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# SINTEF REPORT

TITLE

## Using qualitative methods in studying the link between disability and poverty

### Developing a methodology and pilot testing in Kenya

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ABSTRACT

The report introduces a methodology for qualitative studies on disability and poverty.

The purpose of the methodological approach is to uncover the mechanisms by which various types of impairments interact with barriers in the environment, to limit or influence the economic and social life of people with disabilities and members of their households.

The pilot study was carried out in Kenya, and shows that the methodological tool is well suited to this type of studies.

KEYWORDS	ENGLISH	NORWEGIAN
GROUP 1	Health	Helse
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## **1 The task**

SINTEF Health Research in collaboration with the Department of General Practise and Community Medicine, University of Oslo is engaged to present a methodology for a qualitative study of the relationship between impairments and poverty. The purpose of the methodological approach will be to uncover the mechanisms by which various types of impairments interact with barriers in the environment, to limit or influence the economic and social life of disabled people and members of their households. This methodology will be a template that can be adapted to various contexts.

## **2 Disability and poverty - a qualitative study**

### **2.1 Concepts and perspectives**

When designing a research approach (on disability and other topics) one has to clarify the conceptual basis for the study, because the conceptual basis will direct what kind of data and information one is looking for and how the information is interpreted. Without a conceptual model there is a risk of collecting a lot of irrelevant data and it will be difficult to develop new insights and knowledge on the basis of the data.

In recent years the concept of disability has undergone a number of changes and modifications, and so has the concept of poverty. We will give a brief description of the conceptual basis for a study on disability and poverty, but for a deeper understanding of the conceptual basis, we refer to the literature given in the reference list.

#### **The concept of Disability**

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 integration, focusing on limitations in activities and social participation. We will give a very brief presentation of two alternative concepts of disability: One focuses on the interaction between the individual and the environment. The other focuses on the social barriers that exclude people with certain bodily and/or mental impairments from participation.

A widely used model of disability is WHO's Classification of Functioning, Disability and Health: ICF - The Model of Functioning (<http://www.who.int/en/>). According to the 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, mental or intellectual reduced function. Within this model, understanding disability is to understand the individual and the social consequences of the impairment. The interaction between the individual and his/her environment is in focus, taking physical, personal, social and environmental aspects into consideration. Thus, to understand disability it is necessary to focus on the individual as well as on the family and the social group within which the individual co-exists. One has to understand how the individual and the family functions and copes within their particular social and cultural setting. Within the Model of Functioning both the individual and the environment is focused. To understand disability within

this model, one has to look for elements in the individual as well as in the environment within which the individual lives.

An alternative to ICF is a right-based model of disability, the Model of Social Barriers, as argued by Oliver (1993) and Yeo and Moore (2003), among others. This model focuses on the society's exclusion mechanisms against people with impairments. Within this model disability arises because the society represses or excludes members with or without certain bodily, sensory, mental or intellectual qualifications: 'Disability is a loss or limitation of the opportunities to take part in the everyday life of the community on an equal level with others due to physical and social barriers'. Within this model the need for social changes is in focus.

None of these conceptions of disability takes into consideration the dimension of culture. For example, the ICF-model is designed to be cultural neutral, to be applicable in cross-cultural connections. The question is whether such neutrality is possible or whether it makes the model too general. The perception of 'normality' and 'disability' has a cultural dimension. The personal, practical and social consequences of impairment will differ depending on many factors. Examples are: 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 conception of for example congenital blindness versus accidental blindness acquired later in life will vary according to different cultural circumstances.

### **Poverty**

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 perspective on poverty has developed from a focus on economy and material welfare in a narrow sense, to include human capabilities and how individuals utilize their capabilities. The World Bank Report *Attacking Poverty* (2000) focuses on opportunity, empowerment and security as fundamental 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 concerns many aspects in the individual's life: Lack of income; lack of basic needs such as food, clothing, housing, health; lack of education; lack of capability - seen as the opportunity to achieve some minimally acceptable levels of basic functioning; lack of opportunity to participate and/or decide in communal and political matters. That is, poverty arises when the individual is deprived of the opportunity to lead a healthy life, has no or little access to health services, does not have access to education, does not enjoy a decent standard of living, is not able to participate in elections and communal organs and/or lacks respect and self respect.

Connecting poverty to deprivation involves comparing living conditions to a defined standard or way of living. It is necessary to consider both global standards (for instance standard set by UN: 'people surviving on less than one US dollar a day') and local standards held by the individual's community and society. In doing this one has to consider the dimensions of:

- Income/subsistence and material welfare
- Consumption
- Housing
- Health and access to health services
- Education
- Participation in organisational and political matters
- The experience of respect and self respect
- Human capabilities and the ability to utilize the capabilities

- Participation in leisure and community activities

### **The relationship between disability and poverty**

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). Even though disability does not necessarily cause poverty, and poverty does not necessarily cause disability, the relationship is considered to be 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, still there is sufficient knowledge to conclude that people with disabilities are at risk of being and remaining among the poorest.

At the individual level, the relationship depends on the social and economical circumstances under which the individual is living. Among the most prevailing exclusion mechanisms are exclusion from education and employment; 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 to the impairment. (Elwan 1999, Yeo and Moore 2003) Environmental conditions connected to poverty and causing disability are: 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.

Lack of bodily and/or mental functioning is likely to deprive the individual from access to income and subsistence, education and social participation. In this way, people that have impairment are hindered in obtaining a good living standard, or can be deprived of an already achieved standard of living as well.

The bi-directional connection between disability and poverty trap people in a 'vicious circle' where miserable 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.

## 3 Doing a qualitative study

### 3.1 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. This paper is concentrated on qualitative methodology. 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. For a deeper understanding of the methodology we refer to the literature.

There are several reasons for choosing a qualitative design. 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 study 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. 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. 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.

## 3.2 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.

### **3.3 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.

### **3.4 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.

### **3.5 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.

### **3.6 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.

## **4 Carrying out the data collection**

### **4.1 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)

### **4.2 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.

### **4.3 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.

### **4.4 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.

## **5 Relevant Topics in a study on disability and poverty**

Chapter five presents an interview guide comprising 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.

### **5.1 Interview with persons with disabilities and their families**

This interview guide includes 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 on 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
  - Participation 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. 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 adjustments made to minimize the practical consequences of the disability (technical devices and practical arrangements at work, in school, at home), and the efforts made in connection with these adjustments.
- 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 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 regarding: 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? How does he/she think the living situation will be in approximately ten years from now? What is his/her chances of achieving these 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 to the fact that he/she is disabled.
  - Ask if he/she knows or gets 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?
  - Are there enough persons in the household to care for the disabled member and to support the family? Do family members have to quit a job or not work in the field because of the need to care for the person with a disability?
  - Concerning housing: is their accommodation similar/worse/better than the other community members' accommodations?
  - What is the informant's opinion about the family's social ranking/class?
  - How does the disability affect 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 by noting personalia may under some circumstances be interpreted as an

inquiry, which for some gives associations to very unpleasant experiences or can even be frightening.

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

## **5.2 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 following:

- 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 of these offices often possess general information on the situation for people with disabilities in the area. Examples of 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.

## **5.3 Supporting - information**

As a supplement to the interviews one should always look for information that can deepen the information from the interviews:

- Look/ask for access to or adjustments of public places and buildings such as schools, hospitals and health services centres, post offices and banks, shopping centres, municipal buildings and the city hall, office buildings, and transportation facilities such as busses and trains.
- Look /ask for access to or adjustments 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.

## **6 Results from the field testing of the qualitative design, Kenya, May - June 2005**

### **6.1 Kenya**

Kenya is placed in eastern Africa with a coastline to the Indian Ocean, bordering Ethiopia in the north, Uganda in the west and Tanzania in the south. With a population of 32 million people, it consists of more than 40 ethnic groups, speaking about 45 different languages. Main languages are Kiswahili and English. The climate offers great contrasts due to variations in the height above sea level and terrain. The land stretches from the Indian Ocean in the east, to the snow-capped Mount Kenya with a peak of 5199 meters above sea level.

Kenya is ranged as having the potential to be among the richest countries in Africa. In spite of this, the difference in living condition is extremely high. The number of poor in Kenya increased from 52 per cent in 1997 to 56 per cent in 2002 (UNDP 2003). Pastoralism is the main land use activity. Much of the good farmland is however owned by rich landowners or large private companies, while poor peasants live along the steep mountainsides. Among the poorest are people living in Nairobi's informal settlements (the slums). The slums are estimated to house more than 50 % of Nairobi's citizens, who are living under extremely bad conditions. Jobs, proper housing and affordable water supplies are among the most important general needs in addition to toilets, proper drainage and health services. Compared to other areas in Kenya, including the rural areas, slum residents have worse health and reproductive health conditions. The school enrolment rate in the slum is lower, children have less access to health care and immunization, and the morbidity rate for all major childhood illnesses is higher (fever, cough, diarrhea) compared to the rest of Kenya. (Amuyunzu-Nyamongo and Ezeh 2004, Amuyunzu-Nyamongo and Taffa 2004). It is estimated that more than 50000 children are living in the streets of Nairobi and the number is increasing by 10 % each year (Amnesty International, Norway 2004).

Sanitation and access to clean drinking water is a widespread problem in many parts of the country, as well as access to health services. Malaria is a serious problem in many areas, except in the highlands around Nairobi. Untreated cerebral malaria can lead to brain damage. It is estimated that twice as many die from malaria in Africa than from HIV/AIDS. HIV/AIDS is widespread, estimated at 13.5 per cent in 1998, with more than one million orphans. (Norwegian Ministry of Foreign Affairs, August 2004)

The road quality is very bad in most areas and suffers under lack of maintenance. This leads to transportation difficulties. As for education, primary school is free, except for the costs of school uniforms. There are special schools for blind and deaf children, as well as children with mental disabilities, mostly boarding schools.

