THE CALL ON HIV/AIDS AND REPRODUCTIVE HEALTH CARE AMONGST DISABLED PEOPLE

November, 2008

A collaborative project between
The Centre for Rehabilitation Studies
Stellenbosch University,
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Unit on Research for Health and Society

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Commisioned by: SAFOD

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1. Introduction

Reproductive health has been defined as a state of complete physical, mental and social well-being in all matters related to the reproductive system *(Population, Reproductive Rights and Reproductive Health with special reference to HIV/AIDS)*. By implication, it means that all people should have a satisfying and safe sexual life. Disabled people should be allowed to reproduce while maintaining the freedom to decide when and how often to do so. This requires that sexual health be included in the entire health package to enhance the personal lives of PWDs so they can take care of any sexually transmitted disease by engaging in prevention activities as well as seeking early intervention *(Population, Reproductive Rights and Reproductive Health with special reference to HIV/AIDS)*. It is within this context that this pilot study seeks to explore the experiences and support given to disabled people in respect of reproductive health and HIV and AIDS in Malawi and Namibia.

2. Methodology

The methods employed in this study were informed by the principles of emancipatory/participatory research which seeks not only to engage participants as subjects, but as equal partners in the research process. This means that disabled people were supposed to participate in the formulation of questions to be asked and then actively participate in the collection and analysis of data together with the appointed researcher. It was envisaged that such a process would not only build research capacity amongst disabled people, but would also allow them to take ownership of the project.

To this effect, in the planning phase of the project, it was envisioned that three visits to each of the target countries would be necessary. The first visit would aim to build relations and map the way forward with DPOs and local researchers. The second visit would involve training of research assistants, including undertaking at least one field trip as part of the training process. Then the researcher and research assistants would be left to carry out the rest of the study and produce a preliminary report. The last visit would be to follow-up and present findings to participants, receive feedback and compile the final report.

However, some of the above plans did not materialise primarily because of time and financial constraints. Apart from the delay in transferring funds to Stellenbosch University, SAFOD gave very tight timeframes that did not match the unforeseen financial implication and long processes involved in the application of ethical clearance in both countries (which is still outstanding). The Stellenbosch University requirements for use of funds entrusted in their care was equally an obstacle to meeting the time frames in this process. The system expects researchers to spend their own money and claim for it on production of receipts, and the invoices to be presented in a specific format. This process was not practical and was a challenge for non-US researchers and DPOs in the target countries.

Nevertheless, in the light of the above challenges, the visits to the two countries were reduced to two instead of three. The first trip served as both an introductory and training one and the second trip was a follow-up workshop to verify and consolidate the findings with the local researchers and the participants. Furthermore, time and financial constrains reduced the initial training period to one instead of three days, which would have included a field trip, conducting at least one focus group discussion and transcribing verbatim as well as analysing the data as part of the training process.

This situation raised different challenges for Namibia and Malawi. The Namibian research was driven by an experienced researcher in collaboration with DPOs, while the Malawian research was driven by the DPOs and a freelance local researcher, as an experienced researcher could not be found at such short notice.

2.1 Malawi

To achieve the objectives of the study a qualitative research paradigm was used. Individual in-depth interviews with six key informants were conducted as well as eight focus group discussions with disabled people from different disability groups.

This study created an opportunity for the local researcher to work with three disabled research assistants. All four were involved in the data collection process, transcribing and typing of the transcripts as well as translation of the transcripts from Chichewa to English. Thus, disabled research assistants were equal partners throughout the research process. Their participation had a positive impact on the participants who openly shared their experiences with fellow disabled people who they considered understood the issues well. This was one way of building capacity amongst disabled people who are often used as research subjects rather than drivers and equal partners in the research process.

Owing to the long process required to apply for national ethical clearance, as well as the fact that this was only a pilot study, the Federation of Disability Organisations of Malawi (FEDOMA) provided permission for interviews to be conducted amongst its members. It is hoped that plans for the bigger study would take into consideration the requirements for national ethical clearance.

2.1.1 Follow-up workshop

A one day workshop was held at FEDOMA offices in Blantyre on Thursday, 24 October 2008, which focused on reflection and drawing on the experiences of participants. It was attended by 12 participants from NGOs and DPOs (MAP, DIWODE, APDM, MACOHA, MADISA, APDM) who are members of FEDOMA, as well as three research assistants, the local researcher and a research consultant from CRS. Participants were drawn from all disability groups, including those with mobility impairments, visual and hearing impairments. Although the workshop was conducted mainly in English it also allowed for translations in Chichewa, the local language. The response to the workshop was largely positive as participants confirmed the findings of the pilot study (See appendix 1).

2.2 Namibia

Interviews were conducted with six key informants as identified during the start-up workshop of the research project. However, only three instead of eight focus group discussions were conducted with disabled persons from different disability groups because of challenges in working with disabled research assistants, who should have helped in the identification of participants.

Some key informants were unwilling to participate in the study without official approval from the Ministry of Health and Social Services and especially the National Ethics Committee. A submission was made to the Ministry for ethical clearance. But since this was a pilot project, we had neither the time nor the resources to follow through the whole process of ethical clearance. Instead we decide to seek permission from the National Federation of People with Disabilities in Namibia (NFPDN). Approval from the Ministry of Heath is still outstanding.

In some cases, key informants requested that we write to their Permanent Secretaries seeking approval for such officers to participate in interviews. In this case, the Ministry of Gender Equality and Child Welfare, as well as the Ministry of Health and Social Services. We drafted and submitted letters as requested and were granted audience with the relevant staff members of the mentioned Ministries.

The research assistants who had been identified at the initial workshop did not show up when it was time to collect data. Thus, in most cases interviews were conducted by staff of the Multidisciplinary Research Centre (MRC) For example, one of the trained research assistants was an employee of a DPO and was out of town attending a training course.

During focus group discussions it emerged that women in the groups were not keen to elaborate on reproductive health issues. This prompted us to form separate groups of women or men only.

Another drawback for the research team was the difficulty identifying participants with various forms of disability to participate in each focus group. However, all the groups as well as the key informants raised the same point over and over again so there was no need to keep asking the groups the same questions since a point of saturation had been reached.

2.2.1 Follow-up workshop

A one day follow-up was held in Windoek, Namibia with the following participants:

Name	Gender	Contact number	Disability/ organisation
Francina Hambira	F	0813933008	NADAWO – physical
Johanna	F	0813310642	CRAVI – visual impairment
Adriano Lisimu	M	0812959863	NAPPD – physical
Sylvia Chidunka	F	0812983557	NFPDN – parent
Elton Kasuto	M	0812134022	NFPDN – physical
J.S. Ambunda	M	081275506	Health – disability and rehabilitation

The response to the report was very positive. They felt that it covered the issues and highlighted aspects that disabled people would like to make others aware of. They felt that it was a good reflection of their comments and that it expressed their views in a satisfactory way (See appendix 2).

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3. *The Aim of the Study*

The aim of the pilot study was to establish HIV and AIDS and sexual reproductive health needs amongst people with disabilities in Malawi and Namibia.

4. *Objectives of the Study*

i To explore perceptions, knowledge, attitude and practices of sexuality and HIV and AIDS amongst people with disabilities
ii To identify the contexts and extent of sexual abuse of women and children with disabilities
iii To assess the extent to which disabled people access sexual and reproductive health services including HIV and AIDS
iv To gain an understanding of the constraints and opportunities that disabled people experience when trying to access sexual and reproductive health services
v To investigate the inclusion of disabled people in HIV and AIDS policy formulation and strategies to combat HIV and AIDS
vi To explore the role of families and community supports for persons with disabilities who have HIV and AIDS; produce outputs that will be applicable in a Community-based Rehabilitation (CBR) context (this will make the project sustainable over time)

5. *Demographic Data*

5.1 Malawi

The age groups across gender represented in the study were between 13 and 60 years. There were 10 children under the age of 18 and the rest were adults. (There is a need to get clarification from the local researcher regarding the measures that were taken to ensure ethical consent from parents and care givers of children under the age of 18).

5.2 Namibia

Name	Age	Gender	Occupation	Type of disability
G. Mutendere	37	M	Project Manager	Physical
Makari	41	M	Advocacy Officer	NANASO
Ilonga Simon	31	M	Researcher	Ministry of Gender Equality and Child Welfare
Dietrich Remmert		M	Senior Liaison Officer	Ministry of Health and Social Services
Anna-Lisa Nekwaya		F	Chief Control Officer Rehabilitation	Ministry of Health and Social Services
Jonas S. Ambunda		M	Chief health Programme Administrator	Ministry of Health and Social Services
Frieda Taapopi		F	Senior health Programme Administrator	Ministry of Health and Social Services
Francina Rusbooy		F	Senior health Programme Administrator	Ministry of Health and Social Services
Francina Hambira	22	F		Physical
Elizabeth Kahenge	27	F		Visual
Ndapuka Albertina	26	F		Physical
Miriam Shimbilinga	45	F		Visual
Kucia Nghuuhange	31	F		Visual
Sylvia Chidunka		F		Parent having a child with disability
Adriano Lisimu		M		Left leg deformed
Hileni S. Endjala		F		
Selma Mukalele		F		Visual
Emgardt Iitula		F		Limping
Elton Kasuto		M		Physical Wheel chair bound
Maria Uanivi		F		Physical
Johanna Amukwaja		F		Visual
Elia Shapwa		M		Deaf
Mirjam Sam		F		Physical
Vilho Kandume		M		Deaf
Valery Bednus		F		Deaf
Peter Mbwale		M		Sign language interpreter
Tjiueza Tjombumbi		M	Disability Advisor to the Prime Minister	Physical
Antsino Nuusiku		F	Education Officer	

The above table shows the profile of the key informants and members of focus group discussions in Namibia.

