with impairments are hindered in obtaining a good living standard, or may be deprived of an already achieved standard of living. Among the environmental conditions connected to poverty causing disability are the following: lack of access to proper nutrition; lack of necessary health care and medication; absence of sanitary installations; contamination of the air, soil and drinking water.

The relationship between disability and poverty is complex, as this figure by Tiroler/Kumlin (1995) illustrates. The bi-directional connection between disability and poverty traps people in a vicious circle as a poor living standard leads to (untreated) sickness or impairment, which leads to disability, which again leads to exclusion from education, job opportunities, social and political participation.

Figure 1: 'The vicious circle of poverty'

THE VICIOUS CIRCLE

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AGGRAVATING FACTORS
exposure
lowered resistance
less access to medical treatments

ALLEVIATING FACTORS
equity in health care
education
immunization
accident prevention
good nutrition

Poverty

Disability

ALLEVIATING FACTORS
adaptation of the society
equalization
information
knowledge
CBR

AGGRAVATING FACTORS
ignorance
prejudice
less access to rehabilitation
less access to compensation
reduced productivity

Tiroler / Kumlin 1995.

2.3 Understanding disability within the context of social barriers

2.3.1 The concept of Social Suffering

The concept of Social Suffering has been particularly useful when analyzing the material from the field work in Kenya. Social suffering has been used by medical anthropologists from Harvard in the study of poverty and suffering in many parts of the world and in particularly by Paul Farmer in his studies of infections and poverty in Haiti (Farmer 1999, Farmer et al 2001). The concept of Social suffering places the focus firmly on the society, focusing political and

economic factors, and the severe constraints these factors may place on the individual's chances to achieve desired goals and alternately it takes the focus away from individual shortcomings such as personality factors, attitudes, beliefs and practices.

Thus a "blame the poverty on the poor" approach is substituted by an approach in which social factors and limitations, under which people live, become the main focus. This is particularly important and useful in the study of disability, where there is an almost universal tendency to blame failure to cope on personal beliefs and negative attitudes of the individual.

2.3.2 The household as a resource system

Another important focus for this study is that of understanding households as a system where resources have to be distributed in relation to the needs of the members in order for the household as a whole to be viable, which is coping in a way that takes care of the needs of every member (Ingstad 1997). With a disabled family member the resources of i.e. labour capacity, time and capital (income, land, livestock), have to be re-distributed. Thus rarely will a person with a disability fare better than the average household member. Generally, regardless of the kind of rehabilitation efforts made, poor households make poor people with disabilities.

The inclusion of a disabled person in a household, whether by birth or by disease or accident later in life, will call for a rearranging of household resources in order to cope with the new challenges of care and to restore viability. If this is not possible, the result will most likely be poor coping both for the individual with a disability and the household at large. Focusing not only on the individual with a disability but on the household of which he/she is a member enables us to identify the factors that create what is called the evil circle of poverty and disability, and thereby hopefully enable us to propose how this circle could be broken.

3 Methodology

Chapter three gives a brief introduction and overview of some principles in qualitative methodology and concepts that has been useful when analyzing the material. The sample of the study is described. The study was undertaken according to the manual of qualitative methodology in studies of the relationship between disability and poverty, developed in the pilot study (Ingstad and Grut 2005)[4].

3.1 A Qualitative approach

The focus of this study is the daily life of disabled people in a developing country and how they cope with their daily life. Since the research questions founding the study required delving into people's private lives, a qualitative methodological approach was chosen. A qualitative approach is likely to be chosen when the focus involves an interpretive approach in which the aim is to understand the meaning the different experiences have on the individual. The intention of a qualitative approach is to develop a fuller understanding of the phenomenon and to enlighten or revise the analytical point of departure of a study.

Furthermore, a qualitative study gives access to people's own experiences and may give access to the meaning they place upon these. It offers a method to explore people's experiences, their view of the different aspects in their lives, and how a phenomenon arises. In addition, a qualitative study is useful if the phenomenon is sensitive and delicate and therefore difficult to investigate. (Wadel 1973, Denzin and Lincoln 1994, Ryen 2002) A qualitative approach involves more or less structured conversations, collecting data which is verbal or metaphorical. This implies an interactive approach as communication between interviewer and informant is fundamental. In this matte trust and respect are important factors in the relation between the interviewer and the informant.

To this study it was vital that the informants trusted us and that they liked to talk about themselves. It was important to be sensitive to the informants' responses on the themes and topics introduced. We let the informant's thoughts and associations dominate the interview situation but at the same time we had to see to that the conversation covered the topics and themes that were listed in the interview guide. Every interview situation was opened by introducing the interviewers to the informants by name and who we represented, and explaining the purpose of the study. The informants were informed that participation was voluntary and that they had the right to be anonymous and the right to choose not to answer or talk about particular subjects. They were also informed that they had the right to withdraw from the interview at any time without giving a reason.

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[4] Appendix III: Methodology

3.2 The interview guide[5]

As mentioned earlier, this project started with a pilot field study in 2005 in different parts of Kenya, developing and testing the methodology and the interview guide. In a research project like this it is important to recognise the value of establishing good rapport with the informant. A 'warming up' conversation is important. We always started by introducing ourselves and the reason for the visit. Then maybe chatted for a while about neutral topics. The interview itself usually started with general topics and questions, gradually becoming more specific. For instance, a typical introduction to the interview could be: *'I can see that there is something with your leg, would you tell us what happened to you?'*- or: *'could you tell us a bit about your situation?'* The sequence of the topics and questions was decided during the interview and was dependent on the informant's associations.

3.3 Ethical considerations in qualitative studies

There are several ethical considerations connected to a study like this that should be taken into account. It is important to be open about who the beneficiaries are: Will the study mainly be of interest to the scientific community, or to the authorities, or will it in the end lead to some improvements of the informants' situation in any way? It is also important to question if the study could lead to any unforeseen consequences for the informants.

The study must be introduced to the informants beforehand. The introduction must include information on the study's purpose and objectives: who the initiator is, how the results are going to be used, who will benefit from the study. The informants must give their acceptance to participate either written or orally. They must be informed about the right to be anonymous and the right to choose not to answer or talk about particular subjects. They must also be informed that they have the right to withdraw at any time.

The study must take into considerations the informants demand for respect, integrity and dignity. Under no circumstance should the informant be forced or persuaded to participate or to answer questions. In this matter the study must be sensitive to different cultural standards.

In disseminating and applying results one must consider the possibility that others can *misuse and/or misinterpret* the results. In principle the informants should have the possibility to see the results of the study, even though this, in many circumstances, is difficult to fulfil. If it is practically possible, one should communicate the results directly back to the informants, either written or orally. If this is not possible, one should inform the informants where and how they may be able to get access to the results.

The interview may trigger emotional reactions that are difficult to cope with for the informant when the interview is finished and he/she is left alone. The planning of the field work must comprise a plan for taking care of informants that could need a follow up and support after the interview.

There is one very serious ethical issue connected in doing a study like this or any study of vulnerable people for that matter. This is the issue of raising expectations that may not be fulfilled. No matter how well the purpose of the study is explained, people who give their

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[5] Appendix II: The Interview Guide

consent to be interviewed will hope that the participation will gain something for them, and that hopefully the researchers represent someone who finally has come to help. This will of course also be the case when someone comes to do an interview for a quantitative survey. We did our very best to explain that we were doing a study on behalf of the World Bank, and the study would be made available to the Kenyan authorities. We explained that this study would not be of benefit to the informants directly, but in the long run could influence policies and practices towards persons with disabilities and their families. Although most people seemed to accept this explanation there were many times we wished we could have done more for the people we met (and who through their participation have contributed to the study). In a few very severe cases we made sure that the people from the Social Development Office was informed of the informants' difficult situation.

3.4 The importance of choosing the right place to interview

The importance of investigating these kinds of research questions by visiting people with disabilities in their homes cannot be stressed strongly enough. By doing so, one gets an impression not only of the individual disabled person, but also of the general living conditions of the family. It also provides an opportunity to gain supplementary information from close family members and sometimes also from neighbours.

During the field work in 2005, we experienced a desire by our facilitators (for the sake of efficiency) to gather people with disabilities in one meeting place. In cases where this could not be avoided, since people were already waiting when we arrived, we conducted focus groups. In the planning of the second field work (2006) we made our desire for home visits clear and managed to see all informants in their homes except for five cases: a focus group in Kisii, an interview at a work place in Kisumu town; one at Port Florence hospital in Kisumu and two at shops in Malindi district.

Interviewing people in their homes, however, is not without obstacles. The arrival of three unknown women (two European and one Kenyan) and sometimes a representative from the local DPO as well as the officer of the local Social and Development Office, tended to be the event of the month in some villages and often attracted a large crowd of curious people. For the sake of privacy we had to limit the crowd to the researchers, plus an interpreter if the disabled person did not speak Kiswahili or English. In addition to this the person with a disability usually wanted someone present to give moral support. It could be the spouse, a parent or sibling or the local representative of the DPO whom he/she usually knew from before.

The main advantage of interviewing in the home is an opportunity to assess the total situation of the household – its viability in caring for a disabled member. Just consider this case as an illustration: A girl aged twelve was born with her legs bending the wrong way and she could only crawl. She has had an operation and is now able to move around with crutches. She is now in standard four at boarding school. If we had met and interviewed this girl at the school we would probably have considered her a case of successful rehabilitation. There is however more to the story:

> We went to her home and met her 80 year old maternal grandmother, a very impressive and proud looking woman dressed in the white gown of a local African church. The grandmother had had 4 sons and one daughter, all of them except a physically disabled son who was now sick in hospital, had died of AIDS. Only one daughter in law, who

was present at the interview, and dressed in the same church uniform as the grandmother, had survived. In total this old lady had 18 orphaned grandchildren, most of them young, requiring care.

One of her daughters, the mother of the disabled girl, had been married far away. When she and her husband died, the father's family took care of the non-disabled son, but left the disabled girl at the age of eight to fend for herself all alone in the empty home. The only way she got food was by looking after other people's children, in spite of not being able to walk herself. When hearing about this from a neighbour the maternal grandmother immediately went and fetched her. By selling a goat and some chicken she was able to get her enrolled in the special school. Her referral for an operation was organised and paid for by the school.

By the time of the interview the meagre few means of the grandmother had been exhausted and she was barely able to feed her large flock of orphaned grandchildren. Also, she was sick. She had been to the doctor but was unable to buy the medication as prescribed. As for the disabled girl, the grandmother's dwindling funds and future inability to pay for the girl's school fees most likely meant that the girl would have to return home.

From this story we see the importance of interviewing in the homes and of focusing on the total situation and viability of the household, and not only the individual disabled person.

3.5 The Districts visited for the field work

A multi-sited approach was chosen for this study. During two periods of fieldwork (May to June 2005 and October 2006) several places in Kenya were visited:

The 2005 field work (the pilot study):
- Nairobi - city and slum areas
- Maragua district in Central province
- Machakos district in Eastern province

The 2006 field work:
- Narok town in Narok district, Rift valley province
- In and around Kisii town, Kisii district, Nyanza province
- Villages outside Kisumu town, Kisumu district, Nyanza province
- Mombasa - the poor city quarters
- Kwale district - villages
- Malindi district - villages

3.6 The sample

As this is a qualitative study, the sample was chosen strategically. The sites were chosen for their diversity, representing a variety of ethnic groups and ecological zones in Kenya as well as covering the urban - rural dimension. The idea was to capture a variety in causes of disability as well as poverty in its different manifestations. Thus for instance we learned that a polio epidemic had left many children paralyzed in Kisumu, Kisii and Narok (and probably many other places) some 25 + years ago while on the coast we saw some of the disabling consequences of severe malaria in early infancy.

The informants were chosen among persons that represented a wide variety of life situations, and we expected them to have much information to share on the topics in question. (Miles and Huberman 1993, Kvale 1997) The type and size of a strategic sample will usually be based on existing knowledge of the research topic and knowledge of the place where one wishes to collect information. The size of the sample is often difficult to assess at the onset of the study and one must often reconsider both the number and the types of informants during data collection .

The identification of the informants was undertaken by local partners with first hand knowledge of the field. The acting director of National Council for People with Disabilities (NCPD) in cooperation with the officers in the Social Development Offices (SDO) in the selected districts addressed the request for interviews on our behalf. The SDOs were asked to identify a sample of informants that as a whole reflected different variables such as gender, age, type of disability, family situation, social and cultural setting.

