

SINTEF A576

# REPORT



## Violence and abuse against women with disabilities in Malawi

Marit Hoem Kvam and Stine Hellum Braathen

**SINTEF Health Research**  
November 2006

www.sintef.no

Address: PO Box 124 Blindern, N 0314 Oslo  
Telephone: +47 40002590  
Fax: +47 22067909  
URL: www.sintef.no/malabuse



**SINTEF****SINTEF Health Research**Address:  
P.O.Box 124, Blindern, NO-0314  
Oslo, NORWAY

Telephone: +47 40 00 25 90

Fax: +47 22 06 79 09

**SINTEF REPORT**

TITLE

**Violence and abuse against women with disabilities in Malawi**

AUTHOR(S)

Marit Hoem Kvam and Stine Hellum Braathen

CLIENT(S)

The Atlas Alliance, Norway

REPORT NO. <b>SINTEF A576</b>	CLASSIFICATION Unrestricted	CLIENTS REF. Rikke Bækkevold	
CLASS. THIS PAGE	ISBN 978-82-14-04183-5	PROJECT NO. 78g173	NO. OF 53/ 3
ELECTRONIC FILE CODE AbuseMalawi		PROJECT MANAGER (NAME, SIGN.) Marit Hoem Kvam <i>Marit Hoem Kvam</i>	CHECKED BY (NAME, SIGN.)
FILE CODE	DATE 2006-11-23	APPROVED BY (NAME, POSITION, SIGN.) Arne H. Eide, Research Director <i>Arne H. Eide</i>	

## ABSTRACT

This research project is a study of the nature of abuse, violence and neglect against women with disabilities in Malawi. The childhood as well as the present situation of 23 women with disabilities in Blantyre district is described. Data was collected in two ways:

- a) Through in-depth individual interviews with 19 women with visual-, mental- or physical disability, as well as women with albinism.
- b) Through a focus group discussion with four women with hearing impairment.

The interviews and discussions were built on interview guides.

Most of the informants reported that during childhood they were treated like the other children in the family. However, education was difficult. The schools and the school material were not adjusted to their needs. The informants stressed the need of more consideration in regards to their special needs in this relation and wanted the society to make education for women with disabilities a priority area.

Many informants felt that men in the society took advantage of their vulnerable situation and promised to marry them. When the woman got pregnant, the man disappeared and left her to be a single mother. Many of the women regarded this as sexual abuse.

The study was arranged as collaboration between SINTEF Health research, Norway, Federation of Disability Organisations in Malawi (FEDOMA) and Disabled Women in Development in Malawi (DIWODE). The Atlas Alliance and the Norwegian Department for Foreign Affairs have given economical support to the study.

KEYWORDS	ENGLISH	NORWEGIAN
GROUP 1	Women with disabilities	Kvinner med funksjonshemming
GROUP 2	Violence and abuse	Vold og overgrep
SELECTED BY AUTHOR	Human rights	Menneskerettigheter

The women on the photo on the front page are partners from Disabled Women in Development in Malawi (DIWODE).  
From left to right: Maria Phalula - interpreter and interviewer,  
Sigere Kasasi - executive director DIWODE,  
Betty Wisiki - sign-language interpreter.

# Table of Contents

<b>Table of Contents</b> .....	<b>3</b>
<b>Preface</b> .....	<b>5</b>
<b>Acknowledgements</b> .....	<b>7</b>
<b>1 Introduction</b> .....	<b>9</b>
1.1 Project Objective.....	9
1.2 List of abbreviations.....	9
1.3 Background .....	10
1.3.1 Violence and abuse against people with disabilities .....	11
1.3.2 Context.....	12
<b>2 Methods and organisation</b> .....	<b>15</b>
2.1 Study Design .....	15
2.2 The research team .....	16
2.3 Location .....	16
2.4 Informants .....	17
2.5 Meeting with DPO representatives .....	17
2.6 Focus group discussion with hearing impaired informant .....	18
2.7 Qualitative interviews .....	18
2.8 Data analysis .....	19
2.9 Quality assurance/ Ethical considerations.....	19
<b>3 Results</b> .....	<b>21</b>
3.1 Description of the informants.....	21
3.2 Getting- and living with disability .....	23
3.3 Access to school and education.....	26
3.4 Sexual abuse, adult relationships, marriage and family life.....	32
3.5 Health .....	37
3.6 Being a woman with disability in Malawi .....	40
<b>4 Discussion and conclusion</b> .....	<b>47</b>
<b>5 References</b> .....	<b>51</b>
<b>Appendices</b> .....	<b>54</b>



# Preface

## **Sigere Kasasi - Executive director DIWODE**

On behalf of the Disabled Women in Development (DIWODE) I feel greatly privileged to provide the preface for this Study Report.

DIWODE is an organisation that seeks to promote the interests of women with disabilities through the promotion of equal participation, capacity building; social and economic development.

I feel greatly honoured to have coordinated and being part of this study on the violence and abuse against women with disabilities in Malawi. This study which is the first of its own kind in the history of disability in this country will assist in shading light regarding the extent of violence and abuse affecting women with disabilities. The study comes at a very opportune time when the level of violence and abuse against women in Malawi seems to be rising. Women with disabilities are very prone and at a great disadvantage due to their various disabilities which make it very difficult for them to defend themselves against any aggressor. Many women with disability face double discrimination arising from being women first and also in having a disability which places them at a disadvantage making them prone to marginalisation and vicious cycle of deprivation leaving them susceptible to abuse. I believe that the results of the study will provide a basis for a further comprehensive study that will assist in giving a very clear picture of the status of women with disabilities in Malawi. This is very important in terms of formulating effective interventions that will help in uplifting the status of women with disabilities and promoting their visibility.

I feel indebted to SINTEF Health in Norway; the Government of Malawi; the Southern Africa Federation of the Disabled (SAFOD); the Federation of Disability Organisations

in Malawi (FEDOMA); women with and without disabilities and other partners who provided support for the Study. Last but not least I thank both Stine and Marit for effectively steering this study. It was indeed a pleasure working with the two.

It is our hope that all stakeholders will commit themselves in promoting change in the lives of women with disabilities in Malawi.

## Acknowledgements

The Norwegian project team would like to thank the Atlas Alliance and the Norwegian Department for Foreign Affairs for funds in connection to the project.

The study has been collaboration between SINTEF Health Research in Norway, and FEDOMA and DIWODE in Malawi. We would like to thank our partners in Malawi for their enthusiasm and help, especially all representatives from FEDOMA's affiliated organisations who participated at the DPO meeting in Blantyre in June. Thank you, Mussa Chiwaula, director of FEDOMA, for excellent help! A special thanks to Sigere Kasasi, executive director of DIWODE; we hope you will find this report useful. We also appreciate the assistance of Betty Wisiki, our sign-language interpreter

We would especially like to thank our interpreter and co-fieldworker Maria Phalula. Without her help and support the project would not have come to an end. She has got hold of our informants, brought us to their homes, taken part in the interviews, acted as an interpreter, and lastly interviewed seven women on her own.

Last, but not least, we would like to express our gratitude to all the brave women who openly shared with us their personal experiences!

*Marit Hoem Kvam*  
(Project Manager)

*Stine Hellum Braathen*





# 1 Introduction

This research project is a study of the nature of abuse, violence and neglect against women with disabilities in Malawi. Through in-depth interviews with 19 women with disabilities and one focus group discussion with four women with hearing impairment, their childhood as well as their present situation was explored, linked to possible abuse and mistreatment in different phases of life. A qualitative approach was chosen to gain detailed information about the nature of mistreatment. The study was arranged as a collaboration between SINTEF Health research, Norway, Federation of Disability Organisations in Malawi (FEDOMA) and Disabled Women in Development in Malawi (DIWODE). The study was partially financed by The Atlas Alliance - Norway, The Norwegian Department for Foreign Affairs and SINTEF Health Research.

## 1.1 Project Objective

The overall objective of this qualitative study was to **improve the living conditions of women with disabilities in Malawi** by disclosing and describing the nature of abuse, neglect, violence and discrimination against this vulnerable group. Through the disclosure of the problems the project aims at giving the disabled people's organisations (DPOs) a document that can be used as a means of influencing and raising awareness among organisations, politicians and policy makers, health care workers, DPO members, and families of people with disabilities.

## 1.2 List of abbreviations

FEDOMA - Federation of Disability Organisations in Malawi

DIWODE - Disabled Women in Development

SINTEF - The Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology (NTH)  
SAFOD - Southern African Federation of Disability Organisations  
DPO - Disabled people's organisation  
UDF - United Democratic front  
GAIA - Global AIDS Interfaith Alliance  
NORAD - Norwegian Agency for Development Cooperation  
UN - United Nations  
SDNP - The Malawi Sustainable Development Network Programme

### **1.3 Background**

United Nations defines disability as functional limitations that may occur in any population and in any country in the world. Disability may be permanent or transitory, and can be physical, intellectual or sensory impairment, medical conditions or mental illness. The disability may lead to limitations, discrimination or loss of opportunities which prevent a person from part-taking in life on an equal level with other members of the community (UN 1994).

Recent studies have documented that people with disabilities in several African countries have worse living conditions than people without disabilities. Problems include those of poverty, participation in education and work, and social and health conditions (Eide et al 2003a; 2003b and Loeb & Eide 2004). A study of discrimination and stigmatisation of people with albinism in Malawi concluded that these phenomena did occur, often due to lack of awareness about albinism in the society in which they live. Despite of this the study found no evidence of stigmatisation or mistreatment by family and friends. On the contrary, the study found that people with albinism were mostly treated equally and with respect by their closest relatives and by their friends (Braathen & Ingstad 2006).

### **1.3.1 Violence and abuse against people with disabilities**

International research, mainly from Europe and North America, has shown that people with disabilities are more likely to be subjected to sexual abuse, physical violence and neglect than people without disabilities (Sullivan & Knutson 2000; Hassouneh-Phillips 2005; Octay & Tompkins 2004; Milberger et al 2003; McNamara & Fields 2002, Kvam 2004 and Kvam 2005).

The same is found in Europe (Brown et al 1995; Sørheim 1998; Finndahl 2001). Norwegian deaf respondents reported three times more often that they were victims of sexual abuse than the respondents in a control group of non-disabled people (Kvam 2004). The corresponding number for blind people was a doubled risk compared to the non-disabled (Kvam, 2005).

Abuse, violence, neglect, and other traumas often lead to mental, social or physical problems by the victims (McMillan et al 2001). The problems may turn out as bodily dysfunction (McCauley et al 1997; Kirkengen 2001), mental health problems (Beitchman et al 1992), depression (Ferguson et al 1997; Kendler et al 2000), unsuitable sexual behaviour (Beitchman et al 1992; Sobsy & Mansell 1994), or externalizing behaviour such as aggression and delinquency (Kendall-Tacket et al 1993). The consequences seem to be even more pronounced when the victim has a disability (Cruz et al, 1998; Sobsey & Mansell 1994; Turk & Brown 1992; Kvam et al 2006). However, despite the greater prevalence and seriousness of abuse against people with disabilities, and despite the more pronounced consequences, such acts are less likely to be disclosed (Kvam 2000). It is believed that there is massive under reporting in Malawi, as has previously been documented in other parts of the world (Kvam 2000 and Jewkes et al 2005). Interventions to assist women with disabilities who have been abused have shown promising results; it is therefore important to gain indicators of the extent of the problem in order to plan interventions (Sullivan et al 1996 and Cruz et al 1998).