No national survey on disability has been conducted in Kenya, so the prevalence is not clear. In 1989 the Central bureau of Statistics estimated the prevalence of disability to be 0.7 %. Surveys on prevalence of disability in some countries in Southern Africa (Zimbabwe, Malawi and Namibia) estimated the disability rate to be between 2 and 5 per cent. The prevalence is likely to be the same in Kenya.

## **6.2 The cases**

All in all 42 interviews and conversations that gave relevant information were carried out:

- 11 interviews gave secondary information
- 4 interviews were group interviews
- 27 interviews were individual interviews

The schedule for the fieldwork was set by the facilitators in the various districts, according to the guidelines made by us. There was no possibility to interfere in the schedule.

### **6.2.1 The first day of the field work**

#### **A visit at special unit for autistic children at City Primary school, Nairobi**

The day started with a group interview with the manager of the special unit and three parents of children at the unit.

The unit was established in 2003, is run and financed by the parents and receives no public support or funding from NGOs. The unit practise a certain diet which is expected to reduce the negative consequences of autism. According to the parents the diet is effective as it reduces the hyperactivity and allows the child to concentrate. We are informed that the diet is very close to traditional diets, and should be affordable for most people. Some of the parents feel that the diet is expensive. The oldest children are trained to follow the diet themselves. It is however a challenge to keep the children from all 'forbidden' foods. In addition to the diet, the children receive training in activities of daily living (ADL). Up to now the parents have managed to finance occupational therapy and employ teachers with special competence in mental disability.

The parents visit other families with autistic children and pass on information about autism and the diet, but they are only able to assist a few. They encourage parents outside Nairobi to build similar units. Very few parents are able to pay the school fees or to practise the diet properly, so some parents have been forced to take their children out of the unit. Since the mental disability makes the children vulnerable in unpredictable social situations, it is difficult to use public transportation. Therefore the parents have to bring the child to the unit themselves.

The parents do not know if there is any public policy for persons with disabilities in general in Kenya, but they do not believe there is (later on we found out that it actually was a disability act recently passed through parliament). Knowledge about autism is particularly low. There is no special education for people working with autistic children - only education about mental retardation in general. The parents recon themselves to be best qualified in these topics in Kenya. They have collected information and knowledge on autism by using the internet, and reading articles and books. Contact with a university hospital in California is mentioned as very important source of knowledge.

The parents say that the main problems with mental disability lie with the negative attitudes and myths of the traditional culture. If a woman gives birth to a disabled child she is very often the one blamed. It is quite common that the father leaves the mother when a disabled child is born. It is said that some people think the disability comes from a curse. Everyone who has a child with a disability is dependent on support from the family, but the parents, and mostly the mothers, are mostly left alone with the responsibility for the child.

The family's income will always decrease when they have a child with a disability. This is because someone has to stay at home to look after the child. In addition, hospitals, doctors and medicines are quite expensive. Some families become very poor because of this. Some parents tie

up their child in order to protect it from getting into accidents. The reason for this is the hyperactivity.

The parents stress the importance of understanding that the fundamental needs of every person is to have enough to eat and to have clothes. The need for education is secondary to these needs. People who lack food and clothes do not prioritise schools for their children, especially not children with disabilities. This is the result of poverty.

The parents worry especially about their children's future. They do not know who will take care of the disabled child when the parents grow old or are not longer there. Young persons with autism are very vulnerable and need continuous protection. They are often taken advantage of and abused by adults - both men and women. This is a big problem for both girls and boys.

A father of a boy said he understood that something was wrong with the child very early on. The child did not communicate in the way the parents expected. The father decided to remain with his wife and to be a role model for other fathers of children with disabilities. He explains this decision by being a Christian and a priest. The income of the family has decreased because the mother has had to stay at home and take care of the child, and it is very difficult for them to manage economically. Knowledge on autism hardly exists among people, and they always have to explain why the child behave the way it does when they are together with others. People misunderstand, and think that the child is spoiled.

Another father relates that the delivery was difficult and the hospital far away so it took a long time before the child came under medical care. The autism was discovered at the age of three. They had been looking for a special school for the child, but it has been an impossible task. The child was not able to settle in any school and no one had any knowledge regarding his particular situation. After the child was admitted to the special unit, his situation improved. One big problem is the cost of the school. It is very expensive and the family struggle to afford the fees. He has not given many thoughts to why this happened to him and his family, but they have received many negative comments from friends and relatives. Other people withdraw from them because of the child's behaviour, and they are sometimes accused of being bad parents. Their family life has changed totally, but they have managed to stay together as husband and wife, although they have lost friends. He explains that it is common that the father leaves the mother or demands that the child be hidden. They are educated people who seek knowledge and are not superstitious when it comes to explaining the child's condition.

### **Comments on disability and poverty**

The interview above was not with the target group, which are poor people with disabilities. This unit is very expensive and thus only accessible to parents who are able to pay school fees. Parents who are unable to pay have had to take their children out of the school, without any other alternative education. The unit suffers from lack of knowledge and competence on autism, and some of the children we saw clearly had Cerebral Palsy and thus not likely to be helped by a diet. But even these children profit from the structure and stimulation they receive.

Even if these families were not poor, their economy was put under strain because of the child's condition and the costs of the treatment. All parents worried about the child's future. Everyone told similar stories about how friends and family had withdrawn from them because of the disabled child. This made the family isolated and vulnerable.

### **Comments on qualitative methodology**

This turned out to be a spontaneous group interview followed by some individual interviews. We did not know in advance how the meeting was planned. Since this was the first day of the

fieldwork we were interested in collecting as much information as possible from the people we met. This would give us the opportunity to formulate and reformulate the questions during the following days. This interview situation exemplifies that one never knows exactly beforehand how the qualitative interview situation will be. We did not meet the target group - the very poor - but the persons we met gave useful information on how difficult it is to manage in a developing country even for people with some financial resources.

We chose to define the first situation as a group interview and thus utilised the information given to us. The group interview gave the possibility for individual interviews afterwards, and an opportunity to follow up the topics that were mentioned in the group interview. The group interview turned out to be time saving, as the individual interviews could focus on the particular child. Because of the information given by the group some topics in the interview guide had already been eliminated and were of lesser importance in the individual interviews. Since these parents regularly visited and guided other families, who were in a less fortunate situation than themselves, they were able to give us some information on the situation for families with scarce economical resources.

### **Interview with a deaf man**

The interview was facilitated by a sign interpreter. The interview with the man was followed by an interview with the father.

The man is born deaf as the second of four siblings. He is about 30 years old. All the others in the family are hearing. His family is well situated economically. For three years he was at a day-care centre together with hearing children. At the age of six he went to a boarding school for deaf children. As a little boy he had hearing friends who were nice to him. Others, though, could mock him and make fun of him, especially when he was using sign language. He was taught the official sign language at the boarding school, which he taught to his mother and siblings. Today they are communicating quite well.

The school recommended him to be a carpenter. This is a common advice to deaf people. He, however, wanted to train in computer science. He completed secondary in a mainstream school, but had to use one more year due to lack of adaptations to his particular disability. This resulted in poor marks. After secondary he was accepted at a college in England. The college was very expensive because the family had to finance a sign interpreter and a note taker to assist him. His father asked his sibling if they would permit him to use some of the family fortune to support his education. The siblings accepted, as all of them were granted the opportunity to study abroad (Australia and USA).

At secondary and college he felt lonely. He had to work harder than the other students to keep up. His father had to have meetings with the head master and the teachers in secondary school to make them pay attention to his particular handicap.

He has completed an education in computer technology but has not succeeded in getting a job, in spite of applying for five months. He believes this is because of the deafness. For a short time he had a job in a telephone company and managed quite well. He communicated with his colleagues by writing on a piece of paper, but he did not have to communicate much with others to do the job tasks. His qualifications were appreciated. He had to leave because his department was closed.

Most of his deaf friends from primary school have not been able to find a job. Only a few friends managed to complete secondary school. Job and education for deaf people is a big problem. Those of his friends that have an education have been taught carpentry. They do not receive any kind of support in getting jobs, in spite of the fact that many of them are quite skilled. Most of them stay at home, maybe having occasional jobs. The biggest problem as he sees it is the bad quality of the special education. Many do not pass the tests and do not manage to complete higher education.

Teachers in regular schools do not master sign language, and sign interpreters are expensive to hire.

He says that deaf children growing up in families without a solid economy face a difficult life. They do not get education above primary school, and therefore no job and income. He has also seen that attitudes of the parents may hinder the child in getting an education. Many parents give up. They do not see a proper future for the deaf child. It was quite a few parents that did not visit their children at boarding school. The head master some times demanded that the parents come for the children, and sometimes drove the children to the parents himself. He knows that some parents do not send their deaf child to school at all. They do not know about the special schools or they do not pay any attention to it. It is a common attitude that one does not spend money on deaf children.

Modern technology has made it possible for deaf people - those who have economy to get access - to communicate by internet and mobile phones (text). This has even made it easy to communicate with hearing persons. However, this increases the difference between people with economical resources and those without.

At the moment he tries to get a job, reading and answering advertisements. He uses his father's professional network in job seeking. In spite of this he has not succeeded in getting a job yet, in spite of his qualifications. His explanation for this is that he is deaf. People have preconceptions on disabilities, which he notices all the time. People believe that he is totally unable to communicate. The biggest challenge is to convince hearing people that this is not the case.

He sometimes gets depressed because of the situation, thinking 'why should this happen to me?' This is especially when he notices other people's prejudice; when people feel sorry for him being deaf or when people avoid him. His family has always supported him, sometimes even being overprotective. In spite of this he feels alone when the others in the family are chatting without taking the time to involve him.

### **Interview with the father of the deaf man**

The parents discovered the child's deafness at an early age. The father was shocked when the doctor informed them on the deafness. No one in the family has ever been disabled. Since the fact was explained to him by the doctor, he never bothered to think about what caused it or why this would happen to them. This was an act of God and the parents look upon it as a mission. The parents agreed to see to it that the son got a good life and succeeded in whatever he was doing.