A qualitative sample is usually small compared to a quantitative one, around 30 cases may be considered sufficient. In this case, joining data from two field works, provided a rather large sample. In all there were conducted 91 interviews during the two field visits:

The 2005 study comprised in all 42 interviews and conversations that gave relevant information to the study:

Secondary information:	11
Group interviews:	4
Individual interviews:	27
In all (2005):	42

The 2006 study comprised in all 49 interviews, including a group interview at the Social Development Office in Kisii:

Men	19
Women	13
Children	16
Round table conversation	1
In all (2006)	49

For the 2005 study the registration of types of disabilities was incomplete. The 2006 study comprised six informants with more than one impairment, usually a combination of a mental impairment and a bodily and/or a sensory impairment:

Types of disabilities, 2006:

Bodily:	33
Visual:	5
Deaf:	8
Mental:	9

Except for an informant in Kwale district the sample does not include mentally ill people. We do not know why but a possible reason could be that mentally ill people are not considered disabled in the same way as for instance people with mental retardation. However, there is reason to believe that mentally ill people are among the most vulnerable in Kenya as in many other countries.

The results of field work conducted in 2005 is presented in a previous report (Grut and Ingstad 2005). Because of this we will build the present report mainly on data obtained from field work conducted in 2006.

3.7 Limitation of method and sample

The two field works were restricted to two full weeks. This implies that we could not visit every district in Kenya. We had to choose accessible places and at the same time obtain as complete data as possible. To meet the requests of adequate samples, we chose populated and also multicultural areas. However, it must be considered a possible bias that some areas as well as some cultures and tribes are omitted from the study. Nor could we interview every person in each area visited but had to pick a sample that could give information covering as many relevant aspects of the research questions as possible. Due to the limitation in time we chose not to visit the more remote areas, (for instance Turkana).

As we were dependent on local assistance to identify informants, we had to choose places with organisations working for the benefit of people with disabilities. This implies a possible bias in only reaching people benefiting from these activities and services and not those who are really poor and do not benefit from any kind of assistance. On the other hand, we discovered that many of the informants, even if they were known by the organisations, did not benefit from any services and were not informed of the possibilities of assistance. Every informant told a story about impairment leading to economic and social challenges for themselves and the family. With a very few exceptions the informants belonged to the so called lower level of the population, and many could be considered to belong to the poorest of the poor. In the first field visit we interviewed some people that had a certain financial basis for survival, but still faced challenges because of the disability. In the second field work the majority of the informants lived under serious poor conditions.

A qualitative sample is chosen with the intent of finding people who represent as wide a range of life situations or problems as possible related to the topic of the study. Thus we may say that a qualitative study focuses on representative or typical problems. The main characteristic of qualitative methods is to bring forward the perspective of the people that are being interviewed. The researcher takes the role of the learner and the person interviewed is the expert on his or her own life situation. Thus by encouraging the persons with disabilities to share their life stories, they may also be given a sense of empowerment in that they can contribute to a pool of knowledge that may be beneficial to others. Several of the informants expressed thankfulness for being interviewed, which they never had been before: *'You have seen me, I thank God for that'*. On some occasions people with disabilities that we had not been informed about came to us asking to be interviewed. On other occasions people heard that someone interested in disabled people was in the area, and they came and asked us to go and see other disabled people in the neighbourhood.

In order to achieve this kind of trust the interviewer(s) have to have good knowledge about the topic being studied and knowledge about the country and culture, which we obtained through our Kenyan counterpart and to some extent from other anthropological studies as well as the study in 2005. It is also imperative that the researcher(s) do the interviews themselves, using an interpreter, only if necessary.

Finally, a criticism that may be raised against a study like this is the risk of subjectivity – of the researcher putting her own ideas and preferences into the analysis. Experienced

qualitative researchers, are aware of this risk and try not to be influenced by their own biases.. Researchers must give an account of their own conceptual position (which is done in the introduction) in order for the reader to judge the validity of the study for him/herself. On the other hand, no social science research is completely objective, and even in the most carefully developed studies (qualitative and quantitative) the ideas and preferences of the researcher plays a significant role.

4 How poverty generates disability

Chapter four gives a presentation of lessons learned from the field work. We will turn to what is called the vicious circle of poverty and disability, with reference to an earlier chapter on this topic – the model of the poverty trap (Figure 1). Chapter six opens with looking at the findings of how poverty generates or worsens disability.

4.1 Health factors

The reasons for an impairment leading to a disability may be manifold: Genetic, congenital, complications in pregnancy or during birth, illness later in life, accidents or environmental conditions. Since there has been no national survey on disability done in Kenya, and even less knowledge exists about their causes it is not possible for us to describe the relative importance of these factors.

Among the people introduced to us, physical disability was by far the most common, and we believe that this reflects the way Kenyans think about – and use – disability as a term, more than the relative prevalence.

4.2 Genetic and congenital conditions

We saw less genetic conditions in this study than we did in a similar study in Yemen (Ingstad and Grut 2006) where cousin marriage is practiced more consistently than is the situation in Kenya. Although some Kenyan ethnic groups also have this practice, there seemed to be more openings for exceptions. Young people are more free these days to choose their own partners wherever they meet and may not always check if there is a close relationship as was the case traditionally. However, we did see a few cases where there was a reason to suspect a genetic cause. One case was a family with a deaf mother and four deaf children, all with clear light blue eyes in spite of their dark skin. We were told by a representative of a local DPO that the blue eyes come together with the deafness and that this condition is genetic.

Another case was a young girl with a very short body and a very peculiar malformation of the legs. One of the researchers has observed families with several members with the same condition in a previous study in Botswana. A third case was a family with a blind father and two blind daughters. The family expected the blindness to be genetic because the paternal grandmother also was said to have been blind. Although these disabilities are caused by genetics, poverty affected the quality of their life. None of these informants had been taken to a specialist to get a diagnosis, or receive counselling, thus families did not know about the probability of the condition reoccurring in successive children or generation (although the girl had had an orthopaedic operation on her legs), and thus the families did not know if the condition could reoccur in successive children or not.

We were not introduced to anybody with Down Syndrome, but on two occasions we noticed children with such a condition playing with others in village settings as we drove by. We tried to locate one of them a few hours later but were unsuccessful. Similarly we were not

introduced to anyone with albinism, and we saw fewer persons with such a condition in Kenya than what we have seen in other African countries. However, we did meet several persons with congenital malformation of the legs, and one man who had been born without a hand.

Relating poverty and the despair it may cause people, we might have expected to see cases of foetal alcohol syndrome, especially in the urban and semi urban areas. Such a diagnosis calls for better diagnostic skills than we possess (although we suspected it in at least one case). On the other hand, extreme poverty may also serve as a protective factor against such a condition because women cannot afford to buy alcoholic beverages. The most important protective factor, however, is religion. Several Christian churches and the Muslim religion in general ban alcohol.

4.3 Conditions occurring in pregnancy and during birth

When it comes to conditions occurring in late pregnancy and during birth we saw a clear connection between poverty and damage done to the child. Most births seemed to have taken place at home with the help of a grandmother or a local traditional midwife. This was partly due to tradition, but undoubtedly also because of lack of money to travel to hospitals located far from where rural people live. Thus tending to emergencies is delayed as long as possible in order to save expenses, or simply because the money is not there:

A woman on the outskirts of Malindi had been in labour for two weeks with sporadic bleedings before she was taken to the hospital. She gave birth to a boy who was now 17 months old. Not only did she wait in seeking help with the delivery, but she also waited to get anti-malaria medication, receiving it only towards the end of the pregnancy. The boy got severe malaria soon after birth and was now blind, possibly partially deaf and physically quite delayed for his age.

We visited a family with a mentally handicapped child. The father told us that the mother had been brought late to the hospital, and only after several attempts to get her to deliver at home. The baby was finally delivered by a C-section and because of what the father described as a harsh handling from the nurse the baby was brain injured.

We see from these cases how poverty not only can delay mothers in seeking help during labour but also keep them from regular pre-natal visits and treatments. This is probably a common cause of disabilities in children.

4.4 Illnesses occurring later in life

Illnesses occurring later in life and leading to impairment and disability are many. Polio is considered to have been eradicated in Kenya in the early -90ties, and we saw no recent cases of polio. Whether the polio epidemic that ravaged Kenya some 25 + years ago, leading to a large amount of people with different degrees of paralyses, was due to official neglect, national or individual poverty we do not know. At that time there were effective vaccines in place. Some of our informants told us that they suspected the vaccine to be the cause of their polio. Vaccine and vaccination failure is however always present. The cold-chain for transporting and storing the vaccines may have been insufficient thus leading to inefficient

vaccines, especially in the more remote areas. A poorly developed primary health care system may not have been able to reach all children, especially those in more remote villages. There is also a possibility that poor people, lacking money for transport, were bringing their children to the health clinics to a lesser degree than those with some money. Finally it is quite likely that poor and often malnourished children got polio more easily than those who were better nourished.

Another illness which may cause impairment and disability is malaria which is particularly prevalent and severe along the coast and in the Kisumu area. Several of the informants with polio had been told by their mothers that their illness had started with malaria and then turned into polio and paralyses. It is not possible to determine whether this was a confusion of symptoms or the actual situation. Malaria prophylaxis is not commonly used in endemic areas, except during the last part of pregnancy. Medicines are reserved for treatment in order not to create resistance. While people who have money may buy such medicines in pharmacies and treat themselves at the first symptoms, people without money may end up seriously ill before they end up in the hospital. The ministerial declaration of October 2006 stating that all those suffering from malaria should receive free treatment at health facilities represents a possible improvement. However, poor people in the rural areas have to get to the health centres to receive the treatment, which for many is a very long way to go. The most commonly used prophylaxis for malaria is a bed net combined with the spraying of insect repellent. For poor people this is a cost they often cannot afford. Very few of the people we interviewed had such nets, and the ones we saw were dirty and with big holes and thus not very effective.

Epilepsy is another condition which may be caused or worsened by poverty. Caused in the sense that it may come about as the result of trauma in pregnancy, at birth or due to illness as discussed above. Worsened in the sense that parents may fail to seek a diagnosis and medication for a child due to lack of money for transport; or may discontinue the medication because they cannot afford to pay for refills :

A boy with epilepsy and slight mental retardation used to "fall" several times a day. Eventually he was taken to a doctor where he got two different types of epileptic medicines. When the initially dispensed medication ended and there was not much change in the boy's condition, the father decided, on his own, to discontinue the medication. They now resorted to prayers and had built an altar inside their small house. They claimed this was more effective.

Both the first and the second field work had many cases of children with untreated or incomplete treated epilepsy and consequently increasing mental retardation. Judging from the medication shown to us, epilepsy treatment in Kenya (at least for those who cannot afford private hospitals) is rather standardized and lacks the possibilities for individual control and adjustment that is done in more developed countries. Thus, the chances of stopping the convulsions and thus minimizing the damage done to the brain become less.

We did not meet any persons with disability caused by meningitis and only one that was explained to us to be caused by measles, which also tend to strike the poor and malnourished children more than the well nourished ones. There is, however, all reason to believe that there are more such cases. Some of the parents we interviewed had lost children to both measles and malaria.

The HIV/AIDS epidemic affects people with disabilities in several ways: directly through sexual intercourse (see gender issues below) and indirectly by seeing that the people around them who would be expected to help are dying. As said by one disabled man in a village near Kisumu *'There is no family around here that has not been severely affected by AIDS'*. He had lost all his brothers and was left as the only provider of a large family of orphans.

Disabled women are also vulnerable to HIV/AIDS because some men tend to consider them 'clean'. We were told that there is a common belief that disabled women are not sexually active, and therefore many men expect them not to be infected by the virus. (see under Gender issues).

4.5 Accidents

Traffic accidents is a common reason for disabilities in all countries. In developing countries such accidents are even more frequent as traffic tends to be rather chaotic, the control of drinking and driving can be poor, the cars often are old and worn out and the roads are in bad condition. The very poor people do not have cars but are likely to be hit by cars with poor headlights when they walk along the road at night, especially if they are deaf and do not hear the car coming. They are also more likely to get lifts on overloaded cars of poor quality. In the rehabilitation centres in Nairobi we met people who had spinal injuries and thus paralysed due to car accidents. None of them had been particularly poor before the accident occurred. Ending up in a wheelchair had however left them without a job and thus a considerably lower standard of living.

