



Disability, HIV and AIDS Trust

Creating an Inclusive Society

Disability, HIV and AIDS National stakeholders' Meeting Lilongwe, Malawi



Lingadzi Inn, 20th – 21st February 2011

Draft Report

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Abbreviations and Acronyms

AIDS	Acquired Immunodeficiency Syndrome
APDM	Association of the Physically Disabled in Malawi
ART	Anti Retroviral Therapy
CBOs	Community Based Organizations
CSO	Central Statistical Office
DPOs	Disabled Peoples Organization
DIWODE	Disabled Women in Development
DWOOM	Disabled Widows Orphans Organization in Malawi
FEDOMA	Federation of Disability Organizations in Malawi
GF	Global Funds
HEARD	Health Economics and Research Division
HIV	Human Immuno-deficiency Virus
JFA	Joint Financing Agency
MACOHA	Malawi Council of the Handicapped
MADISA	Malawi Disability Sports Association
MANAD	Malawi National Association of the Deaf
MANASO	Malawi Network of AIDS Service Organization
MPWDE	Ministry of People with Disabilities and Elderly
MoE	Ministry of Education
MoH	Ministry of Health
MUB	Malawian Union of the Blind
NAC	National AIDS Council
NGOs	Non Governmental Organizations
NSP	National Strategic Plan
PMCT	Prevention of Mother to Child Transmission
PODCAM	Parents of Disabled Children Association in Malawi

TAAM	Albino Association of Malawi
TWG	Technical working Group
ToR	Terms of Reference
SAT	Southern AIDS Trust
UNAIDS	United Nations Joint Programme on HIV and AIDS
UNICEF	United Nations Children's Emergency Fund
VCT	Voluntary Counseling and Testing
VIHEMA	Visual and Hearing membership Association

1. Executive Summary

The National Disability and HIV and AIDS stakeholders meeting in Lilongwe, Malawi held on 20th and 21st April 2011 at Lingadzi Inn is one of the four meetings that the Disability, HIV and AIDS Trust planned to hold in Botswana, Malawi and Zimbabwe. One of the objectives of the meeting was to advocate for the mainstreaming of disability into HIV and AIDS responses to ensure that HIV and AIDS policies and programmes and legislation address the special needs of PWDs.

The rationale of the meeting emanates from the backdrop of issues surrounding the exclusion from and non-involvement of PWDs in mainstream HIV and AIDS interventions. The workshop focused on disability, HIV and AIDS in relation to existing policies, legislation, programming and interventions that relate to HIV and AIDS.

The workshop was attended by 22 participants from disability organizations, ASOs and Government and the National AIDS Council. The key issues resulting from the workshop was that there is a general lack of knowledge on disability issues regarding access to information on HIV and AIDS is prevalent in Malawi. For example, people with disabilities are stereotyped as not sexually active and that sexual intercourse with a disabled person can cure AIDS.

Information about HIV and AIDS still remains inaccessible to many disabled people due to the lack of appropriate formats. People with disabilities do not participate in the affairs of the Technical working Groups (TWG) of the NAC in Malawi. However, it was also learnt that the MPWDE and MACOHA are members of the TWG on disability and HIV and AIDS. In addition, there are no formal and targeted strategies and activities for disability and HIV and AIDS in MANASO HIV and AIDS programming. MANASO acknowledges the inadequacies and proposes the inclusion of disability issues during strategic review and planning processes in the organization.

In Malawi, the Constitution under section 30 espouses the promotion of the equalization of opportunities for persons with disabilities economically, socially, politically and culturally, and discourages any discrimination. The National Youth Policy encourages action on HIV and AIDS for all youths including those with disabilities. The meeting also called for an urgent need to have interventions that addresses HIV causing disability.

In order to advocate for all issues that were identified and recommended for action, the task team composition to lead the task of advocating for the mainstreaming of disability into HIV

and AIDS programming was proposed. However ToRs of the task team will be drawn by DHAT regional and circulated for the input of the task team.

2. Introduction

People with disabilities face a number of challenges in the realm of HIV response. The challenges are a result of the lack of inclusion and involvement of people with disabilities from HIV and AIDS interventions. In many areas of policy, legislation and programming, people with disabilities are outrightly ignored and not involved in the policy making, legislation and planning of programmes.

With a myriad of studies and subsequent information collected about HIV infection and impact on the mainstream population, very little of information is known about the impact of HIV on people with disabilities. This is also in contrast to amount of knowledge known about other marginalized groups such as MSM and commercial sex workers.

It is evident from other studies that HIV infection in PWDs maybe higher or equal to the mainstream population. In addition, it is known that disability increases vulnerability to HIV infection. The vulnerability to HIV infection is compounded by the subjection of disabled people to negative attitudes, perceptions and myths that predisposes them to HIV infection. ASOs and other service providers lack information on how to provide health services to disabled communities. Therefore, much as HIV prevalence rates are falling, it maybe that HIV prevalence rates could be higher among disabled people. Excluding the disabled from the mainstream HIV and AIDS prevention, care and support systems has adverse effects on averting the spread of the virus.

In view of the above, DHAT organized these national workshops that will define national advocacy issues and provide a regional advocacy analysis and prioritize research requirements and resources. The workshop looked at disability, HIV and AIDS in relation to existing policies, legislation, models and disability organizations, ASOs and government ministries that will work with DHAT to address matters of mainstreaming disability and HIV and AIDS into respective programming. This workshop was designed to start the process to include and involve disabled in HIV and AIDS policies and programmes, planning and implementation processes; as well as to raise awareness for service providers to be more responsive on disability and HIV and AIDS issues for the improvement of access to HIV and AIDS information and prevention, care and support services by people with disabilities.

3. Workshop Opening Remarks

Mr. Phillimon Simwaba the Executive Director of the Disability HIV and AIDS Trust thanked all participants for coming to the workshop. He acknowledged the presence of Mr. Rex Kilembe the Assistant Director in the MPWDE and Mr. Novice Bamusi the Malawi country programme office of SAT. He was delighted that DHAT and SAT relationship is growing from strength to strength.

