

FEDOMA CIDA GESP **PROJECT FINAL REPORT**

1. Title of report:

Final Report for: FEDOMA “Effective HIV/AIDS and Reproductive Health Information for Persons with Disabilities: A Right’s Based Approach”

This report covers the period from April 2003 to October 2006 in which the activities under this project were implemented.

This report is being submitted by the Federation of Disability Organisations in Malawi (FEDOMA) to CIDA/GESP.

2. Introduction/Background

The aim of this project is to ensure men and women with disabilities are included in the national HIV/AIDS policies, have equal access to information and actively participate in HIV/AIDS awareness and initiative programmes.

The project contains three components: A research component; To identify an effective and accessible method of delivering HIV/AIDS information to people with disabilities, A capacity building component; To ensure disabled women’s organisations are well equipped to carry out sustainable HIV/AIDS awareness programmes and an Awareness component to ensure people with disabilities have access to information about HIV/AIDS and that the mainstream community is aware of disability issues.

FEDOMA is an umbrella organisation for all the Disabled Peoples Organisations (DPOs) in Malawi. The affiliated organisations that form the federation include:

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

FEDOMA finalised its five-year strategic plan. The process followed an extensive stakeholder consultative approach to ensure that the contents were representative of the actual needs of the people on the ground.

As part of this process a needs assessment exercise for all the affiliated organisations was carried out. During these assessments the issue that was commonly raised by the DPOs was lack of access to information about HIV/AIDS by people with disabilities.

HIV/AIDS continues to be a life-threatening phenomenon with more and more people contracting the virus. It is estimated that 250* Malawians contract the virus that causes AIDS everyday and the rate of spread is escalating.

The pandemic continues to create many problems both at national and domestic level including:

- High mortality rates depriving the nation of its productive human resource
- Creation of orphans. It is estimated that 70 000 children* in Malawi are orphaned each year.
- High national and domestic expenditures on HIV/AIDS related illnesses.
- Personal suffering due to HIV/AIDS related illnesses.

Looking at the severity of its effects upon the society it is inevitable that all sectors of the society join hands in the fight against the pandemic. However many HIV/AIDS Programmes by various service providers in sensitising the community on the dangers of HIV/AIDS have failed to include disability issues thereby excluding a significant proportion of society. This therefore leaves people with disabilities practically vulnerable and at risk to the pandemic.

This is due to a number of reasons

- Failure to fully access the information on HIV/AIDS because of the current presentation formats i.e.
 - a) People with visual impairment cannot access printed information both in text and graphics. Televised messages are equally inaccessible.
 - b) Albinos can hardly access information in the *normal* print format.
 - c) People with hearing impairment cannot access spoken messages through awareness campaigns radio and all other oral formats.
 - d) People with physical disabilities fail to access information and education and counselling centres due to physical barriers and inaccessible structures.
- Lack of special training to meet the needs of people with disabilities for many service providers resulting in non-effective or failure of communication of information to People with disabilities. Most public programmes do not include people with disabilities. For example the Behaviour Change Intervention (BCI) Strategy has no strategies for people with disabilities though these were identified as a vulnerable group.
- Poor societal attitudes and discrimination against people with disabilities resulting in people with disabilities being excluded from targeted information audiences.

While it remains a fact that all people with disabilities experience similar problems and barriers when trying to access mainstream information, the problem is compounded for women with disabilities due to the general lack of gender balance in the Malawian Society.

* Behavioural Change Intervention (BCI) September 2002

* BCI 2002

In general, within Malawi, women and girls have a lower status than men and boys and “are one of the groups most prone to poverty and marginalization” (Mvula and Kakhongwe, 13, 1997).^{*} Females have lower educational attainment, lack access to finances and property, have greater workloads, greater mobility restrictions and lack control over their own destinies.