Another type of accident which is seen frequently among poor people is burns. In both field works we met people with severe burns - where the burns had deformed arms and legs - either because they had fallen into the open fire as a child or because they as a grown up had an accident while cooking or because the house had caught fire. Houses made of wood, cardboard or dried cow dung burn easily, and there is especially a risk if food is made on open fire inside the house:

> We met a woman who had experienced such an accident with the house burning down. She was the mother of a severely multi-handicapped boy needing a lot of special care. Her underarms and legs had gotten severely burned. Now, thirteen years after the accident, the wounds on one leg had gotten infected and the infection had extended into the bone from where discharge was coming out and flies were gathering. It was very painful and the doctors had recommended amputation of the leg but she had refused; claiming that this would make her even more helpless and she would not be able to take care of her household chores and her disabled son if she were to loose a leg.

4.6 Environmental conditions

The most important factor of the natural environment influencing disability and poverty in Kenya is that of draught in some areas. Malnourished children are more vulnerable to illnesses and more likely to develop serious and lasting consequences when illness occurs. Only one of the areas we visited, around Narok, belong to the dry zones but there is all reason

to believe that in other even dryer areas, for instance Turkana, children with disabilities are the ones to die first when severe draught strikes.

> In Kwale district people have had periods of draught, and the area was still dependent on food relief. One of the young men we met survived on charity from the neighbours and food supplies from the local Red Cross. However, he had to go to town to pick up the food supplies, something that was quite an effort for him. Because of damaged legs he did not move around easily. He had lost his job when he was disabled and thus had no money to pay for transport.

Another environmental condition that may be of importance for disability is pollution, toxic substances, or insecticides. We suspected such poisoning as an alternative explanation for the blind father with the two blind daughters. All three had become blind within a fairly short period of time and one of the daughters had developed a particular trembling affecting her head and limbs (see 6.1.1). But there was no way we could find out more about this and there were other members of the household (mother and brother) who had not been affected.

> In the Mukuru informal settlements (slum) of Nairobi, which is located beneath high voltage power lines said to be leaking power, children are said to get leukaemia to a much larger extent than elsewhere in Kenya and in Nairobi in particular. Epilepsy were also said to be much more frequent, and the social workers who worked with some of the epileptic children we met there blamed these lines for the condition.

4.7 Access to health care

Finally we must also consider how poverty limits the access to health care for poor people with disabilities. Lack of money for transport has already been touched upon. But even if people manage to get to the hospital they are not guaranteed to see a doctor. Several families mentioned how they got appointments to see specialists and managed to raise the money to go, only to be told when they got there that the doctor was not in and asked to come back several months later. Not knowing how to raise the money a second time they might easily give up at this stage:

> Aisha is twelve years old and born with deformed legs. She lives with her parents and three younger siblings on a small farm in the rural areas at Kisii in western Kenya. The mother works in the fields and the father is a day worker. Aisha was born at home and the parents understood that something was wrong with her after 2 days. She has never been taken to school because it is too far for her to walk and the parents are not able to take her. As she is the first born there is no elder brother or sister to assist. She is able to walk with a stick but it is difficult and she gets tired easily. The parents brought her to several hospitals to ask if something could be done about her condition. They were applied to the APDK for funds to pay for an operation and five years ago this made her able to walk a bit. She should have had another operation, also paid by the APDK, and they went to the hospital but had to go home because the doctor did not show up. They have been given a new appointment for the end of the year and must raise money for the bus, which is quite expensive.

Private hospitals, who usually offer the best services, are out of the question for poor people unless they find a sponsor. In the first field work we met some cases of poor children that had

been picked up by missionary organisations and sent abroad for an operation. We saw how this changed their opportunities to have a better life dramatically. Those who have got orthopaedic operations in public hospitals usually have not had to pay, but the threshold to learn about and get referral to such services is high unless someone helps them. In Kisumu we met several families who had been helped with such a referral by the NGO-run special school for disabled children, for example the girl in the family with 18 orphans (see 3.3).

Health care facilities lack sufficient personnel. Children with treatable conditions are not treated because of lack of both knowledge and equipment. The health services in the rural areas/districts are dependent on foreign medical personnel who visit on an irregular basis. Because of this situation, conditions that would be considered rather trivial in developed countries will worsen and disable the child in a developing country. This was the case for children with visual problems but also for children with hearing and bodily impairments.

Families living in rural areas face more obstacles in their access to modern health care than those living in urban areas. As mentioned in the introduction the primary health care system is not sufficiently developed to cover all of Kenya. As health care is institution based, people have to be able to come to the hospitals or medical clinics to get help. While the antenatal care seems to be in place, there seems to be very little or no follow up of the children that do not develop normally. This is left to the initiative of the parents and it is often pure luck if a representative for a foreign NGO or a DPO happens to come along to help them.

Even when a disabled person manages to come to the medical clinic, there are many obstacles at the clinic. Several of the bodily impaired people we met told us that they had to queue up like the other patients in spite of the difficulties connected to walking and standing - *'to treat me the same way as the non-disabled is to discriminate me because I am not able to line up in the same way and if I go and sit I loose my place in the queue'* one woman said. A clinic's requirement to treat everyone the same way can also hinder a young disabled mother to take her child to the health clinic if she cannot have someone to accompany her and carry the child for her.

4.8 Assistive devices

There is a thorough lack of assistive devices, and particularly in individually adapted devices. The devices we saw were without exception old and worn out. Wheelchairs were very often too heavy for the individual to operate by him/herself and difficult to use in the rugged terrain. The few wheelchairs we saw stood in a corner and were not used. The explanation to this was either difficult terrain or there was no one to push the disabled person. Crutches were typically not adapted to the individual's body. Especially for children this has severe consequences as the child will grow and the impairment will aggravate because the crutches that once were given to the (small) child does not grow with the child. The result is a paradoxical situation where the aid that was intended to minimise the consequences of the impairment instead increases them.

Jenny is a young woman with polio. As a young girl she got a calliper and crutches. Now she has matured and both the calliper and the crutches are too short. Still, she is dependent on the devices to be able to walk around. When she walks, she has to bend down and this has caused postural related dysfunctions that also gives her pain in the back and the hips. She contacted the hospital about a year ago to ask for new crutches,

but with a negative result. *'Maybe I will get some next year'* she says hopefully. But after a short pause she adds: *'But I am used to these ones so will manage'* indicating that she does not really expect to have new ones.

4.9 Traditional medicine

For cultural reasons as well as barriers to access modern health care for poor people, traditional medicine and faith healing is an option for many. We saw several children with amulets for healing, and there are many signs advertising herbal medicine in villages and slum areas. While use of traditional healers is far from being free, payment may sometimes be delayed or received in kind. To what extent traditional medicine is the first or latter choice compared to modern medicine is not clear from our study. One young man gave us a smile when we asked him about traditional medicine and after a while he said: *'There are many traditional healers around here so I have many options'*. However one father said it like this: *'I wait for the doctor to tell me they have given up and then I will go to the healer'*. An adult brother of a disabled woman told us they have had a discussion within the family whether to go for modern medicine or traditional healing. The solution was to try both: *'I am a modern man and I look upon traditional healers as a waste of money but my mother wants to try everything to help my sister'*.

Traditional medicine is also attractive because contrary to modern medicine it offers an option of complete cure for a person with a disability. If you think that you or your child have been impaired by witchcraft or an evil spirit, removing that spirit or witchcraft would in theory mean bringing the person back to normal. This was the case of the mother mentioned above. The daughter had been healthy and used to work as a teacher before she suddenly got sick, and no modern doctor had given a satisfactory explanation for the daughter's condition or offered a treatment.

Faith healing is another type of treatment common in Kenya as in most African countries. Praying in churches or being prayed for by special healers is usually free, and thus an option for poor people with little or no money to spend. Many of the informants told us they prayed, not so much to be relieved from the impairment, as to overcome the consequences of it. Their prayers could be about finding a kind husband for a disabled woman or to be able to pay for boarding school for a disabled child.

4.10 Access to education

Children in poor families are less likely than other children to attend school, and even less likely to go beyond elementary schooling. This is even more so if the child is disabled. The importance of money for sending children to school was clearly demonstrated when free primary schooling was introduced in 2003 and the number of children enrolled in school increased dramatically. But even free education does not guarantee education for the poorest ones. In reality, school is not free in the sense that the parents still have to contribute substantially. Money for books, uniform, shoes and transport have to be provided and in some schools the children also have to pay for lunch. Boarding schools for those coming from remote areas are even more expensive and some of the special schools for children with disabilities start charging school fees when foreign donors withdraw. The result is that the expenses connected with having a disabled child in school easily exceeds the expenses for the

non-disabled one. Faced with such expenses, many poor parents still have to make priorities among their children and often end up sending the able bodied to school before the disabled ones.

From the case of the grandmother with 18 orphans to care for (3.3) we saw how a major effort of sending the disabled girl to a special school (selling goat and chicken) probably would end up with her being withdrawn after some time because of lack of money to continue paying school fees. She was already in arrears with payments to the school. We saw many similar cases :

> A mildly mentally retarded boy in the poor areas of Mombasa was attending a special class in a normal school in the neighbourhood. The mother, who was a widow, worked all day as a very low paid housemaid (1500 Ksh a month). The school was free, but children who were not able to pay for the food programme were sent home at lunch time, and not allowed to come back that day. The mother could not afford the food programme, so the boy was missing the opportunity of a nutritious meal and half a day's education. Thus the boy strolled around in the streets begging for food until the mother finished work late and he got less education than his classmates from better off families.

Many of the parents we met had a year to year perspective of their child's education. The parents of Sarah had faced a similar situation:

> Sarah was sent to school for the first time at the age of twelve when the parents managed to pay for a boarding school for disabled, and she completed primary. After that, the parents were not able to afford schooling so she was moved to a local normal school which was a lot cheaper. But she was not treated well by her school mates and quit after a year.

Lack of education for poor families and their children also lead to reduced self confidence and gives less knowledge of where to go for help, no money to buy a radio to listen to informative programmes and fewer opportunities to utilize the help that is actually offered, such as places in special schools and special classes.

4.11 Families overwhelmed – give up

A final point to be made on how poverty influences disability is that some poor families seem to have lost what we may call a "fighting spirit" and they seem to have given up. Faced with the many losses and obstacles that poverty creates, the care for a disabled family member is one burden too many and just becomes too much. The fragile viability that kept the family going gets off balance and there is just not enough labour capacity, resources or time to give the disabled person proper care, seek help or receive help that is available:

> A boy, 14 years of age, with Cerebral Palsy and epilepsy had been walking around with callipers and crutches until about a year ago when his fits started to increase, probably because the family could no longer afford to pay for medicine. Within a fairly short time he was not able to walk anymore. We found him lying on a plastic sheet on the concrete floor of the family's small house in the poor areas of Mombasa. His legs had become very spastic and to keep them from crossing the family had kept the callipers on. This had given him big sores on the knees and the heels on which the flies were feeding, and

he was crying desperately in pain when we tried to turn him around. He was very dirty and smelt of urine. We mentioned that the parents should get him up from the floor and on a softer bedding, maybe use one of the car tires that lay outside the door to sit on. But the parents only gave us a blank, helpless look. They only had one mattress to share among the family members and could not afford to have it soiled by urine. Neither did they have money to buy another one. A comment from us that the boy should at least have a pillow under his head (he was lying on the stomach) made the mother retort: *'Which pillow? We have one and that one is shared among the other ones. From where shall we get money to buy one only for him to use?'*

This case could reasonably be interpreted as one of extreme abuse and neglect – in fact it was the worst case we saw in this field work - and at first we thought we were dealing with a case of parental neglect, as we had been told about so many times before. However, we have chosen a different interpretation. What we saw in the eyes of the parents was not lack of love and interest, but desperation over a situation in which they were not able to cope anymore; they were unable to care for the disabled boy or with his four other non-disabled siblings. The father was unemployed and only occasionally got small day-jobs. On days without work they often had to go without food. The mother was the lady with the burnt leg mentioned earlier. So how can we accuse them of abuse and neglect? We find it more fruitful to see this as a case of social suffering in which this family is the victim of poverty created mainly by social and political forces outside their control and by a weak social security system which is not able to detect and prevent situations like this. Thus the best way to help this boy is first of all to help his family regain a viable way of life in which the fulfilment of his needs is only one of many pieces in the puzzle of coping.

Another similar case was a family with a mentally handicapped boy who wanted to go to school. When visiting their home we met the father and the boy. The father stayed at home in order to take care of the boy while the mother worked in the fields. The boy suffered from epilepsy and his social behaviour sometimes caused conflicts with the neighbours. No one had ever offered counselling to the family on how to deal with the boy's behaviour and the father was exhausted and worried about the boy's and the family's future.