However, Mr. Simwaba was not delighted with Global Funds and other organizations' funding requirements. He said that DHAT has challenges to access funds from the Global Funds because of undesirable eligibility requirements.

He gave an example that FEDOMA is an umbrella body of DPOs and it is important that the organization is considered as a sub-recipient of Global Funds. He noted that CBOs, FBOs and other organizations are recognized. However, DPOs are evidently ignored by organizations that disburse Global Funds. He said if DPOs are grouped into CBOs or vulnerable groups. There is a danger of them being sidelined. He also advised ASOs to consider mainstreaming disability into their strategic plans.

Mr. Simwaba also explained that DHAT is working in Botswana, Malawi, Zambia and Zimbabwe. The regional office was initially registered in Botswana because HIV prevalence rates were comparative higher than in other countries in the region. However, because of the progressive graduation of Botswana into higher levels of middle class economic statuses, donor funding opportunities are very scarce in Botswana. DHAT secretariat was compelled to relocate to Harare Zimbabwe. In conclusion, he said that DHAT has strategic partners in other countries of the SADC region.

4. Workshop Official Opening

The meeting was officially opened by Mr. Kilembe who is the Assistant Director in the Ministry of People With Disabilities and Elderly was standing in for the Principal Secretary in the Ministry. He observed that the programme was interesting and therefore informed participants that he came in as a participant and a guest speaker. He was delighted to officially open the national Disability and HIV and AIDS workshop. On the other hand he was also delighted that the dream of DHAT has come to fruition at the right time since DHAT is advocating for filling the gap that the Government and other stakeholders are not doing in service delivery to people with disabilities relating to HIV and AIDS. He stated that the

national workshop discussed ways of enforcing advocacy for service delivery to people with disabilities in Malawi.

There are very few organizations in Malawi that carry out service delivery to people with disabilities. He gave an example of access to ART, information packages and lack of accessible VCT centres. Policies do not also show desired treatment for the disabled.

He said that he was looking forward to the workshop recommendations emanating from the workshop that will inform policy and decision makers to fill the gaps in service delivery to people with disabilities. He said that the issues about disability and HIV and AIDS are human-rights issues. Mr. Kilembe emphatically said there is no excuse to the lack of or inadequate provision of services equivalent to people with disabilities.

MANASO and NAC champion goals that aim at addressing issues of HIV and AIDS. However, a lot of information does not reach people with disabilities in programming. He mentioned that HIV and AIDS information is not available in large print and audio formats. Let alone, sign language is virtually unavailable for the hearing impaired categories. He said that the situation was pathetic.

Mr. Kilembe encouraged DHAT and SAT to influence government to include issues of disability into service delivery. He advised that all challenges are not insurmountable. He therefore noted that issues of disability must be addressed adequately. Government and all stakeholders should ensure that the “talk” must be in tandem with action. He said that mitigations should reach people with disabilities and all decision makers should show commitment.

Therefore, recommendations from the meeting must be followed closely and put into programming by all participants that included Mr. Kilembe. In addition he advised that relevant instruments must be installed that will address concerns of people with disabilities. In light of the discrimination against people with disabilities, he encouraged all participants to create opportunities for people with disabilities. He gave examples of provision of assistive devices and funds to people with disabilities by the MPWDE. He noted that the provision was inadequate and requires non-state actors to collaborate with government ministries and work together in the provision of services to people with disabilities. For example water service points are designed for able bodied but not for people with disabilities.

In conclusion, he informed participants that the issue of culture and customs was missing in the programme. Faith-based organizations and activists should also have been included in the participants list. He advised participants to fully participant in the workshop programme.

5. Meeting Goal, Objectives and Rationale

5.1 Goal and Objectives

To reduce the vulnerability of people with disabilities to the impact of HIV and AIDS

Objectives

- To advocate for mainstreaming of disability into HIV and AIDS response to ensure that HIV and AIDS policies and programmes address the special needs of people with disabilities
- To achieve consensus and commitment on the mainstreaming of Disability, HIV and AIDS
- Build strategic alliances and networking that will contribute to innovative approaches and development of sustainable programmes on Disability, HIV and AIDS

5.2 Workshop Rationale

Mr. Phillimon Simwaba of DHAT spelt out the background of the hosting of the meeting in Malawi. He said that several consultations and workshops with stakeholders on disability, HIV and AIDS at national levels have been held in Botswana, Malawi, Zambia and Zimbabwe. The workshops focused on disability and HIV and AIDS missing links and roles of DPOs in mainstreaming HIV and AIDS. The workshops identified the missing links in service provision, policy and legislation in responding to HIV and AIDS interventions. Prior to this meeting a workshop with theme "Role of leadership in Mainstreaming HIV and AIDS in DPOs" was held in Zambia (June 2007).

The results of the workshop show that people with disabilities are at high risk of exposure to HIV because they are subjected to extreme social, political, economic, financial and cultural marginalization and that PWDs are excluded in the HIV and AIDS response. The consultations also show that people with disabilities are excluded in the conception, planning and implementation process of policies and legislations. There is need for increased inclusion and participation of PWDs, to ensure that they have access to HIV and AIDS services which are both designed to their diverse needs and equal to services available to others in the community.

The issues of concern raised and noted at the workshop were mainly:

- Observed lack of knowledge of HIV and AIDS issues by PWDs (prevention, treatment, care and services available)
- Lack of involvement of PWDs in the current HIV and AIDS response by both government and civil society
- Limited access for PWDs to information and services on HIV and AIDS because most of the information is in formats that is not accessible to the hearing and visually impaired

6. Presentations

6.1 Challenges faced by persons with disabilities in HIV and AIDS issues

The presentation was conducted by Mr. Mussa Chiwaula, Executive Director of the FEDOMA. He said that DHAT was becoming an influential organization in the area of mainstreaming disability and HIV and AIDS into programming in the region. He emphasized that FEDOMA is also for people without disabilities. He said that every human being is potentially vulnerable to being disabled. He advised all to work with organizations of people with disabilities.