- Adult literacy stands at 72% for males and 49% for females (NSO and ORC Macro, 2000). Any information format that assumes literacy is therefore inaccessible by most women. The problem is compounded for disabled women. For example the only form of mainstream communication for the people with hearing impairment is written information. However considering the literacy levels in Malawi it can be rightly concluded that people with hearing impairment lack even the basic knowledge on HIV and Aids and other issues. Basing on the above statistics women with hearing impairment stand an even greatest risk in terms of vulnerability and exposure to the pandemic due to lack of information.
- Community stigma and negative attitudes are likely to impact more on women with disabilities than their male counterparts. The research carried out by the University of Malawi’s Centre for Social Research (2002) indicated that women with disabilities are generally more vulnerable than men. The following facts were observed both in the research^{*} and the needs assessments for example
 - a) The belief in the society that an HIV positive person can be cleansed by sleeping with a person with a disability. This makes the lives of many disabled women even more vulnerable.
 - b) The assumption that persons with disabilities are not sexually active and therefore information on reproductive health and HIV/AIDS is irrelevant to them. Health workers discourage women with disabilities from getting pregnant.
 - c) The general feeling of exclusion and inferiority in the women with disabilities themselves coupled with belief in the society that women are supposed to be submissive renders them exposed and open to abuse. Females with disabilities have greater problems finding a marriage partner than males up to a point that any sexual advance to them is deemed as an honour. Respondents narrated incidences of abuse by their partners due to this.
 - d) Women are generally less financially independent than men. A need for money compounded by lack of HIV/AIDS information puts women at greater risk to any sexual advances in exchange for money.
 - e) Female children with disabilities also appear to face more problems than male children. In particular respondents indicated that girls with disabilities are more at risk from sexual abuse, often by people in positions of authority, than male children with disabilities. This leaves girls with disabilities vulnerable to sexual assaults and consequently to contracting HIV/AIDS, other sexually transmitted diseases (STDs) and to falling pregnant.

The Project Goal

^{*} In Mobility and Transport Research for PWDs. (University of Malawi. 2002)

^{*} Mobility and Transport Survey for people with disabilities (2002)

The goal of the project is to ensure that men and women with disabilities are included in national HIV/AIDS policies, have access to information on HIV/AIDS and actively participate in HIV/AIDS awareness programmes

Project Objectives

RESEARCH COMPONENT

- To identify the problems people with disabilities experience in accessing information on HIV/AIDS .
- To identify where the main gaps in HIV/AIDS related knowledge exist for people with disabilities.
- To recommend an appropriate and effective information delivery system for people with disabilities.

CAPACITY BUILDING COMPONENT

- To ensure disabled women acquire skills in Advocacy, organisational management, programme planning, proposal writing, monitoring and evaluation and financial management.
- Disabled women to design an advocacy programme to deliver recommendations of the research findings.
- Practice the advocacy programme with other people with disabilities in the disability sector

AWARENESS COMPONENT

- To lobby government and non-government stakeholders to include disability issues in their policies and programmes.
- To encourage government and non-government organisations to implement research recommendations.
- To inform civil society of disability and HIV related issues

3. Wider Context/ Area /District/ /Region Context

- *Highlight notable events (environmental factors/issues - political, economical, social, and technological) that have or may have affected the implementation and results of the project.*

Research Component

Under this component the following factors had an impact on the implementation and results of the project.

- There were challenges that were encountered in communicating with respondents with hearing impairments. The sign language interpreters in the project at times could not understand the signs used by some respondents who were not familiar with the sign language used.
- Delays in releasing the results of the study by Centre for Social Research delayed the implementation of the subsequent activities that depended on the use of the expected results according to the activity plan.

- The involvement of persons with disabilities as enumerators in the project assisted in creating a rapport that eased the communication problems with the disabled respondents.
- The results of the research were used as a basis for planning for the awareness campaigns and the stakeholders' workshop.

Capacity Building

- The project witnessed a number of alterations in response to the emerging needs that came about during the implementation of the project. For example, women clearly stated that as this project was about effective communication of HIV/AIDS information for persons with disabilities that they expected to learn about HIV/AIDS during this project. This however was a big oversight in the design of the project but on reflection it is a strong recommendation for the success of this project if a workshop on basic HIV/AIDS education could be added. Such as the difference between HIV and AIDS, transmission, prevention and ARVs.
- It was realised in the course of implementing the project that more time was needed during training workshops because the subject matter was new and communication was more time consuming; translating into Chichewa and using sign language interpreters.
- The participants designed a workbook containing the workshop handouts and the group work assignments which apart from assisting the participants to follow the subject matter and make note taking easier, it was used to act as a resource tool for the participants in their organisations.