In this regard, Disabled People's Organisations (DPOs) in the Southern African region has in the past few years started the process of putting issues of sexual abuse, violence and neglect on the agenda. This report from the project Violence and abuse against

women with a disability is a part of the attempt to disclose the nature of abuse, violence and neglect against women with disabilities in Malawi.

### 1.3.2 Context



The **Republic of Malawi** is located in the Southern Central Africa, and has a population of 12, 8 million people. It is a very poor country; one of the 11 poorest in the world by UN estimates. English and Chichewa are official languages, and the literacy rates are 76, 1% for men and 49, 8% for women (GAIA 2006).

Malawi's economy is predominantly agricultural, and approximately 90% of the population live in rural areas (Loeb and Eide 2004, p. 29).

Malawi was a British protectorate, then under the name of Nyasaland, from 1891 to 1953. In 1953 Nyasaland joined a federation with Rhodesia (now Zimbabwe and Zambia), and this federation was dissolved in 1963. In 1964 Malawi became an independent country, with Hastings Banda as president. Banda's presidency soon developed Malawi into a dictatorship (NORAD 2003). After three decades of repressive one-party rule, Malawi became a democracy in 1994, with the election of President Bakili Muluzi (from the United Democratic Front; UDF), who presided for ten years. New elections were held in June 2004, with the election of the current president; President Bingu Wa Mutharika (also from UDF).

The school system in Malawi consists of primary school (standard 1-8), secondary school (form 1-4) and university (4 years). Primary school education is free, but students have to pay school fees to attend secondary school and university (SDNP 2005).

The Federation of Disability Organisations in Malawi (FEDOMA) is an umbrella organisation which was established in 1999. The mission statement of the organisation is to '*enhance the welfare of all persons with disabilities and enable them to assume their rightful role in society*' ([www.fedoma.org](http://www.fedoma.org)).

FEDOMA has seven affiliated organisations:

- Malawi Union of the Blind (MUB)
- Malawi National Association of the Deaf (MANAD)
- Disabled Women in Development (DIWODE)
- Malawi Disability Sports Association (MADISA)
- The Albino Association of Malawi (TAAM)
- Association of the Physically Disabled in Malawi (APDM)
- Parents of Disabled Children Association in Malawi (PODCAM)



## 2 Methods and organisation

### 2.1 Study Design

The data collection methods in this study were qualitative; more specifically one focus group discussion with DPO representatives, one focus group discussion with 4 hearing impaired informants and 19 qualitative individual interviews with women with disabilities. The three interview guides were written by the Norwegian team and revised on the background of comments from FEDOMA and DIWODE. The purpose of the interviews was to gather narratives about circumstances and situations that are expected to increase the risk of violence and abuse in the lives of women with disabilities, as well as the consequences of such abuse.

The study has aimed to understand and explore an area where previous knowledge is very limited. In this project, and others like it, it is impossible to predict the outcome, and hence it is necessary to use methods that will reveal the research questions from the data (Morse & Richards 2002, pp. 27-28).

The aim has thus been to learn from the subjects about their views and knowledge, to explore their points of view. To do this, Morse & Richards (2002) argue that 'you need methods that will allow you to discover and do justice to their perceptions and the complexity of their interpretations' (quote p. 28).

Qualitative research interviews are like conversations, but these interviews are not conversations between equal partners (Kvale 1996, p. 6). The conversations are controlled by the researchers, who are the ones with a purpose and goal with the interaction. The researchers introduce the topics and guide the conversation (Kvale 1996). One of the biggest challenges with qualitative interviews as research methods is the validity of the knowledge obtained for the social world in which it is found (Kvale



1996). Validity is connected to interpretation. This could be the interpretation of the interviewee of the question asked by the researcher, or it could be the researcher's interpretation of the respondent's answer. To ensure validity the researcher must make sure that questions and statements are clear and easy to understand, and avoid ambiguous words and formulations. On the other hand, to ensure the validity of the subjects' responses, the researcher can ask follow-up, -and clarifying questions, or repeat the answer and say 'is that what you are saying?' (Kvale 1996, pp. 217-228).

## **2.2 The research team**

The research team consisted of senior research scientist Marit Hoem Kvam (project manager) and research scientist Stine Hellum Braathen, both from SINTEF Health Research, Norway. They planned the study in co-operation with FEDOMA and DIWODE. DIWODE arranged with Mrs. Maria Phalula to act as an interpreter during the field work together with the Norwegian partners. During these interviews she was trained to take part in the interviews and act as the sole interviewer for the last part of the study. The focus group discussions and the first 12 individual interviews were conducted by the whole team. When the Norwegian team had left Blantyre, Maria Phalula conducted the next 7 interviews alone.

## **2.3 Location**

The study took place in Blantyre district, Malawi. Blantyre district was chosen mainly because most of the DPOs are located in or near Blantyre. The tight budget and timeframe for the fieldwork also made it impossible to travel long distances during fieldwork. Most of the informants were interviewed in their own home, but in some occasions it was more convenient for the respondent to do the interview at their workplace or at the FEDOMA office.

## **2.4 Informants**

Informants in this study were women with disabilities in Malawi. The collaborating partners in Malawi agreed to be in charge of finding informants living in Blantyre district. Criteria for inclusion for informants were that they had a hearing impairment, visual impairment, physical impairment, albinism, or a mental impairment. In interviews with deaf informants, a sign-language interpreter, Betty Wisiki, was used. Women with mental impairment were assisted by a female spokesperson. Informants spoke either English or Chichewa (the most widely spoken local language in Malawi). Women who spoke any of the other local languages were excluded from the study. An English/Chichewa interpreter (Maria Phalula) was present during all the interviews. The informants were 18 years or older, and in cases where the girl with the disability was younger than 18 years, her mother was the informant for the interview.

## **2.5 Meeting with DPO representatives**

A meeting with representatives from DPOs was arranged before the field work started. The meeting took place at FEDOMA offices in Blantyre, and participants at the meeting were representatives from all the DPOs under FEDOMA. FEDOMA has seven member organisations, and for this discussion one or two representatives participated from each organisation, in addition to three people from the FEDOMA general office. The meeting was arranged by FEDOMA and DIWODE, and lasted for approximately three hours. Topics covered in the meeting were the situation for women with disabilities in Malawi, compared to women without disabilities, men with and without disabilities, as well as general issues of violence and abuse against women with disabilities in Malawi (see Appendix 1 for more details). This session gave a good pointer as to what the DPOs know about these issues in a Malawian context, and also helped to identify informants from the different groups of people with disabilities. The interview guide for the qualitative interviews was discussed and finalised in this meeting.

## **2.6 Focus group discussion with hearing impaired informant**

A focus group discussion was conducted among people with hearing impairment (they were all completely deaf). The focus group discussion was chosen instead of individual interviews because of the special communication problems met by deaf people. All the four hearing impaired informants in this group were totally dependent on sign language, so for this discussion a sign-language interpreter was present in addition to the interview team. The interview took place in the FEDOMA offices, and was arranged by FEDOMA and DIWODE. Topics that were covered in this focus group discussion was the situation for women with hearing impairments in Malawi in relation to all aspects of life, as well as issues of violence and abuse against women with hearing impairment (see Appendix 2 for more details).

## **2.7 Qualitative interviews**

Individual, qualitative interviews with 19 women with disabilities were conducted. The interviews were organised in close co-operation with DIWODE, who had also appointed an interviewer/ interpreter to take part in the fieldwork (Maria Phalula). Maria Phalula received training to be able to assist during the interviews and later on conduct interviews on her own. The interviews were based on an interview guide, covering background information including age, type/ degree of disability, additional difficulties/ limitations, housing, work, family situation, children/ the children's father, etc. It was preferable in the interviews with openly and freely told life stories, which described the life-situation for the women. The interview guide asked for issues about childhood and family, disability, human rights and violence and abuse (see Appendix 3 for more details). Most of the interviews were taped in order to ensure good quality of the study.

Sexual abuse and violence are sensitive issues in any context. There are often unreliable figures, and for several reasons difficulties in acquiring information from victims. A particular problem arises due to the fact that many of these problems are found within households, i.e. the victim and the perpetrator will in many instances live under the

same roof. It was therefore critical to identify settings for the interviews where the respondents felt safe, and where anonymity could be ensured. In this study this was done together with the informant.

For informants who had been subjected to violence and/or abuse, the interview team had information about where she could get help and assistance to deal with her problem. This information was found by FEDOMA and DIWODE before fieldwork. The information was on medical treatment, legal support, psychological support and guidance.

## **2.8 Data analysis**

Data analysis was carried out by the Norwegian team in Oslo during August, September, October and November 2006.

## **2.9 Quality assurance/ Ethical considerations**

*'[Qualitative research techniques] are [...] the most invasive, intrusive, and morally challenging; the only reason a researcher should consider using them is that the research problem requires them'* (quote Morse & Richards 2002, p. 29).

Taking into consideration the statement above from Morse and Richards (2002), measures were made in this study to make sure the project was ethical. All participation in this study was voluntary, and the informants were free to withdraw at any time. The informants are and will be kept anonymous. When they are quoted in this report it is without a name reference, and some details in the quotations has been changed to make sure that the quotes can not be traced back to the informants. The information above was given to the informants before the interviews, and they always gave their consent before they were interviewed.

Ethical clearance was sought and obtained from the National Health Science Research Committee in Malawi.

Considerations were also taken as to assure the quality of the study:

- The interview guide was discussed with the organisations in Malawi.
- Two Norwegian researchers were active talking and taking notes during the interviews, together with the Malawian interpreter/ research assistant who was at the same time trained to be an interviewer on her own.
- Detailed notes from the interviews were compared and written down straight after the interviews. The interviews were tape recorded, and in cases of disagreement/ if something was unclear the interviews could be listened to again for clarifications.
- The informants could choose between English or Chichewa language in the interviews.

### 3 Results

As the data collected in this study were all of a qualitative nature, there will be some overlap in the results chapter. Some stories are relevant across chapters and topics. Quotations will be used to underline the results. To keep the informant anonymous the quotations are not referenced with names.

#### 3.1 Description of the informants

All of the informants in this study were women, 18 - 61 years old. Of the 23 informants six were in the age group 18-27 years, eight in the age group 28-37 years and nine were 38 years or older.