6. Study Setting

6.1 Malawi

The study was conducted in Blantyre at the following institutions, including one residential area:

- The Federation of Disability Organisations of Malawi (FEDOMA)
- Malawi Council for the Handicapped (MACOHA) Head office
- MACOHA Weaving factory
- Malawi Against Physical Disabilities (MAP)
- Montfort Schools for the Blind
- Chileka women
- Various government ministries and organisations

6.2 Namibia

The study was conducted around suburbs in Windoek

7. Data Collection

Two methods of data collection were used, namely, individual in-depth interviews and focus group discussions.

7.1 Malawi: Individual in-depth interviews

As previously stated, individual in-depth interviews were conducted with six key informants from the District Commissioner's office and the District Health Office. Others were drawn from non-governmental organisations such as the Federation of Disability Organisations of Malawi (FEDOMA), Malawi Council for the Handicapped (MACOHA) and Malawi Union of the Blind (MUB). The Special Assistant to the President on Disability Affairs also participated. All interviews were audio-taped and they lasted about an hour. Data were transcribed word for word and transcripts were stored with the local researcher.

7.2 Malawi: Focus group discussions

Participants to the eight focus group discussions were drawn from students at Nguludi Schools for the Blind (girls and boys, two groups). Employees at the MACOHA head office (one group) and the Bangwe Weaving factory (two groups). Other participants were drawn from Malawi Against Physical Disabilities (MAP), FEDOMA and the Chileka women with disabilities. Different disability groups were represented in all the focus group discussions and there was equal representation across gender and age. There were participants with visual impairments, those with albinism, physical disabilities, speech and hearing impairments and mental health impairments.

Each focus group discussion comprised five to eight participants. Some groups comprised male or female participants only and others both sexes. All interviews were conducted in Chichewa and audio-taped. Interviews were transcribed word for word and transcripts were then translated from Chichewa into English.

7.3. Namibia: Individual in-depth interviews

As previously stated, six key informants participated in individual in-depth interviews, followed by focus group discussions in which disabled people from various disability groups participated. Some focus group discussions comprised women only, young people alone and others had both men and women participants.

8. Data Analysis

Thematic content analysis was done based on the following pre-determined themes:

- Social relationships
- Sexuality and gender
- Sexual and reproductive health care
- HIV and AIDS prevention

Emerging themes arising from the data were also noted alongside the above themes. Letters of the alphabet were used in referring to participants in order to protect their identity.

9. Findings

9.1 Malawi

9.1.1. Social Relationships

Most participants were married with children of their own, except for a few that are single. Similarly, most participants were employed except for the women in Chileka and the students from Montfort School for the Blind. Those who are not employed had working spouses or business men and women spouses. There were a few couples that run joint businesses together. Owing to the nature of their jobs and the little salaries they earn, most of the employed participants wished they would be involved in small businesses as well to supplement their income, but they lack financial resources to do so. The following were some of their comments:

A: The first source of income is through employment. Secondly, is that I have my own plans which I use to source money. I have a house for rent where I get money every month end on top of my salary. My wife is a business woman; she sells freezes, vegetables and spices.

B: I earn a living from my salary and I do farming business and other things, I also do shoe repairing during my free time.

C: Besides my salary I am a tailor. During my free time I sew.

D: I depend on my salary.

The above quotations show that although they are working, the participants' salaries are not adequate. Therefore, they expressed the need for extra money to assist them start small businesses in order to help supplement their salaries. Most participants indicated that they spend their free time listening to the radio, taking care of their homes and sharing the Word of God. Some said they spend their free time chatting with their families. Others said they play sports and games like football and net ball during their free time, and one said he plays the guitar.

9.1.2. Sexuality And Gender

Generally, sexuality is defined according to appearances and gender roles. Naturally, men grow a beard and they wear trousers while women have breasts and wear skirts and dresses. Others said sexuality can be defined according to the work they do. For example, men dig graves and women give birth to children.

Cultural/religious beliefs

> *G: Some people believe that if they have sex with persons with disabilities, their wealth will increase. Are we medicine? This scares us because people take us as medicine. Some people steal white canes and it is believed that they use them for juju (traditional medicine).*

There are others who believe that all disabled people are beggars and they treat them unfairly as it was with a physically disabled man quoted below:

> *H: What I have experienced is that people discriminate persons with disabilities. One day I wanted to board a minibus. But somebody shouted and said, 'Do not let that man in this minibus'. This was very humiliating.*

There are some religious beliefs that say that when a person is disabled, it means he is a sinner and that he should not give offering but should be given alms. Another man said according to his experience in his church, everybody is equal and has equal responsibilities in church. There is no discrimination in his church (Namiyango CCAP Church).

> *J: At my church there are many disabled people. I have a position and I take care of the parish where the Reverend lives. We have others who are visually impaired, and according to their gifts they are responsible for teaching Sunday school and catechumen classes and preparing the young ones for confirmation. In addition, because of the interest they have in the church and its people, the visually impaired also teach the new converts that have just joined our church. They use books written in Braille. We also have disabled women who are church elders and have joined the women's guild. Other disabled women who use crutches are doing guild classes and will be graduating in November this year. Therefore, in my church there is no discrimination of the disabled, we work hand in hand and in unity. Leadership positions are given according to a person's spiritual performance in church, we don't look at physical or outward appearance.*

Sexual relationships/marriage

People with disability do not feel differently from their able-bodied counterparts in terms of sexual expression. They have feelings just like any other person and are equally sexually active. They do marry and have children. However, they have challenges in having relationships, especially women who are just taken for a ride and left with children to look after. A single lady said:

> *K: I will give my own experience of marriage. I married the father of my 2 children, then his parents discouraged their son saying that this lady you have married is disabled and is she going to help us with household chores, like drawing water? We will not manage to stay with her. She won't help us, so their son got discouraged and broke our marriage.*

Another lady said:

> *H: Sometimes men just want to use you (sleep with you). They will propose relationship but not marry you and will say, should I marry this disabled girl? They leave you because they are afraid of being laughed at by their friends for going out with a disabled girl.*

> *J: I come from a well to do family. When my husband proposed at me, there were rumours that my father had advertised in the news paper that who so ever would marry his daughter, would obtain some benefits. There were others people who said that my husband was attracted to me because of my family wealth. People used to go to ask my in-laws why they accepted their son to marry a disabled person. They said, how is she going to assist you? Lucky enough my in-laws were not concerned and they used to say to people, we have two other sons who are married, have you ever seen my daughters in-law coming to work for me? With these words we were encouraged to get married. But when we were preparing for engagement, my husband's elder brother refused to come and meet with my family. He thought that my husband would put them in problems should he change his mind in he future and their family would be blamed. In the end, their younger brother took the responsibility and after that their uncle took over. The issue is about both families understanding each other and agreeing on what to do. But with our culture, sometimes it is difficult because men go by what their parents prefer compared to women. When a woman is told that the parents do not want your choice of husband, if the man is in love with you, you can still go ahead with your plans but not with men.*

The other participant in the group said:

> *O: I will stand for the women because I am the one who interacts with the men most of the time. Most men say that disabled women/girls do not have a chance of having relationships therefore, can not acquire HIV and AIDS. They therefore manage to convince the woman by promising that they will marry her. But in the end such marriages are not good or happy. Most men when they marry disabled women, they really fall in love at first but later they say they just wanted to see how she was born and leave her. As a result, most disabled women do not get married because they give in easily to men who propose to them in sexual relationships.*

Sexual abuse

Many disabled people have been abused but in most cases, there is silence over the matter. One lady recited a story that happened in her area.

> *B: It is difficult for the community to intervene in rape issues because they don't believe a disabled person and they don't care. There was an incident that happened at Machinjiri where a disabled child was raped by a Shehe (a Moslem priest), who was taken to court by a lady working for MACOHA. This case kept being adjourned until it was not heard of any more.*

This shows that the laws of our society do not help disabled people but when a disabled person commits an offence or does something bad, then it will be in news papers quickly. There is no support for people with disabilities. In most cases men take advantage on disabled women. They say it is easy to approach a disabled woman than an able-bodied woman. Because of poverty a disabled woman will give in to the men for money but they will just abuse and leave her not knowing whether she will contract a disease or not. Another lady said:

> *D: There is visually impaired lady who was neglected by her relatives (family) who could not even visit her and most times she had nothing to eat. Men started taking turns in having sex with her; they each promised to give her money. In the morning she would ask her friends how much money she had made the previous night, only to discover the notes were all newspapers.*

Malawi Council for the Handicapped (MACOHA) helped on this issue. They called the lady and counselled her and they also called the family members and counselled them as well and asked them to help their relative as she was being abused because of poverty.