Awareness Component

- The women who underwent the capacity building training in this project are far more conversant on HIV/AIDS issues than their fellow members. The women were notably more confident in community awareness campaigns settings and able to speak up, even in their communities they are able to organize groups and educate them on HIV/AIDS. Their presentations skills markedly improved including use of visual aids and researched facts and figures.
- The formation of Public Relations and Desk Officers in all the DPOs helped a great deal in footage gathering for the radio programme. Their inclusion in the programme ensured that the needs of all disabilities were catered for.

4. Major activities and accomplishments

4.1 Outline Results in details:

- *Activities achievements*
- *Outputs achieved from the activities*
- *Outcomes from outputs*
- *Impact so far if any from the outcomes*

Activities

Indicator	Progress this reporting period	Cumulative Progress	Comments
Activity 1: <i>Research Component</i>			

	<p>33.5% of men with disabilities compared 26.1% in this study get information through the radio.</p> <p>23% of men with disabilities compared to 37% of women with disabilities get information through health facilities.</p> <p>10% of men with disabilities compared with 11.8% of women with disabilities get information through friends.</p> <p>9.6% of men with disabilities compared to 5% of women get information through the church.</p> <p>87.3% of people with disabilities in this study have heard of HIV, -Types of disability to have <u>not</u> heard about HIV are: 45% of people with speech impairments, 33% of people with mental challenges 11.5% of people with visual impairments not heard</p>	<p>Other organisations like MACOHA have used the statistics to produce leaflets and posters.</p> <p>FEDOMA managed to transcribe the National Aids Policy in Braille</p>	<p>Study reveals that men have more access to information from the radio than the women.</p>
Activity 2: Capacity Building Component			
	<p>100% of women benefited from the capacity building component which comprised :</p> <p>Organisational Management, Advocacy Skills Training , Awareness Raising, National HIV/AIDS Policy Review and the Public Relations and HIV/AIDS Desk Officers orientation</p>	<p>-24 disabled and 6 personal assistants attended the capacity building training</p> <p>-6 women plus 9 representatives from other stakeholders took part in National HIV/AIDS Policy Review</p>	<p>-Some women have demonstrated their skills by improving the management of their organisations.</p> <p>-Trained women were able to design, arrange and successfully community awareness campaigns</p> <p>-Each DPO has a Public Relations and HIV/AIDS</p>

			Officer
Activity 3: Awareness Component			
	Managed to hold 3 awareness campaigns which attracted crowds of a mixed multitude comprising approximately 60% girls and boys and 40% men and women. Out of 60%, 80% were girls and 20% boys, 85% women and 15%men.	3 awareness campaigns attended by mixed multitudes of approximately 800 to 1,500.	Speakers engaged the audience, for example, the audience were taught a bit of sign language.
	Held HIV/AIDS stakeholders meeting and 27% of the invited organisations turned up.	1 man and 3 women from the stakeholders attended the workshop. These were from the 4 organisations that turned up out of the 15 invited. 3 trained women from FEDOMA facilitated the workshop.	Most invitations were sent through local post and it took a long time for the invited participants to get them. The trained women made impressive presentations which included demonstrations
	100% of radio programmes have been broadcasted this period 12 organisations were interviewed,	25 radio programmes have been broadcasted this project.	Interviews went on well and the participation of DPOs gave them a sense of ownership of the programme.
	Policy Review meeting was attended by 15 participants from DPOs and other stakeholders.		