Similarly we met people with disability themselves who had given up trying to control the situation. We usually ended each interview by asking if they had any dreams for the future and how they saw themselves ten year from now. Most of the people interviewed had hopes and dreams for a better life, although not always realistic ones, but a few refused to answer such a question and the expression on their faces indicated little hope.

Someone could suggest that maybe the neighbours should contribute in such cases. This we discussed in a group interview in the first field work when talking to family members and neighbours of disabled people in a village in Maragua district. The neighbours defended their non-involvement by saying that they did not have money, food or time to spare. They already found themselves in a strained situation, looking for work, fetching firewood and water, or farming their small piece of land.

5 How disability generates poverty

In chapter seven we will change the focus to how having or getting a disability may throw a disabled person and family into poverty, or keep them from getting out of it.

5.1 Access to education, employment and resources

Lack of education for a person with a disability is not only a question of being able to afford to go to school, but also of accessibility and suitability of the school itself. Most schools have not attempted to make the classrooms accessible for children with physical impairments or on wheelchairs. If they have, the transport to and from by public busses or simply by walking along the road is prohibitive. Several of the parents we met said that they had not sent their disabled child to school because the child was not able to walk that far and there was no possibility for transport. Ordinary schools have huge classes, especially after primary school fees were dropped, and the teachers are rarely qualified for dealing with the special needs of a disabled child. Lacking are also supplies of adapted teaching materials or equipment in the ordinary schools. If a disabled child needs assistance during the day in a normal school, the other students are the ones that are set to help. If they refuse, the child is left on its own. A mother had taken her child out of school because of this: *'When she moves around in the buildings she has to crawl and nobody is willing to help her when she needs to go to the toilet. I do not want my child to crawl in the other children's droppings.'* Parents of disabled children often make very realistic assessments and conclude that their child will not be able to cope in such an environment. Thus they choose not to send the child to school at all or they take him/her out of school:

> A girl, born deaf, went to ordinary school for three years and learned nothing according to the mother. There was no money to send her to the boarding school for the deaf. She is now in her twenties, illiterate, and lives together with her mother. She never goes out except to church with her mother and she has no friends. Mother and daughter communicate with a home made sign language which only they understand.

> The two blind sisters mentioned previously (6.1.1) had both been in ordinary school when the teacher realized that their sight was fading. The youngest one was completely blind and was taken out of school. The oldest one still has some sight left and was able to get to school by walking slowly on the side of the road and sitting in the front row in class. No one has mentioned the possibility to try a mobility stick or other assistive devices. It is probably only a question of time before she also would stop going to school as well. Her highest wish was for more education, but the family, who were subsistence farmers, had no money to send the girls to the school for the blind. A suggestion had been made that they take the girls as well as the father to Tenwek mission hospital, about one hundred kilometres away, but to date the family had been unable to raise funds for transport.

Although we did meet parents that simply did not consider sending their disabled child to school at all or gave priority to non-disabled siblings, most parents would have liked their disabled child to be educated if they had only been able to get them there or pay the school fees.

Lack of education most often means lack of opportunities for employment and although some people with disabilities are able to make themselves useful around the house, on the farm or looking after the livestock, they rarely manage to fulfil the tasks of a non-disabled person and thus do not get the recognition of a fully useful family member:

> We met a bodily disabled young girl who liked to help her mother with the housework and the mother was proud of her. Still, she was not allowed to do the cooking because the mother feared she could burn herself because of her reduced ability to move around. Another girl, visually impaired, was not able to help inside the house as she could not see anything in the dusk light inside. Some young bodily impaired boys could not work in the fields because they were not strong enough.

Being disabled almost as a rule means loss of employment and severely lowers the ability to do income generating activities:

> A man in his fifties suffered from advanced syphilis and had lost much of the strength and feeling in his legs. His mental state did not seem to be much affected yet and he could move around in the village with a walking frame. Upon diagnosis some years back his wife had left him and taken the children with her and he has not seen the children for more than a year. Before he became disabled he had been a bus driver and was also trained as a welder and an auto mechanic. With impaired legs he could no longer drive a car - and nobody had ever mentioned to him that there are possibilities to adapt a car so that it can be operated even with an impaired leg - *'Nobody wants to employ a disabled man, the only solution is to start on your own'*, he said. Without income he had no money to buy welding equipment. He had gone back to the village where he had inherited a plot of land and a small house made of logs and mud after his grandfather, but without a wife he could not work the land. He spent most of the days sitting outside his house receiving handouts of food from neighbours. Not surprisingly he was one of those who expressed no hopes for the future – he had lost everything.

A probable solution for many people with disabilities to provide for themselves is, like this man said, to start up a one-man business. Many of the disabled men and women we talked to have had the opportunity to get skills training, but without capital to buy tools and other necessary equipment to start up a business they were left only with the dream. Several times we asked about micro-finance loans but we were told that disabled applicants could not get such loans because they were not thought to be able to pay back. In some of the districts we visited we were told that *'they (disabled people) are not in the priority programme which is only for the young ones and for women'*. One could question why no young disabled or female disabled were accepted by the programmes. However, in one district, some disabled people had started a group and they had applied, but they had no initial capital and thus could not prove their ability. In this way the very needy - those whose only resources are the skills and the desire to manage on their own and be independent - will not benefit.

While urban poverty in Kenya may be of the extreme kind, rural poverty is sometimes reduced by the fact that most people have at least a small plot in which to put vegetables for their own consumption and perhaps a goat and a few chicken. Also, they often have relatives living nearby and may get some help from them if crises occurs. However, the urban poor are often alone with their families living far away. Since farm work is considered women's work it is dependent on the availability of female labour. If a disabled man has no wife and no

money to pay for labour as in the case of the man with syphilis above, the land may easily end up lying idle or being taken over by someone else.

Similarly, a disabled child may cause one of the parents to remain at home and thus tip over the vulnerable viability of an already poor household as was the situation of several of the families with mentally disabled children. None of the families with mentally disabled children had received counselling on how to deal with the child's behaviour in order to make the child adapt to the village life and be accepted by the neighbours. All of them were struggling on their own. If the parents received assistance of any kind this came from an adult son or daughter. Another example of a family's care for a disabled member is the case of the woman who had suddenly fallen ill several years ago:

> She was in her fifties and was taken care of by her old mother and her brother. When we first saw her she was lying motionless on the bed and we thought it was a case of spastic cerebral palsy. However, when they made her sit we discovered that she was not spastic at all but was holding her limbs in very peculiar positions. She made no indication of seeing us or reacting to anything that was said, just looked stiffly straight forward. However, her brother told us that she usually responded to them when they talked to her and cared for her. She had been a teacher for many years, but one day she had simply run away. When the mother found her she did not speak and behaved strangely, and since then her condition had deteriorated over many years. She was kept spotlessly clean and so was the room she was staying in. The walls were plastered in a nice colour and the bed had a nice bed-cover. Her hands were nice and the fingernails clean, as was everything about her. It was clear from the way they talked and looked at her that both the mother and the brother cared a lot about her. The brother had been trained and had worked as a computer operator, but when the company he worked for was discontinued he decided not to apply for a new job but to go home to the village and help his mother. He had to leave his wife and two children back in Mombasa. The wife had been working in a restaurant but was presently without a job which made the situation of the extended household critical.
> However, what hurt the brother the most was that no one was willing to visit her and none of her former friends asked about her: *'it is as if she is dead'*. Their situation exemplify how alone and isolated a family can be with the care of a disabled family member.

5.2 Gender issues and vulnerability

In both our field works we saw clear evidences of how vulnerable people with disabilities can be when they are exposed to the world outside the close family and the village. In the village they are protected because the people know them and their family.

The risk of mistreatment is particularly present for girls but also for disabled young men, something we saw many examples of in the first field work. The social workers that accompanied us in the informal settlements in Nairobi introduced us to what they labelled a 'typical case':

> A mentally disabled young boy that had been 'taken care of' by some young men who made him steal for them. This is a particular risk for mentally disabled young men, who have difficulties discerning right from wrong. The young man was caught by the police

but was unable to explain himself so the police took him for a drug addict and imprisoned him. Because the young man was unable to explain who he was, the family was not informed so they could not pick him up. The traumatic experience severely reduced the young man's functional ability.

We did not meet many mentally disabled young men in the second field work, but we met concerned fathers with mentally disabled boys who had experienced others hitting and kicking the child because of his somewhat strange behaviour. As a result, none of these boys were permitted to move too far away from home as was the case for David:

> David is seven years old and mildly mentally retarded. He is a nice and gentle boy and an adult brother and his wife have already agreed to take care of him when the parents become too old. He can dress himself, go to the toilet and eat by himself. David's father says that he adapts to the community but *'he does not always know the difference between right and wrong'*. This worries his father because some of the neighbours hit him because of his behaviour. The father has explained to his neighbours that the boy is not bad but sick, and some understand this, but others do not.

5.3 Lack of ownership and inheritance to land and livestock

A striking feature when one looks at disability issues in Kenya (as in most other African countries south of Sahara) is the vulnerability of disabled women. This of course reflects the vulnerability and lack of rights for women in general in these countries, but like most other issues it becomes aggravated by the special problems that disabled people are facing.

Traditionally women do not inherit land or livestock in Kenya but in most tribes girls move away from their natal household and to the husbands homestead upon marriage. Women who do not marry (which traditionally has been extremely rare) remain dependents on their parent's - and later on their brother's - household for the rest of their lives. Only very recently has a bill been proposed to parliament which - if passed - will give women equal rights to inheritance.

Some of the widows with disabled children came from other places, but had moved into a nearby town after the husband's death. In one case the widow told us she had been chased away from the land of the deceased husband by his family. Another widow with a disabled child had been offered to move into town to live close to a relative of the deceased husband, who then shortly after had moved back to the village - *'They just wanted to get rid of me'*.

In the case of the grandmother of the 18 grandchildren, the disabled grandchild and her brother were supposed to inherit their father's property consisting of some land and a cottage. But the father's family sold the land, took care of the non-disabled brother and left the disabled girl behind.

In modern days there are of course many options for single women. They may get education and employment or start their own business, and some modern women even choose to remain single. But disabled women from poor families clearly have less such options. Similar to the study in Yemen we met few married disabled women. Two young disabled single mothers said: *'A disabled man could easily get married, but not a disabled girl even if*

she got money'. Unlike the Yemen study we met many disabled women with a child (or several) to care for. Some young girls we met at a resource centre said it this way: *'Men do not like to walk with a disabled girl freely, but many like to walk in darkness'* - meaning that men would willingly have a sexual relationship but no kind of commitment - neither for her nor a possible child.

Marrying and moving away from ones own family means that the control over the woman's labour capacity and childbearing is transferred to the family of the husband. When asked about plans for marriage, several parents expressed a fear that their disabled daughter would be treated badly or end up as a second or third wife to an old man if allowed to marry. Thus they preferred for them to remain home and unmarried, even if they got a child:

> A Masai father had in addition to the traditional herd of cattle also acquired some farmland near Narok. When his daughter, disabled in one leg by polio and walking with a calliper, expressed a wish to get married he refused fearing she would be mistreated in another family. Instead he gave her a considerable piece of farmland, enough to feed herself and the four children born out of wedlock over the years. Her mother lived nearby and was able to help her with the farm and the children. The livestock, however, had according to tradition been inherited by her brothers only, but she had been given the permission to milk one cow. In spite of no intention of marrying her off she had been taken through the tribal puberty rituals and thus was respected as a full worthy adult woman.

> Another woman we met, affected by polio in both legs, had been proposed to and wanted to get married. Her parents however insisted that upon marriage the husband should move to her place in order for her not to risk being mistreated by the husband's family. The family had some farm land and a nice and well kept farm so the husband had agreed to this and they had been promised a share of the family land upon her parents' death.

We met families in similar situations in the first field work as well, and talked to fathers that had accepted marriage for the (often very beautiful) daughter on the condition that the couple settled close to the girl's parents so they could keep an eye on them.

These examples show how concerned parents go out of their way, and even against tribal traditions, in order to protect their disabled daughter from what is perceived as a danger of abuse and mistreatment if she is left in the hands of a strange family. We have no data to show whether such mistreatment actually takes place. Most likely it does in some cases and not in others.

