

**NATIONAL MEETING ON DISABILITY AND HIV AND AIDS**

**22<sup>nd</sup> - 24<sup>th</sup> NOVEMBER 2010**

**ST LUCIA PARK, MARLBOROUGH, HARARE, ZIMBABWE**

**THEME: Improve Access to Information and HIV and AIDS Services for People with Disabilities:**

## **TERMS OF REFERENCE**

This workshop is the result of a number of DHATS consultations and workshops with stakeholders on Disability, HIV and AIDS at national level in Botswana, Malawi, Zambia and Zimbabwe.

These consultations and workshops reveal that people with disabilities ( PWD) were excluded from the HIV and AIDS response. PWDs needed more access and participation in the response to enable services to be tailor – made to their diverse needs.

Previous consultations and workshops had participants who had knowledge and experience in disability. Major concerns relating to HIV and AIDS could not be addressed adequately. This workshop by DHAT was ensuring that the relevant key stakeholders from both the HIV and Disability sectors were participating. Participants were drawn from Disabled People's Organisations ( DPO's), AIDS service organisations ( ASO's), government departments and other National strategic partners. Please refer to the register of attendance attached. ( Annexure A)

The key mission of the 3 day workshop was to stimulate an intergrated approach to the streamlining of HIV and AIDS into DPO's, and disability into ASO.

### **OPENING SPEECH BY RUDO CHITIGA: ( VICE CHAIRPERSON: DHAT)**

The workshop was officially opened by the Vice Chairperson of DHAT, Rudo Chitiga. DHAT was aiming at mainstreaming HIV and AIDS into DPO's, and disability into ASO. This 3 day workshop was a stakeholders' meeting where strategic key partners would meet and map the way forward on a united front in the fight against the epidemic of HIV and AIDS in general and disability in particular.

DHAT's role was to stimulate synergies and partnerships between key stakeholders in DPO's, (with special mention to the umbrella pivotal role played by the national association of societies for the care of the handicapped – NASCOH) and ASO and the Ministry of Health & Child Welfare ( MOH).

This workshop was in line with the work in progress world over to champion the need for the eradication of HIV and AIDS. There was need for more information to be accessible to PWD and HIV /AIDS. There was need for a research based agenda guided by correct priorities. Priorities should be enriched by lessons learnt. DHAT in collaboration with strategic partners should progressively close gaps and missing links in advocacy, networking, research and resource sourcing.

The consultancy workshops and meetings were not expected to come up with recommendations and reports only. This workshop was expected to come up with an action plan. The action plan should have tangible activities which would be implemented by identified task teams with specific duties. These task teams should have identified members who would be expected to accomplish their goals. It was very important therefore, at such workshops to have;

- Clear targets
- Identify who does what
- With whom
- And whom to report to
- And where

Out of these activities, will be derived a national framework of plan of action which would advocate for the mainstreaming of disability issues into national HIV/AIDS policies and programs, and an enactment of disability and AIDS policies on the health agenda.

DHAT through such workshops was precipitating the identification of key result areas which would be attainable. DHAT had relocated to Zimbabwe. This was partly attributed to the country's receptiveness to HIV /AIDS and disability. Zimbabwe had done commendable work and a lot had been achieved. With clear objectives, Rudo Chitiga saw no reason why this workshop would not succeed in initiating a clear national plan of action.

## **CONTENTS**

### **DAY 1: MONDAY 22<sup>ND</sup> NOVEMBER 2010 : SCHEDULE OF PRESENTATIONS & ACTIVITIES:**

- OBJECTIVES : Ministry of Health
- Video Presentation and Discussion ( Journey into the Unknown)
- NASCOH: Presentation & Discussion
- DHAT : Presentation and Discussion
- Testimony :Visually Impaired : Presentation and Discussion
- Testimony : Hearing Impaired : Presentation and Discussion
- Ministry of Health : Presentation and Discussion