Mr. Chiwaula informed the participants that the FEDOMA presentation was a departure from what was in the programme because of the challenges in communication between DHAT and FEDOMA. However he was delighted to share with the participants on results of a study that FEDOMA conducted recently. The title of the presentation in the programme was “Mainstreaming HIV and AIDS into FEDOMA programming”. Mr. Chiwaula presented on “Challenges faced by persons with disabilities in HIV and AIDS issues”. The following are the details of the presentation.

Firstly Mr. Chiwaula gave the background of FEDOMA as an umbrella organization of Disabled People’s Organizations (DPOs) in Malawi, founded in 1999 and registered in 2000 under the Trustees incorporation Act. The following are the member organizations: 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), Albino Association of Malawi (TAAM), Association of the Physically Disabled in Malawi (APDM), Visual and Hearing membership Association (VIHEMA), Disabled Widows Orphans Organization in Malawi (DWOOM)

FEDOMA has a mission of enhancing the welfare of persons with disabilities and enable them play their rightful role in society. To achieve this FEDOMA has the following objectives:

- ▶ To promote and advocate for the rights of persons with disabilities
- ▶ To advocate for and monitor the equalization of opportunities for persons with disabilities as stipulated in the United Nation's Standard Rules Convention on the Rights of Persons With Disabilities
- ▶ To promote and advocate for inclusion of persons with disabilities in all development activities
- ▶ To coordinate and strengthen the capacity of the affiliated DPOs

Secondly Mr. Chiwaula highlighted on misconceptions about disability. He said that People with Disabilities are stereotyped as not sexually active and that sexual intercourse with a disabled person can cure AIDS

The results of the study with reference to respective challenges faced by people with disabilities are as follows:

Channels of Communication: Radio, television, drama, posters, print, and electronic media constitute some of the common ways of communicating HIV and AIDS messages. The total sample of respondents was 341 individuals. Those that said they communicated with others using speech were 98%. Sign language use was at 2%. The proportion of respondents that had access to radio was 84% because they had physical disabilities, 5.9% had access to television, 45.2 to drama, 44% to posters, 27.9 to posters.

Knowledge about HIV and AIDS: Those that had sex constituted 76%. Those that had the first sexual encounter out of choice were 83% and 17% were forced. Ages of the first sexual encounter ranged from 15 to 27 years while others had difficulties entering into intimate relationships due to stigma and difficulties in mobility

Respondents that had heard about HIV were 87% and 94% heard about AIDS showing that knowledge about AIDS among disabled people is basic.

Knowledge about HIV and AIDS: Approximately 36% of the respondents mentioned that HIV is AIDS and 42.5% would be able to tell if a person had AIDS by looking at the symptoms. On transmission of HIV the majority said it was transmitted through sex without a condom while others said sex with a condom, mosquitoes, eating with HIV⁺ person can transmit HIV. The major methods of preventing the transmission of HIV mentioned included abstinence (40%), use of condoms (31.6%) and avoiding multiple partners (14%).

Knowledge about HIV and AIDS: On contracting HIV and AIDS 55% of those interviewed said there was no possibility for them to contract HIV because of a number of reasons including sex before marriage, faithfulness and use of condoms. About 90% said that their disability did not put them at risk of contracting HIV. During the FGDs it was mentioned that people with hearing and visual impairments were at the risk of contracting HIV as they may not know much about AIDS.

Sources of Information about HIV and AIDS: Most of the respondents heard about HIV and AIDS through radio, and this was followed through the health facilities and friends. Other sources included teachers, peers, religious leaders and NGOs. Only one person had heard about HIV and AIDS through sign language. People with visual impairments never heard about HIV and AIDS through printed material. Some problems mentioned included lack of radios, need for someone to read especially for the visually impaired, lack of outreach programmes, long distances to health facilities and mobility problems.

In Conclusion the study results from the presentation showed that; 76% of the respondents were and have been sexually active and that general awareness about HIV and AIDs is high but knowledge is low, hence people with disabilities are vulnerable to contracting HIV.

Most persons with disabilities learnt about HIV and AIDs through radio or health facilities suggesting that these are good channels of communications yet some people with disabilities do not have radios, and for the deaf radio is an impossible means of communication. It is also evident that stigma and negative attitudes towards people with disabilities were prevalent.

The study highlighted the general lack of knowledge on disability issues regarding access to information on HIV and AIDS and need for stakeholders in HIV and AIDs work to market their activities and encourage active participation of persons with disabilities and their organisations.

6.1.2 Comments on the FEDOMA Presentation

A question was raised by David Njaidi (MoEST) whether the study results have been disseminated. It was noted that the workshop was one of the avenues that the study results were disseminated Mr. Njaidi underscored the assertion in the study results that people with disabilities were sexually active..

Ms Sigere Kasasi of DIWODE also mentioned that awareness programmes on the results of the study were conducted for instance in Lilongwe and Mzimba during peer educators workshops.

6.2 Challenges to Access HIV and AIDS Services by Persons with Disabilities

Mr. David Njaidi of Ministry of Education Special Needs Department presented on the "Challenges in Accessing HIV and AIDS Services by Persons with Disabilities in Malawi". His presentation focused on Policies, legislation and programming.

In the preamble, of the presentation, it was noted that Malawi has a HIV prevalence rate of 12%, one of the highest in Southern Africa and that by WHO; 10% of the total population in Malawi constitutes people with disabilities.

On Policies and legal framework targeting people with disabilities, the following were noted:

The National Policy on the Equalization of Opportunities for Persons with Disabilities, section 4.13: focuses on promotion of access to HIV and AIDS information and health care by persons with disabilities and empowerment of persons with disabilities to develop and maintain safer sexual and reproductive health practices.

The national HIV and AIDS Policy section 11 emphasizes that government through the NAC undertakes to ensure that HIV-related prevention information, education, treatment, care and support strategies are tailor-made for and accessible to people with disabilities. Secondly, ensure that all decision making forums and structures provide for the full and active participation of people with disabilities. Thirdly, ensure that all responses to HIV and AIDS consider the implications for people with disabilities and plan for more effective responses based on models of national and international best practices.