The father is head of an organisation of parents of children with hearing impairment in Kenya. He thinks that the greatest challenge such a child faces is whether or not the parents are willing to use money to the benefit of a disabled child. His wants his son to be a role model for others. Therefore it is important that he succeeds when it comes to education and getting a proper job. It has been difficult to give him a good education. There has never been much information on possibilities and opportunities. They have had to strive to find a proper school. The father says that he has been working real hard to support his son. When he applied to secondary school the son was denied at first because of the deafness. The father made a complaint to the Ministry, and this gave a positive result.

At college in England they had to pay extra for assistance from a sign interpreter and a note maker. There are no earmarked scholarships for children with disabilities when it comes to higher education. The father has spent a lot of money to support the son, and never received a penny from the Government. He has never had the opportunity to buy an expensive car or other expensive articles. He tells us that he is bitter, among other things because he has not really succeeded with the son as long as he is unemployed. He says 'pride is connected to having a job'.

### **Comments on disability and poverty**

Case 4 and 5 exemplify that a rich family can support the disabled child and secure its future, but even for a rich family this is not easy. They have had to work hard to secure the child's education, and the child had to work hard to succeed in school. In spite of their wealth, they have experienced resistance when they tried to find a good school for the child. This exemplifies the general fact that persons with disabilities do not have equal access to education and jobs. In spite of a wealthy family and a high education the young man has not yet been able to get a job. Case 4 and 5 exemplify further the necessity of private resources in a society where public resources and accommodations are absent. When a family member has a disability this has consequences for the whole family.

### **Comments on qualitative methodology**

In the cases 4 and 5 the informants did not belong to the target group. As planned we interviewed the young man with the disability first (without the father who volunteered to go out) followed by a short interview with his father (with the son present). In doing this we gained information on both the young man's and the family's situation from two points of view. This made us able to contrast two different experiences on the same incident. The young man's story about school friends that did not have the same opportunity, gave us information on the situation for deaf people with lesser economical resources than himself.

### **Visit at Kenya Association of Paraplegic**

It was arranged for us to meet the manager of the Association, who is an attorney by profession and a paraplegic, but he was absent. We met the vice manager who gave a brief summary of the organisation's activities.

The organisation was established in 2004. The main tasks are mobilizing, awareness building and service provision. The office is situated close to a rehabilitation centre for people with spinal cord injuries, which is the only state run rehabilitation centre for this group in Kenya. The centre serves three countries (Kenya, Uganda and Tanzania), offering short term rehabilitation. The clients are referred from hospitals. The Association do follow ups within two years after the first stay, and cooperate with the few local user organisations and local services that exist in offering training and supervision. The main problem is lack of public funding. All economical resources come from NGOs and private persons. They also lack facilities as buildings, training equipment, skilled personnel and medical services. The centre offers services to people with scarce economical resources. People that can afford to prefer to go abroad for rehabilitation.

We were informed that the death-rate among people with spinal cord injuries is high. Up to 70 % of the victims do not survive five years after the accident due to lack of medical care to prevent infections caused by pressure wounds and urinary tract infections. Suicide is also a common cause of death. Unemployment is a severe problem for people with spinal cord injuries. The few who have income run their own small scale businesses. Access to buildings and transportation is difficult, if not impossible, as buildings are not accommodated. Wheelchairs are difficult to operate in remote areas where the roads are in a bad condition and the terrain is difficult. Wheelchairs are expensive. Some are handed out by NGOs, but they are few compared to the needs.

### **Comments on disability and poverty**

The visit gave information on the rehabilitation situation for people with spinal cord injuries. Poor people have very few possibilities for medical services, few rehabilitation possibilities, low survival rate and low employment rate. People with a solid economy go abroad to get the necessary help. They as well suffer from the difficulties in getting jobs, which may put them in an economically bad condition.

### **Comments on qualitative methodology**

This visit is an example on an interview that did not go as planned, but which still gave interesting information. The visit was however a 'door-opener' for the next two interviews: case 6 and 7. These interviews were not on the agenda, but happened spontaneously.

### **Interview with two persons with spinal cord injury using wheelchair**

We noticed a woman and a man sitting in wheelchairs outside the building at the rehabilitation centre. We went up to them, introduced ourselves and asked if we could interview them. They agreed.

The woman had a good job in a bank when she had an accident and got injured. She is aware of being exceptional in that she was welcomed back to her job by her employer after the accident. Her colleagues were cooperative and accepted her new situation. However, the building where she worked was not accommodated to her new condition. She stayed in the job for two years after the accident and ended it because she wanted to try something else. Now she is running her own business as a consultant. Economically she is able to have her own car with a driver. She also volunteers as a support person for new patients at the centre. She is active in capacity building and awareness building activities, and has friends that are both disabled and not disabled.

Her main problem, she says, is other people's negative attitudes towards persons with disabilities and their low expectations of them. Peoples negative attitudes comes from the traditional believe that disability is a curse. Most people loose their job because disability is connected to a negative stigma. Others consider them as people that do not cope, that people with disabilities are dumb, stupid and poor beggars.

She faces practical problems especially when she is visiting her family in the countryside, where she has a house of her own as well. Due the bad condition of the local roads and the sandy terrain she is not able to move from the main road to the house or to move around in the neighbourhood with the wheel chair, but has to be carried.

The man suffered a spinal cord injury from an accident at work. He had manual work, and lost his job because of the disability. He could easily do other types of tasks in the same firm in spite of his disability, if given the opportunity. But he was told by his boss that it was against the policy of the firm to employ people with disabilities. Accidents at work places happen all the time and most people who become disabled have manual jobs. That is why it is difficult to get a new job.

He is married and has two children who have been born after the accident. He needs help from his wife to do daily activities. The wife quit her job to help him. She earns some money by doing counselling. His children have never minded the fact that he is disabled. The economy of the family has worsened due to his accident. He does not receive any kind of pension or social security money. They can not afford a car, so moving around is difficult.

He has lost many of his friends because of the disability. They do not contact him and when he contacts them they are often too busy to see him. He is afraid of being a burden for his family as well. When visiting his family in the countryside his brother has to carry him around because of the sand. He finds this humiliating and is afraid to be a burden for his brother. However, he has

got new friends through the rehabilitation centre and the engagement in the disability movement. He is working hard not to pity himself, not to be depressed and to keep his family together. The disability challenges his male identity. He is no longer the person in the family that takes care of the other ones; he has become dependent on his wife. This is difficult for both him and the wife. A big problem in addition to the difficulty in moving around is other people's negative attitudes. The other day he went into a shop and was refused as a beggar even before he had presented his request. He definitely does not look as a beggar.

### **Comments on disability and poverty**

These two cases illustrate that life becomes difficult when a disability occurs. They do not exemplify the situation for the very poor, but gives good illustration on how disability puts a strain on the family life and economy. The man is an example on how personal identity is challenged when a disability occurs.

### **Comments on qualitative methodology**

The cases illustrate that a spontaneous interview can give important information. In qualitative research it is important to utilize every situation that may represent potential information. We intended to interview the manager of the Association, who was absent. Instead we had a short meeting with the assistant. After this meeting we had a short conversation with the managing occupational therapist, who informed us about rehabilitation and the living conditions for people with spinal cord injuries in general. We started to think that the visit was a waist of time when we spotted the two persons outside who were sitting talking to each other. We interrupted this conversation, introduced ourselves and our purpose of being in Kenya and asked if we could ask some questions. The interview situation became a conversation between the two of them together with the two researchers. The interview benefited from both of them commenting on what the other one said.

### **Visit to an education unit in computer technology**

We visited an educational unit in computer technology that is run by a young woman. She is married and has one child. She suffers from the consequences of polio in childhood. She was totally paralysed for six years, but has recovered to some extent. She is able to walk with support, but she does not walk well.

As a child her mother did not expect her to manage school and did not support her in the same way she did to her non-disabled younger sister. In spite of this she managed to finish school, but had to use four more years than her sister. Her church, a Baptist church, financed her secondary education as well as education in computer technology in Japan. Returning back from Japan she raised funds from the church and different NGOs to establish an educational centre in computer technology for people with disabilities. This is her mission in life. She is busy lobbying the government and the ministries to get funds.

She educates approximately 25 students each month offering courses from one week up to six weeks. Her courses are cheaper than similar educations, still they are too expensive for many students. Many students must confine to one or maybe two weeks of schooling because they cannot afford to pay the fees. To stimulate integration many of the courses are offered to non-disabled students as well. By doing this she hopes to convince non-disabled students that people with disabilities are fully capable of doing the same job.

Her church - both in Kenya and in Japan - sponsors some of the activities and equipment. They have also received some support from the Finnish embassy. The vice president's office has donated money to pay school fees for some of the students.

The school offers services to companies with computer systems to repair and update the systems. When they get a request she always sends one of the disabled students. By doing this she hopes to convince the companies that a disabled system operator is as skilled as a non-disabled one, and the students have the opportunity to introduce themselves. In spite of this it is very difficult for students with disabilities to get a job.

It is a challenge to find accessible localities. Earlier they were situated outside the city centre because of the lower rent. But located in a suburb they were inaccessible for many of the students, as all transportation goes into the centre. Now, when they are in the city centre, it is easier for the students to attend the courses. However the rent is too high so she is constantly looking for a better place. They have not succeeded in finding a place that is accessible to persons using a wheel chair.

The main problem for people with disabilities when it comes to employment is to convince others that they are qualified and able to work. Some people with disabilities lack confidence in themselves as well. There is a general lack of knowledge on the different kinds of possibilities, both by disabled and non-disabled. Information distribution is therefore very important. Awareness building and sensitisation is lacking on all levels. People living in the rural areas face the biggest problems because of lack of infrastructure. They are not able to move around. Because there are no public resources for people with disabilities, they have to rely solely on their family, private well-wishers or NGOs.

She was involved in the development of a national policy on disability. Earlier the same day we asked others (at the autistic unit) if it is a national policy in Kenya, and they were not aware that it existed.

