

SUMMARY REPORT

"EFFECTIVE HIV/AIDS AND REPRODUCTIVE HEALTH
INFORMATION FOR PERSONS WITH DISABILITIES"

RESEARCH CONDUCTED BY THE UNIVERSITY OF MALAWI
CENTRE FOR SOCIAL RESEARCH AND IN COLLABORATION
WITH FEDOMA.

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MARCH 2005

Summary of the report on "Effective HIV/AIDS and Reproductive Health Information to People with Disabilities."

Introduction

Malawi is considered to be one of the most affected countries in the world by the HIV/AIDS pandemic. The government of Malawi in conjunction with the international donor community and non-government organisations are working hard to inform, educate and influence behavioural change, in order to protect the lives of Malawians and the development of the nation.

But do people with disabilities have access to this information?

It is well established that some persons with disabilities need to use alternative forms of communication other than the mainstream such as: sign language, Braille, signs, symbols and pictures or computers with speech and Braille facilities. However many of these methods have not been adopted by stakeholders who disseminate vital life changing information about HIV/AIDS.

Using recent statistics from a study conducted on the living conditions of people with disabilities in Malawi (Sinteff, CSR, 2004) it was discovered 4.2% of the Population of Malawi has a disability that is at least 462,000 people in Malawi has a disability. Yet we feel that many of these people are denied access to information on HIV/AIDS because society has failed to meet their needs.

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disabilities actually using condoms. Despite women saying “use condoms” as their most common answer to preventing HIV transmission, only 21.4% of women with disabilities in this study have used condoms compared to 30.5% of the men.

Table: 13 Knowledge about condoms

Knowledge of condoms	Men with disabilities %	Women with disabilities%	MKAPH survey 1996 Men	MKAPH survey 1996 Women
Know what a condom is	82.6%	80.3%	97.9%	91.2%
Don't know what a condom is	17.4%	19.7%	/	/
Know how to use a condom	64.1%	47.5%	/	/
Don't know how to use a condom	35.9%	52.5%	/	/
Have used a condom	30.5%	21.4%	/	/

5.1 Reasons for Using Condoms

The main reason for using condoms was 66.2% to protect from HIV/AIDS and 33.8% as a family planning method. However it would appear from this study men with disabilities know more about condoms than women.

5.2 The main reasons for not using condoms:

Many of the reasons given were linked to lack of personal risk,(see table 14). However some smaller percentages related to poor knowledge of condoms such as: "don't know how to use them," "condoms are only used by men," "Increases the number of viruses in the body," they "cause pain" and they "cause sores on private parts." Unfortunately from this study we do not know if the misconceptions lie with the men or the women?

Table: 14 Reasons for not using condoms among people with disabilities

Reasons for not using condoms	Percentage of persons with disabilities
Never had sex before	15.4%
Don't like it	14.9%
Not promiscuous	12.8%
No use for them	11.2%
Don't have a partner	7.4%
I'm always with my husband	6.9%
My partner and I trust each other	5.3%
Don't know how to use them	4.8%

5.3 Difficulties using condoms

77% of the respondents said they had no problems using condoms but 23% of the respondents reported some difficulties and these were related to the different types of

disability. It was said during the focus group discussions that people with visual impairment are unable to see the expiry dates or read the instructions and people with weak hands cannot handle the condoms.

5.4 Access to condoms

The most common place stated to get condoms is the health facilities followed by shops. However from our results more men know where to find condoms than women. (See table 15)

Table: 15. Where do people with disabilities get condoms?

Where do you find condoms?	Men with disabilities %	Women with disabilities%
Health facility	56%	50.5%
Grocery/shop	33.3%	29.9%
Don't know	9.5%	16.5%
Trading centre	0.6%	0

In this study most people with disabilities, men and women, learnt about condoms from predominantly health facilities, followed by the radio and peer groups.

6. Awareness about Voluntary Counselling and Testing (VCT):

70% of the respondents did know about VCT but 30% did not. Out of the 70% that knew about VCT they gave the following descriptions: "A place to go for blood testing and counselling," 87% "a place where you can know your sero status," 12.4% "a place to know your blood group" 0.3% and "don't know" 0.3%.

Table: 16 What is Voluntary Counselling and Testing?

What is VCT	Persons with disabilities%
A place to go for blood testing and counselling	87%
A place where you can know your sero status	12.4%
A place to know your blood group	0.3%
Don't know	0.3%

Of the 70% of respondents that knew about VCT, 73.5% also knew where to go for VCT services.

53% of these respondents heard about VCT through the radio while 30.5% said they had heard through health facilities.