Table 1: Age of onset of disability and type of disability by group (N=23)

Type of disability	Age group - years					Total
	0 - 2	3 - 6	7 - 12	13 - 19	20 /more	
Physical	5	3	1			9
Blind	1	2		1		4
Albinism	4					4
Deaf		3			1	4
Intellectual	1		1			2
<b>TOTAL</b>	11	8	2	1	1	23

Table 1 show that physical disability is the most common form of disability in this group (9 people). The women differed in the extent of their physical disability, as some were dependent on using a wheelchair to move, whilst others could move around with a crutch, with callipers, or were just limping. Four women were totally blind and four had albinism. However, the women with albinism had - as part of their disability - a visual impairment, and thus the group of women with visual impairment included eight people. Four women were hearing impaired, all of them totally deaf. The two women with intellectual impairment constituted the smallest group. It is unknown what type of

intellectual impairment they had, but one of them most likely had Down's syndrome. Three of the informants reported that they had more than one disability, which made their situation even more complicated.

One woman with a physical disability and all those with albinism were born with their disability (0 years). The same was probably the case with one woman with an intellectual impairment (probably Down's syndrome), but her parents did not realise her problems until she was about 6-7 years old. Nineteen of the women got their disability before the age of seven. That means that the majority had a disability when they started school. About half the informants said they got the disability after a fever illness (malaria, polio, etc.), three thought (or had thought for many years) that the reason for the disability was witchcraft and some thought it was God's will.

Approximately half of the informants reported that they had grown up in a rural village, and the other half that they had grown up in a town or in a city. Most of them had grown up with both parents, part from four who had grown up with other relatives. All informants had some education. Four had not finished primary school, six had passed form 4 and seven had some sort of higher education (university/ college). Eight of the women had never been married<sup>1</sup>, five were married today, one was a widow, and the rest were no longer married. Three of the women were students in college or at university, four said they were doing business, four worked in an office, three were teachers, four were unemployed and four were doing other kinds of work (one informant did not reply to this question). 13 of the women had children, and one woman had given birth to two children who were both dead, so she did not have any live children today. Most of the women said that all their children had the same father, part from one who had three children with three different fathers. Five of the women

---

<sup>1</sup> They generally used the concept *marriage* synonymously with *living together with a man* as well as *having a marriage certificate* (civil marriage).

said that they, in addition to their own children, also looked after other children who are not their own.

### **3.2 Getting- and living with disability**

Most of the informants did not know for sure the reason why they had become disabled, but they told us what they had heard from parents and other relatives.

*My mother told me that she discovered my albinism one month after my birth. It was so because I was born without hair on my head, so she could not discover my albinism immediately. After one month, she took me to hospital because she noted that my eyes were not like other children. It was then that she was told that I am an albino. ... I don't know why I am an albino.*

Two blind women told us about the reason for their disabilities;

*At three months my eyes became red and gradually degenerated. I became totally blind when I was 5 months. At least, that is what my parents told me. My parents took me to the hospital. The doctor said it was due to lack of vitamin A.*

*According to my parents I was five years old when I had some puss coming from the eyes. Another girl had the same. Both of us came to hospital, and the doctor told me that I was blind. The other girl got her sight back. Maybe I was taken too late to the doctor. They never found out what had happened.*

Another woman, with a physical disability, explained that she got paralyzed after an injection at the hospital;

*I got sick when I was very young - may be 2-3 years. At the hospital the doctor injected me with a needle, and then I got paralyzed in my leg.*

Most of the women emphasized that the parents reacted to their disease or disability in a natural way.

*They took me to the hospital and gave me medicines. They also gave me traditional medicine, and that helped relieve my pain.*

But to some parents it was hard to recognize that their child had become disabled, and they felt ashamed towards neighbours and family. One woman had been abandoned by both parents very early on in her life, and was left to grow up with her grandmother;



*I have never seen my father. And when my mother saw that her baby had this disability, she wanted to throw me away. Then she ran away. I grew up with my grandmother and have never seen my mother. ... I have often been wondering why I am disabled. Maybe my mother took some drugs or did some tricks to have an abortion when she was pregnant? Maybe my mom knows why I am disabled. Abortion is illegal in Malawi, but it is not uncommon for people to try various forms of drugs and traditional healers to induce abortion.*

Another woman had also experienced her parents' shame because of her disability;

*My parents felt bad and would not reveal to their relatives what was wrong with me. They visited a witch-doctor because they thought that I had been bewitched. The witch-doctor told them that I was not bewitched. My parents believed him and they accepted the situation. They took care of me. But they were afraid of having another baby, so they waited for a long time to give me a sister.*

Some parents, family members and people from the neighbourhood had supernatural explanations for the disability;

*I became physically disabled when I was about 19 years old. I was feeling pain on my waist, especially the left leg, and then I could not walk. I stayed in hospital for three months, and later I was told that my leg has been affected by polio. My parents could not believe it, so they took me to a witchdoctor, who said that I had stepped on something which was put by a certain woman who was not happy with me. He said I had been bewitched. ... Other people regard my disability as witchcraft. They say that I fell from a witchcraft airplane at night while going to bewitch other people.*

The informants themselves also sometimes believed that there were supernatural explanations for their disability;

*I think that the disability was caused by jealous people from my village. My relatives were jealous of our family because my mother was the only one who had many children.*

Also the families of the parents (especially the fathers' families) had opinions about the reason for the child's disability;

*My mother told me that they felt that bad luck had befallen them. My father's sister advised my father to chase my mother because they said she was the one who brought bad luck to the family. My father started beating my mother and he stopped caring for us. My mother never gave up and she started for prayer fellowships. After one year of hardship, mother got pregnant again and my father changed his bad character. My mother gave birth to a normal child.*

Most of them said that the families seemed to accept the disability as time passed.

*My mother felt bad at first and when she informed my father, he was equally worried. As time went by, they accepted the situation.*

In one family the disability had turned out to be a positive challenge.

*My mother, after having an albino baby, she trained to be a specialist in optometry. My sister has just finished the same education. To be an albino in Malawi is a big problem. People don't accept, they don't understand. Where I was born there was a white priest. People thought that I was the priest's daughter. But my father did not think so. He is very supportive to my mother and me.*

In many cases the relatives were supportive. They took care of the children in the family, also the disabled child when needed.

*Yes, they assisted my family to take care of me. They said it can happen to any child.*

The informants generally told that they were treated just like the other children in the family. They got the same amount of food and were "scolded" just like the rest of the family. However, a few of them had to move to relatives and part from their siblings. This may have been the best solution for the family at that time, and moving children between close family members is not uncommon in the Malawian society.

**Summary:** As a conclusion on the interviews concerning disability and family life one can say that the parents love their children in Malawi as in any country, and they try to treat them as best they can, disabled or not. According to most of our informants the parents - especially the mothers (or grandmothers) - have been showing love and interest for all their children. Some fathers seemed to have been less interested in the upbringing of the children, and a few felt that the father had left because of the disabled child. The women meant that violence was rare during their childhood, and the parents generally did not use more violence or other forms of punishments against the child with a disability than against the rest of the children.

The poor economical situation was typical to practically all the families. It will therefore be of great help to the families to get economical support when a child has a

disability, so that the extra costs and extra work could be compensated for. More information about disabilities and the needs in that connection would be welcome.

The most striking difference from a traditional European setting is the belief in witchcraft found in some of the cases. However, our informants often claimed that this was not so common today as it used to be. Also the lack of accessibility to technical support attached to the disability is evident, but it seemed that the children were brought to hospitals and medical doctors to be cured as far as possible when they became disabled.

### **3.3 Access to school and education**

For a child with disability education could be difficult. Some of them were not even encouraged to get good marks and take formal education.

*I grew up in a village where people disregarded education. So when I quit school, no one encouraged or persuaded me to go to school. But I regret it now. I am glad that my children are at school.*

Other parents were thinking of education for their children;

*My parents were very considerate. They sent me to a boarding school together with one of my sisters, so she could look after me. It was a catholic school, with catholic sisters and just girl-pupils.*

The economy of the parents (or other relatives) seemed to be an important factor for the education of women with disabilities. Primary education is free (standard 1-8), but they had to pay for secondary education. Several of the informants told us that they had to quit school earlier than they wanted because of shortage of money;

*I did only primary education up to standard 6. I then left school because my father had no money to pay for school fees and school uniform. By then, I was not disabled. After leaving school, I was just at home helping parents with household chores.*

*I only did primary and secondary education - two years of secondary in stead of four - because my father had problems finding school fees.*

Education above secondary school seemed to be closely linked to the parents' economy, as well as the parents level of education. It looks like the higher the parent's education, the more likely they are to give their children a good education.

*I went to college to learn accounting. My parents paid for me.*

Informants with severe physical limitations faced several problems in school situations. Three of them told us that they did not attend school at all for longer periods;

*I got polio when I was 5 years old. I stayed in hospital for 4 months. I had to crawl, because I had no wheelchair. Therefore I could not attend school, but my mother taught me to read and write. I stayed at home until I was 17. Then I got a wheelchair and could be brought to school. I started school in standard five. All the other students were much younger than me. Some teachers said: 'No disabled children can go here!'*

*I lived with my grandmother. I used to crawl in the house, but grandmother used to carry me to school.*

*I became disabled at 1 ½ years. I got malaria, and after that I could not walk. I started using calipers and crutches when I was 13 years old, and then I started school - standard one. Up till then I was just sitting - for ten years! Up till then moving and even eating was difficult, and I could not speak. I learned speaking when I was 13 years old. I started school when I was 15 years old. I was much older than the other children.*

The schools were not adapted to serve children with disabilities. The first point was the access to the school site. The children with albinism were afraid of walking to and returning from school in the sunshine, and thus get sores on their skin;

*I had to use long sleeves and a hat against the sunshine. The school uniforms have short sleeves. I was teased.*

Those with a physical disability had problems with their legs on a complicated pathway. The same was the case for the blind children.

*I could not walk to school. But my father was a postman, and he would sometimes drive me to school when it was necessary.*

The second difficulty was the compartments inside the school, which could be an important obstacle for the learning situation, especially for those with a physical disability.

*In secondary school I went to a boarding school (for girls). I had to change to that school because the steps there were smaller than in the previous school.*

*What was difficult was the toilet situation. The doors to the toilet were so narrow that the chair could not get in. ... There was no lift, so I had to sit downstairs when the education took place on second floor. But the other students took notes for me (Physically disabled woman in wheelchair).*

A third obstacle was the learning material. The women with albinism had troubles reading books and seeing what was written on the blackboard. A special obstacle to the totally blind women was the lack of material in Braille.

*I attended secondary school, which was a boarding school. All the 13 blind students lacked material for blind (Braille books). That was very difficult. A relative paid for me there. ... Afterwards I stayed at home, but somebody told me about an advertisement about teachers college. I applied and came to interview and got a place. The government pays for the study. ... I like all subjects, like life skills, agriculture and mathematics. But I cannot do much mathematics because it is not in Braille. ... I have not yet got the results from the exams, but the other students have. This is because there is no one who can mark exams in Braille, it has to be transcribed into print, and then marked. Now a special teacher will come and translate from Braille into general letters, but he is a specialist in agriculture.*

The women who were deaf during childhood had great problems understanding their teacher. Nobody at the school used sign language during the lessons.