### **Comments on disability and poverty**

This case illustrates the situation of a person with a mobility disability who has managed to complete education in spite of a family that did not encourage her. She managed to succeed because she got the necessary support from her church that both encouraged her and funded the education. The case illustrates that a person with a disability is dependent on support from others to fulfil his/her goals. If the family is without means, the person is dependent on a private founder, either an NGO or a private person. The interview confirmed once more that it is very difficult for people with disabilities to convince a potential employer of their ability to work and to get a job according to their skills.

### **Comments on qualitative methodology**

The interview situation was not optimal here. We were placed in a small room that was crowded and noisy, as it served as a classroom and the informant's office at the same time. Because of this we chose not to interview about her daily life, but concentrated on her experiences in getting an education and a job, as well as providing education and job to the people with disabilities attending the courses. The case is an example of the importance to grasp the situation 'as it is' and focusing on the aspects that enlighten the informant's most important experiences when it comes to the topics.

## **6.2.2 The second day of the field work**

### **Visit to Maragua district in Central Province**

#### **Meeting with the district officer of the social services and the deputy, who accompanied us the rest of the day**

Maragua district is situated in the mountains rising up to 3000 meters above sea level. In the lowlands mainly corn, beans and pineapples are grown, and in the highlands tea and coffee. Most of the land in the lowland is owned by Del Monte Pineapple Company. The terrain is steep and it is laborious to fetch water and firewood as well as cultivating the fields. Electricity is rare and only accessible for the few who can afford it, and lives nearby the electric lines. Water is mainly fetched from the rivers. The few that can afford it have hoppers or bore holes. Some have domestic animals, mainly goats and sheep but some cows as well. In spite of a fertile soil the area for grass cultivation is too small. Due to this the farmers collect forage along the road sides, which is laborious. Some tie their animals at the edge to fodder them there even if this is forbidden.

The district officer gave a short but accurate report on the status of the district, the situation for people with disabilities in general and the initiatives to improve their situation. There has been no attempt to estimate the prevalence of the different kinds of disabilities in the district. The district is divided into four local districts with 17 locations and 76 sub-locations. Except from the sub-locations each district and location has a district officer. There are some minor governmental funds for people with disabilities as well as some financial support for two public vocational training centres where one has to pay school fees. Except from this they are fully dependent on support from NGOs.

We are informed that most people with disabilities do not benefit from the assistance provided because of their poverty. In this area people live scattered, which leads to a need for transportation, especially for people with mobility impairments. Very few people have money to pay for transportation. Among other things this prevents disabled children from going to school.

We were informed that the main problem was considered to be that people with disabilities do not come forward with their needs, and that some are even hidden in their homes. Changing people's attitudes was considered to be important.

#### **Comments on disability and poverty**

The district social officer was sincerely engaged in disability matters, but he was limited by scarce public resources. Most of the activities are funded by NGOs. He did however not at any time complain about the lack of public funding. It is interesting to note that the informants very early introduced us to their beliefs on 'the hidden disabled'. They could however not state any specific examples to illustrate that this is a fact in the district.

#### **Comments on qualitative methodology**

It is necessary to establish contact with the relevant authorities on different levels before starting the field visit. This meeting is an example of a compulsory courtesy call that gave interesting information on living conditions for people with disabilities in this particular district as well as of the attitudes of public officers. The informant were well prepared, which is not always the case. The deputy accompanied us throughout the day, also introducing us to the meeting with the people and translating for those who did not understand English. Being accompanied by an

official officer is both beneficial and a draw back. This person can give access and 'open up many doors'. But may also influence what people are saying and the kind of information people choose to give. We had to use this person as an interpreter, but would have chosen another one not representing the authorities if this had been possible.

### **Meeting with a self-help group for people with disabilities**

After a long drive up in the mountains on roads in a very bad condition we entered a small public hall owned by YMCA. Waiting for us was a group of about 30 persons with disabilities and some of their family members, about 18 persons, who accompanied them so they could be able to attend the meeting. The group represented all ages - from little children to the elderly - and different kind of impairment. After a while a group of elderly men and the deputy chief also arrived.

The group of people with disabilities had established a self-help group in 1999. Initiator was the deputy chief (according to himself). Each contribute with 25 Kenya Shillings (0,3 US dollar) every month and assist each other in different kinds of activities depending on what the problem is. Examples are assistance in obtaining special shoes, crutches, wheel chairs. As an income generating project they make envelopes for sale to the bookstore. In addition they have established a revolving fund that can give loans to 10 % interest. We were told that there are people with disabilities in the area that cannot afford to join the group.

We were introduced by the district deputy social officer. We were not allowed to introduce ourselves at the opening of the meeting, but took the opportunity at the end of the meeting. Each and everyone introduced him/herself, except one deaf man who did not wish to be introduced at all. Another young deaf man had written down a presentation that was read aloud. His presentation ended in an appeal for economical help to be trained as a craftsman. We received several requests about contributions of money.

We asked them what kind of problems a person with a disability face at their place.

A short woman with a hunchback (probably TB of the spinal cord) stood up and said that the main problem was that the government overlook the problems they had in coping with daily activities and that they get too little information too late. She also felt neglected by the community; no one gave them jobs or helped them in for instance establishing businesses. It is difficult to move around because of steep hillsides and lack of transportation. In addition busses and building were not accommodated to wheelchairs. It is difficult to fetch water in the steep terrain and nobody was willing to assist them. They had no income and could not save money for schools and education for the children. They had no knowledge of the legal system so it was difficult to claim their rights. It was difficult to get a hawkers licence, so when trying to sell their crop or other products in towns they were harassed by the city council.

They do not have money to buy necessary medication. They are not discharged from the hospital if they lack money to pay for the treatment. Disabled children from poor families do not get scholarship for secondary school if the marks are not good enough. Scholarships are only for the poor and bright, not for those who are only poor.

Some claim that the fathers mistreat the mother if the child is disabled because the mother is the one to be blamed. Some fathers leave their family when a child with a disability is born. Some said that children with disabilities are kept inside the house hidden from the neighbours. They said that others look upon them as useless people who are unable to do anything useful.

They were invited to tell about situations where they had been stigmatised. One man told that he had been asked to remove himself from a shop because his presence destroyed the business. Others told that the husband had left when a disabled child was born. Others that the boy-friend did not want to marry when the disabled girl-friend got pregnant. Some told that the marriage was

hindered by the man's family who did not want a daughter in law with a disability. One woman said: 'I was bitter because I wanted to be somebody's wife'. One man with a bodily impairment told that he wanted to marry a woman with a disability. However, his parents made him to cancel, his mother asking "between the two of you, who will fetch water?" An elderly blind man had been married for many years, but was not a widower. The wife had been able-bodied. His clan had a meeting and tried to talk him out of getting married. He told when she was asked why she married a blind man she used to answer: "I did not come to eat his eyes but from his property". There is however some that has been married in spite of a protesting family in law.

At the end of the meeting one of the non-disabled listeners rose up and commented on the complaint from the people with disabilities on not getting any assistance: 'what are we going to give when there is no resources to spare.'

After the meeting we had a short conversation with the chief assistant. He said the community in general had positive attitudes on the disabled community members, but the main problem was the lack of public governmental resources.

After the group meeting, three persons were interviewed individually. We communicated in English and did not need an interpreter. We had already spent some time, therefore we interviewed on certain topics in the interview guide.

We interviewed an elderly blind man lost his sight from a disease when he was ten years old. He became blind because he was brought too late to the doctor. He attended a boarding school for the blind and was taught to be a switch board operator. He did however not succeed in getting a job. After some time without a job he was employed at a farm where he learned to grow flowers for sale. He has been working for many years on that farm weeding. His family was able to keep a cow and some hens. His clan did not approve his marriage, but they married in spite of this. His wife helped him a lot, but she died some years ago. He lives together with three sons who are all unemployed. He is retired with a small pension. He suffers from hypertension and needs medication. His daughter is very sick and he has to pay for her hospital bills and her medication. Due to this he has no money for his own medication.

We interviewed a mother with a mentally disabled and multi handicapped child who suffers from both physical and mental disability in addition to epilepsy. The mother says the reason for the child's disability probably is a difficult delivery or maybe that the father had severe malaria before the child was conceived. The father does not accept him and does not attend to him. The mother says that 'this is my child'. She is obviously very fond of him and cares for him. Her 22 years old daughter lives in the household as well, and shares the household duties with her so they manage the daily activities. The mother is not able to go where she wants or do what she wants because of the responsibility for the child. She has to stay at home to take care of the boy or bring him with her if she needs to go out. The neighbours do not mind the child. They bother neither in one way nor in the other.

We interviewed young woman with a deformed hand and a weakened arm and shoulder. Her impairment is caused by an accident as she fell into the fire as a little baby. She had a boy-friend and got pregnant. Her boy-friend was not permitted to marry her by his parents because of the deformed arm. He obeyed his parents and she has not seen him since the baby was born. Her grandmother looks after the child while she is at college studying to be a pre-school teacher. One of her many sisters pay the school fees. She has a small job in a pre-school but do not get paid because she is not graduated yet. Her only option was teaching, because she is not able to work in the fields in the same way as the others. She cannot dig and she is slow in picking tea leaves. Because of this she earns less money than the others. Except from this she can manage almost every daily activity by herself and do not feel that the deformed hand and weak arm prevents her from doing what she wants. Neither does it prevent her from taking care of the child.

A young deaf man had written a letter to explain his situation. His mother is alone with two children. She works in Nairobi. This is the main income for the whole family. He lives together with his grandmother and six small cousins. He went to a boarding school for deaf children and managed to complete an ordinary secondary school. He did not get any job after finishing school. He would very much like to be trained as a craftsman but has so far not been able to find sponsorship.