### **DAY 2: TUESDAY 23<sup>RD</sup> NOVEMBER 2010 : SCHEDULE OF PRESENTATIONS & ACTIVITIES:**

- Review of first day's work
- ZWIDE : Presentation and Discussion
- NCHH : Presentation and Discussion
- VSO : Presentation and Discussion
- NCDPZ : Presentation and Discussion
- Jill Hanass : Hancoch ( Phd) : Presentation and Discussion
- Introduction To Group Work

### **DAY 3: WEDNESDAY 24<sup>TH</sup> NOVEMBER 2010 : SCHEDULE OF PRESENTATION AND ACTIVITIES:**

- Continuation of Group work
- Group/Team presentations
  - a) Programming
  - b) Policy
  - c) Implementation & Research

- d) Women, Youth and Children
- Close of Ceremony : Phillimon Simwaba – DHAT Executive Director

## **OBJECTIVES OF THE WORKSHOP**

Improving Access to Information and HIV and AIDS Services for People with Disabilities  
(PWD)

### **Objective 1**

- 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.

### **Objective 2**

- To achieve consensus and commitment on the mainstreaming of Disability, HIV and AIDS

### **Objective 3**

Build strategic alliances and networking that will contribute to innovative approaches and development of sustainable programmes on Disability, HIV and AIDS.

### **Anticipated Outcomes**

- Disability, HIV and AIDS awareness raised among policy makers, service organizations, NGOs, donors and other stakeholders to draw greater attention to the rights of PWDs
- Support solicited from Governments and HIV and AIDS service providers to include the human rights and needs of PWDs into national HIV and AIDS strategic plans, policies and planning processes

### **Outcome**

Address myths and misunderstandings about disability and HIV and AIDS with relevant stakeholders

- Mainstreaming of disability issues into national HIV and AIDS policies and programmes understood and supported
  - Draft National framework of plan of action drawn

### **DISCUSSION:**

The task of the participants was to harmonise anticipated outcomes with a view of coming up with a draft national framework of a plan of action. The plan envisaged could be for 2011 to 2013 -2015. Objectives had to be specified into tangible tasks.

### **VIDEO: STEPPING INTO THE UNKNOWN**

#### **DISCUSSION:**

The 20 minute video is on the experience of a group of PWD's with HIV/AIDS who went for bungee jumping. Bungee jumping is for first timers a nerve wrecking experience Like bungee jumping, going for HIV/AIDS testing, fear is a pre -conceived response based upon Psycho social perceptions which make the actual leaping off more scary than the event itself. Apart from all the reassurance and reliability of the equipment used participants were afraid and hysterical.

However, after leaping off the experience was uplifting, building their confidence and self esteem. Lessons learnt were that like going for HIV and AIDS testing people were afraid. PWD and HIV/AIDS had to jump/ make a decision to be tested. For either results Positive Or Negative there was still life.

PWD's in their various forms with HIV/AIDS needed a lot of assistance in information on Prevention, Mitigation, Testing and Counselling.

Visually Impaired : A lot of information in Braille was not being accessed

Hearing Impaired : There was no sign language to differentiate HIV from AIDS and the implication of being Positive from Negative.

Voluntary counselling and Testing centres should have trained visually impaired personnel who will work hand and glove with other visually impaired and HIV/AIDS positive people,

so that confidentiality and post testing is maintained. The same applies for those hard in hearing. PWD need to be more active in these initiatives. They were responsible for designing Braille to be formatted into appropriate signs for condoms as example. For the hearing impaired, a lot of research needs to be done to come up with a universal sign language.

Without being tested, it was difficult for one to make informed decisions on the state of their health as it affects the relationships and plans for the future. There was need for advocacy in bringing forward PWD's to come forward and be tested.

## **NASCOH PRESENTATION ON Disability In Zimbabwe; An Overview**

**BY Farai Mukuta & Fambaineni Innocent Magweva**

### **Introduction**

National Association of Societies for the Care of the Handicapped (NASCOH)

NASCOH is the umbrella body of 53 organizations of and for people with disabilities (PWDs) in Zimbabwe, representing the mentally and physically challenged, the visually and hearing impaired, and those with conditions like epilepsy and Down syndrome

### **MANDATE**

- To initiate and promote the co-ordination and participation
- To lobby for the rights of people with disabilities
- To advise the government on issues concerning the care of people with disabilities.