Some of the fathers of disabled boys made it clear that the situation could have been far worse if the child had been a girl. A disabled boy could get married and have a non-disabled wife to help and care for him, but this would apparently not be the case for a disabled daughter who probably would remain the responsibility for her parents for the rest of her life. When asked about plans for marriage most of the disabled women (or parents of disabled girls) we talked to did not expect to be married while the disabled men in most cases said they expected to find a wife. Upon asking these men if they wanted a disabled or a non-disabled wife all of them said a non-disabled because *'how are we going to manage if both of us need help?'*. Thus their plans for marriage had a very practical undertone.

When asking non-disabled women married to disabled men if they had got any reactions from friends and family to their choice of husband, most of them told stories about surprise and doubts at first, but then about acceptance when they got to know the disabled man. One very beautiful young girl even had to go against the will of her family and moved far away. When asking for her reason to choose a husband with the legs weakened by polio she answered very nicely *'I guess it was just love'*. We think it is likely, and to some extent got it confirmed from these non-disabled wives, that a physically disabled man who has come to terms with his disability in the times of HIV/AIDS often is more attractive to a girl as a loyal and faithful husband and potential father of her children than a non-disabled man who is considered more likely to "run around".

5.4 Fear of rape

It is known from other African countries that women with disabilities are more at risk for being victims of rape than those who are not disabled (Ingstad and Whyte 2007). The fear of rape was clearly expressed by parents of disabled girls and also by the disabled women themselves. To what extent rape actually occurs is not known and we considered this as part of people's private life which we saw no reason to go further into in this study. However, the fear of rape is enough to influence the way of life for a disabled woman. The mother of the deaf girl mentioned above who was never out of her mother's sight, and thus had no friends, was according to the mother being protected by her from rape.

We met a single and disabled mother to a twelve year old boy living in a small town. The son had been accepted for a scholarship for boarding school from a Christian organisation because of her disability. Accepting the scholarship meant that she had to live alone something she considered a risk for herself. For protection she had taken a nephew - a small boy - in the house: *'I know that I am vulnerable as a disabled woman without a husband so I never have male visitors without having someone with us in the house. I must always be careful. I am always accompanied even if it is with the boy. I never go out alone, and there are places I never go because I fear to be attacked.'*

In Kisii we met a lively young girl. We asked her if she could move around freely, and she said she could, but that she was aware that she is vulnerable. She had fears - strange men - but she could protect herself and strike back, she said.

In the poor areas of Mombasa we were told about a woman who had been found "hidden" in the house. We went to see her together with a local representative from APDK. What we found was not a hidden woman but one with cerebral palsy that was (over)protected by a younger sister taking care of her, showing love, care and great concern. *'There are many bad people out there'* the sister said and *'I cannot let her out or let them come in. Therefore I have to look the door when I go out'*. When asked if it was rape she feared she said yes. The disabled sister spent most of the day on her bed. When we came she was being visited by a tenant who was playing music on the radio for her. She could also crawl around in the house and go to the toilet (which was spotlessly clean) by herself. There were also other people and children in the house to keep her company. The sisters had inherited the house from their deceased mother and were renting out three rooms which gave them a meagre living. The young and very pretty non-disabled sister, who had three children without being married, said that she did not want to get married because she did not know who would look after her sister if

she did so. She could not trust that a future husband would support her in the care of the disabled sister.

We see from these examples how the fear of rape and mistreatment tend to organise the life of some disabled women no matter if rape has actually taken place or not. The last case was not a case of hiding but a case of social suffering where being poor and having to live without male protection in a poor area created a situation that implied sacrifices for both sisters.

Another issue is what is actually to be considered rape in situations where a disabled woman who is not able to make herself properly understood all of a sudden becomes pregnant. We saw several such cases in the first field work - severely mentally disabled very young girls being pregnant. It may also be that parents turn their back to what happens hoping that a possible child will take care of the disabled daughter when they die. One of us has encountered several such families in a study of families with disabled members in Botswana (Ingstad forthcoming).

Being raped of course also implies a danger of being infected with HIV, and in this sense we may say that women with disabilities are particularly vulnerable. It is known from other African countries that some men tend to go especially for disabled women because they believe that no other men have wanted them and thus they are virgins and "clean" of the virus. It is also a belief among some HIV infected men that they may "cleanse" themselves of the virus by having sex with a virgin. These were common beliefs – and said to happen – also in Kenya.

5.5 Being left by the child's father

On the other hand several of the female informants had at least one child - born when they were very young - and there had never been a husband or father to accept the responsibility for the child. These women stated that the father(s) had disappeared when they got pregnant and that they did not receive any support for the child(ren).

Being disabled and getting children out of wedlock most often increases the problems and the vulnerability of the women, and they may easily end up in prostitution-like situations in order to provide for themselves and the child. We strongly suspected this in several cases, but decided not to pursue the matter further in our conversation with them. On the other hand, getting a child who is not disabled, especially if it is a son, opens a possibility for the woman with a disability to be provided for in the future. Several of the mothers were quite clear on this and would do their uttermost for the child to get an education. This was the case of many of the young women we met. All of them had been pregnant quite young and were single mothers. They had never been married, the fathers of their children were not around and they expressed little interest in having a husband. In spite of the disability that made it difficult to manage, they preferred to live alone and they also preferred to live away from their parental home. Their future prospects was to keep the child in school and give it a proper education.

5.6 Coping with disability in the context of poverty

After having looked at "the evil circle of poverty" from two different angles we shall now turn to the more encouraging stories and look at the factors of resilience that make some disabled people and their families cope reasonably well in spite of living in poverty.

The most important resilience factors we saw during the fieldwork were:
- Family and neighbourhood support
- Education
- Employment and/or farmland
- Religion
- Support by representatives of DPOs
- Luck

5.7 The supportive family

We have already seen examples of families supporting their disabled members in several ways, the Masai father who against tradition gave inheritance of land to his daughter and the family who insisted that their non-disabled son in law should move to their compound. Even the overprotecting mother of the deaf girl and the sister of the (not so) "hidden" girl were loving and protecting in their way although the result was not necessarily the best for the young girls. There are several more examples:

> A young disabled man had managed to complete a bachelor's degree at the university because he was supported and taken care of by his elder brothers who are now deceased. Because of the death of his brothers he had to stop studying and find a job to support himself and his many little nephews and nieces. We also met a young man with a shop on the street who was supported by his elder brothers whom he lives together with.

> Faith, a young woman, told us she managed to come to her little business because her elder brother had a job and could help her with the necessary capital to buy a sewing machine. She is severely impaired by polio and manages through the day because she lives together with a cousin. They have a joint venture as Faith pays the rent and the cousin does the housework that Faith is not able to do.

Being supported and accepted by others also has implications for the way the disabled person sees him/herself and the future:

> After visiting the house with the blind father and the two blind daughters where the conditions were not so good and the parents found it hard to cope with the disability, we went to a nearby village to visit a deaf girl of about the same age. We were met by a smiling girl who communicated lively with everyone around her using her own home made sign language, and the whole atmosphere was one of love and acceptance. Our visit seemed to be something like the event of the year. The whole family and all the neighbours had come to watch and particularly the young men and women. All of them were asked to leave the cottage, but they crept silently inside one by one while we were talking. Our usual questions for privacy during the interview were simply ignored, and we got a feeling that the whole extended family of aunts uncles and cousins - in addition

to interested neighbours - wanted to take part and tell us about the girl's many good qualities. What made this case such a happy story was the interplay between this girl's charming and self confident personality and the openness and supportive attitude of the parents and the others who attended the interview.

The situation of Faith, the dressmaker, gave the same impression as she communicated the self confidence that comes from contributing to a mutual benefit. Wherever we went we were told about cases of bad treatment and stigmatisation, but more often stories about fear of such treatment. This lead disabled people or parents of disabled children to keep them away from others, an act which may easily lead to suspicion and prevent others from interacting freely with them. The young mentally disabled children we met were constantly supervised by the parents and not permitted to go out of the compound alone. If we have had a superficial look into these cases we easily could have interpreted them as cases of 'hiding the disabled child'. But during our conversation with the parents all of them gave a reason for why they had come to this solution.

> We visited a family with a boy who had a desire to walk along alone and to seek up new places. On one occasion he and his little sister had gone to find the national park and see the elephants. The children's disappearance had caused great fuss in the village. Luckily they had been picked up by a Matatu (the public bus) and taken to someone who took care of them.

We have already mentioned that several of the mentally disabled boys had encountered negative reactions from neighbours who had hit and kicked them because they failed to behave in a manner one would expect from children of that age. Thus fear of stigmatisation and actual stigmatisation is linked in an evil circle. In cases where disabled children had been mocked or mistreated by others there seemed to be few efforts made by the parents to talk to the actual persons. This is a matter where representatives of DPOs often had done an important job in supporting the parents and enlightening the neighbourhood on the acceptance of children and adults with disabilities.

5.8 Education and work

Education and employment are other very important factors when it comes to helping people with disabilities to cope with their situation. However, the general situation of unemployment in Kenya affects the people with disabilities even more than others. Until preferential employment for them is actually practised (see introduction concerning the disability act) many of them are bound to be losers on the labour market. Skills and vocational training is one option which may lead to self employment. Although such training seems to be a way out of poverty for some disabled people it is also a question of the market for the products that are made. Thus when a whole group of men from the poor part of Mombasa are sent for training in shoe repair, and afterwards returned to almost the same area of the city, the number of customers for each is bound to be rather limited. Some people have managed to save up money to start a small business selling cigarettes, matches and the like on the street. But on the whole there are many street sellers and seemingly relatively few customers so competition is high. We were surprised to find that several of these disabled sellers had finished primary school and some even secondary school (and one had even been to college). Thus their present employment is as much a sign of the difficulties people with disabilities face in

achieving their goals as of their success in raising themselves just a little bit above the worst poverty.

In both field visits we met people who had been employed but had lost their job when they became disabled. They were clear examples on how disability leads people into poverty because of the general ejection of disabled people from the labour marked.

In this field work we only met one person who was employed and this was at a carpentry where the owner had a disability too. He is a good example on the positive effect of adjusted assistance:

> Aaron was born with a deformed leg. He had been trained as a carpenter at an APDK vocational training centre and started with a small workshop which he has managed to develop little by little. He kept up the contact with APDK and the organisation had assisted him and supplied him with the tools and equipment he needed. Through APDK he got to know Ben who was enrolled at the training centre to learn carpentry and when he completed he engaged him. Carpentry is hard work so Aaron was dependent on employing non-disabled workers as well. Both Aaron and Ben consider themselves as role models for others. Proudly they tell us that now they are contributors to their families.

The issue of land and livestock is also important for successful coping. As we have seen, those who have or acquire land and/or livestock and are able to take care of it either through own work or by the help of a non-disabled spouse stand a chance of coping better than others. At least they are able to fend off starvation. In general we saw fewer signs of malnutrition in children or disabled persons in the rural than in the urban areas.

5.9 Religion as a factor of resilience

Religion may also serve as a factor of resilience – Christianity as well as Islam. We saw many examples of this, among others the case of the grandmother with the 18 orphans. Her church affiliation as well as that of her only surviving daughter-in-law who was helping her was clearly the main factor that kept her going. We have seen the case of the father who had installed an altar in his house to pray for his epileptic son, and was sure it had helped. We have the case of the brother who had chosen to stay in the village helping his mother to care for his sick sister because this gave meaning to him as a Muslim. We also met parents who said that after overcoming the first shock they had come to see the birth of a disabled child as a challenge and a trust by God and they wanted to proof themselves worthy of this trust. Religious affiliation may also keep people from consuming excessive alcohol, a curse for many poor people of the world.

Traditional beliefs however do not always make life for disabled people easier. We were told many times by the people that accompanied us and facilitated the field work that *'people around here think that disabilities are a curse'* but we did not meet anyone who said so about their own situation. Some said that their parents had thought the impairment was due to witchcraft, a belief which may reflect – or create - difficult relationships in families and neighbourhoods. The belief in good or bad luck or misfortune caused by others or outside forces is strong in many African traditions.

5.10 Sponsorship and fellow support

Another type of luck we saw which contributed to resilience in a very strong way was the luck of running into an organisation and/or sponsors who would help a disabled person through operations, school or vocational training. Several of the disabled people we met that had been at boarding school or through vocational training had experienced such luck. On the other hand we saw several examples of how special schools that had previously had sponsors from abroad had to introduce fairly high school fees when the sponsors decided to withdraw. This led to personal tragedies as the disabled child had to be taken out of school because the family was unable to pay. Most of the poor families with disabled children that we met did not even consider sending their child to a special school because of the costs.