One lady however said:

> *G: I just want to add, it takes two to tangle therefore, I feel that this definition of abuse will be difficult for me because here at the office a woman has the right to say no to sexual abuse. What causes the junior officers to give in to their bosses' sexual desires is seeking promotion or favours from the bosses. By doing this they enter into temptations of having an affair with colleagues or bosses at the office therefore, we can not say it is a form of abuse.*

On this issue, students from Montfort School for the Blind (boys) stated:

> *FGD: There is nothing of that sort (sexual abuse) while on the girls' side one said she has heard of a girl who was sexually abused and was taken to police, then to hospital where she was diagnosed HIV positive. The matter was taken to court but she could not remember the outcome of the court proceedings.*

The reason they gave for their vulnerability was that they can not run (physically disabled) or see danger (visually impaired) and those with speech impairment can not shout for help. These are vulnerable to sexual abuse.

9.1.3 Sexual and Reproductive Health

Many disabled women said that they have problems when they go to the hospital for ante-natal, delivery and post natal services. Nurses treat them as if they are not supposed to conceive and give birth as one lady states:

> *E: Some believe that when a person is disabled, all the children born to that person will be disabled. Others believe that a person with a severe disability can not deliver a baby but will die in labour.*
>
> *FGD: When a disabled woman conceives, she does not receive proper care when she goes to the hospital. Nurses or medical staff has negative attitudes towards PWD. They mockingly ask … who made you pregnant? Doesn't he know that you are disabled and does he not feel sorry for you? They ask such questions and yet we also have a right to child bearing. These questions are not asked of able-bodied persons.*

Another lady said:

> *E: Others ask us; even you getting pregnant? You don't care about you health.*
> *FGD: There is poor care in labour wards, if a disabled woman can not deliver normally because of her disability, instead of helping her deliver through caesarean section, the nurses just ignore her until she delivers a dead baby with serious injuries.*

Another lady added:

> *FGD: The medical personnel make decisions for method of delivery for us. They say this one should go straight to the theatre for Caesar. As for me I delivered the first born child normally. During the second pregnancy, I went to the hospital late and they just said I should go to the theatre but I refused and delivered normally. They make decisions for us that might destroy our reproductive parts or kill us because we are disabled.*
>
> *FGD: When we go to the hospital we meet a lot of problems. Especially in the past we used to be tortured, we were not attended to. The nurses shout at us that when you were meeting with your husband we were not there, you asked for this. Some reach the extent of beating the patients. This is another form of torture, we are not addressed in the right manner.*

Not all the disabled women who have given birth have experienced problems in labour wards. Women from Chileka who gave birth at Mlambe hospital said they did not have any problems. Others had given birth through operation but are not sure whether it was because of the disability or not. One lady had the knowledge that she had an operation because of a narrow pelvis.

> *Y: When I got married I fell pregnant in the third month and my parents took me to the hospital to confirm that I was indeed pregnant. When the time came to give birth I went to Mlambe hospital where I delivered normally. I have nothing to say because I delivered without any problems said one lady.*

Health education

Many women who participated in interviews stated that they had never attended an health education session. This is worth noting, because disabled women are the ones that are equally affected by health issues and they need to know what is happening to their bodies.

> *FGD: In most cases we, as disabled women, find it difficult to access awareness talks on planning methods because we are sidelined in society. When it comes to door to door campaigns, if they see that in this house there is a disabled woman, they just pass by and go to an able-bodied woman because they have nothing to do with PWD and yet we also need such services. It is therefore, very difficult for PWD to access such information.*
>
> *A: We have attended HIV and AIDS education awareness talks here at the office but not on reproductive health.*
>
> *B: There are health personnel around this area but they have never conducted any health education.*

On the contrary, others said that they receive advice at ante-natal clinics as stated by some of the participants.

> *C: We hear of health education when we go to hospital for antenatal care where they tell us that a girl should get pregnant from the age of 18.*

On access to birth control pills, most of the women accepted that they have had no problems with that. Just like any other woman, they go to 'Banja la Mtsogolo' (privately run reproductive health clinic) or government hospitals for birth control methods.

9.1.4 HIV and Aids Prevention

In one of the FGDs, a participant stated that HIV and AIDS is like a double blow, one has to think of disability at the same time think about HIV and AIDS. It is therefore, important to prevent contracting it in the first place.

> *A: Some people think that a disabled person is a cleanser for HIV and AIDS. They believe that disabled people are free from the diseases and if one is HIV positive and has sexual intercourse with a disabled person, the disease will be cured.*

All participants know how HIV is transmitted as expressed in the following phrases:

> *I: When you have sexual intercourse with a person who is infected with the virus you can be infected as well.*
>
> *K: Transmission happens when a man has sexual relations with different women especially sex workers and plays unsafe sexual intercourse.*
>
> *M: Needles and razor blades that have been used on different people.*
>
> *N: Blood transfusion of untested blood especially blood with HIV.*
>
> *O: Mother to child transmission though breast feeding and at delivery.*

It is important to note that some students from Montfort School for the Blind were not very sure of ways of HIV transmission. One student thought that the virus can be contracted through sharing a cup of water with the infected person's spit. Other students corrected him and stated that the virus could only be transmitted if one bathed a patient without gloves on when he/she has cuts or bruises in the hands and not through sharing a cup of water. Similarly, many are aware of the HIV prevention methods as stated below:

> *S: Do not have multiple sexual partners (one man one wife), being faithful to your partner, using condoms, and abstinence. You need to go to hospital for testing and when you are positive you need to tell your partner to go for testing as well. Then you will be counselled on how to take care of yourselves in the family.*

Participants were also aware of the HIV and AIDS treatment and care methods as indicated below:

> *O: Give PLWA nutritious food like body boosters e.g. sibisiso and Likuni porridge. Encourage them to eat so that they get strength.*
>
> *P: Remind them to take their drugs (ARVs)*
>
> *Q: Provide counselling to cheer them up and take them for outing to avoid worries.*
>
> *R: Take them to the hospital once they are sick.*
>
> *T: Bath them with gloves but we don't have those, so we can use empty sugar packets, or else use a wet towel and wipe the sick taking care of our own body to prevent contracting of the virus.*

However, not many participants have been tested and so they do not know their HIV status as shared below:

> *V: Yes I have heard about it (VCT) some of us have never gone for testing others have.*

Others like those who can not communicate without a sign language interpreter feel there is no privacy and therefore are afraid to go for testing. Long distances to VCT centres is also a barrier because people do not have transport money to go to the centres for testing, so they can know their HIV status. Lack of reliable guides to lead the visually impaired people to places they wish to visit. Similarly, those using wheel chairs need someone to push them, if these are not there to take them to VCT centres, they can not be tested.

Many are aware of the importance of getting tested. Some said:

> *P: Once you know your status you can protect yourself from further infection.*

If you are lucky that you are negative, you can find ways of protecting yourself and if found positive you can get counselled on positive living so that you can stay a little longer. When you are sick or you see strange signs you know it is because of your status but when you don't know your status you don't know what is going on in your body.

One participant said

> *G: Once you know your HIV positive status, you can start preparing for your future e.g. making a will for your children, sharing equally knowing that anything can happen any time.*

And on this, another one jokingly said:

> *You can buy a coffin in advance.*

HIV risk factors

As discussed in 4.2 many people with disabilities, especially women are vulnerable to HIV and AIDS because they can not protect themselves by running away from perpetrators of abuse.

Lack of accessible information on HIV and AIDS, especially for the visually impaired who need such information in Braille.

People believe that when an HIV positive person has sexual intercourse with a disabled person, he/she gets cured. Therefore disable people are at risk of being raped by HIV positive people.

Poverty also puts disabled people at risk of HIV infection because they need even little money to buy food. For this reason disabled women have sexual relations with any man that comes their way.

9.1.5 Access To Sexual And Reproductive Health Care

Almost all participants go to the hospitals for sexual and reproductive health services including HIV treatment and care. However, there are some that go to traditional doctors as one said:

C: Those who went to school, they rush to the hospital but others use traditional medicine which delays them and ends up destroying their organs. We need to take care.

In some areas the hospitals are private and you need to pay as one of the participants stated:

> *D: The first problem is that many Health Centres belong to missionaries and they are run privately so persons with disabilities are unable to pay due to poverty. At Chingale Health Centre, disabled people asked their association to pay for them because their children were dying due to lack of access to treatment.*

9.2 Namibia

9.2.1 Sexuality and Gender Issues

Participants were asked to define the word sexuality and the following were some of the responses:

> *A: Sexuality defined as a process of making love. It can also be describe as a process of sexual intercourse between two people, but it is different for both boys and girls. In most cultures parents often tell their kids not to play with girls and vice versa, there is no straight talk about sex.*
>
> *FGD 1: Sexuality is a concept that is hardly spoken about. Only the elders use the term. With regard to local definition in Otjiherero, sexuality is referred to as Orakatuko and in Oshivambo it is refered to as Ilhulo or Okulalathana.*
>
> *WFGD: Sexuality means people making love, a lady and man that is what I understand. Sexuality can also be different between a female and male. In Otjiherero they call it Orukatuko (sexuality) sometimes referring to the making of sex because when you say to make love, love is many things, with sex, that is straight. Tjimatuhingire ohunga norukatuko mbatuhingire ovantu wevari mbumaveya pamwe okuhakeyena monyama (that means sexuality).*
>
> *FGD 2: In Oshiwambo we say atuti okuyaminghulo (sexuality) like sexual intercourse man and lady they busy doing sexual intercourse. Also in Oshivambo they use the word omilalo meaning the same as the above. Mmal moshiwambo hinghulo oshima, inghulo ondishando ishinima oshinai, oshimango shili po oshinai ilo atutui ilalo ngo?*

The group mostly spoke about one Angolan ethnic group who live in Katima Mulilo, north east of Namibia. In this culture, sexuality is not talked about or mentioned during conversation because is a sensitive subject.