### **DISABILITY? WHO ARE THE DISABLED**

- NO AGREED DEFINITION
- DEPENDS WITH WHO DEFINES IT AND WHO BENEFITS
- Each Model defines disability differently
- Charity model
- Medical model
- Social Model
- African model
- International

In all model its agreed that there is an impairment

- The ICF defines disability as “an umbrella term for impairments, activity limitations and participation restrictions.
- Functional limitations occur as a result of the interaction

Operational Definition of Disability

- Any impairment that, when combined with environmental and societal barriers, limits the person’s functional ability to perform major life activities.

## • **2.1 AN OVERVIEW OF DISABILITY IN ZIMBABWE**

- Main Causes of Disabilities (WHO 2000):
- Infectious diseases (poliomyelitis, leprosy, meningitis, measles, malaria, onchocerciasis)
- War, trauma, accidents (home, work, road)
- Congenital and non-infectious diseases (epilepsy, ageing, psychiatric illness)
- Every day many people are disabled by malnutrition and disease, environmental hazards, natural disasters, traffic and industrial accidents and political conflict
- Poverty and health services-related causes
- (lack of adequate medical services)

### **Disability and Poverty**

- The vicious cycle of poverty and disability.
- This cycle exists for PWDs around the world, but its implication can be especially devastating for those living in developing countries.
- Disability may lead to poverty due to lower access to work opportunities from the social discrimination
- Disability does not just affect the individual, but has an impact on the whole community.
- The cost of excluding PWDs from participating in community life is high and has to be borne by society, particularly those who take on the burden of care.
- The exclusion often leads to losses in productivity and human potential.
- The UN estimates that 25% of the entire population is adversely affected in one way or another as a result of disabilities



## **ACHIVEMENTS SINCE 1980**

- Zimbabwe is the mother of disability
- Legislation
- Specialist teachers training at UCE & UZ
- Rehab technicians training at Marondera & therapists at UZ
- Increase in enrolment of Lwds in schools & tertiary institutions
- More organizations formed
- DPOs
- Shift in policies e.g. CBR

## **ACHIEVEMENTS**

- Legislation e.g. DPA of 1992
- Social /human rights model
- Increased donor funding 1980-1999
- Status of PWDs
- 10% prevalence rate
- But as high as 20% of the poor.
- As many as 80% of working age pwds are unemployed..
- Only 1% of disabled women are literate.
- School enrolment for pwds is estimated at no more than 5-10%.
- A consequence of living in poverty with a disability is serious secondary conditions and general deterioration of the quality of life.
- Social stigma associated with disability results in marginalization

## **CHALLENGES**

- Education
- Not all CWDs have access to education
- No qualified psycho-social staff

- Inter & intra organizational fights
- Lack of organizational capacities
- Paradox of disability

( Service which benefit the provider more than the target group)

## **CHALLENGES**

- Limited or no access to;
  - VET
  - Employment
  - Land & agriculture programmes
  - Poverty alleviation programmes
  - Education
  - Health
  - Information including hiv & aids
- Very limited social safety net programmes
- No proportional representation

## **DISABILITY, HIV & AIDS**

- Unlike any other epidemic in history, AIDS poses one of the most brutal attacks the world has witnessed.
- Africa is the hardest hit and SADC region is the epicentre of the epidemic.
- SADC population is only 3.5% of the world totals yet the region accounts for 37% of the world people living with HIV and AIDS (PLWHA) cases.
- About 14 million adults are infected and SADC prevalence rate of 19.4% is quite high in comparison to 7.5% for sub-Saharan Africa as a whole.
- Linkage between HIV & poverty & disability & poverty

## **Disability HIV & Poverty**

- The poor are likely to destroy the environment and behave in a manner which exposes them to HIV as they search for survival.