It was very encouraging to see the role that some local representatives of DPOs played in relation to other disabled people. In several of the districts we visited they worked closely together with the officers of the Social Development office in detecting cases, offering advices and counselling and referring them when severe needs were detected. *'He (or just as often she) knows everything about the disabled people here'* some of the district officers said when we were introduced to the representatives of the local DPO. They also worked with their fellow disabled and their families in order to create acceptance for their situation and showing them that it was possible to live positively with a disability. These people however worked for free, for idealistic reasons, only rarely had they sporadic sponsorship from NGOs, and there was consequently a limit to how far they could go and how much time they could spend on the task.

Engagement in the DPO gave the volunteers an opportunity to contribute to their own coping with their situation and to help other people with disabilities. This added qualities to a life that otherwise easily could have been quite without meaningful activities.

We met a disabled woman that worked at a Hospital as a voluntary counsellor on HIV/AIDS. She was a trained counsellor. Because of her disability she had a particular interest in counselling disabled people and was engaged as a volunteer by the local DPO to counsel people with disabilities about the same problems. This counselling, similar to all the other services that could improve the situation for people with disabilities was in principle institution based and not ambulant, but she had realised that if she should reach disabled people she had to seek them up. She said that disabled people even more than others for many reasons do not seek counselling: Because of ignorance of the problem and the possibility of counselling, because they fear to be even more stigmatized than they perceive themselves already, and because they have difficulties in getting to the hospital. Many, and in particular mentally disabled and deaf people, have very limited information on risk factors and where to seek help. Usually she was told by the people's friends about the problems and then she went to see them and talk to them.

In both Narok and Kisumu we met young disabled men and women who had built self-help groups to support each other and other disabled people. The group in Kisumu had even succeeded in getting financial support to start a workshop even if it was very hard to make the workshop viable. Their hope were that the group could offer a way to a future income, but most important was the practical, moral and emotional support the members could give each other.

6   Concluding remarks and recommendations

6.1 The complexity of the situation for people with disabilities

Through this field work we have demonstrated the necessity of a family perspective and a focus on "disabled households" in stead of focusing only on the disabled individual in order to understand the complexity of the situation for people with disabilities, and the poor disabled people in particular. Consideration should be made on how to make such households viable. In doing this one should focus political and economical factors both for the family and for the neighbourhood within which the family exist.

The apparently common belief that the family is 'hiding the disabled family member' and that they look upon 'disability as a curse' easily blames the individual for the unhappy situation and permits the local authorities and professionals not to seek other explanations and solutions. The field work has demonstrated that many families care for and protect a disabled family member within their scarce resources as well as how important an accepting family is for a disabled person. However the ties of the extended family is not as strong as we saw in a similar study in Yemen. Disintegrated families (due to HIV/AIDS, migration into towns/cities to look for work) increases the vulnerability for men and for women in particular.

In understanding the cases in this field work from the perspective of social suffering it is relevant to look for viable solutions that takes into consideration elements outside the family to improve the situation for the family and the disabled family member. Society offers obstacles in abundance when it comes to participation for people with disabilities. One should focus the necessity to adapt the schools (buildings, teaching, materials), the health services (structure, buildings, knowledge and competence), work places (public and private), and public places and buildings among others accessible to all members of the society regardless the type of disability.

This field work has identified a need for programmes of specific outreach to families with disabled members to improve the family members' knowledge on disability. Programmes should be developed on education and training of parents and other family members on how to contribute in improving their disabled relatives' functional capacities. This is particularly important for families with mentally disabled members. There is a need for support to family members in order to lessen the responsibilities that affect decisions to attend school and find employment. Further, there is a need for programmes on community awareness building concerning the situation for people with disabilities in order to sensitize the communities on disability issues and stimulate the positive signals of inclusion that are seen.

6.2 The vulnerability of the independent individual

There is a strong impression that people with disabilities seek to be independent and to manage on their own. This strategy of surviving seems to be encouraged by the DPOs that encourages disabled people to achieve individual independence. Ideologically this must be

understood as a move away from the attitude of 'being taken pity on and being taken care of'. Practically there is a need to provide for oneself to survive and the more disabled people rely on others the more vulnerable they become. Individual independence can be a solution when the family is non-supportive, but we have seen that those who manage almost as a rule have a supportive family to rely on.

When young people in the town build groups to support each other this could be interpreted as a 'peer family' - a reaction to and a replacement of a family that is not around and do not support them. The peer groups could be understood as a way of building a social security network in a society where family ties are about to weaken and public social security is almost absent.

6.3 Lack of adapted services and counselling

Services for disabled people seem fragmented and possibly with low competence and with a serious lack of trained personnel. Regarding schools the knowledge on how to adapt the teaching to disabled learners seems very limited. The only examples we got on strategies on adapted teaching in regular schools were to place the learners at the first row in the class. Nobody had been given compensatory teaching.

Most services are institution based and this represents a problem when people live scattered and they are unable to move for long distances by themselves. In order to be accessible for people with disabilities there is a need for local based - village based and ambulatory - services and activities.

We have seen a general lack of counselling on how to deal with for instance a mentally disabled child in order to help the child to develop its abilities. In the first field work we met some parents of mentally disabled children in Nairobi. None of these parents could be said to belong to the poorest ones, as they had a job (and thus a regular income). But they faced the same problems as poor parents in not getting any assistance or counselling on how to deal with the disabled child. Because they were resourceful and had access to internet they had found a way out of the problem as they could seek for information and knowledge through internet. They had managed to fund a day care centre for their children and carried out a trial and error strategy on the development of the children guided by whatever information they got through internet. The point is, they knew nobody within Kenya who could provide professional guidance. We saw similar situations in the similar study in Yemen where social workers with access to internet used this to educate themselves as trainers and counsellors for parents of mentally disabled children. Poor people and people in rural areas do not have opportunities like this.

Without counselling and with resources limited to a minimum it is difficult to think of alternative solutions for activities when the disability makes it difficult to do things the 'usual' manner. This easily creates a fatalistic attitude. What do you do when the child is not able to walk to school, there are no spare hands to carry and no money for the bus, and no other options are offered from the society?

Health care and rehabilitation is fundamental in improving disabled peoples' living conditions and well-being. Because of this one should focus more on outreach health care and rehabilitation services as this could improve the access to treatment, training and provision of

assistive devices. Likewise training and rehabilitative programmes should be developed according to local needs.

6.4 The need for affirmative actions

It seems that the overall policies on health and educational issues do not benefit the poorest disabled – those without resources as knowledge and money. No matter the situation of the disabled person, there is always a demand for a certain capacity to pay and for knowledge on where to turn to and what to ask for. To seek for solutions to problems like this one has to realise that equal treatment is not always equal treatment in its consequence. The authorities should therefore discuss the need for affirmative actions (positive discrimination) - as is often articulated with regard to gender - to secure access to services and the opportunity to participate in social activities for all disabled member of the society.

In some of the areas we visited people with disabilities were represented in the public committees. As a result of this the local authorities had started to gain a better understanding of the poor disabled people's situation. This clearly demonstrates the need to include people with disabilities in decision making processes. Probably could local DPOs play a role in local based and ambulatory counselling and provision of low technology devices provided that they are granted some financial resources.

6.5 Education and Employment

In order to include people with disabilities in the labour market on an equal basis there is a need to employ people with disabilities in both private and public enterprises and offices. The obviously one-sided focus on self employment for disabled people can easily be a pretext for doing nothing by the authorities when it comes to put a pressure on public and private enterprises and offices to employ disabled people.

Improvement of a population's educational level is of vital importance in the struggle against poverty in every society. Because of this there should be a particular focus on affirmative actions to strengthen inclusive education (instead of establishing special schools) as inclusive education could improve disabled children's access to education. There is a need to develop more knowledge and further initiatives for special education within the ordinary schools. Within this there is a need for adapted teaching materials as well as a need for accessible school buildings.

Schools should be free, including school uniforms, teaching materials and transport for children who need this.

6.6 Suggestions for policy and programmes

NGOs must be considered as a blessing and a curse when it comes to assisting people with disabilities in coping. A blessing because NGOs run activities that are of vital importance to the people that need them. A curse because they can withdraw their resources and then the

activities are shut down or become very expensive. Additionally, their presence permit the governmental actors to be complacent and not deal with or plan for the situation.

On the other hand DPOs are very important as they are run by and for the people with disabilities themselves. In many countries DPOs play an important role in the civil society among others as an implementing partner of public services as well as a body for advocacy. People with disabilities have first hand knowledge on how to manage as a disabled person, and they are in a position to give peer counselling and act as role models for others. There is however a dilemma as this to some degree could relieve the authorities from their responsibilities. Disabled people engaged in the local DPOs are volunteers but it is our opinion that they should be paid as they do a job that in most developed countries is the responsibility of the authorities. Considering the very limited resources for the DPOs, they appear to play a significant role in the services to disabled people. The resources - economy and competence - of DPOs should be strengthened.

The delivery of disability programmes serving disabled people needs improvement in particular when it comes to the follow-up of those who benefit from them. There is also a need of awareness campaigns so that disabled people know about these programmes as well as other services. It is vital to link new strategies, programmes and activities with already existing programmes to strengthen the effectiveness and the economic viability of those programmes.

Further there is a need of developing application procedures that accommodate the functional capabilities of disabled people.

The challenges connected to accessibility to public buildings are not elaborated in this report (except for the accessibility to schools that were discussed in the first field work), but there is a need for a strategy to create an inclusive environment to ensure that public buildings will be accessible for disabled people. It is clearly a need to adopt the principle of inclusive design in Kenya as in most other countries. The principle of inclusive design caters for the needs of all members of society and ensures the development of solutions accessible for everyone.

6.7 Knowledge and Research

During this study we have noticed the lack of relevant research that could elaborate the findings even more. There is a need for further research to build a knowledge base for policy development and further developments of programmes and activities. There is a need for knowledge based evaluation of the tools (concepts and methods for data collection) that are used to produce statistics on disability. There is also a need for comparative studies on the situation for people with disabilities vs. non-disabled. Likewise there is a need for knowledge based evaluation of ongoing programmes and activities directed towards people with disabilities. This could improve the accuracy of the programmes.

Further, there is a need for studies on the situation for people that are mildly impaired, and who maybe find themselves in some kind of a 'grey area' between disabled and non-disabled. There is also a need for surveys and censuses in general to be sensitive to the concept of disability as a social concept.

There is particularly a need for research to enlighten the situation and gain more knowledge of how to improve the situation for people with mental disabilities and people with mental illnesses. There is also a need for more knowledge on the circumstances of disabled children in general.

A situation analysis of the services provided to disabled people should be carried out as well as post training follow-ups of graduates after vocational training. There is further a need for deeper knowledge on rehabilitation, especially of methods that could facilitate individually adapted practices. There is also a need for research to see how knowledge is or could be translated into good practice.

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Appendix I Districts visited

Districts visited at the first field work (2005):
Machakos is a district in Eastern Province of Kenya. The capital town, Machakos, is a major rural centre, and also a satellite town due to its proximity to Nairobi. Machakos was established in 1889, ten years before Nairobi. Its population is rapidly growing and is 144,109 (as of 1999). People who live here are mostly the Akambas. Town and the district were named after Masaku, an Akamba chief. Machakos is surrounded by hilly terrain, with a high number of family farms. Machakos was the first administrative centre for the British colony, who moved the capital of Kenya to Nairobi in 1899 since Machakos by-passed the Uganda Railway that was under construction.
Maragua is a district in the Central Province of Kenya. The capital town, Maragua, is located along Thika - Sagana road just 10 km south of Murang'a. Maragua town has an urban population of 4,286 and a total population of 27,384 (1999 census). Maragua District has a population of 387,969 (1999 census). Maragua district is divided into four administrative divisions: Maragua, Kandara, Kigumo and Makuyu and has four local authorities: Maragua town council, Maragua county council, Kandara town council and Makuyu town council.
Nairobi is the capital of Kenya. Founded in 1899, the city was handed capital status from Mombasa in 1907. It is also the capital of the Nairobi Province. The city lies on the Nairobi River, to the south of the nation, and has an elevation of 1661m above sea-level.
Nairobi has the highest urban population in East Africa, estimated at between 3 and 4 million (according to the 1999 Census). Since its foundation as a railway camp in 1899, Nairobi has grown to become the largest city in Kenya, and one of the largest cities in Africa. Nairobi is one of the prime cities in Africa politically and financially. Home to many companies and organizations, Nairobi is established as a hub for business and culture. The area was an essentially uninhabited swamp until in 1899 a supply depot of the Uganda Railway was built, which soon became the railway's headquarters. The city was named after a water hole known in Maasai as *Ewaso Nyirobi*, meaning "cool waters".
After independence, Nairobi grew rapidly and this growth put pressure on the city's infrastructure. Nairobi is a cosmopolitan and multicultural religious city, with many immigrants from former British colonies, including India, Somalia and Sudan.
Nairobi is home to several slums. To accommodate the growing middle-class, many new apartments and housing developments are being built in and around the city. The most notable development is *Greenpark*, at Athi River town, 25 km from Nairobi's CBD. Over 5,000 houses, villas and apartments are being constructed at this development, including leisure, retail and commercial facilities.
 Most Nairobi non slum-dwellers live in relatively good housing conditions, which is a striking contrast to the living conditions of the slum-dwellers. The growth of these slums is a result of migration from rural areas to the capital. Unable to find work, these migrants settle in the slums.
Kibera is the largest and poorest slum in Africa, and is situated to the west of Nairobi. Between 500,000 and 1 million people live in Kibera, which dates from a 1920 settlement for Nubian soldiers ("Kibera" is the Nubian word for "forest"). The slums cover two square kilometers and is on government land. We also visited **Mukuru** slum.