On returning to Nairobi after the meeting we visited his home. Twelve persons live in a tiny house built out of clay or soil with roof of corrugated iron. The house is placed directly on the ground. The house lies in a steep hillside and in periods of heavy rainfalls all the houses in the area are at risk of being swept into the river. There are three small rooms in the house: a kitchen, a bedroom and a living room, all in all maybe 15 - 20 square meter. The living room is filled up of a sofa, two chairs and a table. The kitchen contains of a small bench with pots and pans and an open fire placed directly on the floor in one corner. There is one window in the house. The grandmother is 66 years old, but looks a lot older. She grows avocados for consumption and sale, but there is no market for the avocados so they are difficult to sell and the prices are low (at the best 1 Kenya shilling each). They have a small field to grow corn, but this year the crop has failed.

The grandmother looks after the grandchildren while her own children are away trying to get a job. There are four sons, all day-workers, and the daughter who works in Nairobi.

### **Comments on disability and poverty**

The meeting with the self-help group gave a lot of useful information. The difficult terrain was apparent to us. We did not have to ask to understand that it is nearly impossible for people with mobility difficulties to move around.

We got information on how poverty creates disability in the case of the blind man who came too late to treatment for his eye disease as a child. The reasons for this were both lack of money to pay for the treatment and difficulties and costs for transportation to the hospital. Now he is old and suffers from hypertension, which is untreated. He has a sick daughter and chooses to pay for her medication instead of his own, as it is not enough money to pay for both of them.

Another example is the young woman, a single mother of a small child. She fell into the fire as a baby because the cooking fire was placed on the floor in the kitchen. This would not have happened had the family afforded a stove. Maybe the multi-handicapped child could have been helped if there had been proper health services - both delivery services and training services - in the area. The mother is not able to have a job or get some income because she has to stay at home to look after the child.

The young deaf man showed us how disability leads to poverty as he has not been able to raise money to go to a vocational training centre after finishing school. The young deaf man who refused to speak in the meeting is an example on a person who has not been trained in sign language and who therefore refuses to communicate with strangers. It is quite common that deaf people who has not had the opportunity to go to school has learned 'survival sign language', that is, sign language that is developed and functions within the family. They may feel inferior when they come together with other deaf people that have been taught sign language, and they often refuse to communicate with hearing people. They are very isolated and totally dependent on their family.

The interviews during this day showed that offering special schools for children with disabilities is not sufficient if there is no possibility for further education or a job. Both the blind man and the deaf boy illustrate this. It is useful to compare the situation of this poor deaf young man with the rich deaf young man we met earlier in the field work. The two of them are quite different when it

comes to socio economic situation, but they end up in the same situation: Unemployed in spite of skills (the poor man) and education (the rich man).

The people in the self-help group were poor, but probably not among the very poorest of the poor, as they had some income. They had an agreement to pay a monthly fee to their self-help group to assist each other if necessary. This, we were told, prohibited those that could not afford to pay from joining the group.

### **Comments on qualitative methodology**

This visit was pre-arranged by the social worker. We were to meet the local self-help group in this particular village. The interview was therefore conducted as a group interview followed by some individual interviews. We encouraged the people to speak the language they preferred, either English or local language. Some of them spoke quite good English. As for the other ones, translation was taken care of by the social worker or sometimes by one of the other group members. A problem when it comes to translations is that one does not know if the translation is correct. On this particular occasion several of the informants spoke English and could control the translation. The social worker, who translated most of what was said in local language, had a tendency to answer on behalf of the informants. She apparently knew them well, and seemed used to act on their behalf. We had to stress the necessity of letting the informants speak up for themselves several times until she realised that she had to be quiet and let them speak for themselves.

At the beginning it was difficult to make people speak up. No-one wanted to be the one that started. However when we suggested to talk about the possibility to have a married life, people started to engage themselves in the discussion. This was a 'door opener' to the other topics. The group interview lasted for more than two hours. In the end everybody was tired. The group interview gave much information, as the people were very frank once they started to talk.

### **Visit to a primary school with a special unit for children with mental disabilities**

The unit is governmental, under the Ministry of Education. The unit is a class with eight children with learning difficulties and mental disabilities. We met the headmaster, the teacher for the special unit, the children and some parents. The teacher had no assistant. The children received a meal every day donated from the local chief. One of the children received training at home due to hyperactivity. Two of the children were siblings. One of the girls was a daughter of a mother with a mental disability. Judging from the learning material in the class room they were trained in reading and writing English, learning about categories, colours, and animals and so on.

The eldest pupils were teenagers, the young ones about ten years of age. The only offer in this area is primary school, therefore the children remained in the school in spite of being too old. The teacher informed that this lead to unwanted sexual behaviour in the class room. Teaching the young ones acceptable sexual behaviour and preventing the young girls from getting pregnant was a challenge, according to the headmaster and the teacher. Sometimes the parents did not mind the girls being pregnant, in spite of the fact that they could not even take care of themselves.

The headmaster stated that not everyone could attend the school due to lack of money for transportation and school uniforms. This was the situation for children with disabilities as well as for the other ones. The transportation is a particular problem when it comes to the children with disabilities as they must be accompanied to school.

### **Comments on disability and poverty**

The most important experience from this meeting was once more to learn how children from poor families do not have access to primary school because they lack money to pay for uniforms, and that children with disabilities do not go to school because the families cannot afford to pay for transportation. For children with hearing or visual impairment, as well as for many children with mental disability, the family do not afford to pay for boarding school.

We were informed that the Ministry of Education support special units for children with mental disabilities within ordinary primary schools. In spite of this not all children with disabilities have the chance to go to school.

### **Comments on qualitative methodology**

At this place it was organised a group meeting as well. We did not try to change this, but invited the parents to engage in a discussion by asking each of them to comment on our questions. It was no time to arrange for individual interview at this time of the day as we had to drive a long way to reach back to Nairobi before it was too dark. Some of the parents answered with very few words. We did not challenge them to be more specific because they spoke in front of the others. At this meeting most of the information came from the teacher and the head master, and some of the parents gave comments.

### **6.2.3 The third day of the field work**

#### **Visit at APDK (Association of Physically Disabled in Kenya)**

Our main purpose for the visit to APDK was to visit a CBR-project in one of Nairobi's slum areas. To do this we need to be accompanied by social workers. The project in the slum are run by APDK. APDK is one of the earliest NGOs for people with disabilities in Kenya. The organisation is represented in the regions by eight departments. We were given brief information on the different activities and guided around to have a look. In addition to awareness building, the organisation runs a workshop where the main production is wheelchairs and tricycles, a rehabilitation centre, a day-care centre for children with mental disabilities connected to a cbr-programme in the Mukuru slum, a cbr-clinic which among other services offers physiotherapy and occupational therapy. As a part of an empowerment strategy APDK supplies some of the parents with micro-credit to assist them to establish small businesses or to go to school. This is in cooperation with Ministry of Health.

#### **Visit at a day-care centre for children with mental disabilities**

The Mukuru slum is one of several slum areas in Nairobi. It is estimated that about 800000 people are living there. Mukuru is situated in an industrial area and the air, soil and ground water is severely polluted. Most of the inhabitants are unemployed. They live at the industrial area in order to get day-to-day work. Many of them have moved from the rural areas where they have their extended families. In a society that considers the extended family the fundamental social support unit, this makes them very vulnerable. Many mothers send their children to grandparents in the countryside because they are not able to raise them themselves in the slum.

An electric power line crosses the area. We were told from the social workers that the power line is leaking electricity. The houses are made out of clay and corrugated iron, and when it is raining the corrugated iron sometimes becomes electrified. We were told they had noticed a high incidence of epilepsy, which untreated often leads to mental disability, in the area placed under the high-voltage line. They suspected the electricity to cause this, but had not succeeded in getting

anyone to cheque it out. They have also registered a large incidence of people with chronic eye-infections, which untreated leads to visual impairment.

None of the schools in the slum area offers special units for children with disabilities. Parents usually do not have money to send children to boarding school, so children with disabilities are usually not sent to school. The day-care centre is organised by APDK as a part of their cbr-programme, and is run by the mothers on a voluntary basis. There are four mothers working there. The centre offers day care for 10 children (out of total population of 800000). APDK has provided for college education as a preschool teacher for one mother, and plan to finance similar education for the two other ones, one each year. They plan to finance education for the mother running the kitchen as well. The fee is 100,- Kenya shillings (1,3 US dollar) per month and 120,- Kenya shillings per week for the meals. It is not uncommon that the parents cannot afford the fees. Children are however not excluded because of this. The parents are given the opportunity to pay in instalments or they can assist by fetching water, which is laborious and must be done every morning and afternoon.

In addition to the day-care centre the social workers at the cbr-programme train local field workers to do home visits to families with children with disabilities. The main tasks are to give information, raise awareness and teach the parents how to train and stimulate the child themselves. The social workers have visited many similar projects and seen that field officers often become over-worked. Therefore they train the parents so they can take responsibility for the child and not hand it over to a project. In the beginning parents are visited every week, then after a while every second week, and finally once a month for a longer period.

At the beginning it was difficult to recruit children to the centre. Now, when they are known in the community, mothers bring their children to them. They have to dismiss most of them as they can only help very few. The mothers that are refused are offered a visit from a local cbr-worker. The social workers say that mothers turn to them and want to hand the full responsibility for the disabled child over to them so that the children can be taken care of. All in all 1248 families are visited by this strategy. Still there are no resources to help older children.

The preschool teacher at the day-care centre is a mother of two children. The eldest child has a disability - a minor learning disability and a minor mobility disability. He can walk with support. Until recently he has been at the day-care centre, but is now integrated in the normal school as a part of the cbr-programme. He has transportation to school every day. The mother gets up every morning at 5.30 to be able to care for the son before he leaves for school. She washes him, dresses him, feeds him and assists him to the bus. She has a three year old son as well. The mother is not able to take care of both of them, so the youngest one is taken care of by the grandmother who lives in the countryside.