> *B: Even amongst family members they do not talk about sexuality matters. Consequently, talks about HIV and AIDS are neither mentioned nor encouraged in the presence of children because sex is regarded as an issue for parents and married couples. Similarly, people in our society do not talk about condoms, What it means in the end is that in our African tradition there is no talk about sex as it is regarded a subject for adults only. An example is that sometimes parents tell their girl children not to play with boys, yet boys are not told the same, why? Meaning that socialisation at an early childhood is denied.*

People with disabilities are often victims of family abuse. What transpired from the interviews with the women group is that:

> *WFGD: Especially Black men, they have this negative attitude towards women. Often this does not come from the person himself, but from his social environment. If disabled women fall in love with able-bodied men, the men suffer abuse at the hands of their families and then take out that abuse on to*

> *their partners. Such practices are common in the Oshivambo culture, where an able-bodied person is not allowed to be involved with a disabled person.*

Another point raised was the issue of belief systems. In most cultural groups if a child is born with some form of disability, the family believes that there is a curse resting on that household. Already, the platform for negativity is laid down in the upbringing of the child. Automatically, the household with a disabled child is pushed into the periphery of the family and denied any interaction with close family members. This situation creates an environment in which the family is denied socialisation within the context of the extended family system and ultimately society at large.

Narrative 1

> *D: Okay, I am talking from my experience. We were five girls in the house about the same ages. My parents were worried about me, when I go out and I am hanging out with boys, my parents always thought that maybe I have done something bad. They did not allow me to stand and talk with boys, but they allowed the others to do so. Okay, when I grew up and realised the difference between me and the others was that I am a disabled or what is the difference, we are all ladies about the same age, some are allowed and I am no allowed. The problem is also with parents they think a person with a disability needs to be taken care like a kid. You don't have a right to choose for yourself, they have to do it for you. In some families, when you are disabled you are rejected. Like in the village I come from, I know a lady; she's disabled, and has 5 kids. None of these kids has a father because she doesn't know who their fathers are; her parents build her a house very far from the others. Any man who wants to go to her does so because there is no one to protect her. Even if I am a disabled person using a wheel chair, when I am already on the bed, I can't go back to close the door. it will be open and everyone will come to have sex with me because there is no one who can take care of me, my family has rejected me. Like my tribe, the Otjiherero speaking people believe that if you give birth to a baby with a disability, it is a curse and that disabled child must not be amongst you, she is like an animal. Sometimes it is our parents, it depends on the way they have treated you form childhood, sometime it helps when they treat you very well, not in a dictator way. When you are grown up, you have your own mind to choose what is good and what is bad for you. But when they leave you like that everyone comes to use you as sexual a sexual object.*

Another respondent indicated:

> *E: Disability in most cases is a result of health problems. For example in most case it is genetic; if a person is blind, she might also give birth to a blind child, it is the same if the person has a hearing impairment.*

9.2.2 Disability and Sexuality

Disabled people are looked down upon and are not expected to form any sexual relationships. The perception of the community is that if you have any form of disability you are not supposed to form a relationship or have children of your own. People with disabilities should be catered for by able-bodied persons. They must not be allowed to have a free life otherwise they would be rejected by members of the society. In summary, the view is that in most cases, disabled people are denied sexual and reproductive health services. They are perceived as incapable of sexual engagement and so are regarded as asexual.

> *FGD: 'Able-bodied' people do not want to associate themselves with disabled people sexually, they do not want to marry them. Not all of us are born with a disability, disability is not a curse from birth, but it is just an unfortunate situation.*

Narrative 2

> *FGD 2: Can I start as a parent? Actually, when the father of my son died, it was really difficult because at that time my child couldn't sit, he couldn't walk, he couldn't do anything. Men were just coming to propose and when they see my boy they say 'Aha', okay! You could just see from their expression that they are coming to apply to marry you. I was telling them that I am having a special child, the way you are going to love me is the way you have to love him also. So then you know at this stage the modern life we are living in, only few men can expect to take care of a disabled child. So I said 'no', I cannot have any relationship with you or any love if you don't commit yourself that you are going to take care of my child and then they would leave me, I could see them going. But the man I am staying with now, the one I got married to is the only one who accepted to take care of my child, whatever happens, I am going to take care of my child. Through my experience, I have seen how parents of disabled children are suffering. Even the fathers of those disabled children are neglecting their children, they see that it is real a burden and it's true it is a burden. Only few men will come and propose to you as a parent of a disabled child and only few men will accept to stay with you, otherwise men run away.*

People with disabilities also suffer low levels of marriage. In most cases when men are in search of someone to marry, they patronise women. They show interest but are not keen to be part of you. A woman relates her story:

> *H: I was suffering humiliation at the hands of my in-laws. I was blind and I got married. The family always ask my husband why he got married to this blind person. 'Why did you not look for another one?' The family did not attend our wedding and does not visit us. In most cases being married to people with disability is regard as a thing for the rich. The opinion expressed is that people with disabilities get married only if they are coming from a very wealthy background, but if you are poor marriage is out of the question.*
>
> *FGD: Furthermore, if disabled people want to get married, or are involved in a sexual relationship, women often suffer the most. If disabled women fall pregnant, society responds: 'What did they do to this poor woman?' 'Who is that cruel man that did this?' These are the experiences that we encounter and are mostly as a result of ignorance, so we are denied the social lifestyle that others are enjoying.*

Another respondent also related her experience:

> *FGD: I got involved with someone, but often when we had to go out and visit friends, he would always ask me to wait outside as he wanted to see who is inside. According to him people would discriminate against me and would ask, 'What are you doing with an omukaindu oshupi movarapi (disabled woman)?' Gender roles also play an important role in the level of discrimination towards people with disabilities. In the context of rural settings, married women are supposed to milk cows, but if you have a disability, this function cannot be fulfilled and your husband suffers discrimination, people say: 'What are you doing with this disabled woman who cannot fulfil her duties?' And the outcome is that often splitting-up or divorce.*

People with disabilities often blame the issue of culture towards some of the discrimination they experience. They indicated that as adults, they practise the learned behaviour as prescribe by their parents. What they were taught is still fresh in their minds as a form of discipline. These disciplines have become myths which cannot be questioned. Another point dealing with perception is also the issue of conceiving or giving birth to a disabled child:

> *FGD: If a man notices that a child is disabled, he does not want to be associated with that family and leaves both the woman and her child. The notion is that in his family there is no one with a disability, meaning that a disabled child could not be his. Another layer of discrimination is also the role of society in this context. Pressure is exerted by friends and family who often disassociate themselves from the disabled person, who in turn suffers. In most cases if it is a child s/he is put indoors or taken to the village to stay with the grandparents. In that way, the child is being denied a social life with all its added benefits. Another form of exclusion is done by some parents. In most cases parents who have a disabled child do not take that child to town with them. They are scared to be victimised by friends or society at large and prefer to have the child in the confinement of their home. In a related incident, those able-bodied men who are involved with us usually visit us in the quiet hours of the night and leave early in the morning for fear of being seen by others that he is having a relationship with a disabled woman.*

With regard to vulnerability, the following emerged:

> *F: In most cases women are the ones suffering the most. An example is that of a blind women who is currently having four children. This woman was abused by able-bodied men, and she does not know who the fathers of her children are. She related that often men would enter her room, touch her and do their 'thing' and leave. She does not know if they are from her own environment, their position in life, etc. Nobody in society wants to admit that these are their children, because she is blind. Who wants to be associated with a blind woman? The result is that women often suffer emotionally as well as financially, as nobody wants to assist them in bringing up children in the context of a family life. Another form of vulnerability suffered by disabled women is in the context of pressure exerted by physically strong over weaker women, men often force themselves on women. There is a perception held by some people that violence experienced by disabled people is acceptable, and it does not constitute any crime against the perpetrators. The view is that disabled people cannot be reliable witnesses as confirmed by case study 3 underneath.*
>
> *G: People with disability are also marginalised. In the discussion it transpired that a disabled child was taken to a farm by his wealthy parents. The child was lock up in a room close to the farm workers and denied all his rights.*

Narrative 3

Personal experience of one key informant with regard to sexual exploitation:

> *Key informant 1: It happens in most cases that those people at great risk are more vulnerable than others. Like the experience of disabled women and girls in my own village. There was a girl who was mentally retarded and she became a victim of some guys in the village because she could not talk. So these guys came and just abused her sexually and left. It only became known when she became pregnant. Then the guys were gathered together for her to select who she had had sex with, but she did not know who was responsible for her pregnancy. Because she could not express or assert herself to say, 'You, you came to me and said this and that'. These guys denied the allegation and insisted that they wanted an oral testimony from the girl to say it's 'you' but because she could not talk, so she became a victim that these men took advantage of. When the guys approached her she may have felt*

> *lucky because the majority of men do not turn around to look at a disabled woman. She thought the guys loved her when they only took advantage of her.*

9.2.3 Sexual and Reproductive Health

Participants were asked to state what sexual and reproductive health (conceiving and giving birth) problems are common in their community. They indicated that the most common problems they experienced in accessing reproductive health services are attitudinal. In most cases service providers question disabled people's ability and why they need such services. Worse still, these service providers do not have separate queues for people with disabilities. They must use the same line as able-bodied persons, and are subjected to abuse by the service provider. The view expressed by the FGD is that in banks you find a queue for senior citizens, but this is not the case in hospitals, clinic, or any institution that is dealing with reproductive health services.