Districts visited at the second field work (2006):
Narok is an old town west of Nairobi in south-west Kenya, along the Great Rift Valley. Narok is the capital of the Narok District and has a population of around 40,000 people, mostly Maasai. The Narok District is located in the Rift Valley Province, and has a population

of 365,750. Along with Kisii District, Narok District has been identified as having the highest level of practice of female circumcision in the country, despite being outlawed in 2001.

Kisii District is one of the twelve districts of Nyanza Province in southwest Kenya. The capital town is Kisii. The district is mostly hilly and is dissected by rivers flowing west into Lake Victoria. It lacks infrastructure like electricity, telecommunications and good roads, inhibiting the full exploitation of resources. The hilly nature of the district leads to serious soil erosion and makes road communication difficult, especially in the rainy season when many roads (only 10% with tar) become impassable. By 1996 the annual population growth rate of 3.6% mean that the population is well over 2,000,000 (19% of whom live in urban areas). This makes Kisii district one of the most densely populated in Kenya, with around 50% of the population being below the age of 15 years. In most areas the sex ratio is disproportionate due to labour migration to other districts and cities.

Due to the high population density, almost all land in Kisii district is put to maximum agricultural use. Land is subdivided within families, meaning that plots are becoming ever-smaller and the average farm is only 15,000 m² in area. Intensive farming in hilly regions has increased the rate of soil degradation and erosion, while the application of farm chemicals has polluted surface and groundwater sources. Enrollment in school has traditionally been low but is increasing. Female enrollment in secondary school is at 45%, while adult literacy is 56% which is high in relation to much of Kenya.

Kisumu is the third largest city in Kenya, a port city at Lake Victoria, with a population of 322,724 (1999 census). It is the principal city of western Kenya and the capital of Nyanza Province. It is also the headquarters of Kisumu District.

Mombasa (around 900,000 inhabitants (1999 census: 665,018)) is the second largest city in Kenya, lying on the Indian Ocean and is located on Mombasa Island, which is separated from the mainland by two rivers. The town is mainly occupied by the Muslim Mijikenda/Swahili people. Over the centuries there have been many immigrants, particularly from the countries of the Middle East and Indian sub-continent who came mainly as traders and skilled craftsmen and even after four or five generations. Recent immigrants are peoples from the interior of Kenya brought to the area by employment opportunities in the tourist industry.

Kwale District is an administrative District in the Coast Province of Kenya south of Mombasa. The district has a population of 496.133. Kwale is mainly an inland district, but it has coastline south of Mombasa. The capital town is Kwale town with an urban population of 4200 (1999 census).

Malindi District is an administrative district in the Coast Province north of Mombasa with a population of 544,303. Its capital is the coastal town Malindi. Tourism is a major industry while inland areas are rural. The capital town is Malindi on Malindi Bay at the mouth of the Galana River,with a population of 117,735 (in 1999 census).

Appendix II The Interview guide

Relevant Topics in a study on disability and poverty

The interview guide comprises the topics we consider relevant in a qualitative study on disability and poverty. The guide is build upon the concepts of disability and poverty, as presented in the beginning of the report.

In an interview situation the guide as presented here is not always used to its full extent. Depending on the circumstances, various sections will be more or less relevant for the interview.

Interview with persons with disabilities and their families
This interview guide comprises topics that will be relevant in a qualitative study on disability and poverty. The relevance of the topics for each specific interview will vary from one interview to the other. It is the informant's history and experiences that will decide which topics it is important to focus in the various interviews.

- The Opening: Introduce yourself and give the formal information about the study.

- Ask the informant to tell about the reason for the disability, as well as the reason for the onset of the disability. Try to get the detailed story:
  - Please describe or explain to me about your impairment.
  - What happened, when and how?
  - Why do you think this happened to you? This question is an attempt to find out if the informant believes in 'other' explanations (witchcraft, ancestors' anger, evil spirits etc.).

- Ask the informant to describe his/her activities and tasks, the role and responsibility connected to:
  - Household duties
  - Participation in work or school
  - Participate in social activities
  - Private activities as hygiene, toilet, dressing etc.

- Invite the informant to tell about the daily activities, describing the activities from morning to evening. When asking the informant to tell about activities, one has to arrange this according to the informant's age, sex, family position/role etc. Be careful to encourage the informant to be specific and to illustrate by examples. Is this what he/she always does? What additional responsibilities would he/she have if it were not for the disability? Would the activities be done differently if he/she was not disabled? Is this what others in the neighbourhood usually do? Is this the way he/she thinks it should be done (ideally).

- Relate the activities to the bodily and/or mental functioning:
  - Ask the person to describe how the disability affects the performance of the activities.
  - Ask the person to describe any assistance given and by whom the assistance is given.
  - If the person does not participate in some of the activities: Ask the person to reflect on why he/she does or does not participate in the activities.

- Ask the person to describe what others (non-disabled) in the same situation do with regard to the activities mentioned.

▪ Adaptations relevant to the disability:
  - Ask the person to describe adaptations made to minimize the practical consequences of the disability (technical devices and practical arrangements at work, in school, at home), and the efforts connected to make these adaptations.

▪ Ask the family members to describe how they take care of the disabled family member:
  - How does the situation with a disabled family member affect their personal as well as the family life?
  - In what way does the disability affect some of the household members' ability to work, access to employment, go to school or participate in social activities? Ask them to reflect on why the situation is like this.

▪ Access to health care and medical services:
  - What kind of health service and/or medical care has the person received, *or not received*, because they have a disability?
  - Ask for experiences on: modern health care, traditional health care, self care in the family.

▪ Participation in organizational activities:
  - What kind of social and/or organisational activities does the person participate in? Tell about what happened last time they had a meeting?

▪ Invite the informant to talk about the future: What are the dreams and plans regarding education/schooling, employment/economic support, having a family of ones own? How does he/she think the living situation will be in approximately ten years from now? What is his/her chances of achieving he goals. What would be the hindrances?

▪ Reactions to disability:
  - Ask the informant to explain about his/her reaction to being/becoming disabled.
  - Ask for their experiences with other persons' behaviour, reactions and knowledge on the fact that he/she is disabled.
  - Ask if he/she knows or comes together with other persons with disabilities in the village or the community.

▪ Ask the head of the family to tell about the family:
  - How many family members, and how many disabled members (age, sex) are there?
  - How are the consumed goods obtained?
  - How does the family get their income? Is the income sufficient to support the family?
  - Is it enough persons in the household to care for the disabled member and to support the family in the daily living? Do family members have to quit job or not work in the field because of the need to care for the person with a disability?
  - The housing: is the accommodation similar/lower/higher than the other community members' accommodation?
  - What is the informant's opinion on the family's social ranking/class?
  - How does the disability infect the family life all in all?

- Note age, gender, and sometimes name, of the informant if this has not been noted earlier in the interview. Biographical data are often given quite early in the interview as a natural part of the conversation. One should however notice that it is not always wise to open the interview situation with these questions. On the one hand this information is not directly related to the reason for the interview and may therefore be disturbing when it comes to the importance of getting a good start. On the other hand one must be aware that opening an interview noting personalia under some circumstances can be interpreted as an inquiry, which for some gives associations to very unpleasant experiences or even can be frightening.

- Closing the interview: Acknowledge the informant's cooperation, time spent and information shared.

Interviews with other relevant actors
There are many other actors that may give relevant information concerning the situation and living condition for people with disabilities in the village, community or district. Make appointments for interviews with:
- The head of the village or the community, the district officer.
- The head master of school.
- Teachers.
- Health and/or social workers.
- Employers.

The representatives for these offices often possess general information on the situation for people with disabilities in the area. Examples on questions that could be relevant to ask:
- What are the main problems related to disability in the area?
- Are there people who do not have access to schools, jobs, public buildings and other public or common goods?
- What kind of consequences does this have for those who do not have access?
- What do you know about the living condition for people with disabilities in the area/district?
- What is done to improve the living conditions?

Ask for their opinion on participation and integration in the community/society for persons with disabilities. Ask them to illustrate with examples on what has been done in their own community/village/school.

Supporting - information
As a supplement to the interviews one should always look for information that can deepen the information from the interviews:
- Look for/ask for access to or adaptations in relation to public places and buildings. Some examples are: schools, hospitals and health services centres, post offices and banks, shopping centres, municipal buildings and the city hall, office buildings, transportation facilities such as busses and trains,
- Look for/ask for access to or adaptations in relation to public information.
- Ask for information on systems concerning social security and pensions; if there are any destitute rations or drought relief; the occurrence of supplements for children and destitute; activities funded and run by government or NGOs.

Appendix III Manual on qualitative methodology

Core Principles in Qualitative Studies

The purpose of the study and the framing of the research questions should be decisive in the choice of the research design and the methodology. Therefore, it is fundamental to have a clear opinion on what type of knowledge one wishes to obtain. A research approach may however comprise both qualitative and quantitative techniques - sometimes called triangulation of methods. Qualitative and quantitative data may supplement each other in order to broaden the perspective on the studied phenomenon. A qualitative study may precede a quantitative one in order to get a better understanding of the problem studied before designing a questionnaire, or a qualitative study may follow a quantitative one in order to get a more in-depth understanding of findings from the quantitative study.

A qualitative approach is likely to be chosen when the focus involves an interpretive approach in which the aim is to understand and interpret the meaning the different experiences has to the individuals. A qualitative approach may give access to people's own experiences and the meaning they place upon these, and offers a method to enlighten people's experiences, their view of the different aspects in their lives, and how a phenomenon arises. It is useful when the phenomenon is sensitive and delicate and therefore difficult to investigate. (Wadel 1973, Denzin and Lincoln 1994, Ryen 2002)

A qualitative approach involves more or less structured conversations, collecting verbal or metaphorical data. Doing qualitative interviews implies an interactive approach as communication is fundamental. Usually the communication is 'face-to-face', even if telephone interviews sometimes may be used, depending on the informants, the setting and the research questions. It is important to be sensitive to the informants' responses on the themes and topics introduced by the interviewer. The aim for the interviewer is to take the role of a student – someone who wants to learn from the informant who is the expert of his/her life situation. This involves encouraging the informants to *like* to tell about themselves. The interviewer must let the informant's associations dominate the interview situation and at the same time secure the interview to the topics and themes listed in the interview guide. It is not necessary to follow the interview guide precisely from beginning to end. One should invite the informant to talk freely about the topics as they come to mind, and return to those that were not touched at the end of the interview. In a qualitative study neither the research question nor the interview guide is fixed at the beginning of the data collection, as in a quantitative study. The researcher must reconsider the research questions and the interview guide during the interview process according to the new information gained through successive interviews. One must continuously consider if the informant gives information on topics that will be important to include in the following interviews. If so, the guide has to be revised. In this way one may say that interviewing, interpretation and analysis are carried out as a circular process. That is, the researcher must analyse the meaning of the phenomenon, as communicated from the informants to the researcher, according to a. more or less explicit, theoretical model. The intention of this process is to develop a fuller understanding of the phenomenon and to enlighten or revise the model. A qualitative design may involve different degrees of involvement from the researcher as well as from the informants ranging from telephone interviews to fieldwork interviews. The researcher has to decide whether to choose a participatory or non-participatory approach. The different approaches will give different types of data, as the actors will respond to the researcher in different ways. The different techniques in collecting qualitative information can be used either alone or in combinations: - Individual interview - a conversation between the researcher and one informant that is more or less spontaneous or may be more or less structured by a guide consisting of key words. It is not advisable to write out the whole question since this tends to put a strain on the

conversation and may easily turn it into a questionnaire interview. - Group interview - a conversation with several informants grouped together, where the conversation between the informants often has informative value on its own. The group may be planned (for example as a focus group interview) or spontaneous. - Observation - the researcher does not ask questions but observes what is happening and listens to the conversation between the actors. Because the interaction between the researcher and the informants is important in a qualitative approach, one must take into consideration the researcher's personal qualifications. Interviewing should be done as much as possible by the researcher him/herself (with the help of a field assistant/translator when necessary). Access to the field depends on gaining confidence, as well as working through 'door openers'. Dependent on the purpose of the study, the topics in question and different cultural settings, there are different characteristics of the potential informants one ought to consider:

- *Ethnicity*
- *Language skills*
- Education - *Gender*
- If the interviewer should be *disabled* or not
- *Age*

These are examples of characteristics that will influence the communication between the interviewer and the informant, and thus the information given, - sometimes even hinder access to important information. If the researcher and the informant are very far apart, for example regarding age or culture, it may influence the possibility to gain confidence, and get the informant to open up and be informative.