The Malawian Constitution, Section 30 espouses the promotion of the equalization of opportunities for persons with disabilities economically, socially, politically and culturally, and discourages any discrimination. The National Youth Policy encourages action on HIV and AIDS for all youths including those with disabilities.

Successes in disability and HIV and AIDS programmes were also noted: These are: Government has conducted HIV workshops among people with disabilities and that some HIV and AIDS materials have been transcribed for school children and adults. NAC has also funded some organizations in the disability sector to undertake HIV and AIDS interventions, e.g. MACOHA, Montfort College, Special Needs Department, MUB (Malawian Union of the Blind).

Challenges in disability and HIV and AIDS programs: It was stressed that HIV and AIDS information still remains inaccessible to many disabled people due to lack of braille, large-print, audio materials and sign language services and that most services in HIV and AIDS

are housed in inaccessible buildings or places, e.g. VCT or PMCT. This places many disabled people's lives at risk. Secondly, many workplace HIV and AIDS policies exclude disabled people, especially in implementation and most NGOs' HIV and AIDS programmes do not reach out to people with disabilities both in programming and implementation. Thirdly, attitude problems against disabled peoples exist in many hospitals, health centers or personnel. Lastly, most DPOs and their members lack capacity to fully realize the National HIV and AIDS related policies and most of the DPOs and disabled people lack skills in advocacy for HIV and AIDS services.

Key partners in policy, legislation, programs and implementation: The key partners in legislation, legislation, and implementation programmes are of Government Ministries and Departments, NGO leaders, Community leaders and traditional structures and the Health sector.

Recommendations for improved HIV and AIDS services among PWDs: The following were recommendations were listed in the presentation.

- Empower PWDs to develop and maintain safer sex practices and encourage them to access HIV counseling and testing
- Promote active health care services to people with disabilities
- Encourage PWDs to embrace openness on sexual health issues as an important aspect of prevention of HIV and AIDS
- Encourage DPOs to develop and implement organizational policies that promote positive practices around HIV and AIDs for people with disabilities
- Work alongside NAC, MANASO and other NGOs to work with DPOs and people with disabilities on HIV and AIDs interventions
- Build capacity for DPOs in the area of advocacy and policy analysis

6.2.1 Comments on MoE Special Needs Department Presentation

Ms Sigere of DIWODE pointed out that the word “tailor made” means something that is difficult to perceive. It is better to mention what the tailor made programme is. Tailor made could mean something that is everyone does not even know.

She said that disability issues are straight forward issues that do require obscure statements and words to describe them. She said that disabled people have faced challenges for a long time because of obscure statements.

Mr. Chiwaula of FEDOMA compared "tailor made" to the word "vulnerable groups". He said when we say vulnerable groups we should mention the actual groups that we refer to as vulnerable groups. Mr. Chiwaula said we should say No to words such as "vulnerable groups" and "tailor made". Mr. Chiwaula raised the issue of capacity building for DPOs. He noted that MoUs with networks specialized in various areas of capacity building are very important. He also said that written workplans and strategies are important in implementation of DPOs programmes. The importance of Monitoring and Evaluation was also noted.

6.3. Innovative Approaches to Advocacy

A documentary entitled "stepping into the unknown" was shown. In light of exclusion of the disabled people from mainstream HIV and AIDS interventions, disability advocates and researchers have been raising awareness regarding the fact that people with disabilities have been left out of HIV prevention, treatment and care and support. The UNAIDS has identified people with disabilities as a key group at increased risk of exposure to HIV. Recent prevalence studies in Kenya, Cameroon and South Africa confirm the claim and show that the HIV prevalence among people with disabilities is as high as and often higher than national average.

Disability and HIV is still a neglected issue and as recent analysis of East and Southern African NSPs seldom included into the national response to HIV and AIDS. HEARD and DHAT have developed a documentary that aims at bringing the issue of HIV and AIDS to a larger audience

The film features a unified group of four disability and HIV activists who shared their experiences with the audiences. The event was chosen to combine their gathering with an extreme event (bungee jumping) so as to raise maximum awareness.

The film aims at raising awareness to the issue of disability and HIV within a wider audience highlighting issues that people with disabilities are excluded from mainstream interventions, prevention and care. Desperate circumstances call for extreme action to create awareness, to stand up and be noticed. Using the jump as a metaphor, the film explores how when one tests and jumps, one is scared, but can have the support from family, friends and the disability community

The group symbolizes strength in numbers and a support network and also agency to advocate and encourage policy makers to take note, listen and react. There is also fear in disclosure of status. This associated stigma is the fear of the unknown of how people will react one's disclosure. Stepping off the cliff symbolizes stepping away from stigma and fear.

The documentary will be translated into Cichewa and distributed to all relevant stakeholders and the Ministry of Health in Malawi.

6.3.1 Comments on Innovative Approaches to Advocacy

Mr. Chiwaula said that it was delightful that people with disabilities themselves were getting involved in raising issues about disability and HIV and AIDS. It was also shown in the movie that persons with disabilities can also be infected with HIV. The testimonies are in the movie. It was also learnt from the documentary that HIV causes disability. Mr. Njaidi recommended for an urgent need to have interventions that addresses HIV causing disability. Mr. Bamusi advised that there is also need to distinguish issues of HIV according to people with disabilities and the non-disabled because experiences are different. Bernard Mandere noted that "stepping into the unknown" is a documentary of hope. Therefore, change of attitudes and strategies in support of people with disabilities are imperative. He said that the documentary counters attitudes and stereotypes and that the participants must do positive things in solidarity with issues raised in the documentary.

6.4 HIV and AIDS Mainstreaming Guidelines (NAC- Malawi)

The National AIDS Council presented on HIV and AIDS mainstreaming guidelines in Malawi. The presentation was conducted by Stella Masangaro

In her introduction, Stella quoted "Individuals with disability are equally at risk but it is assumed that they are not sexually active and at little or no risk for HIV infection. The Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank has proven this assumption wrong. Individuals with disability have equal or greater exposure to all known risk factors for HIV infection".