> *H: People with disabilities in most cases have to access information in the same way as the able-bodied persons. No distinction is made with regard to the various forms of disability. This has resulted in us not having the necessary information at hand. Secondly, we are subjected to the attitude of these service providers. They do not know how to communicate with us and therefore, we are not properly advised on our health and so we are not taken care of properly.*

Participants were further asked if they had ever attended a health education/awareness talk addressing sexual and reproductive health issues.

Most respondents indicated that they did attend some of the following services:
i 'My future my choice' – making the right choices about relationships
ii 'Good Hope' dealing with Christianity and also including reproductive health
iii Workshops on 'gender and disability'
iv Workshops on HIV/AIDS that includes how to deal with visually impaired persons
v Workshops on the 'rape act', writing of one's will and testament
vi Training on how to use a condom
v For the hearing impaired a workshop was conducted on how to protect yourself against HIV/AIDS by having always a condom at hand and to prevent unwanted pregnancy

Do you have easy access to birth control pills or routine check up for such health issues?

As indicated by the respondents, disabled people are subjected to various forms of questions by service providers. They often question the need for this group to have access to contraceptives, meaning they are not entitled to such, or there is no need for them to be provided with contraceptive as they are not supposed to be in sexual relationship. Some respondents indicated that, when one is assertive, he/she might be lucky to get them. The challenges faced by people with disabilities with regard to HIV/AIDS and reproductive health can be summarised in the words of participant K:

> *K: If you look at the health system, the starting point should be at the community level. People with disabilities in most cases are regarded as people that are not entitled to a family life and are not supposed to marry, as well as engage in sexual activities. The thinking of society is that people with disabilities are sick persons and these activities cannot be exercised by them. The end result is that this type of thinking also influences our health system, especially the mind of service providers.*

Often women suffer the most with regards to these services. Often they are told 'but you are not allowed to do these things' (having sex), it is just a waste, especially the use of condoms. In terms of reproductive health, these are some of the challenges faced by disabled people. Another problem experience by people with disabilities in accessing services is the question of distance. Service providers often are located outside immediate home areas, meaning disabled people have to make used of public or private transport. For the visually impaired, this is a major problem. As related by participant I:

> *I: I was on my way to the hospital. At the taxi rank I met a woman who was blind. The taxi driver was not prepared to take the person as she did not know where to get off at the hospital. Furthermore, he was reluctant as she did not know how to pay him. I came t this blind woman's rescue as I was also on her way to the hospital and was prepared to accompany the person. The taxi driver showed his unpreparedness as she was also partly disabled. In the end he obliged and took us to our destination. Another major problem identified is the whole issue of the visually impaired and those that are blind. The main obstacle from the side of the service provider is how to interact with these people in providing them with the necessary services.*

9.2.4 Facts About HIV and Aids

With regard to HIV and AIDS and its impact on disability a situational analysis was presented by one key informant and it is presented underneath:

> *Key informant 3: One has to say, it is a very unfortunate situation we are finding ourselves in. NANASO is an umbrella body to whom all disability groups are affiliated. It is our responsibility to make sure that all people who are breathing on earth are just as equal and as the same as any other person, be it a person with a disability or without. As much as I have the right to get involved in sexual activities, the disabled person has the same right. The disability, which one person has by virtue of what happened or how the person was born, does not deny him/her the right to get whatever he/she might desire. Hence, no one should have the right to say, people with disabilities should not do ABC. They have the right to reproduce and to say 'NO', I do not want to be pregnant and I do not want to have children, if that is their wish. What is supposed to be the case for any society including Namibia is that we were supposed to assist disabled people with whatever they need for them to look after their children. We should help create an enabling environment for them to practise what is desirable for any human survival. NANASO's responsibility as an umbrella body is to make sure that people with disabilities are assisted accordingly.*

> *Key informant 4: One of the challenges normally faced by people with disabilities is lack of resources in the area of HIV/AIDS. Disabled colleagues are not yet assisted accordingly, to be able to access information as they wish. Talking about visually impaired people, I do not think they have informational materials on HIV/AIDS developed by them. I also think there is no information catering for deaf people and those with physical disability. Hence, these groups do not participate in activities of NANASO. The bottom line is therefore to ask, how can we help people with disabilities meet the challenges that might have an impact on their sexual lives and their ability to reproduce? As NANASO, as Namibia, as the world at large, how do we assist people with disabilities?*

People with disabilities are well informed about HIV and AIDS related issues. Respondents know about the VTC services in their vicinity. They are also aware that HIV infection is transmitted through unprotected sexual intercourse, as well as through blood transfusion, sharing needles, etc. However, they were unsure if one can get AIDS by sharing food with an infected person. In terms of treatment, participants are aware of the availability of anti-retroviral treatment, they also know about an organisation called Lironga Eparu that is working amongst People Living with HIV/AIDS (PLWA). They know where to get ARVs, and which organisations deal with mother-to-child-transmission. In most cases those on ARVs are provided with food by DPOs at some selected centres.

Participants were asked to share what factors place disabled people at risk of HIV infection and the following were their responses:

> *L: When we are having unprotected sex.*
> *A: Some of us disabled people cannot reach the places where we can get condoms, that puts us at risk.*
> *C: In some cultures they practise forced marriages. Traditionally you are obliged to inherit your in-laws after your brother's death. This is an order that cannot be refused, meaning that we put ourselves at risk.*
> *B: Sometimes we do not know the status of our partners.*
> *D: Often we are in need of money, so we get involvement in sexual activities for monetary gain.*
> *E: We are also abused by able-bodied persons due to the fact that we are unemployed; we lack proper education which hampers our access to information.*
> *F: In most cases when we are in a monogamous relationship and a child is born, we are subjected to divorce by our partners as they do not want to be involved with a disabled woman and a child. We as single mothers often find ourselves in unwanted relationships only for the gains we can get out of it.*
>
> *Key informant 5: Another factor that puts people with disabilities at risk is their unmet sexual needs. As indicated by a KI 5, society views us as people who have unmet sexual needs. These are the factors that place us at risk because of the notion that our 'sexual needs' need to be satisfied. Able-bodied people therefore, want to engage with us sexually and as human beings, we fall into their hands. There is also this notion that we are HIV free due to the fact that people shy away from us and so people who may be HIV positive approach us thinking that we are free. So we engage in risky sexual activity as we are not in a position to negotiate the sexual terms.*
>
> *Key informant 6: When people with disabilities are institutionalised, there is also this ill informed notion that sexual abuse takes place amongst them, but this is an issue that needs proper investigation before we can say there is abused amongst us which might put us at risk of contracting HIV.*

Participants were asked if most disabled people know their HIV status and the following were their responses:

> *K: When we are HIV positive the attitude of nurses is often very bad. They do not want to give us the necessary information and services, they give us insufficient information. In most cases we are not aware of disabled people knowing their status as we are often told that this is a 'killer disease', which makes us fearful.*

10. Conclusion

10.1 Malawi

This study has revealed key issues concerning people with disability in Malawi. One important issue is the way they are treated when accessing health services especially reproductive health. Most of the disabled women are not respected in labour wards and at other hearth services. Health information on HIV and AIDS and reproductive health is not easily accessible in sign language and in Braille. Even for those that are illiterate, pictures can be used as a means of disseminating information.

The participants were free to share their views, may be because the research assistants were also disabled. One concern that was raised is that there have been many research studies conducted on people with disability, but there has been no feedback and no change of policy. There has been research on accessible transport for disabled people and on HIV and AIDS. But when it comes to implementation, disabled persons are sidelined; they are not even invited to listen to the findings of such studies. What they want is feedback.