A young man with learning difficulties passed us when we were driving into the slum area. The social worker told that he is one of their clients. He has been trained in personal hygiene, dressing and social behaviour. As a result of this he can move around in the neighbourhood and socialise to some degree with others without being mocked. He does not speak and he is unable to protect himself. Because of this other persons have misused him as a courier for drug trading. They reckoned that the police would not stop him because of his mental disability. He was however arrested. The police did at first not understand his disability, but took him for being doped. He was in prison for two days before he was released. The family did not know where he was and were not contacted by the authorities. This young man has never been out of the slum before but he managed to return by himself after some days. No one really knows what has happened to him during these days.

We met a young girl with learning difficulties after finishing a home visit. She does not speak, but smiles and greets us. She lives with her mother, who is taking care of her. The girl has been trained in basic self care, personal hygiene, dressing and social behaviour. As a result of this she is

able to move around in the neighbourhood. She has been abused by a neighbour, a father of five children, who made her pregnant. Both the girl and the baby are taken care of by the girl's mother. She is an example of a very vulnerable person: a girl with an intellectual disability. The social worker informs us that they do not know how to fully protect her in the future. It is not unlikely that she will be abused again, having more babies or maybe hiv/aids.

As we drove out of the slum we passed a young woman with a little child. The social worker told us that this child had a disability. They are offering the mother consultations, but she refuses any contact with them. The social worker labels the child as an 'IGP' - an income generating project. According to her the mother utilises the child for begging in Nairobi city and is not interested in receiving any kind of support from the cbr-programme.

We visited a young family with three children living in the Mukuru slum. Both the mother and the father participate in the interview. One child is three years old and has a mental disability and cerebral palsy. The family lives in a small hut (4 - 6 square meters) made out of clay placed directly on the ground. The ground can be soaked in the rainy season. The roof is made of corrugated iron. Their extended family lives in the countryside far away. The mother regards herself as a social person, so she told everyone about her worries when she understood that it might be something wrong with the child. Some neighbours told her about the cbr-programme and advises her to contact them. The mother talks about this as a positive experience for the whole family. She receives micro-credit from the cbr-programme to run a little shop, but the child cannot be left alone and the mother spends most of the day together with the child. The mother has been taught how to train the child and does this every morning and afternoon. The training is time consuming, but has led to that the child walks. There are two elder siblings who assist the mother with the disabled child. The father spends the whole days looking for part time jobs.

The father says it was terrible to have a disabled child, but he has learned to accept the situation and has decided to stay with the family. Both he and the mother have received counselling from the social workers through the cbr-programme. Because of this the father decided to stay with his family and share the responsibility with the mother. We are told that this is not a common reaction from men when a child with a disability is born. The mother says that the counselling from the cbr-programme has helped them to understand what is wrong with the child, to accept the situation and stimulate the child, and to keep them together as a family.

When we leave the family the social worker says that this family exemplify the ideal situation. The mother and the father have received counselling separately and also together for a long period. This has led to a positive result according to the social worker.

### **Visiting Kibera slum**

A representative for an NGO (Sight Savers) working with visual impaired people in the slum area had organised a group meeting in the afternoon. About 40 people with different kinds of disabilities were there to meet us. Because we arrived late in the day we could only interview some of them. We arranged for a meeting with six persons. The other ones had to go home. The informants told their story one by one with the other ones listening because it was not possible to have a separate room.

We interviewed a severely bodily impaired old man with a small and deformed body, probably a neurological disease. He uses a wheelchair and is accompanied by one of his sons. He was born normal but developed a disability after a disease when he was seven years old. The disability gradually got worse. Due to his disability he has never been taken to school. He is a widower with eight children. He characterises his life as very miserable. His children assist him in everything and he is dependent on them both day and night. The eldest son takes him up in the morning, dresses him, feeds him and brings him to Nairobi city where he subsists as a beggar. The son

comes and brings him home in the afternoon. He has no pension, but receives charity gifts from the church from time to time. He is totally dependent on his children. If they leave him he will die, he says.

A deaf young girl tells us that she is one out of ten siblings, and that five of them are born deaf. She is married to a deaf man but has not yet any children. The husband works as an unskilled worker at the state hospital. She and her siblings have all attended boarding school, paid by a missionary organisation. She has not been able to get a job, but tries to earn some money as a hawker. Because it is difficult to get a hawkers licence she is constantly chased by the police. As a deaf person the main problem is to communicate with others. She feels isolated. As long as the husband keeps his job their situation is good. If he loses the job she does not know what will happen to them.

A woman is the mother of two mentally disabled children, one and four years old. She is married and the husband is away the whole day trying to get part-time work. She stays home the whole day looking after the children. The days are filled with house work and care for the children. She can only go out of the house when they are asleep. Because of this she is unable to contribute to the family's income, and to socialise with other people. The eldest son was born normal but got epilepsy. He cannot walk. She took him to the hospital and got medication. Medicines are expensive, and since the medicines did not improve the child's conditions she stopped buying them. He has about ten fits every day and the mother has to stay close to him all the time when he is awake. She has not taken the child to the hospital after the first time because they cannot afford it. The youngest one has learned to walk and this is a relief to her. Her husband accepts the children and tries to support her. She says that they are Christians and that the children are the will of God. The neighbours do not accept the children, neither do they help her. She says they will only help if she pays, but they have no money to buy any assistance. Some of the neighbours are afraid of the child when he has fits, as they believe it can be contagious, and they withdraw from her.

The father of a nine years old multi-disabled boy says he believes the disability was caused by a difficult labour. But he is not certain. The child did not cry for five hours after delivery. No one informed them that this could indicate that something could be wrong with the child. At first they were convinced that the child would die. However, when they left the hospital they believed everything to be fine. Gradually they understood that something was wrong with the child as he developed slowly. He started to walk late and he hardly speaks. They took him to the state hospital where he got physiotherapy to learn to walk. Then nothing was done until he started school. The school refused him and sent him for assessment. Now they are waiting for admission to a boarding school. The boarding school is expensive, but they will try to afford it because this is the only option. They have waited for two years for a school to accept him. In the meantime the boy stays at home. At the age of nine he has not yet been at school. They have a younger child as well. This one was sent to the grandmother as a baby because it was too much work to take care of both of them. Now he has reached school age and will be taken back to the parents. He will be at school during the day and in the afternoon he will assist his mother. The father says they feel very alone with the responsibility for the disabled child. The neighbours show different reactions. Once in a while some are willing to assist, but most of them do not offer help at all. The child is isolated as it has not learned to socialise with other children.

An old woman with a neurological disease that looks like it could be Parkinson's disease tells her story. She is in a wheel chair. It is very difficult to understand what she is saying. She is accompanied by her sister who is the one that takes care of her, interprets what she is saying and sometimes speaks on her behalf. She has been married and is the mother of four children who all have died from different diseases. When she got sick her husband ended the marriage and sent her back to her brothers. Since then she has not heard anything from him. The brothers transferred the responsibility for her to the sister. The sister, who is elderly herself, is fully occupied in taking

care of both of them. The disabled woman is totally dependent on her sister who helps her in all the daily activities - washing, dressing and feeding. She also speaks for her as she is difficult to understand. The sister has several children. One of her daughters has a job in Nairobi and she supports both of them. This is how they survive.

### **Comments on disability and poverty**

Once again we see that a disabled child from a poor family has very few opportunities in getting an education. In the slum a disabled child is hardly likely to go to school at all unless it is intercepted by an NGO-project.

The field visit in the slums showed clearly how poverty creates disability. Our examples are about pollution as well as lack of proper medication and that people do not afford to seek health care when that is necessary. People with mental disabilities, especially the young ones, are very vulnerable in a deprived social setting as a slum area.

Mothers living separated from their extended family tend to be left alone with the care for a disabled child. Some mothers send their children to the grandmother when a child with a disability is born. The mothers we interviewed had chosen to send the non-disabled child away and take care of the disabled child by themselves.

### **Comments on qualitative methodology**

The visit to APDK illustrates one of the many courtesy visits one has to pay. There is a risk throwing away valuable time if these visits are not kept as short as possible. At the same time courtesy calls are necessary because such visits can give valuable information on the situation for people with disabilities in that particular area. In many cases one will not have access to the field without them. In our case we would not have been able to visit the people living in the slum and interviewing them without the assistance from the social workers at APDK.

People running projects are eager to show their projects, especially if they are successful, and there are always questions about sponsorship. It is however important to keep in mind the main purpose of the visit, in our case the need to interview the people with disabilities themselves, and in particular the poor people.

This day showed that it is important not to have a too tight programme. It is advisable not to visit more than one place every day because driving from one place to another is time consuming as are the courtesy calls on every new place. This day was too busy. The field work was interrupted by too tight a programme and we got no opportunity to change the programme because it was settled the day before. We wasted too much time with driving from place to place and paying courtesy visits. The information from the people working with projects and activities were relevant, but it is a general problem that they are time consuming and prevents us from talking to the people we really want to meet. Because the time span was short we did not have the opportunity to come back to these places for more information. Therefore we lost a lot of good information. In spite of this the visits in the slums gave us much. Especially in Mukuru slum we were assisted by a very skilled and well oriented social worker who guided us around in the slum area.

Once more we learned that the best information comes when we interview the persons with disabilities themselves, and visit them in their homes or at their work. We also learned that field work in slum areas needs facilitation from people who are known by the people living there and have the necessary confidence.

## **6.2.4 The fourth day of the field work**

### **Visit to Machakos district**

Compared to Maragua the terrain in Machakos is levelled and the climate is drier. The district is considered to be poorer than Maragua. Water resources are scarce and most people have to fetch water from a long distance. The soil is not as rich as in Maragua but there are both high-potential and low-potential areas. The most common types of crop are sorghum, and beans, in addition to fruit farming. The farmers keep sheep and goats.

In the morning we met with the head of social services at the district counsellor's office. We were given a brief report on the situation for people with disabilities in the district. It is no overview of the number of people with disabilities in the district. It is estimated to be maybe 1 % maybe more. People with disabilities receive help from different stakeholders. Among the most important ones are: African brotherhood church, association for physical disabled, the Catholic Church, Ministry of Health and Ministry of Education. There is a public boarding school for children with mental disabilities and one for children with visual impairment in the district, in addition to a technical school for blind and deaf students and a poverty eradication fund providing micro-credit.