6.1 People with disabilities using VCT services

However 89.2% of respondents had never gone for testing and only 10.8% had gone for testing. (See table 17)

Table: 17 People with disabilities gone for testing

	Gone for testing
Men with disabilities	11.3%
Women with disabilities	3.7%
2000 Demographic Health survey Men	15.2%
2000 Demographic Health survey Women	8.5%

This study shows that less people with disabilities have gone for testing compared to the general population as shown in the 2000 Demographic health survey. Women with disabilities are even less likely to go for testing than men with disabilities this pattern is similar in the DHS.

6.2 Reasons for not using VCT services

The main factors among people with disabilities not going for an HIV test are thinking they are O.K 42%, not knowing what VCT is 19.1% and mobility difficulties 5.9% (See table 18).

Table:18 Reasons for not going for testing

Reasons for not going for an HIV test among people with disabilities	Percentage
Thought they were o.k	42%
Do not know what VCT is	19.1%
Not being able to walk	5.9%
No transport	4.9%
Not wanting the test	2.4%
No one to assist/guide	2.1%
Old age	1.7%
Laziness	1.4%
fear	1%
Belief all the blood will be pumped from the body.	0.3%

People with disabilities appear to be motivated for testing if "they have sex with someone they are not sure about" 24.4% or if they "get sick" 18.6% and other reasons were mentioned

such as a “partner dying from HIV/AIDS related illnesses,” or “wanting to get married.” (See table 19)

Table: 19 Reasons to go for testing

Reasons to go for testing among people with disabilities	Percentage
Wanting to know sero-status	32.9%
Having sex with someone you are not sure about	24.4%
If one gets sick	18.6%

7. Disability and risk of contracting HIV

Only 10.3% of the men said disability does increase the risk of contracting HIV and 13.2% of the women said yes it did.

Some of the reasons given during the focus group discussions were associated with type of disability for instance people with hearing impairments because of communication difficulties are less likely to go to school, are therefore unable to read and are not exposed to information. Therefore they will “accept proposals without knowing the risks.” For “people with visual impairment because they also go to drinking places they are tempted by the bar girls.” In this study we expected to find lots of cases of abuse, where people are sleeping with disabled persons in order to be cleansed of the virus. However this myth was mainly only found in Ntcheu and Ntchisi.

7.1 Cultural practices that influence the risk of HIV transmission.

The majority of people with disabilities in this study said there were no cultural practices that prevented them from adopting HIV prevention methods. 19.4% of the males thought there were some cultural practices that prevent them from adopting prevention methods and 18.1% of women. Of this percentage the majority said wife inheritance as the major risk for contracting HIV, followed by non-use of condoms, religious beliefs and initiation ceremonies. (See table 20)

Table: 20 Cultural practices that increase the risk of HIV/AIDS

Cultural practises that increase risk of HIV/AIDS	Men with disabilities%	Women with disabilities%
Wife inheritance	45.2%	52.4%
Non-use of condoms	16.7%	4.8%
Religious beliefs	9.5%	23.8%
Initiation ceremonies	7.1%	9.5%

8. Knowledge about family planning among people with disabilities:

72.2% of the respondents do not use any form of family planning whereas 27.8% do use. Unfortunately this information was not disaggregated by sex.

8.1 choice of family Planning

The main choices of family planning were condoms at 31.9%, traditional methods 27% and the injection at 24.5%. (See table 21)

Table: 21 Methods of family planning

Method of family planning	Percentage of persons with disabilities %
Condoms	31.9%
Traditional methods	27%
Injection	24.5%
The Pill	6.4%
Kuteseka (vasectomy)	3.2%
Sterilization	2.1%

The reasons given for not using family planning are rather surprising considering 76% of the respondents said they were or have been involved in sexual relationships. The majority said they were either single 28.9%, still young 6.2%, or never had sex before 11.6%. Other reasons were because they have stopped giving birth 9.8% or need to have children 0.4%, or take time to get pregnant 1.3%. Negatively some said they didn't want to 10.7%, the husband refuses 0.9% or they were afraid 0.4%.

8.2 Access to information on Family Planning

The majority of respondents got information about family planning through Health facilities 48.7%, the radio 29.9%, and teachers 28.9%. Surprisingly NGO's only comprised 0.7%.

Very few people with disabilities access information of any kind through NGO's, CBO's, therefore more disability awareness is needed among these organisations to encourage inclusive programmes.

The study explored the problems faced by people with disabilities accessing information on family planning and these were related to not having a radio 23%, no organisation close by to inform them 11%, hospital is too far away 9%. (See table 22)

Table: 22 Problems accessing information about family planning.