- Various forms of environmental degradation affect the general health status of people and increase their vulnerability.
- When HIV/AIDS is added to the list, there is a danger that people cannot make a living any more.
- The small margins shrink and disappear. The result is a reduction – or total elimination – of food security”

### **Disability HIV & Poverty**

- HIV/AIDS was regarded for far too long as exclusively a health problem.
- It is only in recent years that international organizations, donors and national governments have started to give attention to the epidemic as a general development issue.
- Today, an increasing number also make the assessment that HIV/AIDS undermines long-term sustainable use of the environment and natural resources

### **Disability HIV & Poverty**

- Poverty and vulnerability are some of the primary drivers of HIV pandemic and most of the HIV/AIDS initiatives and programmes have concentrated on containing the epidemic.
- No sufficient interventions have been put in place to address the drivers of the pandemic.
- Poverty also means that people have fewer possibilities to make choices
- Fewer possibilities to protect themselves and
- Change patterns of behavior that lead to a high risk of infection

### **HIV & Poverty**

- Poverty can make labour migration necessary, which increases the risk of exposure to infection.
- Poverty can also put pressure on women to offer sexual services in exchange for food and other resources
- In the most seriously affected countries, the AIDS epidemic has probably started to have negative effects on the use of the environment and natural resources at all levels, and these effects will grow as the health status of the people deteriorates further and more people die of AIDS

### **Challenges**

- Rural and urban poverty are closely aligned with the burdens of Disability, HIV and AIDS, and each aggravates the other.
- When considering policy implications of morbidity and mortality, it is important to address chronic poverty: through micro-credit, employment options, food production, nutrition, rural infrastructure, social services, health care, etc.
- Unfortunately, this is not an easy task—decades of development assistance have not eradicated poverty (and may in fact have helped to perpetuate it:

### **Challenges**

- HIV/AIDS was regarded for far too long as exclusively a health problem.
- Poverty and vulnerability are some of the primary drivers of HIV pandemic and most of the HIV/AIDS initiatives and programmes have concentrated on containing the epidemic
- The Livelihoods Approach is extremely relevant to appreciating how AIDS can and does intersect with rural resource use and management through the five forms of capital (human, natural, physical, financial, social),

### **Challenges**

- A Disability and HIV and AIDS situation analysis commissioned revealed that people with disabilities are particularly vulnerable to AIDS due to ;
- Their low literacy levels,
- little access to health care,
- high vulnerability to sexual abuse,
- lack of information on AIDS especially for the visually impaired and hearing impaired, and
- consequent lack of inclusion in AIDS intervention programmes.

### **Challenges**

- Stigma, fear and ignorance results in the majority of PWDs refraining from accessing available services such as VTC, Antiretroviral therapy, home based care and counselling
- Inability of HIV & AIDS workers to deal with disability
- Although Zimbabwe has succeeded in reducing the prevalence rate this success story does not, regrettably, include people with disabilities

- PWDs have been systematically sidelined from all HIV and AIDS intervention programmes in the country

### **Challenges**

- Exclusion has been the biggest problem
- Hearing and visually impaired people registered lower scores on the HIV/AIDS Knowledge Index thus indicating low levels of awareness of AIDS issues.
- The incidence of alcohol abuse within the hearing impaired community is estimated to be at 35% compared to 12-14% incidence among the general population.

### **Challenges**

- Compliance and adherence to TB medication is very low for the mentally ill, and homeless.
- Access to information and treatment, and issues of social status has been noted to be issues of real concern for women with disabilities.
- A strong connection between increased risk taking behaviour and risk of contracting HIV has been documented among adolescents hospitalised for emotional behaviour.

### **Challenges**

- It is estimated that 1 in 7 hearing-impaired persons has substance abuse problems, compared with 1 in 10 in the general population.
- People with serious mental illnesses have a lower level of self-efficacy where taking protective measures is concerned..
- People with learning disabilities have difficulties in negotiating safe sex. Incidences of homosexuality are also noticeably higher among this group
- HIV & Poverty

### **Success**

- NASCOH produced a video on HIV & AIDS sign language vocabulary
- Documentary on Disability, HIV & AIDS by HI for the HI
- Audited HIV & AIDS policy to include disability
- Brailed the National HIV & AIDS policy
- Trained sign language interpreters