*In school people say teachers should speak to deaf children, not use sign language. There is a battle between hearing society who thinks we should speak, and deaf society who thinks we should sign. I was forced to speak at school and at home, because no one spoke sign language.*

No extra service was given to the girl with Down's syndrome, who went to the local school for many years without learning anything. The mother said:

*My daughter was always alone (at school), and she could not speak, - she was only crying and could not tell me what happened. When she was in Standard two in the normal school, the teacher said to me that (she) was not like the others, that she did not learn anything, and that I should take her to (a special school). I should have taken her to this school much before that. ... She learned to speak here, and she can now write something. (She) likes to be here, and she has many friends.*

Some of them told about teachers that were very thoughtful, while others told us about ignorant teachers. One woman remembered an episode when a teacher in the local school acted in a way she felt was cruel.

*I only experienced psychological abuse when I was at school. Once a teacher asked each of the students to bring six sticks (small but hard). He told each student to break the sticks using the left leg knee - all the sticks at once. Since my left leg is the one which is disabled, I did not break the sticks. The teacher asked me why I did not break them. I tried to explain, but he did not listen and he started shouting at me, saying that I was stupid and that I will get zero marks. I really felt bad in front of the other students, who were also laughing uncontrollably. I felt bad and I could not concentrate anymore in class for two days.*

The other pupils in the class or in the school reacted in different ways to the pupils with disabilities. Some were positive and helpful, but not all.

*One girl in school (deaf boarding school) was taking a bath outside, and she was punished by the sister, who was catholic nun. The girl was beaten with a large stick so that she had to be sent to the hospital.*

*Yes, at the boarding school I was teased at the beginning. But some friends were helpful. They gave me notes, by God's grace.*

*When I started school, my schoolmates used to call me "Mzungu" (European) because I am an albino. I felt bad at first and wanted to quit school, but the teachers encouraged me to attend classes.*

*In school other children were laughing at me, and refusing to sit close to me. They were afraid that albinism is infectious. This was a burden. Also one teacher refused to have me as a pupil, - 'I am not supposed to teach a shortsighted pupil', he said. Because of this teasing I left public school and changed to a private school. It was better at the private school. They often dictated to me when they used the blackboard, because I could not see what was written, and they gave me their notes.*

The teasing of children with disabilities is not uncommon in any country. Also in Malawi it is common, and it is always a burden to the victim. But it seems that most of our informants have coped with the teasing. But for some, as for the girl who could not speak, it was probably a great burden.

The economy and educational level of the parents seem to be determinants in the lives of children with disabilities. There is, naturally, a close link between education and economy, and the children of more educated parents are more likely to go to school, and therefore get better chances in life. This is most likely the case also for children

without disabilities. Parents who are poor are not always able to send all their children to school, but we have found no evidence that children with disabilities are more likely to be excluded from school for this reason.

The mother of a mentally disabled girl followed her and stayed with her at the special school from morning till 12 o'clock to help her get some education. Two informants said that the parents paid for a private school for her as a child to give her a better opportunity for education, even though the informants regarded the parents to be "poor". Often this was the priority of parents who also had some education themselves. In some cases relatives or a non-governmental organization was supporting the education. The government has arranged with loans to college studies, but there is a great problem with getting money for the exam fees.

The lack of adapted schools, teachers of special education and adapted school material is evident. It has been troublesome for the children with a visual or a mobility difficulty to get to the school and to get around in the school; the deaf or blind students rarely have teachers who master sign language or Braille, or material adapted to their educational needs. As told by our informants this is no better today. Hence better technical aids are necessary, as well as adapted books and material. Also it is important to put an emphasis on better education for teachers of special education needs. These teachers will be able to advice the schools as to the best ways of supporting the pupils with special needs, the best ways of using the limited recourses, and the best ways of compensating for the lack of accessibility within the buildings. Also people with disabilities can be trained as teachers of special education needs. It is of immense importance that the people with disabilities are natural partners when national or local school authorities make plans for public education in the country.

Education is perhaps the main key to less discrimination and better integration. One of our deaf informants was educated as a teacher of special education needs. She was proud of her important job. Education makes women with disabilities more self confident. A blind teacher said:

*The blindness has affected my life, but now I have accepted it because of the work I am doing. Blind people can do anything! ... I am a teacher.... And I can cook for the family when I am at home.*

*People have changed their attitude towards me because of what I have accomplished. I have accomplished. ... I have a junior certificate and I also have a teacher's certificate. ... I have a house of my own (woman with physical disability).*

To reach the necessary degree of education it is essential with better grants for women with disabilities who want to study.

*I am still in school, studying business, management and administration (four exams to be passed). The school fees are given me as a loan to be deducted from my work salary later. The examination fee is MK 51 000, but I don't know how to pay that.*

Education is a key to a better life for women with disabilities. It is crucial that the authorities make priorities in that direction and go for a better education from the first day of compulsory school to end of the highest desirable/possible education for a suitable job. As one woman says:

*I want that society should regard disabled as normal. They should have education and get chances from the government. They must get employment. Then they will recognize that disabled people can be capable of any job.*

**Summary:** Compared to other female members of the family our informants were not generally discriminated in education. However, there were exceptions, mainly because of lack of knowledge in the family. Education is perhaps the best way of preventing discrimination, but the Malawian society has made no, or insignificant, efforts to adapt the schools and the curriculum to the informants' special needs. We regard it as crucial that more resources are put into this subject and more consideration given to ensure that children with disabilities have the same access to education as all other children.



### 3.4 Sexual abuse, adult relationships, marriage and family life

We asked the women if they had heard about sexual abuse of children in Malawi. Most of them said that they had learned about it the last years. They had heard it on the radio or they had seen it in the newspaper. But apart from two of the informants, the rest claimed that they did not personally know any girl who had been the victim of sexual abuse.

*I have heard stories, but not about persons I know. I have heard stories of cleansing of HIV, but I do not know if that is why so much abuse happens.*

*I have heard of rape involving two teachers - the girls were not disabled. The first teacher raped a school girl. The girl reported to the authorities, but the teacher refused, saying it was an agreement. The teacher was not punished. The other teacher impregnated another school girl. The girl revealed that it was her teacher. Parents of the girl reported the matter to the District Education Manager and the teacher was dismissed from his service.*

*I heard a story about a mentally disabled child abused by her brother and a blind child abused by teacher. But I do not know them.*

Many of them thought that it was an increasing problem, partly due to the "cleansing of HIV" and partly due to the increase in alcohol- and drug abuse.

*More and more people abuse drugs and alcohol; very often use mandrugs, and when they do they often become violent.*

They were also asked if they themselves had experienced attempts of sexual abuse during childhood. The way the women were acting during the interview and the openness they demonstrated during the sometimes sensitive questions, made us feel that they told us the true story in all the individual interviews. None of the individually interviewed women had - according to their own stories - been the victim of sexual abuse during childhood.

*No, I have never been sexually abused.*

*I have not experienced sexual abuse, only bad language.*

*No. But I have heard of rapes somewhere, but not in our community. I think that people keep secrets.*

Those who had attended a boarding school said that they were glad that the staff consisted of females. The mothers of the girls with mental disabilities had been considering the risk, and therefore took their precautions to prevent their daughters from being abused.

*I am always afraid that some cruel man will come and abuse my daughter. So I make sure that before sunset she is at home in the house.*

*I refuse any proposal from a man - this is to control myself. My mother is also very strict; she does not want me to do the other things that girls do...*

The group interview with sign language interpretation was not as transparent as the personal interviews. This may have made it more difficult for the informants to tell a possible story of abuse and at the same time made it more difficult for the interviewers to detect hesitations and signs of distress.

Some of the informants knew stories of adult women with disabilities who had been victims of sexual abuse.

*I can tell a story from 1989. A lady went to an orthopedic clinic. She had to take of her prosthesis. She was sitting on a chair, unable to move, and the man came and raped her. Another doctor came and saw what happened, and the man was dismissed from his job. But the woman did not receive any help after the assault, and she did not report it.*

Our informants talked much about family and marriage. Most of them had, or wanted to have a husband and children of their own.

*I have no boyfriend or husband and no child, but I want to be married one day and have my own children.*

At the same time they are afraid that disability will make them less attractive. In that relation they gave a hint that some woman with a disability might have smaller expectation and make smaller demands on the personality of the husband. Some confessed that they had been thinking (when they met a man) that "*maybe this is my chance?*" They also noticed that other people often discussed the relationship between a woman with a disability and a non-disabled man.

*It is a problem for me to get married. People say to my boyfriend who is black: Why do you want to be married to such a person? Remember - my father's*

*relatives were saying to him that he should divorce my mother because she had got an albino baby.*

*Women are not a problem, but men were always saying that none of them could propose marriage to me. They said that I would bring bad luck in the family.*

But also when a woman with a disability wanted to marry a man with a disability, she might meet obstacles.

*My right to marry was at one time violated. When my husband came to ask for a hand in marriage, my uncle would not hear of it. He said that the man was disabled, and how were we going to assist each other? The two of us knew what we were doing. You know, he was the first man to propose to me and I knew that he was the one for me. After several meetings with my uncle, he then gave up and now we are happily married.*

Our informants generally used the concept *marriage* synonymously with *living together with a man* as well as *having a marriage certificate* (civil marriage). To be married seemed to be important, and those who were not already married, often mentioned that they wanted to have a family. In connection with marriage some stories were told of mistreatment and sexual abuse;

*Oh no. He did not respect me and treat me well. He said: 'I made a mistake to marry a person with a disability.' He said I should be thankful that he married me. I was more like a slave in the house, and when he came home to find that I was not there, he could accuse me of being unfaithful, and he would often beat me. I had no peace of mind; he used bad words to me and treated me like a slave.*

Some of those who had been married claimed that the husband had left them because of their disability, which he knew about in advance.

*My ex-husband did not contribute at all in the household, even with money. He went out drinking, and probably with other women. Some people were saying to him: Why have you married her? She is disabled. He said: Because I love her. But after that he divorce and by now he has married four women.*

*Women with disabilities are sexually abused by being used as wives. The men give them children and go away. Most disabled are alone with their children. I was abused in this way by my husband. ... I am divorced, - I got divorced in 1977, and he is the father of all four children. He now lives in another place with a new wife and children. He contributes very little with the children, has only paid school fees. He said he was tired of looking after a disabled woman, so he left. He used to say: It is a problem to look after a disabled. He expected more*

*than I could give; or maybe it was only what I thought. I always thought the divorce had to do with my disability.*

One woman blamed her disability for her divorce. But at the same time she is wondering if there are other reasons: ... *or maybe it was only what I thought.* But most of them were certain that when a woman with a disability was abandoned by the husband, it was because of the disability.