The public policy is to integrate children with disabilities in the normal school, but no one has a clear view of how this functions. They encourage people with disabilities in the villages to form self-help groups. Because the local understanding of disability is that it is a curse, parents with disabled children are reluctant to seek help.

### **Visit to a secondary school for blind children**

The school started in 1958 offering rehabilitation to blind soldiers by teaching them technical skills. After a while the organisation Sight Savers was involved and improved the quality of the education and re-organised the whole concept. Today the school is public and the NGO has withdrawn. They offer education to people with visual and hearing disabilities, and non-disabled people as well, as a part of an integration policy. It is the only school that offers courses in woodworking and leatherwork. Lack of finances and technical equipment is a thorough problem. The 106 students come from whole Kenya and the school has to dismiss many applications. At present they have 72 students who were blinded from the bomb blast in Nairobi in 1998. In addition they have several who have been blinded after drinking methanol. We are informed that blindness from drinking methanol is not uncommon in the poor areas. In addition to this they have students who have been blind because of a dangerous work situation.

We are told that the job situation for blind people is very difficult as is the possibility to get an education. Secondary schools are expensive and most of the people with disabilities are too poor to pay for it. Students with disabilities pay 6000,- Kenya shillings (about 78 US dollar) each term, all in all three times a year. The non-disabled students pay 9000,- Kenya shillings each term.

Several of the students suffer from depressions. The staff is not qualified to offer treatment for mental sickness and the result is a high incidence of suicides. Another problem is the lack of local based health services and pharmacy. The blind students are not able to seek the health services and pharmacy by themselves. The school encourage the students to participate in sports. In spite of a general lack of sports equipment one of the blind students won a gold medal in the last Paralympics.

After the visit at the school we visited a family with a mentally disabled daughter, 26 years old. They live in a small house with two rooms - all in all about 15 square meters - in Machakos. The father is a small farmer, having some goats and growing vegetables. The house is one of the few we visited that has a masonry floor and a window with a curtain in the living room. The daughter is the second of four siblings. She is a pretty and charming young woman. The parents did not understand that something was wrong with her before she started school. She has however completed grade eight, but had to use some more years than the norm. She speaks only a few words, but understands what we are saying when we talk to her. She answers by smiling and mumbling. The parents understand her well and talk on her behalf.

After finishing school she had a course in tailoring, organised by an NGO, and has been given a sewing machine. She is able to sew but needs assistance to cut the fabric. She does some sewing and repair work for the family and some of the neighbours but is not able to make a living out of it. Her family loves her very much and wants to give her a good life and as much personal freedom as possible. They realise that she is vulnerable as she is a nice and affectionate person. Because she has been permitted to move around in the neighbourhood by herself, she was made pregnant by a young man. The parents regret this as they realise she will never be able to take care of a child of her own. They are however looking forward to have a grandchild. The father has not yet met the young man's family, but he intends to ask them to permit the man to marry her. If he marries her she will have to move to the man's family. This worries the parents because they cannot be certain that she will be treated well. The parents will see to that her in-laws treat her well. If not, they will take her home again and take the responsibility for her child as well. The father says he hopes she will not have more than one, at the most two, children. He does not believe she will be able to cope with more children. Even with one or two children she will need assistance. The girl is fully dependent on being taken care of by somebody. The parents are prepared to see to that she is taken care of, but is worried about what will happen to her when they grow old. Her siblings may take care of her and her child if they decide to stay in the village. However, the father does not take this for granted.

In the afternoon we visited a family with six children. The mother is deaf as well as five of the children. The deaf family members have all blue eyes, and we were told that this comes from the deafness which is heritable. The family lives in a small house with two small rooms. The house has a masonry floor. The family communicate by sign language. They do not socialise with other deaf people in the village even if they know that there are other deaf people there. The oldest daughter is fifteen years old and deaf. She is in boarding school. The next one is a deaf boy. He was supposed to start school this year, but the father took him out after a month because he is unable to pay the school fees. He hopes to be able to send him to school next year, but is not certain of this. The father once had a job on the boarding school for deaf children, but now he subsists as a day-worker. The possibility to get a new regular job is very small. Since the father is a day-worker the family's income is very unstable.

The biggest problem they face at the moment is when the wife needs to communicate with others, for instance when she has to see a doctor. This means that the husband has to assist her and then they will not have an income that day. None of the parents regret that the children have a disability. The father worries about the children's future, though. He fears they will face a difficult life. Their only hope, as he can see, is to have an education. This is a big challenge as they already have problems paying for boarding school for two children. The parents hope the two girls in the family will get married and in that way be taken care of, but they do not take this for granted.

The little girl of about two years of age seems to be undernourished. She is still breastfed. When we mention this to the social worker who accompanies us she is not willing to discuss this because health issues belong to the Ministry of Health and not to the Ministry of Social Affairs which she represents. She is not willing to refer the case to the health workers.

When we drove back we interviewed the driver that accompanied us in Machakos. He was originally not recruited as an informant but was engaged to take us around, as he works with people with disabilities in the local communities, the deaf people in particular, and knows them well. He is a preacher in a local Baptist church and a teacher at the boarding school for deaf children. He tells us that he comes from a very poor family. His family are small farmers living in another rural area in Kenya. He was born as a hearing child, but suffered from chronic otitis which was untreated. At the age of six he was completely deaf. As the family is Christian he was given the opportunity to go to a boarding school for deaf children, run by the Baptist church. There he learned sign language. At the age of sixteen he and three other deaf children was chosen by the church to go to the Netherlands to have ear drum transplantation, paid by the church in the Netherlands. At first the parents refused to let him go. They feared he would be kidnapped and sold. The people from the church had to do a lot of persuasion before his parents let him go. He tells that his mother thought she would never see him again. After the operation he could hear again and had to learn his mother tongue again. Because he was a bright boy the church sent him to USA to study and he got his master degree in sign language and deaf communication. In USA he learned to speak American. Now he sees himself as more fluent in American than in the language of his family. He has returned to Kenya to 'pay his debt' and is now working for the benefit for deaf children.

### **Comments on disability and poverty**

This day gave examples on children being disabled because of improper nutrition, not being medicated or given health treatment according to their needs.

As for the family with the deaf mother and children the mother is dependent on her husband when she needs to communicate with other persons that do not master sign language. The parents seem to be unable to provide for school for all their deaf children, if not an NGO by any chance offers a sponsorship. So far this has not been the case.

Once more we were confronted with the vulnerability of people with mental disabilities. Even if the parents try to protect their children, they will not be able to follow them all the time if they wish to allow them some personal freedom to move around and socialise with others.

### **Comments on qualitative methodology**

Once more we had to handle time consuming introductions about the organisation's effort to run projects and the problems connected to funding. Introductions are inevitable, but must be kept as short as possible.

We learned once more that relevant information may come from unexpected directions. Our driver was not engaged as an informant but as a facilitator. His history is interesting, though, illuminating how an untreated chronic illness leads to a disability because the family lacks money, does not have access to proper health care and has no information on which possibilities that exist.

We did not have much time when we visited Machakos. The time span was shorter compared to the visits at other places. Because of this we could not follow the interview guide as we had planned, but had to improvise and pick the most relevant topics. We learned that it is not fundamental to go through the whole guide every time to get interesting information. It is possible to get an overview over the situation quite quick. An example is the interview with the family with a deaf mother and children. Another example is the interview with the parents of the mentally disabled daughter where the main topic in the conversation was the daughter's vulnerability and the parents concern about her future.

### **6.2.5 The fifth day of the field work**

We went on our own to a rural area quite far from Nairobi. There we happened to meet the head master and a teacher from the local primary school. We invited them into a discussion on the situation for children with disabilities in the area and the situation at the school where they were working.

A young man in a wheelchair was employed at the place we were staying. We introduced ourselves and asked if he would participate in an interview, upon which he agreed. He was disabled in early childhood. As a child he used churches. After finishing primary school he was sent to the special school in Machakos, the one we visited the day before. The school provided him with a wheelchair and taught him leather craft. The teacher at the school got a new job in Masai Mara and brought the young man with him because he is talented. He was able to do this because the place, which is run as a partnership between the local Masai community and Scandinavian investors, has integration as a part of their policy. The young man makes leatherwork to sell to the tourists who visit the place.

He is able to carry out the activities of daily living by himself and to move around by himself. He comes from another part of Kenya and misses his family. In spite of this he hopes to stay because this is the only chance he has had to manage on his own. He does not know how his life would have been without this opportunity. He considers other possibilities to provide for himself as small. His friends from the school in Machakos are unemployed and dependent on being taken care of by the family.

Later the same day we invited some local Masai women into a conversation on children with disabilities. None of the women spoke English so we needed a translator. The information clerk at the place we were staying facilitated the translation. They told us there are no children with disabilities in the community. However, we have learned from the literature that the Masai do not have a word for 'disabled' in their language. Later the same day we invited the head of a local Masai family to discuss the same topic. He gave us some information on how children with disabilities are taken care of within a Masai community. Every child, also children with disabilities, is taken care of by their mother in cooperation with the other wives of the husband. As for the Masai girls, he said, it is vital that she is able to carry out the role and duties that is expected from a female Masai. Then no one pays attention to her impairment. It is important that she is able to do ordinary household duties. This will be of vital importance if she is going to be married. If she is not, she usually will stay home together with her mother and assist her as much as possible. We were told that a disability may reduce the young girl's 'value'. If she is married she will probably be the wife of a man that already has several wives, or maybe the father just gives her away.

### **Comments on disability and poverty**

The situation of the young man in the wheelchair illustrate once more that people with disabilities are dependent on private initiative or NGO-activities. It seems that it is coincidental whether the person gets an education or a job or not, and not a result of the persons capabilities.