### **Concepts**

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

### **Equality of opportunity;**

- Accessibility
- Concepts contd
- Respect for the evolving capacities of children with disabilities and respect for the rights of children with disabilities to preserve their identities.
- Gender equality
- Mainstreaming
- Livelihood programmes to be part of HIV & AIDS intervention strategy

**Thank you, Tatenda, Sibongile, Tabonga, Twalumba, Dankie, Asante Sana**

NASCOH was founded in 1969 to promote the rights, interests and needs of PWD. NASCOH would achieve its goals through:

- Lobbying and advocacy
- Training and capacity building
- Co-ordination of activities and programs
- Research of information dissemination

Service providers were institutions like St. Giles, Jairos Jiri Centre, Emerald Hill School for the Deaf, to mention a few.

DPO's were specific organisations oriented towards specific needs in either physical, hearing, mental and visual impairments. NASCOH's role was to coordinate and bring together these DPO's, as we have at this workshop, and address their concerns to government in a unified voice. The MOH and the Ministry of Public service, Labour and Social Welfare carried the ultimate burden. Their participation in streamlining HIV/AIDS into DPO's and disability into ASO's, was very strategic. The implementation of a policy on disability coming out of the national action plan would address i.e; the establishment of a Braille centre on disability, HIV/AIDS.

## DISCUSSION

Poverty was not the only cause to the vulnerability of PWD's to HIV/AIDS. Multiple concurrent sexual partners was another contributing factor. There was no scientific research on the reason for the decline in the prevalence of HIV/AIDS since 2002. There was need to research on the impact of the side effects of ARVs on disability and HIV/AIDS. With the assistance of various strategic partners as VSO's, USAID, etc, there was need for continuous lobbying to government for the mainstreaming efforts.



**Disability, HIV and AIDS Trust (DHAT)**

Tel: (+267) 3971774

Fax: (+267) 3971773

Email: [info@dhat.bw](mailto:info@dhat.bw)

<http://www.dhatregional.org>

## **Regional Perspectives: DHAT Advocacy Work and Intentions**

*Presented By:*

**Phillimon Simwaba  
DHAT Executive Director**

### *Creating an inclusive society*

#### **Background of DHAT's Advocacy Work**

Advocacy is DHAT's mandate and its work is a result of the following key drivers or cardinal issues:

- ❖ Myths and beliefs about disability. E.g. Stereotype that PWDs are asexual, sex with PWDs cures AIDS
- ❖ Vulnerability, Stigma and Discrimination
- ❖ Lack/inadequate access to HIV and AIDS Interventions;

E.g Prevention, Treatment Care and Support that violates the human rights

- ❖ Limited access to social, economic and political decision making opportunities; to empower PWDs

### **DHAT'S ADVOCACY**

**DHAT's Advocacy work is based on achieving the theory of change, that sets/focuses on two programming goals:**

- ❖ Mainstreaming HIV and AIDS into Disability Programmes (DPOs)
- ❖ Mainstreaming Disability into HIV and AIDS Programmes (ASOs, Governments, CSOs, private sector, Universities and donors)

DHAT's advocacy work is based on the Human-Rights Based Approach: E.g.

- ❖ No discrimination in the provision of HIV and AIDS services
- ❖ Breaking barriers of stigma and stereotypes against PWDs
- ❖ Empowering PWDs to participate in HIV and AIDS