*Women with disabilities are more vulnerable. People take advantage of their disability and also the myths that people with disabilities are a cure for HIV. This is not true because any person can have HIV.*

*I met a man who wanted to marry me. He was kind at the beginning, and we had a civil marriage. ... He moved to another town when I was 6 months pregnant. When we met he was already married, but he did not tell me this; he cheated me. Yes, he cheated me. He was already married. He was never brutal to me, but he has got a mental sickness.*

*When I got married, people began saying that the marriage is not going to last because I will not be able to fulfil household chores. When a year passed without me becoming pregnant, they started back-biting and it was worse when the marriage ended.*

*Yes, the men are cheating and tricking – they say they want to marry, but they just want sexual experience.*

*I have three children, and all have different father. I got my first child while I was in school, the father said he would marry me, but he left. The second father said he would marry me, but he left when the baby was 3 months old. Now I am divorced from my third husband. We separated because we were on different class. Since he left there has been no communication. But he did not leave me because of my disability.*

The women were very engaged when they told their stories. They felt that they had been used as sex-partners and that the husbands from the beginning had no intention to marry them and stay with them throughout life. To be left by the husband is a defeat and may cause much sorrow. The families can see their vulnerable situation. But not all men are unfaithful;

*My first husband left me when I got pregnant. So when I met my present husband, my parents were very afraid that I should have to go through the same as with my first husband. So they asked him: Why do you want to marry her? There are so many people without disabilities to marry? He said: I don't see her different from others.*

It is obvious that the informants felt that they were in a vulnerable situation because of the disability. The men took advantage of their situation and promised marriage without seriousness. Their vulnerability could also make them suffer in relation to children. One woman told a story of her own daughter being sexually abused.

*My daughter was sexually abused. She was raped several times from when she was 10 years old till now, when she is 13 years old. I discovered it this year, when I saw that my daughter had some money and some new exercise books. I had to beat my daughter till she told me where the money came from. My daughter then told me that the man used to pick her up from the house and take her to his house. He would give her 100 MK every time, and she would go with him. He is old, and he is married. He used to tell my daughter that he was going to marry her in the future. The girl is now HIV positive. She has got medicines for trying out what she will need. When I found out what had happened, I went to the police, and the case is now in court. The man is now in prison. He said that the girl was his girlfriend, but the police said that she was too young to be that. The girl said that the man had said that if she told anyone he would kill her. The man's family has offered me money not to prosecute him.*

For the mother it has been a terrible experience, and her burden is not lessened when many people say that the abuse of the daughter happened because the mother failed to look after the daughter in a proper way. She herself was doing her best and thought that she was a good mother. One cannot for sure say that the disability of the mother was the reason for the abuse. But one can at least say that her disability may have contributed to the daughter having less resistance (less money) and the offender choosing just that girl (the mother will not discover). And most certainly: The mother feels that her own disability is the main contributing factor.

All the women were eager when asked what could be done. They were glad that it was more openness about the problem today.

*It has been silent when sexual abuse has happened, but now an abuser can be taken to court. I hope in the future that we will have more awareness, lobbying to put up a policy, but we have to go to grassroots for awareness.*

*What can be done? Government should make a policy to make stiffer punishment for men who abuse women. Punishment today - it is a lot of corruption and the offender can easily buy himself free, especially if he has a good position. By law the punishment is minimum five years.*

*Abuse, especially sexual, is bad. It takes away one's virginity and it haunts them forever. One also gets HIV through sexual abuse or rape. Abused women need counselling.*

The family life when the mother had a disability seemed in many ways to be the same as one would expect from other people in Malawi, apart from the fact that many of them had broken marriages. They took well care of their children, wanted them to take education, received help from the family and gave help to the family. It was common to have other children, especially nieces and nephews, living in the household, or they let their own children live with their uncles and aunts for some time when it was convenient.

**Summary:** The informants did not tell us about own personal experiences of childhood sexual abuse. However, the lack of personal stories is no guaranty that sexual abuse has not happened. The informants were eager to tell about sexual abuse in adult life. Many of them used the tern *sexual abuse* about the marriage situation: Men came and offered marriage, but left when the woman was pregnant. They were strongly engaged in this theme and wanted society and the authorities to take action by making also the fathers economically accountable for the children. The bad economy was evident in many of the families with single mothers.

The women with disabilities and their families helped each other when needed. This open and generous family system was a positive surprise to the Norwegian team.

### **3.5 Health**

Most of the women said that their health today is good or okey. A few of the women in the age groups 38-47 and 48-57 said that their health is getting worse every year, and that they experience more pain today because of their disability than they did when they were younger. That was especially common in the group who had mobility difficulties. Even the women who stated that they had good health told us that they sometimes experienced pain because of their disability, or had high blood pressure, a tumor, etc.

Most of the women had access to healthcare through public hospitals or health clinics, but for some the cost of medication was more than they could afford.

A few women had access to health care and free medicines through their job. One physically disabled woman told us that she had high blood pressure and a tumor in her stomach, but apart from that she felt healthy. She has a medical scheme at work, so they go to a special hospital, and they are treated well. Her workplace is especially for people with disabilities, and those who work there get good medical help because of their disability.

Others had problems finding money for their medicine. One woman with albinism had a cancerous growth in her face, but she had to stop the treatment because she did not have money to continue.

Another woman, who stated that her health was good, told us that she visits the doctor every 3 months. She has had high blood pressure, but takes medicine, and she also takes medicine for rheumatism. Before she got that she had to crawl on the floor, she was in so much pain she could not stand up. She complains that it is expensive to go to doctor, and also to get medicine.

A lady with albinism thinks that her health is good, only that;

*I only feel pain in my eyes, especially when I walk in the sun without protective devices, such as sunglasses.*

She only visits the hospital if the pain is acute. She also collects sunscreen lotion from FEDOMA.

Some of the women, however, did not see the need to seek help through healthcare professionals, as their health problems could be solved or caused by other things than bad health and good healthcare. An example of this is when women explained that the cause of their health problem was witchcraft, or bad-wishing from close relatives or

friends. Similarly, one woman with high blood pressure told us that the main reason for her getting better was other people praying for her:

*People are praying for me. And I have cut some food because of the weight.*

Another woman had been given similar explanations for her disease when she was a child, but she did not believe them. She told us that when she was seven years old she got sick. She was taken to a witchdoctor by her parents. She probably had polio. Her leg was damaged. The medicine from the witchdoctor did not help her. The witchdoctor said she had been bewitched, but she did not believe it. She started using crutches two years ago. Now she has also got rheumatism, and the pain of that prevents her from doing a lot of things. Her good leg is burdened and painful as a result of the rheumatism, but she gets painkillers which helps a lot.

Most of the women had only good experiences with the hospitals and health care professionals they had visited, but one deaf lady complained that;

*Health care professionals never speak sign-language; for example when I was giving birth to my first child and the nurse was screaming instructions at me: 'do this, do that'. I said 'I am deaf' and the nurse said 'what do you mean? Don't hear????'*

Visiting a medical doctor is not always giving good results. One woman told a story about a physically disabled lady who went to the orthopedic clinic at the hospital, and she had to take off her prosthesis. She was sitting on a chair, unable to move, and the doctor came and raped her. Another doctor came and saw what happened, and the man was dismissed from his job. But the woman did not receive any help after the assault, and she did not report it.

**Summary:** Most of the informants felt that their health was good, despite their disability, and despite other health problems they may have had. Almost all had good access to health care, only a few told stories of bad health care, such as adjusted health care to people with special needs due to their disability. However, some did not get the medicines they needed because of scarcity of money. It would be of great help to them to get free medical care and medicines needed to compensate for the disability.



### 3.6 Being a woman with disability in Malawi

Some of the informants said that they experienced a triple burden; being a woman, being disabled and being poor. This was also the general point of view of the representatives from the disability organizations. As mentioned earlier, many of our informants had education, but this may not be representative for women with disabilities in other parts of Malawi. Our informants were all living in Blantyre district, and many of them had grown up there. Blantyre is mostly an urban district, and the people living in urban areas are often more educated and more aware than those living in rural districts. Blantyre district (city) is also where most of the disability organizations are situated, and all of our informants were somehow connected to a disability organization. Blantyre has a much better infrastructure than the rest of Malawi, and this can also contribute to making the situation better for women with disabilities in this area. In spite of this, many of our informants felt that they were discriminated against;

*My experience of being a woman in Malawi is that we live a hard life. What I mean is that we struggle, especially when you are a woman with disability. The man suffers at the expense of the family, especially if the woman is not working.*

*Men are pushed up – women are pulled down. It is better now; more girls from the villages are coming to school.*

*Women are nothing to a man, they have no say in anything, they can not say no to anything. They must stay yes thank you, yes thank you. They are forced to say yes thank you. You can not say no to anything concerning the children and the house. The women will not speak their minds when men are present, but they talk when they are only amongst other women. The woman is blamed if a couple can not have children. Are men afraid that women with disabilities can not give them children? Maybe, but they are more afraid of the practical things; can she carry water and so on.*

*My experience of being a woman in Malawi is not good, especially as a blind woman, I feel neglected by the society.*

Discrimination of girls and people with disabilities sometimes start as a early as childhood;

*In education sector women are less favored. Girls are less likely to go to school, especially those with a disability. For an albino it is difficult to go in the sun home by lunch time.*

*A woman must work more than a man. Only 5 of 36 in the government are women. Families prefer girls to be at home and boys go to school. Disabled girls are doubled blow. More disabled are violated. I have not been violated, I hear bad words only. In the minibus I must sit in the front, so that they don't waste time waiting for me to get out. I think 95 % of people with disability are not working.*

Some of the women did not think that being a woman was a burden, but rather having a disability;

*A Malawian woman is like any other woman. But a woman with disability in Malawi is taken as a nobody. I have heard some disabled women speaking on radio but they always sorry or complain of something. This shows that a woman with disability in Malawi is always complaining, there is nothing good for her.*

*A woman with a disability is never taken out by her husband (able-bodied), but often a disabled man is seen out with his able-bodied woman. Still if the man is disabled he is respected more in the family than women. The woman is always controlled by the man. If she borrows money to make some business the man will take the money and use it for other things. If the woman is disabled, may be he will use the money to go out with able-bodied women.*

*There is nothing wrong with being a woman in Malawi. These days women are coming up and are competing with men. A woman with disability faces a lot of discrimination. Sometimes people don't buy from me. They say that I might be better than them. My things are not expensive, and I don't know why they don't buy the things.*

A physically disabled woman told us that she faces a lot of challenges;

*We have a women's group in the community, but when we want to choose representatives, my name is not mentioned. I think it is because of my disability. But I can do better than the able-bodied.*

She also mentioned that some men have commented that if she was not disabled she could have a nice figure and would attract men.