OUTPUTS

Indicator	Progress this reporting period	Cumulative Progress	Comments
Output 1: Persons with disabilities are less aware about HIV/AIDS issues compared to national figures due to communication problems and inaccessible infrastructure			

	45% of people with speech impairments, 33% of people with mental challenges and 11.5% of people with visual impairments have not heard of HIV/AIDS Reliable data on disability and HIV/AIDS	Produced a summary report of the study	Study reveals that men have more access to information from the radio than the women
Output 2: Trained women acquired knowledge and skills to carry out sustainable HIV/AIDS awareness programmes			
CAPACITY BUILDING	Trained women able to effectively run their organisation and also to monitor and evaluate.		
	Women are now confident to speak in forums on HIV/AIDS and disability issues.		
	Trained women are now peer educators and desk officers on HIV/AIDS in their organisations		
	Acquired skills in designing and implementation of awareness programmes.	Planned and conducted successful campaigns in 3 regions. 100% of the trained women participated.	Women to solicit resources to carry out more awareness campaigns
Output 3: Advocated for the mainstream society and government to include disability issues in HIV/AIDS programmes.			
	30% of organisations carrying out HIV/AIDS programmes not inclusive of disability needs	3 out of the 10 interviewed organisations (Television Malawi, MANASO and ADRA) were implementing HIV/AIDS programmes which are not disability inclusive.	FEDOMA to follow up with organisations to ensure their programmes are inclusive of disability needs
	Identified gaps in the National Policy on HIV/AIDS	Recommendations drawn from the gaps identified	
	Community leaders and NGOs were sensitised through the community campaigns and radio programme		

OUTCOMES

Indicator	Progress this reporting period	Cumulative Progress	Comments
Outcome 1: Review of the National HIV, AIDS Policy to identify existing gaps			
RESEARCH	Policy on HIV, AIDS was		

	review and gaps identified		
	FEDOMA and other stakeholders managed to transcribe other relevant material in Braille and also introduced a television programme with sign language Other stakeholders used the findings of the research to produce HIV/AIDS posters	Some visually and hearing are accessing HIV/AIDS information in accessible formats. Posters distributed and others available at FEDOMA resource centre	
Outcome 2: Effective management of women's organisations and wings			
CAPACITY BUILDING	Other women are sensitising the community on HIV/AIDS and disability. Others have mobilised women into self help groups. Trained women have been able to restructure their organisations/wings to effectively deal with challenges that meet their membership. Trained women have acquired self confidence and have changed their sexual behaviour.		
Outcome 3: Sensitised society on disability and HIV/AIDS.....			
AWARENESS	FEDOMA invited to by various stakeholders to participate in HIV/AIDS forums e.g. Pakachere Series, NAC workshops, City Assembly	Recognition of disability issues by some organisations dealing with HIV/AIDS	
	Some people with disabilities went for VCT		
	Institutions like PSI introduced sign language in their HIV/AIDS Videos		
	Some invited HIV/AIDS organisations missed the sensitisation workshop	Lack of knowledge on disability needs in HIV/AIDS	Need for FEDOMA to follow up
	Formation of DPO desk officers and Public Relations Officers to		Need further training of he desk officer and PROs to effectively carry out

	sustain the HIV/AIDS and disability awareness efforts		their mandate.
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IMPACT

Indicator	Progress this reporting period	Cumulative Progress	Comments
Impact 1: RESEARCH RESULTS.....			
	FEDOMA has used the results as an advocacy tool during awareness campaigns.	FEDOMA has distributed the summary report on request from within and outside the country e.g. Uganda, U.S.A, Kenya The report has also been circulated to as far as India, Bangladesh, and UK.	There is need to conduct more research on areas not covered by this study.
Impact 2: CAPACITY BUILDING			
	More effective advocacy work on disability and HIV/AIDS is being conducted by competent women with disabilities	Trained women with disabilities are able to claim and defend their rights.	There is need to train more men and women to continue with the advocacy work.
Impact 3: AWARENESS			
	Increased number of people and organisations are aware of disability and HIV/AIDS issues in the community Other HIV/AIDS stakeholders have introduced disability friendly formats in their sensitisation programmes e.g. PSI.	Most chiefs and communities visited during the campaigns have become aware of the challenges faced by persons with disabilities regarding HIV/AIDS.	There is need to make follow ups.