programme design, planning and implementation processes

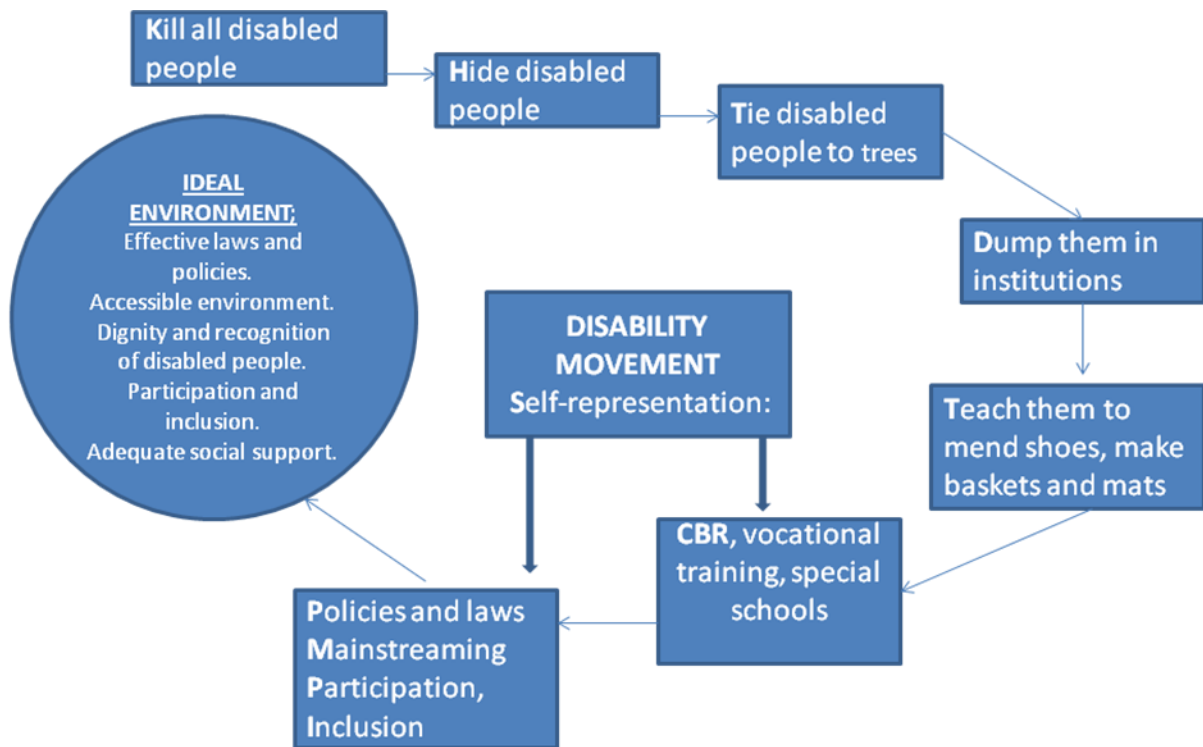
### **HUMAN RIGHT - quote**

**“Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his/her life”.**

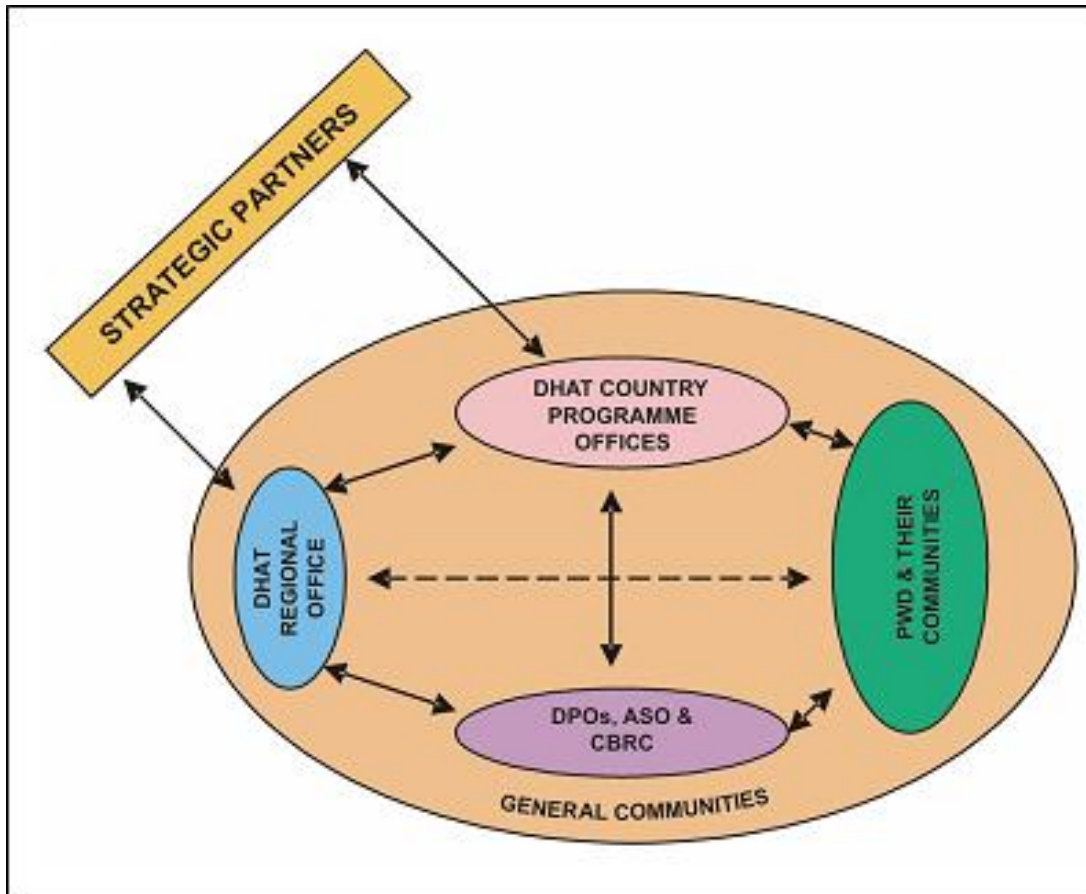
### **DHAT'S ADVOCACY**

**Based on Discrimination of PWDs**





## WHAT OPERATIONAL MODEL TO ACHIEVE THEORY OF CHANGE



### **DHAAT'S Lessons from ADVOCACY Work**

- ❖ Increase networking and information exchange between HIV & disability services, disability advocacy & human rights organizations
- ❖ Ensure disability services, such as support for independent living, are available to people living with HIV
- ❖ Advocate for persons with disabilities to have full sexual & reproductive rights, & freedom from physical & sexual abuse
- ❖ Advocate for persons with disabilities to be included in the planning, implementation and evaluation of HIV programmes

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- ❖ Advocate for persons with disabilities to be included in the planning, implementation and evaluation of HIV programmes
  
- ❖ Ensure campaigns to combat stigma and discrimination of persons who are HIV positive are accessible to persons with disabilities

#### **DHAT's Advocacy Intention**

- ❖ At *national level*, DHAT seek to work or network with DPOs, CBRCs, ASOs, Governments, NACs in mainstreaming of Disability, HIV and AIDS and developing disability friendly IEC materials
- ❖ Training service providers (ASOs, Medical Staff, Police, etc in areas like sign language and disability.
- ❖ promote, support and facilitate Interventions, ideas, research and Approaches addressing vulnerabilities, empowerment and active participation of people with disabilities.