She also gave two definitions of mainstreaming as follows: Firstly, "Placing HIV and AIDS at the centre of the development agenda or mainstreaming is a process whereby HIV and AIDS actions become part of the normal and routine functions of a sector/organization" (**UNDP**). Secondly, "Putting HIV and AIDS lens to all activities and utilize comparative advantage to respond" (**SADC**).

Stella said that the concept of mainstreaming is usually not understood by most stakeholders. She gave an example of FEDOMA having programmes of HIV and AIDS besides its core programmes. The two should not be considered as separate programmes but holistically as one programme. In the event that HIV and AIDS dry up programming should still continue in the area of HIV and AIDS if considered as one with core programmes

HIV and AIDS mainstreaming means each institution or organization must determine how HIV is spread and how their organization has contributed to the spread of HIV and how the epidemic is likely to affect the organization's goals, objectives and programmes. Secondly it means where an organization has a comparative advantage to respond or limit the spread of HIV and to mitigate the impact of the epidemic and how to address HIV and AIDS in their organization and their core business.

It also means bringing AIDS to the centre of the development agenda and at an operational level- responding to questions: What is the impact of AIDS on development (people with disabilities), how can this be minimised? What are the impacts of development responses on the epidemic? How to work in ways that do no harm?

Internal mainstreaming of HIV and AIDS involves addressing workplace environment by looking at the work place programmes to prevent HIV infection and reduce the impact of HIV and AIDS. This involves emphasis on policies that affect staff and the business.

Stella also mentioned that external mainstreaming means integrating HIV and AIDS in the core functions of the organization. In this case emphasis is placed on comparative advantage of the organization to implement activities based on the mandate of the organization. She explained that HIV and AIDS should be part and parcel of the core functions and fully integrated into core business of the organization.

So to include people with disabilities requires to reduce poverty among disabled people and accelerate development programs and determine and set disability-specific indicators. In addition we need to increase disability-specific research and raise awareness among disabled people on HIV and AIDS whilst creating communities with competence to deal with AIDS and ensure access to information amongst disabled young people. Need to be consulted and be assisted in order to participate and make inputs in the development of HIV and AIDS related programmes, strategies, policies and legislation is also important. Further, we need to train sign language interpreters to be allocated to VCT centres and access to ART accredited sites. Others are to facilitate the inclusion of disabled people in prevalence studies by changing or amending protocols and instruments used to determine prevalence at

national and international level, recognize disabled people as a vulnerable group alongside other recognized groups and fast track measures for accessible transport to enhance access to services.

HIV and AIDS Mainstreaming Guiding Principles: These were categorised as follows.

Mandate Analysis: The overall objective is to assess the organization's strategies which need to be reviewed to address staff or the organization's vulnerability to HIV and AIDS.

Impact analysis: To understand the impact of HIV and AIDS on the staff and the organization.

Policy, regulatory and cultural environment: To understand how the mainstreaming process in the organization fits with the broader policy, regulatory and cultural environment of the country.

Entry points and process alignment: To Identify key opportunities for mainstreaming HIV and AIDS e.g. during review of Sector Strategies, Policies or Plans.

Mainstreaming interventions: To develop actions or plans to mainstream HIV and AIDS in the organization.

Case Study: Mainstreaming HIV and AIDS in MoE was an example: In this case two analyses have to be conducted. These are mandate analysis and Impact analysis.

Mandate analysis: MoE needs to fully understand its mandate, objectives and functions and how the impact of HIV and AIDS would prevent it from attaining its mandate goals and objectives.

Impact Analysis: MoE needs to fully understand the relationship between HIV and AIDS and goals of the ministry (Special Needs Unit). If the impact is felt, it needs to respond appropriately and if not, it needs to plan to prevent the staff from the impact of HIV and AIDS. e.g. MoE would initiate a survey to fully establish knowledge, attitude and practice towards HIV and AIDS among staff.

The survey would help to identify interventions to prevent further spread and mitigate the impact among staff and students. The survey would also help MoE in its strategies for quality education to limit the spread of HIV and also identify practices that spread the virus.

How MoE would identify the impact of HIV and AIDS? The following were itemized in identifying the impact of HIV and AIDS. The MoE would look at illness trends and frequency

on its staff at all levels. MoE would analyse expenses illnesses as well as funeral expenses for a specific period. MoE would analyze high vacancy rates which results in poor services and over working of existing staff and analyze increase in costs for training and re-training of staff. Prevalence rate within the staff would also be required to be investigated and looking at knowledge levels among staff towards AIDS.

Examples of interventions (workplace programmes): Examples of workplace interventions were also given. These were: Development and implementation of workplace programs for staff, curricula review and implementation for colleges and holding of prevention sessions for staff e.g. awareness sessions. The development and distribution of IEC materials in relevant formats, peer counseling and education for staff and role modeling for student in colleges were also noted.

Monitoring and Evaluation

Monitoring and Evaluation for HIV and AIDS mainstreaming in the organization must be part and parcel of the HIV and AIDS National Monitoring and Evaluation Framework. On site monitoring for outreach programmes must be conducted together with review meetings with stakeholders.

The following were noted as challenges in mainstreaming: The concept of mainstreaming is not adequately understood by stakeholders, limited ownership and commitment towards HIV and AIDS programmes, often associating HIV and AIDS mainstreaming with financial support, taking HIV and AIDS as an extra responsibility with a special budget and staff and reluctance of Institutions to allocate own funds/resources for HIV and AIDS programmes

In conclusion mainstreaming requires advocacy sessions targeting leadership in all sectors, provision of technical support for HIV and AIDS mainstreaming, support best practices in HIV and AIDS mainstreaming and training of sector staff in HIV and AIDS mainstreaming.