NOTES:

Progress this Period to capture:

- Summary statistics/percentages (refer annex of tables, graphs with details)
- This to clearly show number of men, women, boys and girls affected/benefited directly and indirectly from the project.
- Case studies/testimonies highlights (refer annex for whole case studies/testimonies)
- Highlights of pictures (refer annex for actual pictures)

Cumulative Progress to capture:

- Summary statistics/percentages (refer annex of tables, graphs with details)

- Provide a grand total statistics from the start of the project (clearly break down in men, women, boys and girls)
- Provide an insight of trend so far (refer graphs/tables and averages on annex)

Comments to capture:

- Why that progress (either lower or higher than expected)
-
- What is the way forward

5. Challenges and Mitigating Factors

- Short description of challenges and issues that hampered project efforts.
- Also outline possible solutions for addressing the problems.

During the period of completion the project met with a number of challenges. Due to a number of unseen circumstances a number of activities were not able to completed within the time as planned.

During the research stage

- Delays in releasing research report affected the progress of the project since subsequent activities were dependent upon the findings of the research for their implementation.
- The resignation of two Project Coordinators during the course of implementation also hampered projects efforts. There was no proper handover because the resignation was sudden and therefore created a vacuum when the organisation was looking for a replacement of both the accountant and projects officer. The resignation of the last project officer before the completion of the project has also placed a strain on the lean FEDOMA staff to finalise the project.
- Delays in feedback from both parties especially CIDA/GESP was also a mitigating factor in the implementation of the project according to plan. For instance, when FEDOMA had planned to hold a workshop at a particular time, sometimes CIDA took time to respond and this interfered with the timing of the activities.
- The project also encountered many alterations because of some issues that emerged during the implementation which were felt to be of vital importance to the project.
- Communication problems that arose due the lower levels of illiteracy among some of the participants who were not conversant with English which was used during training. In one workshop some of the participants ended playing the role of interpreters and this delayed the process.

In order to address these challenges the following are proposed solutions: -

- Future projects should ensure that full time project officers are recruited
- Both parties should be conscious of time by giving feedback in good time and also giving priority to urgent matters
- Future training sessions should ascertain the calibre of people attending and provide mode of communication

6. Lessons learnt:

- *What have the different groups (beneficiaries and the implementing organisation) learnt from the experience that may be considered new and worthy sharing? (Are there any*

notable changes in terms of policy dialogue? Are women better able to engage in discussions/decision making deliberations within the various institutions that affect them?)

- The women who have undergone the capacity building training workshops in this project are far more conversant on HIV/AIDS issues than their fellow members. The women are notably more confident in workshop settings and able to speak up, even in their communities they are able to organize groups and educate them on HIV/AIDS. Their presentations skills have markedly improved including use of visual aids and researched facts and figures. Although as an observation the women still need further encouragement to build unity and work together with other disabled persons organizations, the organizations still tend to work in isolation of one another.
- Because of the experience and confidence they gained, some women have been able to form self-help groups in order to support themselves and sensitise members on the danger of HIV/AIDS. One such group is running a very vibrant project on chicken rearing and dairy farming.
- The project assisted in FEDOMA in identifying gaps in the national HIV/AIDS Policy as they affect people with disabilities and also key strategic areas of focus for FEDOMA to pursue for inclusion in the national HIV/AIDS policy.
- One woman with disabilities who went for testing and found positive has taken upon herself to encourage others to take her example. She has addressed other members about her experience.
- Persons with disabilities participated in the research as enumerators and this is a lesson that if persons with disabilities are given skills, they can deliver.
- FEDOMA has been invited to attend a number of HIV/AIDS related workshops including the TV programme 'Pakachere' by PSI. Through this FEDOMA has learnt what other organisations are doing.

7. Future activities

- *Include work plan for the coming period.*
- *Highlight the planned and any unplanned activities that have resulted from the project at this level.*
- *What recommendations do you and/or beneficiaries have for a similar project?*

As a result of this project, FEDOMA established a task force whose role is to come up with a Position Paper highlighting all relevant Policy issues on HIV/AIDS which will be presented to the Office of the President for inclusion in the National Policy on HIV/AIDS.

FEDOMA also plans to develop a programme on the sensitisation of people with disabilities and other service providers on HIV/AIDS throughout the country through the use of all media of communication.

8. Attachments:

- Posters, photos, tables, names of participants and facilitators and any other important data and/or research reports/findings and availability at the organisation.
- Case studies and testimonies