It is important for a woman to be able to fulfil her duties as a woman, but sometimes a disability can stand in the way of her doing her tasks. Several of the women with

physical disabilities said that they had problems doing simple daily life things such as carrying water on their heads, cooking, lifting heavy things with their arms, taking care of the small children, etc. Many of them get help with these chores from their children, neighbors and friends. One woman found it difficult to cook because she could not use the disabled arm to hold a pot when she wanted to cook, and she expressed sadness at this;

*Family and friends feel sorry for me. Even my children fail to go very far or to be away for a long time because they fear that I will not manage to cook. I am able to carry a pail of water or basket on my head, but still I have to be assisted to put it on my head. ...*

*My disability is now getting worse because of my age. I get help around the house from my daughter, and the people in the village/ the neighbors are good to me. I can not carry some heavy luggage, so when I want to go out I need help to carry.*

For some of the women their disability made it impossible for them to carry out certain activities without help, and the help that they need cost money. One blind woman said that she needs someone to assist her for example when she goes to the market, but she can not afford to pay someone to assist her. Another lady with a physical disability said that she needed help to look after her children when they were little, but it was difficult for her to find the money. The women with albinism can not stay outside in the sun, because then they get sunburnt. This is a big problem to most of them, as Malawi is a country where many daily-life activities happen outside. If they want to stay outside they have to use sunscreen (25 or higher), or wear long sleeved clothes and a hat. This costs money, which many of them do not have.

In some households the woman and the man were equal; they both contributed to the household chores, and in the raising of the children. A man's role in the village or family is to make sure that the family has something to eat, while a woman's role is cook and do household chores.

*Both I and my current husband contribute to the household economy. My wage is not good; MK 5300 per month (this is normal in overall society in relation to her education). I have worked at (my job) since 1991, and think my wage should be higher considering how long I have been there. Usually in most Malawian families, the husbands pay for everything, and the wives take care of the family.*

*In marriage women have the same rights. My husband was kind to me.*

*A man's role in the family is the same as a woman's role. They are "one body" and they should do things together.*

Not all of our informants were treated well by their husbands;

*A man thinks that his role is to rule the woman because he thinks that he is better than the woman. But in fact, they are the same and their role in the family is the same.*

In some households the women were left with most of the duties by themselves, even making money and raising the children. Several of our informants had been left by their husbands and the fathers of their children;

*My ex-husband did not contribute at all in the household, even with money. He went out drinking, and probably with other women. Some people were saying to him: 'Why have you married her? She is disabled?' He said: 'Because I love her.' But after the divorce he has married four women!*

*Women with disabilities are abused by being used as wives. They give them children and go away. Most disabled are alone with their children. I was abused in this way by my husband. There is no law to protect the women-such a law could make situation better.*

*Women in Malawi have to face many problems. We are not used to doing so many businesses. Men are not good at helping out in the families.*

Sometimes the mothers of children with disabilities are blamed for their child's disability;

*My father's relatives were saying that he should divorce my mother because she had the albino children.*

*My mother told me that they felt that bad luck had befallen them. My father's sisters advised him to chase my mother because they said she was the one who brought bad luck to the family. My father started beating my mother and he stopped caring for us. My mother never gave up and she started going for prayer fellowships. After one year of hardship, mother got pregnant again and my father changed his bad character. My mother gave birth to a normal child.*

Many of our informants felt abused by men they had had a relationship with in the past. The abuse was seldom physical abuse, but rather what the women referred to as 'being

tricked into marriage'. Mabel described this as; *Able-bodied men come to disabled women and take advantage. Trick them into marriage and later on abandon them. They often get them pregnant also.*

This abuse is not rape, but many of the women sees it as being forced into having sex, and the men promise to marry them. This type of abuse was very common among our informants, and they said it was common in society in general, especially for women with disabilities. The reason why women with disabilities are especially prone to this type of abuse was explained by the women to be that it is difficult for women with disabilities to find someone to marry them, so when someone wants them, they give in easily.

One lady met a man who wanted to marry her. He was kind at the beginning, and they had a civil marriage (marriage certificate). They are still married on paper. He moved to another town when she was 6 months pregnant. When they met he was already married, but he did not tell her this; he cheated her. She got a son 7 years ago. The father assists with some money and some clothes.

*He cheated me. He was already married. He was never brutal to me, but he has got a mental sickness. (My son's) father tried to fool me. People fool me- men- they want sex. But I refuse it nowadays.*

With much keenness several of our informants told us that they were tricked into marriage;

*Men sometimes use violence against women. Mostly with disabled women they just come and give us children and leave. The worst problem is that men are giving them children, and than they disappear. My husband left. He said 'I am coming', but from that time he disappeared.*

One woman told us that as a child, she did not experience any violence, but she takes as abuse the divorce. She said that;

*It was not my wish to be barren, so I was sexually abused and I cannot marry again. Now, I have a man friend (married man) but he only wants to have sex with me. He has never talked of marriage.*

Another woman was sexually abused when she was impregnated with her first child.

*I was sexually abused when I was impregnated with my first child. The man said that he was going to marry me and I was staying with him at my home. When I asked him to arrange for the marriage, he said he had to wait for his only uncle who was in Mozambique. I cohabited with him for eight years and after giving me three children, he left me and I don't know where he is up to now. To me, this was sexual abuse because he only wanted to use me. I don't know his relatives; I only heard later on that he was a business man from Mozambique.*

*Malawian men are difficult to understand. They would propose love to a disabled woman, not out of love, but to abuse her sexually. A certain man proposed to me. After a short time of our affair, he started showing signs of wanting to sleep with me. I resisted, and he called it quits. I knew then that he was not serious.*

Some of our informants were positive about the future, and said that the situation for women in general and women with disabilities was better today than in the past;

*In the past they did not know much, but now they are learning more and can better look after themselves. It has been a problem, but is better today – women can have their own money. Today they get the same education as boys.*

*Women in Malawi are now being recognised may be because of democracy.*

When asked what could be done to empower the women, our informants spoke with great enthusiasm;

*Women should be active, make some groups, not only depend on the men, but make money so that she can assist her children and herself.*

*Get better education and give them jobs, so that they can look after themselves.*

*Information and education is important.*

*Government should empower women with disabilities with various skills for them to be self-reliant.*

**Summary:** Many of the women felt discriminated against because of their gender, and because of their disability. Some felt more discriminated because of their disability than their gender. Discrimination occurs in several aspects of life, but what was talked about the most was discrimination in relation to education and in marriage. Some of the informants felt that they were treated well by men, but many talked about the phenomena of men tricking women into having sex with them. This was particularly

common for women with disabilities, and had happened to several of our informants. When asked what could be done to make the situation better for women, access to education was most commonly mentioned. Some of the women expressed hope for the future, and said that democracy and education had already made the situation better.

## 4 Discussion and conclusion

The overall objective of this qualitative study was to **improve the living conditions of women with disabilities in Malawi** by disclosing and describing the nature of abuse, neglect, violence and discrimination against this vulnerable group. Through the disclosure of the problems the project aimed at giving the disabled people's organisations (DPOs) a document that can be used as a means of influencing and raising awareness among organisations, politicians and policy makers, health care workers, DPO members, and families of people with disabilities.

The results from this qualitative study are not meant to represent the situation for all women with a disability in Malawi. The sample is limited and the informants are not picked by random. The 23 informants were selected through the knowledge of the local disability organisations, mainly through membership. It is likely that members of the DPOs are more aware of their own situation and of human rights than women who have less education and live in the more rural areas of Malawi. At the same time it might be an advantage that the informants had been selected from the DPOs. It is likely that the informants were more willing to tell their stories because their participation in the study was requested from the organisations and not from "strangers".

Another possible bias is that the informants live in the urban Blantyre district. People living in urban or semi-urban areas are generally more educated and better off economically than people in rural areas, and the narratives might have been different if the informants had lived in a more rural area. A third possible bias in this study is the predominance of people with a physical disability. The study did not, however, intend to describe the challenges specific for each group of disabilities, but rather some common traits in the situation for women with disabilities.



An element of uncertainty is the communication situation. Some informants did not speak English, and in these interviews a translator was used. It should be taken into consideration that some information may have been lost in the translation process. We can not say, however, that there was a noticeable discrepancy between the interviews that were conducted in English and those where interpretation was used. It seemed that all informants knew some English and to a certain degree could follow and control the interpretation. Further more, the translator conducted several interviews on her own (after having been trained in interviewing in the interviews she did together with the Norwegian fieldworkers), and the data from these interviews did not differ much from the stories told in other interviews.

A main question is if the informants told the truth. We have no reason to believe that they were telling stories that were faulty, and no inconsistency in the answers was evident. The risk of hiding important information is more probable, but cannot be disclosed.

This study is a pilot study and has given much information about the situation and needs for women with disabilities in Malawi. The results from this study show that almost all of our informants had been treated well and equal to other girls in the family in their upbringing. They felt loved by their parents, or other family members with whom they lived in their childhood. This confirms the results from the study by Braathen and Ingstad (2006) amongst people with albinism in Malawi, which found that they were not discriminated against by their family and friends, but rather treated equal to everyone else. Some of our informants had been brought up by aunts, uncles, grandparents or other family members. It is not uncommon for children in Malawi (disabled or not) to live with other family members than their own parents; this depends on the economy of the parents, and the other family members with whom they live.

When asked about being the victims of childhood sexual abuse, the informants did not confirm such experiences. This is in contrast to research from Europe and North America, which has shown that children with disabilities are more likely to be subjected

to sexual abuse and physical violence and neglect than people without disabilities (Sullivan & Knutson 2000; Hassouneh-Phillips 2005; Octay & Tompkins 2004; Milberger et al 2003; McNamara & Fields 2002, Kvam 2004 and Kvam 2005). There is, however, no overview of the prevalence of childhood sexual abuse in the general Malawian population.

Several of the women complained that they had been sexually abused as adults. This was explained as 'men tricking women with disabilities into having sex with them'. They were strongly engaged in this theme and wanted society to protect the women by making the fathers economically accountable for their children. The bad economy was evident in many of the families with single mothers. The economical situation was also worsened by the extra costs as a result of their disabilities. This is in accordance with results from African studies by Loeb and Eide (2004).

Most of the informants had access to healthcare, but sometimes the health care is not adapted to people with disabilities. Some health clinics are not accessible for people in a wheelchair or people with crutches. Further, health information material is seldom accessible in Braille, and health care professionals rarely speak sign-language. Medicines are expensive, and some women said that they sometimes drop recommended medicine because of lack of money.

Our informants did not complain much about being violated or bullied. However, they often felt neglected. Society often fails to recognise the capability and willingness of people with disabilities to take part in different forms of organisations and social life.

Many of the women expressed a great concern about people with disabilities being excluded from education for various reasons. They stressed the importance of getting good education and a good job, and thus becoming independent of other people. For this reason it is crucial that the government by law provide for schools and school material adapted to people with disabilities and their special needs. Also education of teacher of special education needs is essential. Grants must be offered to those who want to take further education.