Problems accessing information on family planning	People with disabilities
Don't have a radio	23%
No organisation to tell us	11%
Hospital is too far	9%
Rude hospital staff	6%
People told of the side effects	6%
Disability	3%

However most respondents said they would prefer to get information over the radio. Unfortunately this was not expanded to find out why people would prefer to learn about family planning over the radio and not at a health facility.

9. Women with disabilities and child bearing

75% of the respondents interviewed had been pregnant before. The average number of children was three.

9.1 Access to Antenatal services

The majority of disabled women, 87% do attend antenatal classes, while 13.3% have never attended. As shown in table 23 very few women are taught about HIV/AIDS during antenatal sessions yet a high proportion of disabled women attend antenatal classes. Health services should be encouraged to make better use of these forums to provide information about HIV/AIDS.

Table: 23 Content of antenatal classes.

What women learn at antenatal classes	Women with disabilities
Family planning	51.1%
Nutrition	14.8%
Breast feeding/baby care	8%
HIV/AIDS awareness	6.8%
Have one partner	5.7%
Nothing on sexual and reproductive health	4.5%
Nothing	3.5%

Of the 13.3% of respondents who did not attend antenatal classes their reasons were either because they were "not interested" 25% or "not married" 10% or sadly their "husbands refused" 5%.

9.2 Place of delivery

It is encouraging that over half of the women with disabilities in this study did manage to deliver at a health facility 50.5%, or at a district hospital 16.8%. Home deliveries amount to 2.9% and TBA 3.7%. Again Health facilities provide an ideal opportunity to speak about HIV/AIDS to new mothers.

The reasons given for not delivering at a health facility were: the mother was "too late" 6.7% or she had "no transport" 5.7% or the hospital was "too far" 5.7%. A small percentage said because of "traditional reasons" 2.9% or they were "afraid" 2.9%.

9.3 Childcare

44.3 % of women with disabilities in this study acknowledge problems looking after their children and their reasons were because of "poverty" 59%, because of "activity limitation" 26%, "unable to walk to buy medicines" 10% and because of "frequent births" 5%. (See table 24). This study shows that many women with disabilities do not use family planning methods they end up having large families which are more difficult to cope with. Greater efforts are required to inform women with disabilities about the benefits of using family planning methods.

Table 24: Difficulties looking after children

Difficulties looking after their children	Percentage of women
Poverty	59%

Activity Limitations	26%
Unable to walk to get medicines	10%
Frequent births	5%

90.9% of women with disabilities said they needed help looking after their children and for 36.8% this person was the husband, 26.3% said them selves, 13.2% said a relative and 7.9% said their mother.

9.4 Single parent households

69.5% of families in the study were together to assist one another, unfortunately 30.5% of the households were single parent families either the mother or father was absent.

Table: 25 Reasons for single parent households

Reasons for absenteeism	Persons with disabilities
Father died	25%
He left me	21.4%
Passed away	17.9%
Don't know	17.9%
Home village	14.3%
Divorce	3.6%

The main reasons for single parent households in this study were because of death of the spouse followed by permanent separation. It appears from these results that women with disabilities are more likely to have to bring up their children alone than the men. 93% of absent father do not provide any

child support. However the same question was not asked about absent mothers.

Conclusion

This was a ground breaking study for the disability sector in Malawi the first of its kind, to look at issues concerning the sexual behaviour, reproductive health and access to information about HIV/AIDS, for persons with disabilities. Although it was a relatively small study and unfortunately was unable to involve totally deaf respondents, never the less it did reveal some rather interesting and valuable information about the situation on the ground for persons with disabilities in Malawi.

People with disabilities are sexually active and around 90% have sexual relationships with non-disabled partners. However this study has clearly shown that people with disabilities are less aware and less knowledgeable about HIV/AIDS issues compared to national figures. This puts people with disabilities at greater risk of contracting HIV.

This study also revealed that people with certain types of disability such as people with hearing impairments, speech impairments, mental challenges, epilepsy and people with visual impairment have less awareness and less knowledge about HIV/AIDS compared to people with other types of disability. This is largely due to difficulties accessing channels of communication that caters for and is available to their special communication needs. (Unfortunately this study was not able to explore in detail the communication needs and difficulties of people with hearing impairment).

Disaggregating the information further by sex shows that men with disabilities are less aware and less knowledgeable about HIV/AIDS issues compared to women with disabilities. This can be related to how men access information compared to women. Mostly men tend to receive information about HIV/AIDS and sexual reproductive health via the radio but this does not lend any opportunity for the men to ask questions or discuss issues. Women on the other hand tend to visit health facilities more often because of pregnancies or caring for their children. Therefore women learn in an environment where it can be assumed there is more time for questions and discussions with health professionals thus the learning for women is deeper.