### **Comments on qualitative methodology:**

We have seen that informants carrying relevant information may show up at any time. When doing field work one is at work all the time and must utilize every opportunity to collect information.

The experience with the Masai women shows that it is important to be specific about particular impairments when talking about 'disability', a word which does not have its parallel in many languages. Concepts and categories that are familiar within certain cultural, social or educational contexts do not necessarily give a meaning to people within other contexts.

### 6.3 Reflections on the methodology

- The interview guide was well suited for the purpose, but must be used with flexibility. In most of the interviews only some aspects were relevant. The main cause for this was the problems the people with disabilities were facing, time constraints and the organisation of the interview situation.
- The group interviews had mostly been pre-organised by others and it was no time to reorganise them except for adding some individual interviews with group participants afterwards. This must not be seen as a problem or a constraint but as a challenge and an opportunity to gain information.
- A follow up with individual interviews with some of the participants from the group interview turned out to be useful and informative.
- Focus group interviews turned out to be of minor importance because there was too little time to organise them. Since focus groups seldom give primary information on the situation for people with disabilities and how people with disabilities experience their own situation, we did not make an effort to organise any. They would have been arranged at the sacrifice of interviewing people with disabilities themselves.
- Individual interviews sometimes ended up as group interviews. This is not a problem unless the disabled person looks upon it as a problem. The interviewer must be sensitive to this.
  - Some informants want to bring a support person or two who occasionally are involved in the interview.
  - In many interview situations there are other people around who join the discussion.
- Introductions with officials are time consuming but necessary as they often give both primary and secondary information on their attitudes towards persons with disabilities, as well as the situation for people with disabilities in the area. It is important to follow the courtesy rules of the country, but be very clear about the purpose of the visit; individual interviews with people with disabilities and home visits are the most important source of data. Keep the courtesy visits as short as possible.
  - Do not get too involved in discussions about funding.
  - Do not make promises that you cannot keep.

- In qualitative studies involving field work it is important to catch all possible opportunities for data gathering. Sometimes information may come up when least expected. Consider every person you meet as a potential informant: One day we had a driver with a hearing impairment. His story gave relevant information. At another occasion when we happened to meet a head master and a teacher from a local primary school. We invited them to have a conversation with us on children with disabilities and their chances to get education.
- It can be difficult to meet the ‘real’ informants, that is, the very poor that are not intercepted of a project or an NGO. This is because access to the field generally is facilitated through organisations working (public or NGOs) with people with disabilities. These organisations are eager to show their projects and the good results. Because of this they prefer to connect you to the people that already have benefitted from their projects, and not to those who have not.
- Time necessary to do the field work:
  - It is advisable not to visit more than one community or place every day as travelling and introductions are time consuming.
  - It is useful to have a day without fieldwork in the middle of the first week to write up and discuss the preliminary findings. This ‘day off’ was coincidental for us because of a national holyday, but turned out to be very useful.
  - It is useful to have a second week to go back to some of the cases/places for more detailed information. We did not have this opportunity.
- Qualifications of the researchers
  - Experienced qualitative researchers will give more knowledge in a shorter time than inexperienced ones.
  - Experienced qualitative researchers will be able to utilize more opportunities for getting information than inexperienced ones.
  - It is useful to be two researchers cooperating in the field work and the analyses as this will give more information and detailed analyses in a shorter time span than with one researcher.
  - Data analysis must be done by a qualified researcher, one who has been active in the data gathering process.

## 6.4 How poverty influence disability

- Environmental pollution and constraints lead to disability:
  - Lack of sanitary installations lead to intestinal infections which are likely to remain untreated in a poor environment. People living near industrial areas are exposed to severe pollution through air, water and soil which leads to chronic diseases that untreated may lead to impairments. Lack of nutritious food harms children’s maturation and development which may lead to mental retardation.
- Lack of access to health care creates and/or increases impairment:
  - Lack of medicines and health treatment, either because of costs or because medical services are not accessible in the local area, leads to disability or worsens disabling conditions.

- Expectant mothers may come too late to medical help with complicated pregnancies or with difficult deliveries. This is because the medical resources in remote areas are scarce, transportation is difficult to obtain and costs money.
- People with disabilities have reduced or no physical and/or mental ability to seek health care without being assisted by someone. Except from close family people are reluctant to assist without being paid.
  
- Lack of education and lack of access to information.
  - People do not know when to seek help.
  - People do not know where to seek information.
  - People do not have knowledge on the importance of immunisation and proper nutrition.
  - If educated, people with disabilities seldom have more education than primary school, mainly due to three reasons: They are not accepted in the 'regular' schools, the family is not able to pay the costs and the family is not able to provide for or pay for transportation.
  
- Lack of resources in the community in general:
  - People in the community are reluctant to assist people with disabilities in their daily activities because they themselves lack the necessary resources to cope.
  - Neighbours are willing to assist if they are paid. People with disabilities do not have money to pay for assistance.

## 6.5 How disability creates poverty

- Lack of employment or income activities:
  - Unemployment strikes people with disabilities belonging to all social levels. This may create a situation of poverty for the individual or the family.
  - Many job opportunities involve manual work and are not accessible for people with physical and/or mental impairments.
  - Many jobs could be available with adjustments, but employers do not want to use resources on adjustments.
  - Employers do not hire people with disabilities as a part of their employment policy.
  - Employers have preconceptions on what people with disabilities can and cannot manage.
  
- Lack of adequate education:
  - Children's potentials are not developed because schools (buildings and learning materials) are not accessible.
  - There is a lack of higher education adapted to deaf and blind students.
  - Parents cannot afford the school fees for boarding- or secondary schools, as well as uniforms and transportation expenses.
  - School buildings are not adjusted to mobility impaired pupils.
  - There is a lack of adjusted learning materials.
  - There are few teachers with particular qualifications in teaching pupils with disabilities on all levels.
  
- Lack of information and knowledge on disability and the consequences:

- Parents do not know where to seek for information on how they can help the disabled child.
- Parents are not informed that the child's condition can be improved or how they can train and stimulate the child.
- Preconceptions, attitudes and believes:
  - People with disabilities experience negative attitudes from others.
  - People with disabilities develop low self esteem.
  - People with disabilities may experience difficulties in getting married and having a family life.
  - People with mental disabilities are vulnerable to abuse, both sexual and in other ways. This concerns both girls and boys.
  - A mother giving birth to a disabled child is in danger of being deserted by her husband who may blame her.

## 6.6 Structural constraints

- A family with a disabled family member does not receive support from the other community members (outside the extended family).
  - People without close family members nearby have little or no support in caring for family members with disabilities.
  - Unrelated people have enough problems of their own and tend not to give help. This is more pronounced in urban than in rural areas.
- Outside the family care is supported and provided mostly by private initiatives: NGOs, churches and private persons (well wishers).
  - The initiatives from private actors reach very few among the entire population of people with disabilities.
  - It is coincidental who is benefiting from the actors' effort.
  - Some of the activities are short term, and do not create durable changes.
  - The initiatives direct the individual and do not create durable environmental changes.
  - Private actors may to some extent take the responsibility from the government thus making people with disability rely on charity and NGOs instead of giving them equal rights in the public system.
- In spite of a Governmental policy on disability the actual responsibility taken on by the Government seems far from sufficient:
  - No pension for people with disabilities.
  - Very few initiatives to create job opportunities for people with disabilities.
- Constrains in access to education:
  - Costs for shoes and uniforms keep the poor from attending primary school. School fees for special- and secondary schools have the same effect. Children with disabilities are often kept at home because the parents do not have economical resources to give all children education.
  - Costs for transportation for children with disabilities prevent the children from attending school.

- A tendency by officials at all levels to focus on the attitudes of the people with disabilities themselves and their families, in stead of focusing on structural constraint in explaining the difficulties people with disabilities face. This easily leads to “victim blaming”.
  - People with disabilities and parents to children with disabilities express a need for being offered practical solutions in order to be self subsistent and socialise with the other community members.
  - The grass-root workers, social workers and volunteers, tell that people are relatively easily motivated to come forward once the help and the practical alternatives are there.
- Lack of ideology for positive differential treatment for people with disabilities, for instance when it comes to jobs and school bursaries.
- Lack of knowledge about the potentials for people with disabilities and treatment of disability in schools and at work places.
- Lack of an implemented Policy of employment for people with disabilities.
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- Lack of empowerment:
  - Organisations of people with disabilities are many, small and scattered and do not seem to cooperate much.
  - The strength of collaboration between the organisations seems weak.
  - It seems to be a lack of contact between the organisations for people with disabilities and the poorest of the people with disabilities - the poorest of the poor.

## 7 Concluding remarks

The pilot test shows that the methodological tool is well suited to this type of studies. However, there are some conditions that must be taken into consideration in the planning face.

- ❖ It is an advantage to be two researchers co-operating in the data collection because this will increase the efficiency of the field work.
- ❖ The researchers must have previous experience in doing qualitative studies and must have knowledge of the field.
- ❖ The time for the fieldwork should be a minimum of two weeks. The first week should consist of relatively intensive data gathering, if possible with one day in the middle for reflections and writing-up. The second week should be used to follow up important clues or topics that appeared during the first week.
- ❖ The analyses must be done by the same researchers that do the field work.
- ❖ Gate-keepers are necessary to get access to the field, but one should limit the courtesy calls in time and numbers to what is absolutely necessary. Try to avoid using gate-keepers as interpreters because this may influence the information given.
- ❖ Do not leave the gate-keepers to decide on the programme. Communicate in advance on your aims and objectives and who you want to see.
- ❖ Organisations of people with disabilities should be involved; as a reference group for planning the field work or/and as counterpart in the data collection process. If there is an umbrella organisation in the country, it may be useful to arrange a feed-back meeting before leaving the country. In some countries, like Kenya for instance, the organisations are many and fractioned. This makes it difficult to pinpoint one relevant group to meet. In such a case the feed-back should be given to the relevant public officer, and/or the World Bank officer (which we did).

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