10.2 Recommendations

Both the key informants and the participants in FGDs shared the following recommendations based on their experience:

- The research findings to be further disseminated and be made available in user-friendly and accessible formats to all DPOs that participated.
- FEDOMA should be assisted to implement research into action for the benefit of all disabled people at grass root level in Malawi
- To make a proposal on how disability should be integrated into HIV and AIDS policies and programmes in Malawi across all disability groups, including those with albinism.
- To expand HIV and AIDS programmes to rural Malawi where most disabled people are located.
- DPOs to work hand in hand with the National AIDS Commission (NAC) to assist them to develop HIV and AIDS programmes, which target disabled people as well as to train health personnel on needs of disabled people, including sign language.
- A call to the media to integrate disability in their HIV and AIDS programmes
- Access for all disabled people who are infected and affected by HIV and AIDS to clinics as well as the provision of mobile clinics for VCT so as to reach disabled people in rural areas.
- HIV and AIDS awareness programmes be conducted in schools for disabled children
- Disabled people should be encouraged to test before engaging in sexual intercourse
- The chiefs in the communities should set precedence by taking action as leaders by supporting disabled women when they are sexually abused. In this way the disabled people would develop trust in their leaders and not be silent about sexual abuse
- The government should see to it that people with Albinism are included in its budget (the provision of sunscreen lotions and sun glasses). ARVs should also be provided to people with disabilities
- Improve access to wheelchairs on public roads and buildings as well as access to doctors' rooms.

10.3 Namibia

Challenges involving relationships

Parents of disabled children are in most cases faced with domestic violence, especially women. Their partners reject them, or even divorce them. This is because most men are scared of the responsibilities of caring for disabled family members. This leads to single motherhood and consequently vulnerability. It is very fortunate that sometimes you will find disabled people with caring partners (non-disabled), but this is very rare here in Namibia. Another main challenge is the treatment that one gets from his or her in-laws, regardless of the fact that your partner loves you. In-laws in some cases influence their relatives negatively, and such a person will end up treating a disabled person badly or even divorcing.

Lack of trust when an able-bodied person proposes a disabled woman, as a disabled woman the first thing that comes into your mind is that he is not serious, he is only trying to use you. In some cases, such men are only ours when we are two at a non-public place, otherwise he might not want to be seen with you in public places". Women with visually impaired problem are more vulnerable and at high risk of this situation. If blind people marry each other, in some culture such us Oshiwambo, calls them all sorts of bad names like: Iikanga yi pwikika, which simply means 'two empties cover themselves'.

Men, who are not disabled, do approach blind women for love and sex, mainly during the night times. 'We have feelings just like any other person, that's why sometimes we engage in sexual acts, even with people we don't know (as long as you are approached)'. Women with physically disability also suffer in relationships. 'Normal men mostly run away from us, because of not successful movements in bed'. 'If you suffer from backache, your man might complain that you are boring as you do not make moves during intercourse'.

In most cases, extended family members of your partner do not worry about disabled in-laws in cases where such a person (the disabled) is rich or well-off. People gossip a lot about their poor disabled in-laws.

Violence against women and girls

Although all people with disabilities are vulnerable to violence, the situation is more prominent for women than men.

Disabled women are raped by unknown able-bodied men, especially in cases where a woman is blind. It is very difficult for such women to testify about men who raped them.

The fact that disabled women are in some cases unable to work and make money for them, places them at a risk of entering into sexual intercourse (even unprotected) with men who can provide them financially. 'Some men use their money powers to force poor women into unprotected sex'. 'Poverty makes people to forget or ignore that HIV/AIDS is real'.

Some disabled children are not taken care of by their parents. They are left unattended to and with little or no support. This makes such children, especially girls, at high risk of being violated against and abused.

There are many disabled women in Namibia whose children's fathers are not known. One way of being abused is when a father of your child rejects to be the father of your child, because he is shy that others will laugh at him for sleeping with a disabled person. These situations are often worsened by poverty and vulnerability.

Z's narrative

Z is originally from Gobabis. She became deaf at the age of five as a result of an illness. Because of her disability, her family rejected her, teachers at school and other learners didn't like her too. She realised an opportunity to living well from the day that Mr. X and his colleagues went to Gobabis for a sign language campaign. They informed community members about the availability of schools for people with special needs, such as Eluwa and other opportunities available to people with disability.

With regard to HIV/AIDS, people with disability are at risk of being exposed to HIV because of the following factors:

i They are sexually active persons.
ii Most of them live in bad socio-economic conditions.
iii They are denied the necessary information.
iv Importantly, they also form parts of the ignorant masses. Meaning they show a lack of interest in what is happening in society.
v It can therefore be argued that they are at risk of contracting HIV.

Another problem facing disabled people with regard to accessing HIV information is the attitude of those providing the services. Often they are subjected to negative perceptions by service providers, subjected to inappropriate questions and for those who are seeking these services are required to have a 'buddy' with them. The 'buddy' would be attended to on their behalf and s/he is the one who will be given all the information for the disabled person. The animosity is that at times the 'buddy' can also abuse the person in whatever way he feels desirable. People with disability felt that the system does not trust them which is a major drawback for them in seeking health assistance.

In summary, another aspect that also needs some attention is mainstreaming HIV and Aids in the workplace. Here the issue is that HIV, reproductive health and disability is compartmentalised. Each item is treated as an activity alone and there in no proper linkage between these issues. In the work of WHO, IPPF, UNFPA, UNAIDS, UCSF the linkage is on sexual and reproductive health and HIV. There should be a broader scope to include disability. What transpired from the discussions is that people with disabilities are often regarded as not needing services. According to their physical/mental status, as put across by society, they have no right to engage in any of the mainstream activities. If by any chance they get involved in any of these activities, they do so at their own risk, as society does not have the means to support them.

10.4 Recommendations

- The only way to solve this problem is for the community to have one-voice!
- There is a need to create awareness on how such problems can be solved.
- People should be integrated with one another and try to change anti-social behaviours.
- The fact that most violent crimes perpetrated against disabled people are not publicised and not discussed in the media is a cause for concern.
- The Federation of People with Disabilities should spearhead HIV and AIDS campaigns to reach all corners of society.
- Communities need to work together with leaders such as community activists, social workers and other officials who can inform people with disabilities about where to obtain assistance and the types of services that are available for them.
- The nation and in particular people with disability should be taught about the law, they should be informed about their rights as equal human beings.

- In most cases, abuses are not reported. Many cases of abuse involving disabled people are dealt with in traditional ways, during traditional hearings. Nowadays violence is increasing, so people need to be informed on how to report violent behaviour to the police.
- In any event if there is planning for people with disability, it should be done with them and not for them

Appendix 1

A dissemination report of preliminary findings with regards to HIV/AIDS and reproductive health care amongst disabled people in Malawi

Introduction

This project focuses on the second pilot study listed in the call, HIV/AIDS and Reproductive Health. The aim is of this pilot research was to establish HIV/AIDS and sexual reproductive health needs amongst people with disabilities two target countries in Southern Africa (Malawi and Namibia). This work was led by the Centre for Rehabilitation Studies of Stellenbosch University and carried out in collaboration with the Secretariat of African Decade for Persons Disabilities, Trinity College Dublin, University of the Western Cape and Health and Society Research Unit, University of Stellenbosch.

This particular study has been conducted in the two countries and a draft reports including preliminary findings have been developed by the researchers. Therefore, there was a need for the Centre for Rehabilitation Studies to hold workshops in these two countries Malawi and Namibia to verify the preliminary findings as well as a way to disseminate the findings to the participants in the countries.

Workshop participants

A one day workshop was held at FEDOMA offices in Blantyre on Thursday 24 October 2008, which focussed on reflection and also drawing deeply on the experience of participants. It was attended by 12 participants, which included 7 participants from DPO's (MAP, DIWODE, APDM, MACOHA, MADISA, APDM) who are FEDOMA members as well as 3 research assistants, researcher and a senior lecture from CRS. *(See Appendix 1 for full details of the participants)*.

The workshop was of a cross disability nature, meaning that there was diversity with regards to disability categories. Participants presented with a range of different disability categories for example:

- Physical disabilities: mobility impairments -paraplegia and post-polio
- Sensory disabilities: visual and hearing impairments

Lastly, although the workshop was conducted mainly in English it also allowed for translations in Chichewa the local language.

Aim of the Workshop

At the start of the workshop the facilitator presented the aim and the purpose of the workshop to the participants.

The Primary Aim of the Workshop was to verify the preliminary findings from the focus group discussion and semi-structured interviews with key informants as well as a way to disseminate the findings to the participants in Malawi.

Purpose

To provide the opportunity for the verification and discussion of the preliminary findings from the focus group discussion and semi-structured interviews with key informants by the participants to receive inputs, additional comments and concerns as to improve and finalise the draft report.

Process

Before one discusses the workshop deliberations on the preliminary findings, it is important to discuss feedback with regards to the development of the tool. As this process is important to understand the issues which informed the framework of the draft report.

On reflecting on the process with the local researchers and research assistants prior to the workshop, the feeling was that the project inception related introductory workshop to develop guidelines/tools/schedules that will be used during in depth interviews and focus groups was a hurried process. It was felt the process of developing the tool was done independently from them. It was reported that the interview schedule was e-mailed to the researcher with inadequate engagement with the local researchers to assist in framing questions for the development of the tool that was understand by all concerned, hence no ownership.

As a result of this the pilot research was perceived a survey study where the interview schedule was seen as a questionnaire and at times the content of the interview schedule was interpreted differently, sometimes with limited opportunities for both the participants and researchers to explore the phenomena in-depth.

In conclusion, the extent of capacity building in this pilot research was questioned by the local researchers. Furthermore, the local researchers reported that they experienced challenges at various stages of the research process related to short time-frames, lack of proper project inception and contracting, lack of clarity of different roles and responsibilities, delayed funding and lack of support to local researchers.