Despite this health facilities do not take advantage of every opportunity to inform people with disabilities about HIV/AIDS. More information about HIV/AIDS could be taught during antenatal and post natal clinics. There is also a need for health facilities to develop strategies that can target more men.

However for some people with disabilities travelling to a health facility is a challenge because of difficulties with mobility or finding someone to escort them and often poverty means they cannot afford transport. It would be more ideal if face to face information sharing could take place at home or very close to the home in the community. This may also assist more men to participate. Unfortunately it has come out in this study that people with disabilities are either not aware of Non-Government Organisations doing activities in their communities or they are not invited to attend. There is a need to sensitise NGO's on disability issues in order for their

programmes to be more inclusive and involve people with disabilities.

People with disabilities in this study felt they were at relatively low risk of contracting the virus and this was one of the main reasons why so few respondents said they used condoms. There were also still some misconceptions about condoms that prevented people using them such as they "caused sores" and they "increase the virus in the body." Although women with disabilities knew what a condom was only half knew how to use them. Unfortunately this study did not look into why this was the situation, it can be suggested that more should be done at health facilities to help women know how to use condoms through practical demonstrations. It also came out during the focus group discussions that some people with disabilities have some difficulties using condoms because of visual impairment or weak hands again if one could practice in a demonstration teaching session some of these difficulties could be overcome.

70% of the respondents with disabilities were aware of voluntary counselling and testing but 89.2% of people with disabilities had never been for testing. This is poor compared to national figures. 42% of People with disabilities in this study said there was no need to go for testing because they believed themselves to be "O.K." However in this study we have seen that knowledge and understanding of HIV/AIDS information is below average for people with disabilities putting people with disabilities at a disadvantage for making informed choices about their health. Thus more activations are needed to market the advantages of going for VCT and perhaps strategies such as mobile VCT services would make

testing more available and accessible to people with disabilities and the general population living in the rural areas.

Only 28% of people with disabilities in this study used any form of family planning and the reasons given were mainly because family planning was not appropriate for them or they didn't want to. It appears the respondents are more reluctant to make a trip to a health facility for family planning advice and they would prefer to learn about family planning from the radio. On the other hand the women did complain about difficulties bringing up their children and one of the reasons was because of frequent births. Thus it may be advantageous to advise women with disabilities about family planning during their other visits to the clinics for their antenatal or post natal checks. People with disabilities need to be more aware of the advantages of family planning so that people are encouraged to seek advice.

In this study, women with disabilities in general came out more strongly on knowledge and awareness about HIV/AIDS than men with disabilities however fewer women knew how to use a condom and fewer women had been for HIV testing compared to the men with disabilities. So for the women there seems a gap between knowledge and putting things into practice. Unfortunately this study did not go into depth concerning power, roles and culture in relationships and how these can affect the women's decision making and ability to act on knowledge.

Recommendations

- Further research is needed to explore communication needs of people with specific types of disability such as for people with speech and hearing impairments, mental challenges and people with visual impairments.
- Further effort is needed to increase HIV/AIDS awareness for people with disabilities by:
 - Lobbying government for the inclusion of disability issues in the national HIV/AIDS policy so that programmes are inclusive of persons with disabilities.
 - Sensitising NGO's and Community Based Organisation's working in HIV/AIDS especially at the grass roots level on disability issues so that their programmes are accessible and inclusive to people with disabilities.
 - Encourage more face to face discussions on sexual reproductive health for people with disabilities, through community clubs and Community Based Rehabilitation programmes.
 - Health facilities need to ensure all patients attending any of the clinics are given advise on sexual reproductive health
 - Health facilities need to come up with strategies that specifically target men
 - Ideally more mobile services especially VCT are needed to reach those clients unable to travel easily.

- Information should be available in disability friendly formats such as Braille, large print, simple pictures and diagrams and programmes that use sign language and demonstrations.
- Further research on the influence of power, roles and culture in relationships and how they influence the women's ability to make decisions and take action.
- The Ministry of Health and NGO'S need to increase awareness programmes concerning the advantages and importance of family Planning.
- There is also still a need to dispel fears about using medical health services.
- Strengthen partnerships between stakeholders in HIV/AIDS work and the disability sector.
- Disabled People's Organisations to plan programmes to target other people with disabilities and teach them about sexual reproductive health and HIV/AIDS.
- People with disabilities need to be empowered to make them selves heard in the communities and demand access to services.