6.4.1 Comments on the NAC-Malawi Presentation

Phillimon Simwaba raised the issue of categorization of organizations by the NAC. For example, CBOs and FBOs are mentioned whereas DPOs are not mentioned anywhere in NACs strategies. DPOs are always considered as CBOs. He said that this discriminates and places DPOs on the fringes of funding disbursements from the NACs. Ms Sigere Kasasi underscored what Simwaba raised and stated that NAC should distinguish between organizations for and organizations of people with disabilities. For example it was mentioned

that MACOHA received funding from the NAC. MACOHA is an organization for people with disabilities.

Mr. Chiwaula said that NAC has honoured its policy statement by supporting disability groups e.g. MACOHA and MUB. Every year give funding to disability programmes. However, FEDOMA applies for funding but never receives any support from NAC. So what criteria does NAC use to qualify organizations for eligibility in funding disbursement? It was learnt that NAC has guidelines that it follows and it is better to work closely with NAC so that one is guided in the way proposals are written.

Another concern was raised that People with disabilities do not participate in the affairs of the Technical working Groups (TWG) of the NAC. There are various TWG for specific areas of HIV and AIDS interventions. However, there is no involvement or participation of disabled people. The response given was that it was not by design; however, each particular working group has relevant organizations that are represented. It was also learnt that the MPWDE and MACOHA are members of the TWG on disability and HIV and AIDS. . NAC calls for proposals on each cycle of funding disbursement. So it is the responsibility of every eligible organization to write a letter of interest to ensure that a proposal is submitted to NAC.

Disability organizations are not included because of an oversight. Boniface Mandere of the "Eye of the Child" said that we should stop saying an "oversight". It shows that other sectors are not considered and that it is just very clear that procedural formalities in qualifying for funding from NAC are difficult. Even when one qualifies it takes very long to be granted the resources and there are sometimes instructions when funds are granted that the money must be spent very quickly. What is required is change of attitudes at NAC. He said that NAC sometimes uses resources that were supposed to be spent three years earlier. Stella said that she will follow up on the concerns raised in the meeting to management at NAC.

6.5 HIV and AIDS Interventions in MANASO Programming

The presented was conducted by Edward Chikhwana. Chikhwana gave the background of the Malawi Network of AIDS Service Organization (MANASO). MANASO is an umbrella organization for all AIDS Service organizations in Malawi and was formed in November 2006. The organization was formed through a recommendation of SADC Ministers of Health meeting around 1994. The meeting recommended establishment of national Networks of HIV and AIDS Service organizations in all SADC countries. MANASO has currently over 1000 members. The members include international NGO's, Local NGO's and Community Based Organizations

MANASO Exists to contribute towards the reduction of HIV and AIDS prevalence and alleviation of suffering caused by the epidemic in Malawi through coordination, capacity building, information sharing, mobilization and allocation of resources to AIDS Service Organizations in Malawi.

The Objectives of MANASO are: To facilitate the sharing of information, ideas, experiences and resources in AIDS related among AIDS Service Organizations, to enhance the capacity of AIDS Service organizations in order to improve service delivery, to coordinate HIV and AIDS related functions and activities undertaken by AIDS Service organizations and to represent AIDS Service organizations in high level forums locally and internationally.

Strategies and activities

Capacity Building: MANASO is involved in capacity building of organizations and its strategies and activities include; Technical assistance to ASO's done through site visits and office based capacity building trainings in various technical areas such as M and E, project management, BCC, strategic planning, etc. This also includes sub granting-where small grants are offered to CBO's that cannot get support from big donors. MANASO is also involved in mentoring

Behavior change communication: Under behaviour change and communication MANASO conducts world AIDS campaign, dialogue forums, social mobilization campaigns, support to ASO's to facilitate community open days, BCC trainings for ASO's and community video show.

Networking and coordination: MANASO conducts regional quarterly meetings, exchange visits, national conferences, regional conferences, partnership meetings, stakeholders meetings, information dissemination and resource centers

HIV and AIDS and Disability Interventions

Mainstreaming HIV and AIDS into disability MANASO achieves this approach through targeted and deliberate involvement and participation of DPOs in MANASO programs and activities such as BCC trainings, conferences, regional network meetings and others. **HIV and Disability** as a key theme for BCC activities for instance regional networking meeting, discussion forums and others and also encouraging involvement and participation of the disabled in all community interventions supported or facilitated by MANASO.

Capacity building approach: This approach is achieved through assisting CBOs in designing HIV and AIDS programs for the disabled i.e. VASO in Lilongwe was assisted to translate some SRH/Life skills messages into Braille and FORD in Dedza was assisted to obtain resources from UNICEF for life skills activities with deaf children in Mua.

Key observations on disability and HIV and AIDS: There has not been any formal deliberate and targeted policy/strategy and activities for disability and HIV and AIDS within MANASO. There has not been a strong working relationship between MANASO and umbrella and advocacy organizations for people with disabilities in Malawi. AIDS Service organizations affiliated to MANASO have not mainstreamed disability in their HIV and AIDS programs and activities possibly because of inadequate capacity and a few DPOs have registered with MANASO as members.

MANASO recommends the following in their programming: Taking on board disability and HIV and AIDS as a strategic issue during MANASO strategic review and planning process, developing a clear HIV and Disability mainstreaming strategy, develop a capacity building program for CBO's and NGO's on disability and HIV and to create a formal and meaningful working relationship with organizations for the disabled through DHAT and other forums

6.5.1 Comments on the MANASO Presentation

Clarification was sort on the type of capacity building carried out with organizations in MANASO. Organizations that have little capacity in resource mobilization are taught on how to plan and raise resources for the organization. Small grants are provided and given technical support. It requires a subscription fee to be a member of MANASO. Some DPOs have joined as members of MANASO.

6.6 Research Issues on Disability and HIV and AIDS

The presentation was delivered by Mr. Robert Sinyinza of DHAT. The meeting between DHAT, Frontline, HEARD at the University of Kwazulu Natal South Africa and, ICDR at the University of Toronto, Canada. The meeting was attended by experts from the advocacy and research communities to identify pressing issues in disability and HIV in Zambia and opportunities for addressing these priorities through advocacy and research. A platform of advocacy and research activities to advance the HIV and disability movement in Zambia was developed.