Preliminary findings and discussion

Despite, the challenges noted above the pilot research was conducted in Malawi. Prior to the workshop a session was held with the local researcher to refine the preliminary findings in preparation for the dissemination workshop. The outcome of the presentation of the preliminary findings and the deliberations related to the findings are discussed below.

Social Relationships

- All participants confirmed that they were engaged in social relationships in one form or the other and they were capable of developing interpersonal relationships. They spoke of social relations within their society, community and their families and these relationships included intimate relationships were they were married, or were boyfriends and girlfriends; and partners.
- Participants also relayed to their ability to procreate in these intimate relationships as they are sexually active like their able bodied counterparts.

Sexuality and Gender

- The question about sexuality was vague, therefore, the workshop had to first explore the definition of sex. From the deliberations it transpired the sexuality was more the sex. It was about firstly, how an individual feels about oneself, as well as how the opposite sexes feel about each other.
- The concept of sex was discussed where participants aspired to the ideal situation where a women or man can initiates sex. But, most of the also expressed still living in the male dominated society when in Malawi men still initiates sex and any woman who initiate sex would be seen in a bad light, and may even be physically abused by the partner for attempting sex.
- Participants further explained the above that even in the age of gender equality, when they come home, women were still suppressing the sexual feelings.
- Disabled men and women perceive sexuality differently. Men spoke of physical sex where sex can either be accompanied by no intimate feeling or of they are serious about the relationship the will be more intimate feeling towards the partner.
- On the other hand disabled women spoke of developing an intimate relationship with the partner where trust is developed for a sustained long term relationship.
- The participants also perceived sexuality in terms of appearances, traditional roles and responsibilities of men and women
- It was noted that at times women in general are forced into circumstances where they forced to become prostitute where they engage in sex for the money not for intimacy.
- It also transpired that disabled women have particular challenges in sexual relationship where just by being disabled exposes one to vulnerability of some sort i.e. psychological trauma, manipulation and sexual and physical abuse.

Sexual Abuse

- It was reported that disabled women are more exposed to sexual abuse than their able-bodied counterparts by the virtue of their disability. There are impairments which make some disabled women more vulnerable to sexual abuse where sometimes, the level of abuse varies according to the different impairment and this makes them vulnerable as they cannot protect themselves.
- The whole notion of disabled bodies was reported to be revoking feelings of pity by disabled where men in the community perceive having sexual relationships with disabled women is doing them a favour as nobody would think of having sex with a disabled woman.
- A disabled person is taken as a useless or an insignificant person in the community, even when something drastic like sexual abuse or rape is reported to community leaders there is no follow-up.
- This has resulted in most disabled women being silent about their sexual abuse as they have realised that disabled women experienced lack of justice more than able-bodied women.
- It was reported that poverty also has also made disabled women vulnerable to sexual abuse and in this instance the disabled women have kept silence about sexual abuse fearing about where their next bread will come from
- It was the opposite for disabled men as they experienced limited sexual abuse, however, one cannot say this is entirely as men later shared in the section cultural and religious beliefs towards sexual relations.
- It was noted that schools for disabled learners were not a safe place, the girl-child lacked protection. However this finding could not be confirmed as there was no representative from the youth group but older participants confirmed this by saying this might be the case because for the disabled child, the impairments itself might be a barrier for running away from the perpetrator.
- It was agreed that like other women, disabled women vulnerable were also prone to sexual harassment at work and were they would be promised jobs and/or promotions.

- It was also good to note that the participants felt that help or assistance that was received when they are sexually abused and HIV positive was not from mainstream organisations but Disabled People's Organitions themselves. It was felt that DPO's understood the needs of disabled people better.

Cultural and/or religious beliefs

- Disabled woman are seen by in-laws as inadequate to fulfil their marriage rites. Most disabled women participants could related to this as they were subject to this treatment were seen as unfit to take over house-hold chores and in-laws threatened to take new wives for their husbands.
- Not only disabled women were subjected to cultural discriminatory practices but disabled men too. Almost all the male participants reported that their in-laws refused for them to get married to their able-bodied daughters and in one case were the couple went ahead and got married the maternal in-laws cut ties with their daughter for four years for marrying a disabled man.
- There were contradictory religious beliefs towards disabled people while on the other hand disabled people felt there were discriminatory religious beliefs were disability was seen as punishment for sins were a disabled person is not fit to receive God's blessings. On the other some disabled people felt that they experienced equality in church were they are integrated as part of the congregation and are holding influential position within their churches. However, this assertion was challenged by some participants as they felt that this equality people are talking about was not true even when disabled people in these positions there were salient discriminatory practices, some of these practices are non-verbal.
- Due to the fact that disabled people are seen as asexual in particular disabled women are virgins, therefore, together with girl-child there are seen as HIV/AIDS cleansers, they are unsafe within communities as they are targeted and raped for this purpose/myth.
- Disability within communities is seen as a mystical thing (juju) for example with a disabled person increases wealth, a white cane brings luck and stirring brew beer with a leg with a mobility impairment will draw customers to come and buy your beer

Sexual and Reproductive Health Care

- The participants especially disabled women concurred with the findings that there are negative attitudes towards disabled women seeking reproductive health care by health professionals.
- They related their stories of being mocked and humiliated by nurses especially when they presented themselves pregnant at health facilities to an extent of neglect and being ignored even when they are in labour; and by the time they were attended to there was already fatal consequences for both the disabled woman and the unborn foetus. Disabled women related stories of being punished and physically abused by health professionals for falling pregnant.
- Most disabled women are not informed about their choices on appropriate methods of delivery. The participants felt that critical decisions about methods of child birth were taken for them by health professionals even when they are adults who able to make their own choices.
- When it comes to Health Education with regards to Sexual and Reproductive Health Care disabled people were bypassed by health education programmes found within their communities. In the workshop disabled people commented that when health workers in the village come to a house of a disabled person they skip.

Facts About HIV and Aids

Participants agreed that for a disabled person having HIV/AIDS was like a double blow, one has to think of disability at the same time think about HIV/AIDS. For example: if one gets diarrhoea from HIV/AIDS and has mobility impairment like using crutches where there is lack of ablution facilities in a village everyday life can be very challenging and complex. Hence, everybody shared the sentiment that prevention of HIV/AIDS was of critical importance amongst disabled people.

Most disabled had some knowledge that they have acquired from DPO's with regards to transmission, prevention, treatment and care, prevention, risks and knowledge of status. However, there were certain issues that participants expanded on in the workshop.

- This knowledge has been primarily acquired from DPO's and reinforcement was needed from the mainstream HIV/AIDS programmes to integrate disability issues.
- There was still limited knowledge about HIV/AIDS issues with regards to HIV/AIDS in schools for disabled children and disabled youth is at risk.
- It was noted that a disabled person might□□□ knowledge of HIV/AIDS issues but certain impairments were vulnerable. An example of a person who is totally blind was given that he or she might have the knowledge but when all people can see a fully blown HIV/status; he or she might fall into a trap if she engages with such a person.
- All though many participants agreed that they were aware of the importance of getting tested, in terms the findings that many disabled within the study have not tested the HIV status.
- The feedback from the participants was that disability needs are not taken into account in that when they go HIV testing most of the times they must go with personal attendant and/or an interpreter where they have no choice but to let him/her into their private lives about their status.
- There were other reasons was that the VCT centres are too far for disabled people, when able-bodied people can manage distances, there were cost implications involved for disabled people.
- It transpired that one of the main barriers to disclosure was stigma and negative attitudes by community towards a person living with HIV/AIDS.
- There was a recognition from the participants that knowing status and disclosing your status can lead to a supportive environment, reasonable accommodations, management and prevention; and future planning whether negative or positive

Access to Sexual and Reproductive Health Care

- Disabled women were not satisfied with the public sexual and reproductive health care services that were available.
- Access in terms of distances and affordability was seen as an issue as disabled people in Malawi were not immune to poverty.
- In the absences of access to public Sexual and Reproductive Health Care services and women opt for traditional health/medicine where sometimes because of lack insight into maternal health and disability has compromised the health of the disabled woman.
- According disabled women participants some of the traditional medicine and practices have caused damage to the reproductive organs of the disabled women or for worse even killing their unborn babies.
- Of an interesting phenomenon to the participants is that when they require Sexual and Reproductive Health Care they are met with hostility but when it comes to birth control there is easy access and there are no questions asked.
- Lack of access to information to disabled people in accessible and user friendly formats was seen as a major barrier to accessing Sexual and Reproductive Health Care services; and those with hearing, visual and with mental disabilities or speech and visual impairment were mostly affected by this.