Ethical considerations
There are several ethical considerations in framing the research questions and implementing the study that should be taken into consideration: - Who will benefit from the study: Will the study mainly be of interest to the scientific community, to the authorities, or will it lead to improvement of the informants' situation in any way? - Will the study lead to unforeseen consequences for the informants? The following are the most important ethical considerations in approaching the informants:

- *Informed consent*: The study must be introduced to the informants beforehand, preferably in a written letter. The letter must include information on the study's purpose and objectives, who is the initiator, how the results are going to be used, who will benefit from the study. The informants must give their acceptance to participate either written or orally. They must be informed about the right to be anonymous and the right to choose not to answer or talk about particular subjects. They must also be informed that they have the right to withdraw at any time.

- *Respect:* The study must take into considerations the informants demand for integrity and dignity. Under no circumstance should the informant be forced or persuaded to participate or to answer questions. In this matter the study must be sensitive to different cultural standards. Ethical considerations to consider in disseminating and applying results are:

- The possibility that others can *misuse and/or misinterpret* the results.
- Informants often wish to know *who will benefit* from the study, what the results will be and so forth. In principle the informants should have the possibility to see the results of the study, even though this in many circumstances is difficult to fulfil. If it is practically possible, one should communicate the results directly back to the informants, either written or orally. If this is not possible, one should inform the informants where and how they may be able to get access to the results.

- The interview may trigger emotional reactions that are difficult to cope with for the informant when the interview is finished and he/she is left alone. Who will then give support?
- There is often a risk of *creating unfulfilled expectations* when interviewing people about their daily lives. Therefore, information on the limitations of the study must be very clear.

Involvement and the role of disabled people in designing and/or conducting the study
In every research project one has to consider the qualifications of the participants. Being a person with a disability does not in itself qualify for conducting a research study on disability, as research demands formal qualifications. But persons with disabilities have a particular insight into living with a disability; therefore their contribution to research on disability issues is of particular importance. Participation will be of importance in developing relevant research questions, identifying informants, in the data collection and discussions connected to the analyses. However, one has to consider the risk of political or ideological bias in framing the research questions. Furthermore, one must consider that persons with disabilities represent a complex group where a person with one type of disability not necessarily is in the right position to represent another. Also representatives of organisations of people with disabilities, often being elite members of society, are not necessarily well informed about the life situation of their own poor grass-root members. UN Convention on the Rights of Persons with Disabilities state the equal rights in participation in political and social activities on all levels for persons with disabilities. Involving people with disabilities in the research process is comprehended as a question of empowering disabled people (being in a learning process and in a decision making position); of framing good research questions and developing a good design and of ensuring that the results are communicated to and will be of use to the people that the research concerns. It may be fruitful to engage people with disabilities in the data collection, on the condition that they receive proper training. Their presence might de-sensitize the respondents when it comes to admitting limitations, as well as allowing for follow-up questions that require elaboration.

Sampling
In qualitative studies the type and size of the sample will usually be based on existing knowledge of the research topic and knowledge of the place where one wishes to collect information. The size of the sample is often difficult to assess at the onset of the study, varying from very few to maybe about fifty or more. Very often one must reconsider both the number and the types of informants during the data collection depending on the information gained in the interviews. In qualitative studies the sampling is strategic. That is, it is important to pick informants that are most likely to have much information to share on the topics in question and represent a wide variety of life situations as possible. (Miles and Huberman 1993, Kvale 1997) It is important to pick informants with different experiences regarding the research topic. For instance, when investigating disability issues one should consider the importance of gender, age, type of disability, family situation, social and cultural setting. The sample should reflect these different variables. The importance of each individual informant will be different and dependent on their position and their experiences in relation to the research question. Some informants will end up being key-informants while others merely illustrate the points raised by others. One should consider ending the data collection when there seems to be little new information to obtain. The 'saturation point' when it comes to the size of the sample is decided by the content of the information in relation to the research question, not by the number of informants. Because there is no principal rule regarding the size of the sample and the type of sampling, it is necessary to describe fully, explain and justify, the sampling procedures and decisions, and , discuss strengths and weaknesses of the sampling procedures and the sample.

The Interview guide

The degree of formalisation or structure of the interview guide depends on the aim of the study and the elaboration of the research questions. (Miles and Huberman 1994, Ryen 2002) Qualitative interviews are often labelled as a conversation with a purpose. Flexibility is a key word. It is not uncommon to open the data collection by doing one or two interviews based on general formulated topics. The interview guide will then be elaborated on the basis of the information gained in these interviews.

Strictly following the interview guide may restrict the interaction and communication between the interviewer and the informant. Too much structure in the interview process may mislead the researcher and prevent him/her from discovering new and unforeseen information. However, too little structure may lead to collecting irrelevant information, or risking that important questions are not asked. Most common is a semi-structured interview guide, including the main questions, themes and topics, but without specifying the questions or the sequence of questions. It is a great advantage to learn the interview guide by heart, because reading from a paper does not create a relaxed situation. On the other hand it is useful to browse through the guide at the end of the interview together with the informant, to secure that all relevant topics have been touched upon. If one wishes to compare data across studies, some structure is necessary. If a structured design is preferred one should consider splitting the study in two parts: first a qualitative study with an open, unstructured design involving a few informants, followed by a quantitative part with a questionnaire involving a higher number of informants.

Practical preparations

Getting access to the field and the informants requires many practical preparations. Local involvement and local anchoring is crucial in a qualitative study. Trust, confidence and credibility are fundamental. Therefore, one needs to be introduced to the field and the informants. Some places are not accessible without authorization from the authorities. It is also necessary and wise to pay a visit to the village head/village administration and introduce oneself and the purpose of the study. It may sometimes be difficult to calculate how much time one needs to get the necessary information. An interview will usually last between one and two hours, more if it is a group interview. In addition one has to calculate the necessary time for travelling and for courtesy calls on each location. Doing fieldwork requires a lot of practical details that must be considered, and if they are neglected this may complicate or even stop the fieldwork. The following are some examples of practical details: ensure that all the necessary permissions are acquired in advance for instance when going to places with travelling restrictions; often one will not have access to the field unless approved - and accompanied - by the authorities; remember to fill up the car with petrol; check if a driver and/or a local guide is necessary; check that all necessary equipment as paper, pens, tape recorder, batteries, map, money is in place; one must dress in a way that will not conflict with local codes; ensure that all the necessary vaccinations and medications are taken care of. When going to a remote area it may be wise to bring water and food, as well as checking the possibilities of booking lodging. In some countries, one is expected to pay honorarium if a person assists throughout the day. This must be agreed upon in advance. In some places, one is expected to pay the informants honorarium as well. Remember that many of the informants are unemployed, or looking for day-work. The consequence of time spent with the interviewer is a day without an income. Public employees participating in the planning and preparation usually do this as a part of their job, and should therefore not be paid a compensation even if they may claim it.

Opening the interview
The opening of the interview situation is vital, and will determine the quality of the information. The interviewer must introduce him/herself and the aim of the study. Then he/she should give information about the principles of anonymity, voluntary participation and the right to withdraw at any time during the interview. The opening is a 'warming-up process' where there should be room for 'small-talk' about everyday subjects, finding topics in which the informant is interested. It is vital to let the informant set the topic and the pace. At the end of the interview one must be careful to communicate thankfulness for both the time spent and the information given. (Holstein and Gubrium 1997) When drawing up/formulating questions, one should be careful to ask for the informant's opinion. Ask the informant to talk freely about the suggested topics. Ask the informant to illustrate by giving examples. Be careful not to ask leading questions where the 'right' answer is implicit in the question. Do not interrupt the informant. Note what the informant actually says, do not interpret. Do not moralize or argue with the informant. Do not refuse or deny statements. Do not ridicule something the informant says. (Fontana and Frey 1994)

Registering findings
Decide which techniques will be used to record and preserve the data before the fieldwork starts. This may be notes, tapes, videos, or a combination of several techniques. Very often 'low technology' gives the most relaxed atmosphere as tape recorders and video cameras may have a restrictive influence on some informants. Start the interview with noting date, time, and place of the interview. Very often personal characteristics of the informant as gender, age etc. is noted at the closure of the interview, if it is not noted during the interview as a natural part of the conversation. Start talking about something which is important for the informant, and which is related to the reason you have given for coming, for example ask him/her to tell the story about how she/he was impaired. The internal validity and relevance of the data is taken care of by trying to identify as much different information regarding the research question as possible. It is useful to ask several questions on the same topic or the same question in different ways. The questions and choice of terms and phrases must be accommodated to the informant. Important to consider in this regard is culture, age and level of education. Getting the 'wrong' answer must not be taken as a problem. In a qualitative study there are no right or wrong answers. Quite the contrary, unexpected answers or statements must be look upon as new and interesting information that must be considered. When comparing information from different informants, one must look for answers that complement each other. Do not expect to remember all that is said in the interview. Therefore, take short notes continually during the interview or use a tape recorder. If two persons are interviewing together, one person can ask questions – do the talking – while the other makes notes. It can be useful to exchange roles during the interview or from one interview to another. Transcribing the raw material after each interview gives the opportunity to reconsider the design, which questions to ask in the next interview, and to secure that the interview included all relevant topics. If a tape recorder is used, transcribe the interview as accurately and detailed as possible. As there is a difference between the oral and the written language, make sure that the text expresses the meaning of the informant's statements. If you are making written notes, elaborate the notes as immediately as possible after the interview, but do not interpret at this stage.

Analyses
The analytical approach that was used as a basis for the research questions and the formulation of interview guide is often revised in the analyses of the interview data. (Silverman 2001) Go through the transcriptions and try to find the concepts and explanations

that are most often used by the informants. What are the main issues they try to convey? Systematise the data according to the key concepts used by the informants, and the main points in your interview guide. Use a qualitative data program if necessary (for instance NUDIST6 or Ethnographer) but remember that this only helps you to systematise your data. You must do the analysis by yourself by using yourself and your analytical knowledge as the analytical tool. The most important way to analyse qualitative data is to build on existing theories and literature references. The empirical findings and theoretical considerations will then have a feedback effect on existing knowledge and theories in the particular field, thus creating a hermeneutic circle. There are however other schools of thought concerning qualitative analyses such as Grounded theories which emphasises the importance of starting without theoretical preconceptions and letting the theories 'grow' out of the empirical data.

Reporting
The question of how the results are going to be reported and what type of report one is going to make must be decided in the planning process. One must consider practical implications connected to reporting and what type of report one is going to make: whether the report is going to be written or oral, scientific or popular, or maybe a short note. One should also discuss to what extent one as a researcher may have influenced the data given and the interpretation. Cases should be used to illustrate the analyses, either short ones in the text or longer ones at the end of the report. Cases must be anonymous as much as possible without altering the important points in relation to the analysis. There are ethical considerations connected to reporting as well, as described in 3.2. Of particular importance is the informants' right to be anonymous and not to be confronted with the results or the report in any way afterwards. One should make an effort to communicate the results to the informants.