As one final conclusion of this study the research team wants to point out the need of better education for women with disabilities as a means of empowerment. Through better education they will get better jobs, become economically more independent and get a higher position in society. Thus the whole group will be more respected and get a better life. In stead of being invisible and neglected, they will be a natural part of the Malawian society and contribute to the family and the society in accordance with their abilities.

## 5 References

- Beitchman, J. H., Zucker, K. J., Hood, J. E., DaCosta, G. A., Akman, D. & Cassavia, E. 1992, 'A review of the long-term effects of child sexual abuse' in *Child Abuse & Neglect*, Vol. 16: 101-118.
- Braathen, S. H. & Ingstad, B. 2006, 'Albinism in Malawi: Knowledge and beliefs from an African setting', in *Disability and Society*, Vol. 21, nr. 6: 599-611.
- Brown, H., Stein, J. & Turk, V. 1995 'The sexual abuse of adults with learning disabilities; report of a second two-year incidence survey' in *Mental Health Research*, Vol. 8: 3-24.
- Cruz, V. K., Price-Williams, D. & Andron, L. 1998, 'Developmentally disabled women who were molested as children', in *Social Casework: The J of contemporary Social work*, Vol. 69: 411-419.
- Eide, A. H., Nhiwatiwa, S., Muderedzi, J., & Loeb, M. 2003a, *Living conditions among people with acitivity limitations in Zimbabwe. A representative regional survey*, SINTEF report no. STF78A034512, Oslo: SINTEF Unimed.
- Eide, A. H., Van Rooy, G., & Loeb, M. 2003b, *Living Conditions among people with Disabilities in Namibia. A National, Representative Study*, SINTEF report no. STF78A034503, Oslo: SINTEF Unimed.
- Ferguson K. S. & Dacey C. M. 1997, 'Anxiety, depression, and dissociation in women health care providers reporting a history of childhood psychological abuse', in *Child Abuse & Neglect*, Vol. 21: 941-952.
- Finndahl, K, 2001, *Vaaga se. En studie av forekomsten av vaald mot kvinnor med funktionshinder*, Stockholm: Forum Kvinner ock Handicap (in Swedish)
- GAIA, 2006, *Global AIDS Interfaith Alliance: Fact Sheet on Malawi*, available at: [www.thegaia.org](http://www.thegaia.org) (retrieved on October 26<sup>th</sup> 2006)
- Hassouneh-Phillips, D. 2005, 'Understanding abuse of women with physical disabilities: an overview of the abuse pathways', in *ANS Adv Nurs Sci*, Vol. 28: 70-80.
- Jewkes, R., Penn-Kekana, L., & Rose-Junius, H. 2005, "‘If they rape me, I can't blame them’": Reflections on gender in the social context of child rape in South Africa and Namibia', in *Social Science & Medicine*, Vol. 61: 1809-1820.

Kendall-Tackett, K., Williams, L. & Finkelhor, D. 1993, 'Impact of sexual abuse on children: A review and synthesis of recent empirical studies', in *Psychological Bulletin*, Vol. 113: 164-180.

Kendler, K. S., Bulic, C. M., Silberg, J., Hettema, J. M., Myers, J. & Prescott, C. A. 2000, 'Childhood sexual abuse and adult psychiatric and substance use disorders in women', in *Arch Gen Psychiatry*, Vol. 57: 953-959.

Kirkengen, A. L. 2001, *Inscribed bodies. Health impact of childhood sexual abuse*, Dordrecht: Kluwer Academic Publisher.

Kvale, S. 1996, *InterViews: An Introduction to Qualitative Research Interviewing*, USA: Sage Publications.

Kvam, M. H. 2000, 'Is sexual abuse of children with disabilities disclosed? A retrospective analysis of child disability and the likelihood of sexual abuse among those attending Norwegian hospitals', in *Child Abuse & Neglect*, Vol. 24, 8: 1-12.

Kvam, M. H. 2004, 'Sexual abuse of deaf children - a retrospective analysis of the prevalence and characteristics of childhood sexual abuse among deaf adults in Norway', in *Child Abuse & Neglect*, Vol. 3: 241-251.

Kvam, M. H. 2005, 'Experiences of Childhood Sexual Abuse among Visually Impaired Adults in Norway: Prevalence and Characteristics', in *Journal of Visual Impairment & Blindness*, Vol. 99: 5-14.

Kvam, M. H., Loeb, M. & Tambs, K. 2006, 'Mental health in deaf adults: Symptoms of anxiety and depression among hearing and deaf individuals', in *Journal of Deaf Studies and Deaf Education*, Vol. 12, No 1: (in print)

Loeb, M. & Eide A. H. 2004, *Living Conditions among people with activity limitations in Malawi: A national representative study*, Oslo: SINTEF Health Research.

MacMillan, H. L., Flemion, J.E., Streiner, D.L., Boyle, M.H., Jamieson, E., Duku, E., Walsh, C. A., Wong, M. & Beardslee, W. 2001, 'Childhood abuse and lifetime psychopathology in a community sample', in *American Journal of Psychiatry*, Vol. 158: 1878-1883.

Map of Malawi, downloaded from:

[http://www.worldtravelguide.net/country/map.ehtml?o=158&NAV\\_guide\\_class=&NAV\\_Region=&NAV\\_SubRegion=](http://www.worldtravelguide.net/country/map.ehtml?o=158&NAV_guide_class=&NAV_Region=&NAV_SubRegion=)

McCaley, J., Kern, D.E. & Kolodner, K. 1997, 'Clinical characteristics of women with a history of childhood abuse: unhealed wounds', in *JAMA*, Vol. 277: 1362-1368.

McNamara, J. R. & Fields, S. 2002, 'Perceived abuse and disability in a sample of Ohios' women's correctional population', in *Psychol Rep.*, Vol. 91, No 3: 849-54.

Milberger, S., Israel, N., LeRoy, B., Martin, A., Potter, L. & Patchak-Shuster, P. 2003, 'Violence against women with physical disabilities', in *Violence Vict.*, Vol. 18, No 5: 581-91.

Morse, J. M. & Richards, L. 2002, *Readme First for a User's Guide to Qualitative Methods*, USA: Sage Publications.

NORAD, 2003, *Malawi: Bakgrunn*, NORAD, Oslo, Norway. Available at: [www.norad.no](http://www.norad.no) (in Norwegian).

NORAD, 2003, *Fakta om Malawi*, NORAD, Oslo, Norway. Available at: [www.norad.no](http://www.norad.no) (in Norwegian).

Octay, J.S. & Tompkins, C. J. 2004, 'Personal assistance providers' mistreatment of disabled adults', in *Health Soc Work*, Vol. 29, No 3: 177-88.

SDNP, 2005, *Education in Malawi*, Available at: <http://www.sdn.org.mw/edu/new/> (retrieved on October 26<sup>th</sup> 2006).

Sobsey, D. & Mansell, S. 1994, 'Sexual abuse patterns of children with disabilities', in *The International Journal of Children's Rights*, Vol. 2: 96-100.

Sullivan, P. M., Knutson, J. F. & Scanland, J. M. 1996, *Psychotherapy for sexually abused children with disabilities*, National Clearinghouse on Child Abuse and Neglect, Iowa: University of Iowa.

Sullivan, P. & Knutson, J. F. 2000, 'Maltreatment and Disabilities: A population based epidemiological study', in *Child Abuse & Neglect*, Vol. 24, No 10: 1257-1273.

Sørheim, T. A. 1998, *Vanlige kvinner - uvanlige utfordringer*, Oslo: Universitetet i Oslo, Inst. for allmenntmedisin og samfunnsmedisinske fag (in Norwegian).

Turk, V. & Brown, H. 1993, 'The sexual abuse of adults with learning disabilities: Results of a two-year incidence survey', in *Mental Handicap Research*, Vol. 6, No 3: 193-216.

United Nations, 1994, *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, UN, New York.

# Appendices

## Appendix 1

### *Agenda and information to the participants of the DPO meeting*

#### **1. Presentation of the researchers**

Names:

- Senior researcher Marit Hoem Kvam, Doctor in Special Education Needs.
- Researcher Stine Hellum Braathen, Master in international community health

Work place: SINTEF Health in Norway (the largest research organisation in Norway with about 1700 employees, mainly technically orientated, but we work in the Health Department of SINTEF)

#### **2. The study**

This study is initiated by us in co-operation with Norwegian organisations for people with disabilities. The goal of this study is to disclose the situation for women with disabilities, in order to improve their situation. We want the authorities to know what it is like to be a girl or woman with a disability, so that legislations and local society can be better adapted to the actual needs. The project is planned in cooperation with SAFOD, FEDOMA and DIWODE, and will be carried out by FEDOMA, DIWODE and SINTEF.

We will interview 20-25 women (18 years or more) with different types of disabilities. That means that we would like to get in contact with 3-4 women from each DPO (hearing impaired, visually impaired, with a motor disability, a mental disability or other forms of disability). We sincerely hope that you can help us identify informants for our interviews. The women you identify will - of course - be told that the interview is voluntary. They will be informed about their right to refrain from answering any question, and at any time stop the interview. All the information we get will be kept anonymous. No respondents' name will be used in our papers and reports, and it will not be possible to trace the answers back to the person who gave the information. The study is approved by the ethical committee in Malawi.

- Questions and comments about the study/ the researchers.

#### **3. Each group make a short presentation of their organisation.**

- Which organisation do you belong to?
- How is your organisation organised (nationally and locally)?
- How old is the organisation?
- How are members recruited?
- How do you keep contact with your members?

- How many members are there (nationally and locally)?
- What is the problem when you try to find new members?
- What about the economy? (Funding?)
- Employees or voluntary workers (nationally and locally)?
- How do you work? Plans - wishes for the future.
- How do the authorities regard your organisation?
- What are the obstacles you meet in the work?
- How can you make the situation better for disabled people?
- What do you wish for the future for your national as well as your local organisation?
- (If you have got pamphlets or written papers to give us, we would appreciate it very much!)

#### ***4. Questions to the groups***

- Are girls and women with disabilities visible in society? (Compared to boys and men?)
- Are girls and women with disabilities discriminated against (compared to non-disabled peers/to non-disabled males?)
  - In education?
  - In work? (Wages?)
  - In family position?
  - In economic affairs?
  - In matters of health and care?
  - In society?
- Do you know of any myths about women with disabilities? In relation to sexuality, marriage, family life, etc. What are they?
- How are women with disabilities different from non-disabled women in Malawian society?
- What makes women with disabilities more exposed to different forms of violence and abuse?
- Sexual abuse
- Physical violence (in what situation do violence occur; in relation to power, drugs/ substance abuse - alcohol, etc.)
- Psychological abuse/ neglect (in what situation do violence occur; in relation to power, drugs/ substance abuse - alcohol, etc.)
- What should a woman do when she has been subjected to violence or abuse?
- What should/ can society do to help a women who has been abused?
- What is done in reality?
- Do you have any comments/ advice in relation to the project proposal and the interview guide?