Seven priority areas were identified along with corresponding directions for advocacy and research. These areas are; insufficient statistics on PWDs and HIV, inaccessible HIV services for PWDs, with special concern for confidentiality during provision of HIV services,

need for attention on disability experienced by people living with HIV, Poverty and vulnerability as the context for disability and HIV, limited participation of people with disabilities HIV planning and service delivery, sexual abuse experienced by PWDs and the double stigma of HIV and disability.

The meeting concluded with the identification of actions to be taken against each of the priority areas above: The three areas are advancing the advocacy directions, advancing the research directions and advancing the HIV and disability movement in Southern African region.

Some of the advocacy directions taken were advocating for the central statistical office to advocate for the Central Statistics Office to collect information on PWDs, strongly advocate for inclusion of disability issues in National Strategic Framework, encourage HIV service providers to learn sign language and advocate for every HIV centre to also use sign language, encourage HIV planners and service providers to recognize the talents and potential contribution of PWDs to the HIV effort, advocate for; the involvement of PWDs at centralized and decentralized levels of committees on HIV and AIDS and advocate for awareness and sensitization to the unacceptably high rates of sexual abuse among PWDs and the resulting links to HIV infection.

The meeting resolved for the following research directions. To explore how disability is currently being measured in DHS and other prevalence studies, lessons for mainstreaming disability questions into existing demographic surveys, Promote evaluation of programmes offering accessible HIV services to PWDs to develop a body of research on best practices, explore preferences and health seeking behaviours of PWDs regarding HIV services and advocate for awareness and sensitization to the unacceptably high rates of sexual abuse among PWDs and the resulting links to HIV infection and explore tools and indicators to measure the impact of HIV on PWDs, noting that there are indicators for HIV and mental health but disability is unclear.

6.6.1 Comments on Research Issues on Disability and HIV and AIDS

FEDOMA advised that research findings must benefit DPOs. Research findings require to be disseminated in the region. DPOs also require capacity development in research understanding and organizations require disseminating and using the data findings of research.

7. Group Work Assignments

The output of the workshop was to come up with the national plan of action of advocacy that is going to inform decision makers and programmers in issues of disability and HIV and AIDS. In order to come up with the foregoing three working groups with allocated assignments were as follows: a) Policy and Legislation b) Research c) Advocacy, programming and Resource Mobilization.

7.1 Objective

The objective was to formulate the content (Issues) of the national frame of action plan, and to map the way forward

The group work focused on the question: Mainstreaming HIV and AIDS into DPOs and Disability into ASOs? The question was stripped into the following three sub-questions:

- a) What are the issues and identify the challenges
- b) How to overcome and address these challenges
- c) Who should do what, when and how

Group 1: Policy and Legislation

Issue	Strategies to overcome Issues	Activities	Lead Agency	Collaborating Partners	By When
Issues of people with disabilities not adequately addressed in the national policies i.e HIV and AIDS Policy, Education Policy, National Youth Policy etc	Policy Analysis	<ul style="list-style-type: none"> Identify relevant policies Policy analysis meetings Disseminate the findings and recommendations through position papers Dissemination meetings with relevant government ministries 	DHAT	FEDOMA Government Ministries DPO's	Nov 2011
DPO's and other stakeholders not adequately aware of policies addressing the needs of people with disabilities	Policy dissemination	<ul style="list-style-type: none"> Developing Policy briefs Developing and disseminating policy summaries Translating policies into vernacular Policy dissemination meetings Developing and disseminating IEC materials on policy 	DHAT	FEDOMA MANASO Government Ministries DPO's CSO's	Ongoing
Limited participation and involvement of people with disabilities in development processes including policy formulation	Lobbying and advocacy	<ul style="list-style-type: none"> Advocacy meetings with planners at various levels. Develop and disseminate position papers Develop and disseminate IEC materials 	DHAT Ministry of Person with Disability	FEDOMA	Ongoing
Most of the policies have no legal backing in terms of legislation	Lobbying and advocacy	<ul style="list-style-type: none"> Advocacy meetings Interface meetings with policy makers 	FEDOMA	DHAT DPO's CSO's	Ongoing
DPO's not having organizational HIV/AIDS policies	Capacity building in Policy development	<ul style="list-style-type: none"> Training in Policy development Development of policies by DPO's 	FEDOMA Ministry of Persons with Disabilities	MANASO NAC	By November 2011

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Group 2: Research

Issue	Challenges	Research Strategy	Responsible	Timeframe
Lack of Access to information by people with learning disabilities (PWLD)	<ul style="list-style-type: none"> • Communication with PWLD • Stigma and discrimination against PWLD 	Carrying out a study on best ways to communicate HIV and AIDS information to PWLD	DHAT MoE FEDOMA MoH University of Malawi	2011-2012
Limited access to VCT centres by people with disabilities	Lack of hard data on the number of disabled individuals accessing VCT	Advocating for data disaggregation in VCT centres that will capture number of people with disabilities accessing VCT	DHAT MoE FEDOMA MoH	2011-2012
HIV prevalence rates among people with disabilities	Lack of data on the number of people with disabilities living with HIV in Malawi	Advocating for the Demographic Health Surveys to disaggregate data and include number of people with disabilities living HIV	DHAT Eye of the Child FEDOMA DPOs SAT	2011-2012
Disabling effects of HIV	Lack of data on the number of people with disabilities living disabled by HIV	Carrying out a study on the effects of HIV/ART on individuals taking the drug and number of individuals disabled by HIV/ART in a specific area in Malawi	Chancellor College of Medicine, medical Research Institutes, FEDOMA DHAT	2011-2013