Recomendations

In this section, the facilitator invited each participant in the workshop to share their own perceptions as to how the results of this study should be used in the area of disability and HIV/AIDS in Malawi. Moreover, one participant summarised that the workshop in itself disseminating and verifying the result was a learning tool were participants were afforded an opportunity to reflect, discussion matters related to HIV/AIDS and Disability from angles, thereby becoming an awareness tool to the workshop participants. The participants shared the following:

- The rsearch findings to be further disseminated and be made available in user-friendly and accessible formats to all DPO's that participated.
- FEDOMA be assisted to implement research into action for the benefit of all disabled people at grass root level in Malawi
- To make a proposal how the disability issues should be integrated in Malawi HIV/AIDs policies and programmes.
- To expand HIV/AIDS programmes to rural Malawi were most disabled people are located.
- DPO's to work hand in hand with NAC to assist them to develop HIV/AIDS programmes which target disabled people as well as to train health personnel on disability needs
- A call to the media to integrate disability in their HIV/AIDS programmes
- Access for all disabled people who are infected with HIV/IADS to clinics as well as the provision of mobile clinics for VCT so as to reach disabled people in rural areas.
- HIV/AIDS awareness programmes be conducted in schools for the disabled children
- Disabled people are encouraged to test before indulging in sexual intercourse
- The chiefs in the communities should set precedence as leaders by supporting disabled women when they are sexually abused and take action. In this way the disabled people would develop trust in their leaders and not be silent about their sexual abuse

Wayforward

- Using the feedback and key issues discussed in the workshop the local researcher will continue to consolidate the draft report and send to main researcher consultant. As well as integrate the results gleaned from the key informant interviews in the main findings.
- The facilitator gives feedback to US researchers in SA and furthermore, writes up a workshop report incorporating the process and deliberations of the workshop.
- The main researcher receives improved Malawi report and finalises the report to be submitted to SAFOD.

Appendix 2

Report on workshop for Namibian pilot study on HIV/ Aids and reproductive health care for people with disabilities
Date: 21 October 2008
Venue: Disability Resource Centre, Windhoek
Facilitated by Gert van Rooy and notes taken by Judy Mckenzie

The plan for this workshop as discussed with Margaret Wazakili was to:

1. Give Gert feedback on the report from Margaret and discuss the changes that need to be made
2. Note the challenges and successes of the research process
3. Get feedback from study participants and researchers on the report
4. Identify issues to be noted for future research.

Each of these is discussed below.

1. Feedback from Margaret

Gert noted that the report was done under severe time constraints (hence it is titled zero draft). There is still a FGD report outstanding that he is finding difficulty getting because the students who were responsible for it are now on holiday but he will include it in the next draft which will be edited for language.

- Page 4 –He will include in the demographic information which informants were part of focus groups and which were key informants.
- Page 5 -In the methodology section, each of the focus groups will be described as to who the participants were and then numbered so that the source of the comments can be identified. The key informants should be given pseudonyms for the same reason. When they are quoted this should be done in such a way as to preserve confidentiality. He will give reasons in the limitations of the study as to why intellectual disability was not included. He will also explain how the interviews and focus groups were conducted.
- Page 6 – data analysis. The themes identified here should run through the next section and the discussion should speak to these themes. This will be done as soon as possible since Margaret needs this information to work on her report.
- Case study 1 – this seems to be one person speaking about many people and as such it is not really a case study. Gert will try to focus on the one person and perhaps use the rest of the information quoted to illustrate other points.
- Terminology – Margaret suggested the use of the terms people with disabilities or disabled people rather than people living with disability. However, Gert states that he was told in preliminary meetings with the federation here that the term living with disability is preferred. During the meeting, participants rejected the term ‘people living with disability’. One key informant, a senior government official, stated that the preferred term is people with disabilities. It is therefore suggested that this term should be sued in the report.
- Page 9 –paragraph 3 does not make a distinction between what the researcher is saying and what the participants are saying. It will help to use pseudonyms for individual and FGD numbers to indicate where the information is coming from.
- FGD were divided into men and women. Were there any differences between them? Gert noted that in fact there were very few differences in the views of the different focus groups. He feels that this is largely due to the fact that they are all from the same geographical area (Windhoek) and use the same services. He feels that a wider range of views would emerge if rural areas were included in the study. He will, however, identify which group the various comments are coming from.

2. Challenges and successes

- It was difficult to get hold of people from the ministries. There was not enough time to do FGDs with this group. They requested that approval be gained from the ministry. Gert wrote to the ministries asking for approval but could not wait for their response as time was a factor. To date the ministries have been informed but they have not given written approval. However, representatives from government have been present at all stages of the research and thus they do have knowledge about what is happening.
- Key informants indicated that it might be better to speak to men and women separately and this approach was adopted. The results for the two groups were not significantly different and Gert feels that this is because they draw on the same services and experience a similar environment in Windhoek. He feels that there would be greater diversity of response if a wider geographical area was covered. This is based on his experience on a survey with radio listeners that included people with disabilities where they found large differences between urban and rural populations.
- The time constraints limited the number of interviews. There were 3 focus groups and 6 key informant interviews conducted.
- Involvement of disabled people in conducting the research was limited, largely because of time constraints. People were identified in the initial meeting but some of these people were not available to conduct the research. Gert's concern was also that some of these people needed training and should also have the facility to transcribe the interviews. Time factors made this difficult to do.
- All of the focus group discussions came up with very similar responses. It was difficult to get detailed answers in the time allocated and perhaps additional methodologies should be explored.
- Within the ministry of health there are three relevant units – reproductive health, disability and HIV/AIDS. They do not talk to each other and work together.
- A notable success of the research project is that it opened up space for disabled people to talk about issues relating to sexuality and HIV/AIDS which they have seldom had the opportunity to do.

3. Feedback from participants

The following people attended the feedback workshop:

Name	Gender	Contact number	Disability/ organisation
Francina Hambira	F	0813933008	NADAWO – physical
Johanna	F	0813310642	CRAVI – visual impairment
Adriano Lisimu	M	0812959863	NAPPD - physical
Sylvia Chidunka	F	0812983557	NFPDN - parent
Elton Kasuto	M	0812134022	NFPDN - physical
J.S. Ambunda	M	081275506	Health – disability and rehabilitation

Other participants who had been invited from the relevant sections of the Department of Health confirmed that they would attend but did not show up. There was also an apology from Miriam Sam as she was not well. Two deaf participants also did not attend since they had not been given sufficient notice.

Gert welcomed everybody and explained that this was the feedback on the research. He presented the research, with a PowerPoint presentation which he can make available. He then asked for comments from the floor. We had developed questions for discussions in small groups but since there were so few people present it was conducted in one group.

Response to the report

The response to the report was very positive. They felt that is covered the issues and highlighted aspects that disabled people would like to make others aware of. They felt that it was a good reflection of their comments and that it expressed their views in a satisfactory way. The following questions were raised and responses given:

- What are the issues relating to disabled men as there seems to be an emphasis on disabled women? Participants suggested that often people with disabilities do not form relationships with each other because the disabled woman does not see the benefit in this. There is a connection to wealth here where of a disabled man is wealthy then he will have more of a range of relationship possibilities. This is different for deaf people who are more likely to get married to each other.
- What can be done to address the problems that blind people have? Some suggestions were production of Braille materials, education in schools and collecting statistical evidence to support the need for resources. The participants felt that hospitals should employ disabled people to convey information to others rather than using family because this will have an impact on confidentiality.
- What if there are additional problems that come up after this report?
  Can they be added? Gert noted that the intention is that there should be a follow up study based on the results of this pilot study. There are various aspects that have not been explored, notably the views of service providers which were shown to be a problem in the study. We need to hear their views as well.
- How will we know where the focus for change should be? The provision of service comes from three different sections in the DoH but it is not clear from their records what their impact is in dealing with disability. It was suggested that some way of disaggregating the records kept by HIV/ AIDS, reproductive health and disability sections of the department should be found so as to reflect what specifically is happening where these three come together.

General discussion

Disabled people are often sent to the rural areas and they are not getting the message about HIV/AIDs. This should be on radio and TV. Members of the Federation can help in this regard by mobilising their members to gather disabled people together and share the information on HIV/AIDS.

Parents also need to be made aware as sometimes they do not support the child who is disabled, labelling them as naughty. They need to start from youth.

Disabled people are not included in HIV/AIDS programmes. For example, AIDS CARE does not include them in their meetings even though they share the same premises.

There has been little discussion of intellectual disability. This needs to be further developed as we know that there are a lot of issues around abuse and control of reproduction of this group. In addition, parents need to be considered here as they take the major responsibility for the ID person. These parents are often single mothers and have their own problems with regard to sexuality, reproductive health and HIV/AIDS, some of which are related to their child's disability.

In order to address the issues of HIV/AIDS and disability, everyone needs to be involved and work together. Disabled people have rights and responsibilities and they should take it on themselves to make people aware of their needs. Government is a key player but it cannot be seen as just one entity. Rather DPOs need to identify relevant agencies and work with them. The Federation has a key role to play in this collaboration. It was noted that the government lays down policy but it is then up to service providers to implement it. If this is not happening then government should be approached. An example of this is that reproductive health services are generally available in Namibia but the negative attitudes of service providers on the ground make it difficult for disabled people to access them.

Way forward

- The research report will be finalised and then disseminated by the Federation. Participating government departments should also disseminate the findings amongst their service providers.
- The research should access rural areas as the problems are much more pronounced in these areas.
- Additional information should be sought in the next round of research with regard to men with disability, parents of children with disability, service providers and people with intellectual disability. Heath records should be collected in such a way as to show the impact of health services on people with disability.

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THE CALL ON HIV/AIDS AND REPRODUCTIVE HEALTH CARE AMONGST DISABLED PEOPLE