#### ***4. Help to identify informants:***

- 3-4 from each organisation
- From Blantyre/ Thylo/ Chikwawa areas



- Has to be familiar with issues of violence and abuse, either because they have experienced it themselves, or because they know of someone close to them who has experienced it
- Above 18 years of age
- Has to be women with disabilities

## **Appendix 2**

### ***Interview guide for focus group discussion with informants with hearing impairments/ deaf informants***

#### ***1. Thank you!***

Thank you very much for agreeing to talk to us. We appreciate your willingness and generosity to make time to talk to us. Your stories, opinions and impressions are of great importance and value for the results of the study that we are doing.

#### ***2. Presentation of ourselves***

First of all we would like to present ourselves and the project, so that you know more about us and about the study.

Marit: My name is Marit Hoem Kvam, and I am a specialist in Special Education Needs. I have been working with deaf and hearing impaired people, with blind, and with people with Cerebral palsy. I have worked with children as well as grown-up people.

Stine: My name is Stine Hellum Braathen. In 2004 I lived in Malawi, doing a study on albinism in Malawi. In Norway I have previously worked with children with disabilities, and now I work in research with disability related topics.

We both work as researchers at SINTEF Health. SINTEF is the largest research organisation in Norway, mainly technically orientated, but we work in the Health Department of SINTEF.

#### ***3. The study***

This study is initiated by us in co-operation with Norwegian organisations for people with disabilities. We all believe that in all societies - in Norway as well as in Malawi - women, both disabled and non-disabled, have worse living conditions than men. The goal of this study is to disclose the situation for women with disabilities, in order to improve their situation. We want the authorities to know what it is like to be a girl or woman with a disability, so that legislations and local society can be better adapted to your needs. Thus you are helping other disabled girls and women to get a better chance in life.

Everything you tell us will be kept anonymous. Your names will not be used in our papers and reports, and it will not be possible to trace the answers you give back to you.

Do you have any questions about us or about the study?

#### ***4. Disability***

- How do people look at hearing impairment/ deafness?
- How do you look at it?
- How do your disabilities affect your lives?

- When did you become disabled (or get the diagnosis)? Tell us what happened.
- Do you have any other disabilities?
- How do you feel/ what do you think about your disability?
- Your disability - does it prevent you from doing many things?
- What do you think are the reasons for your disabilities?
- What do your families say about your disabilities? Tell...
- What are your friends saying about your disabilities? Tell...
- What do strangers say about your disabilities? Are you met with any prejudices? Tell...

### **5. Family**

- Does it affect the people in your families that you have hearing impairments/ are deaf? How?
- Does it make a difference for people who are deaf/ have hearing impairments in terms of getting married and/ or having children?

### **6. Human rights**

*How does hearing impairment/ deafness affect the following areas of life;*

- School
- Job
- Health care
- Economy
- Are girls and women with disabilities discriminated against (compared to non-disabled peers/to non-disabled males)?
  - In education?
  - In work? (Wages?)
  - In family position?
  - In economical affairs?
  - In matters of health and care?
  - In society?

### **7. Violence and abuse**

*All over the world women have lower rang in society than men, adults as well as children. In addition women are physically weaker, and have more difficulties defending themselves from physical violence and abuse. People with disabilities, especially women, are even more disadvantaged.*

- What is it like to be a woman in Malawi
- What is it like to be a woman with a disability in Malawi
- What is a man's role in the society/ in the village/ in the family
- What is a woman's role in the society/ in the village/ in the family
- What kind of help/ support (if any) do you receive as a woman and as a person with a disability?
- How are children punished in Malawi
- How are children with disabilities treated compared to children without disabilities

- What is life like for a child with hearing impairment/ deaf child?
- Do you think many children with hearing impairments/ deaf children experience violence? Tell... Have any of you experienced violence as children? Do you think this had to do with your disability? Tell...
- Do you think many women with hearing impairment/ deaf women experience violence or abuse? Have any of you? Tell... (What kind of abuse, how often, by whom, what happens, in what situation do violence occur; in relation to power, drugs/ substance abuse - alcohol, etc.)
- What can be done to help women who have been exposed to violence and/ or abuse? What IS done?
- What do you think is the reason why some women with hearing impairments/ deaf women are exposed to violence and/ or abuse? Do you think they/ you are more exposed to violence and/ or abuse?

## Appendix 3

### *Interview guide/ Women - Malawi*

#### **1. Thank you!**

Thank you very much for agreeing to talk to us. We appreciate your willingness and generosity to make time to talk to us. Your stories, opinions and impressions are of great importance and value for the results of the study that we are doing.

#### **2. Presentation of ourselves**

First of all we would like to present ourselves and the project, so that you know more about us and about the study.

Marit: My name is Marit Hoem Kvam, and I am a specialist in Special Education Needs. I have been working with deaf and hearing impaired people, with blind, and with people with Cerebral palsy. I have worked with children as well as grown-up people.

Stine: My name is Stine Hellum Braathen. In 2004 I lived in Malawi, doing a study on albinism in Malawi. In Norway I have previously worked with children with disabilities, and now I work in research with disability related topics.

We both work as researchers at SINTEF Health. SINTEF is the largest research organisation in Norway, mainly technically orientated, but we work in the Health Department of SINTEF.

#### **3. The study**

This study is initiated by us in co-operation with Norwegian organisations for people with disabilities. We all believe that in all societies - in Norway as well as in Malawi - women, both disabled and non-disabled, have worse living conditions than men. The goal of this study is to disclose the situation for women with disabilities, in order to improve their situation. We want the authorities to know what it is like to be a girl or woman with a disability, so that legislations and local society can be better adapted to your needs. Thus you are helping other disabled girls and women to get a better chance in life.

We are going to ask you about your childhood and about your adult life.

You may find some questions difficult to answer, or you don't want to answer them. You are, of course, fully entitled to refuse to answer any questions you don't want to answer. You may also - at any time - say that you want to stop the interview, and we will respect your decision.

Remember also that everything you tell us will be kept anonymous. Your name will not be used in our papers and reports, and it will not be possible to trace the answers you give back to your name and your person.

Do you have anything you want to say or any questions before we start the interview?

#### 4. *Background and family*

- When were you born? (Age)
- Where were you born? (In a small or large village? In a hospital or at home?)
- Are your parents alive? Where? Tell us about them (age, work, health...).
- Do you have many sisters and brothers? Tell us about them.
- Are you married? Tell us about your husband (age, work, health ...).
- Tell us about your marriage (your tasks, your day).
- Do you have any children (with your husband or with other men)? (How many children do you take care of?) Tell us about them (age, schooling, health...)

#### 5. *Disability*

- What do you regard as your disability? (More than one disability?)
- When did you become disabled (or get the diagnosis)? Tell us what happened.
- Do you have any other disabilities?
- How do you feel/ what do you think about your disability?
- Your disability - does it prevent you from doing many things?
- How do you feel your disability is limiting you?
- What do you think is the reason for your disability?
- What did (does) your family say about your disability? Tell us more.
- What did (do) your friends say about your disability? Tell us more.
- What do strangers say about your disability? Are you met with any prejudices? Tell us more.

#### 6. *Human Rights*

Health Services/ Personal health

- How is your health?
- Do you have any diseases?
- Do you often go to the hospital/ health clinic? Why/ why not?

School

- Have you/ are you currently attending school? What standard have you finished in school?
- When did you quit/ finish school?
- Why did you quit/ finish school?
- Who made the decision that you should quit school?
- What have you done after you quit school/ what did you do immediately after you quit?

Job

- Do you have a job?
- What is your job?
- Is it your wish to work/ not work? Why do you work/ not work?

- What kind of job do you wish to do/ would be suitable for you?

#### Economy

- How is the economy in your family? (Who earns the money?)
- How does your/ your family's economy affect your/ your family's life?

#### 7. *Violence and abuse*

All over the world women have lower rank in society than men, adults as well as children. In addition women are physically weaker, and have more difficulties defending themselves from physical violence and abuse. People with disabilities, especially women, are even more disadvantaged.

We would like to hear about your life; your childhood, your adolescence and your life as a woman, and as a person with a disability. We would like to hear about your experiences, your views, your beliefs and your thoughts, both positive experiences and negative ones.

- What is your experience of being a woman in Malawi?
- What is your experience of being a woman with disability in Malawi?
- What is a man's role in the society/ in the village/ in the family
- What is a woman's role in the society/ in the village/ in the family
- What kind of help/ support (if any) do you receive as a woman and as a person with a disability?
- Do you experience people working against you because of your gender or because of your disability? How?
- Do you experience people helping you especially because of your disability? How?
- Tell us about your relationship with your family, community, neighbourhood and local environment

#### Childhood

- Were you ever punished as a child (compared to your sisters and brothers)? How?
- How were you treated in your family as a child (compared to your sisters and brothers)?
- How did the women behave towards to you?
- How did the men behave towards you?
- Growing up conditions: Were you treated equal to the other kids in the family/ community (compared to other non-disabled children and to boys)?
- Did you get enough food? Good care? Were you seen and treated equal to other siblings?
- What were your chores?
- What kind of help and support (if any) did you get?

- Were you or any of your siblings subjected to any types of violence in your childhood? If so; why, how, by whom, how often, in what circumstances, when, etc.?
- To what degree did your disability influence on the possible violence?
- If it happened; what did the other people in the family say/ do?
- How was corporal punishment seen in your childhood?
- How was violence seen in your childhood?

## Violence

- Have you ever experienced something that you would call violence in adult life (physical/ psychological)? Tell...
- How often does/ did/ has it happened?
- What happens?
- What do you do if you experience violence?
- Does anyone else know about this? What do they do?
- What does the offender do?
- Is he/ she offending anyone else but you that you know of?
- Ask about practices that we have heard of in relation to violence and abuse, do the woman know about these practices, what does she know? Tell...
- Do you know if there have been rapes in the village/ community/ area where you live? How common is it? Who are the offenders (rapist)? Who are raped?
- What is in your opinion the reason for rapes taking place?
- What do girls/ women do if they have been raped (is it kept a secret, or is the rapist prosecuted and/ or punished?)
- Do you know of other forms of abuse that take place in the village/ community/ area where you live? How common is it? Who are the offenders? Who are abused?
- Has any of this happened to you?
- What happened to you? Tell...
- Have you told anyone about this? Who?
- What are people's reactions to what you have experienced? Are you supported?
- How often does assault happen?
- How old were you the first time it happened?
- How does assault happen? Tell...
- Is it still happening?
- How was/ is your reaction to abuse?
- What did you do after the abuse (Tell someone? Seek medical help? Prosecute? Reported to the police?)
- What do you think could be done to prevent abuse against yourself and against other women?
- What do you think is the reason why you were abused? (Was it connected to your disability?)
- How can an abused woman be helped?
- What kind of help would you wish for?



- Do you know of anywhere women can go to get help if they have been abused? Have you been there?
- If you have not been exposed to violence or abuse; do you think that women with disabilities are more vulnerable to these conditions? Why/ why not?