Group 3: Advocacy, Programming and Resource Mobilization

Issue	Challenges	Solution	Strategies	Responsible	Timeframe
Lack of Knowledge/skills in existing policies	Policy gap in using and interpreting	<ul style="list-style-type: none"> Skills in policy analysis Policy sensitization 	<ul style="list-style-type: none"> Training in policy analysis skills Training communication skills Dissemination of findings IEC material development and distribution Community advocacy campaigns 	DHAT DPOS	Starting July 2011 and ongoing
Mainstreaming disability in HIV and AIDS programs	<ul style="list-style-type: none"> Lack of awareness and expertise among stakeholders Piecemeal and ad hoc implementation of HIV and AIDS programs 	Inclusive and sustainable programs	<ul style="list-style-type: none"> Meaningful participation and self-representation of PWDs in planning and implementation of HIV and AIDS programs Translation of policy docs to user friendly language M&E on ASO Programs Networking /partnerships 	DHAT DPOS ASOs Government	Starting July 2011 and ongoing
Lack of Resources	Resource mobilization	Availability of resources	<ul style="list-style-type: none"> Formation of partnerships/networking IGAs/Seed funds Training in fundraising skills Fundraising activities Proposal writing Advocacy 	DPOs NAC MANASO DHAT SAT	From June 2011 ongoing

Comments on the Policy and Legislation

Under limited participation, the Ministry of People with Disabilities and Elderly is also included in the advocacy work. The Ministry of People with Disabilities and Elderly should ensure that it involves other ministries in the processes of policy formulation.

Bamusi (SAT) was concerned about how far policies and legislation are being implemented to benefit people with disabilities. The concern is that there is no monitoring or Evaluation about the impact these policies and legislation are making on people with disabilities. The challenges to this issue must be identified. Why was this happening?

Comments on the Advocacy, Programming and Resource Mobilization

After the presentation on Advocacy, Programming and Resource Mobilization it was suggested that double stigma and discrimination should be added as one of the issues and find solutions how it can be addressed. In addition, VCT model centres for people with disabilities could be piloted to demonstrate how services of people with disabilities could be brought closer. Explanation was given that inclusiveness could be in two ways; services for PWDs should include non disabled and non disabled services should be inclusive of PWDs. For example ramps are not just for PWDs but also able bodied individuals.

Double stigma and discrimination was suggested that it must be added to the group report. This is one of the issues that were highlighted in the documentary stepping into the unknown”.

Chimenya (MANAD) raised an issue about mobilizing resources for DPOs when DPOs are not economically strong. We learnt that the issue was covered in the group report. However, Chiwaula (FEDOMA) asked “Is it skills to generate resources or DPOs have no economic empowerment?” Skills are also lacking in DPOs.

Accessibility to information was also identified as an issue and resolved that it be added to the group report.

Establishment of task team

In order to advance the issues that have been identified in the workshop recommendations the composition of a task team. The following was the composition. The process of proposing the composition of the task team was facilitated by Edward Chikhwana of the MANASO. The team composition of key persons in the Government, DPOs and civil society was suggested that could lead advocacy for issues identified.

The composition of the task team was proposed as follows

Name: National Task Team on Mainstreaming of HIV and AIDS and Disability

Organization	Composition
1. Ministry of Health	1
2. Ministry of Gender and Community Development	1
3. Ministry of People with Disabilities and Elderly	1
4. Malawi Council of the Handicapped	1
5. Malawi Network of AIDS Service Organizations	1
6. Federation of Disability Organizations in Malawi	1
7. Disabled Women in Development	1
8. Eye of the Child	1
9. Malawi National Association of the Deaf	1
10. Malawi Union of the Blind	1

DHAT is part of the composition of the team.

Terms of Reference

DHAT will draft the ToR by May 10th 2011 and float to Task Team for Discussion.

8. Recommendations

The following were the workshop recommendations:

- a) Formalization of working relationship through Memorandum of understandings between DPOs, DHAT and other stakeholders
- b) Capacity building in area of HIV and AIDS to DPOs
- c) National Action Plan that will be implemented
- d) Reviewing and understanding role of stakeholders in HIV and AIDS and disability
- e) Training of DPOs on how they can develop HIV and AIDS policies through organizations

- f) Develop national indicators on disability and HIV and AIDS (“Identify priority areas of interventions”)
- g) Funding agencies to prioritize disability in disbursement of funds
- h) Regular dialogue between FEDOMA and affiliates
- i) Need for research on disabled people living with HIV in Malawi
- j) Possibility of model VCT centre.

9. Conclusion

The following are inferred from the Malawi National Meeting on Disability and HIV and AIDS:

- ❖ Misconceptions about disability and stereotypes about people with disabilities are common in Malawi as in other countries.
- ❖ "Stepping into the unknown" is a documentary of hope and there must be a change of attitudes and strategies in support of people with disabilities are imperative and solidarity must be developed.
- ❖ People with disabilities do not participate in the affairs of the Technical working Groups (TWG) of the NAC
- ❖ Research findings must benefit DPOs and to be disseminated in the region. DPOs also require capacity development in research understanding and organizations require disseminating and using findings of research
- ❖ There must be development of a capacity building programmes for CBO's and NGO's on disability and HIV and create formal and meaningful working relationships with organizations for the disabled through DHAT and other forums
- ❖ The national HIV and AIDS Policy emphasizes that government through the NAC undertakes to ensure that HIV-related prevention information, education, treatment, care and support strategies are accessible to people with disabilities
- ❖ There is no deliberate and targeted strategies and activities for HIV and AIDS and disability within MANASO and there has not been a strong working relationship between MANASO and umbrella and advocacy organizations for people with disabilities in Malawi

10. Workshop Closing Remarks

The workshop was officially closed by Mr. Novice Bamusi of SAT. Bamusi explained that the workshop was an enlightening event in acquiring knowledge in disability and HIV and AIDS. He said that the issues that have been discussed will help organizations represented to move programmes in disability and HIV and AIDS forward. SAT is looking at opportunities at country level in disabilities and HIV and AIDS. He encouraged everyone to share information, focus on relevant issues and develop working interactions. He thanked everyone for participating in the workshop and wished all participants the best of luck on their way back to various destinations.

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11. Participants List

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National Stakeholders' Meeting: Lilongwe, Malawi

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