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- ❖ promote, support and facilitate Interventions, ideas, research and Approaches addressing vulnerabilities, empowerment and active participation of people with disabilities.
- ❖ At *regional level* DHAT seeks to be a Regional disability, HIV and AIDS knowledge management centre ( regional data bank).
- ❖ Initiate reviews and formulation of advocacy strategies, disability related policies and legislation.

## **DISCUSSION**

DHATS focus was on advocating for mainstreaming at the vintage point where DPO's, ASO's and key strategic partners meet. DHAT had catalytic project initiative as a strategy for kick starting and leading the service delivery agenda. Its strategic presence would ensure cost effective and efficient programming and implementation. DHAT foresaw health professionals trained in sign language for the deaf in collaboration with the UZ where they already have a memorandum of understanding.

## **TESTIMONY : RONALD ( VISUALLY IMPAIRED)**

Ronald is visually impaired. He was partially blind when he was diagnosed to be HIV positive. He progressively became blind. There is no scientific proof to give evidence as to what caused the blindness. He doesn't know whether it was caused by HIV/AIDS or by the ARV's side effects.

Ronald's testimony is a model case study of attempts by individuals and support groups where individuals with HIV/AIDS are working with DPO's and ASO's, in an attempt to mainstream HIV/AIDS with DPO's and disability with ASO. The targeted people had no transport to get to meetings, hence it was difficult to gather information on them. Ronald also had transport problems, hence the need for money for transport and wages for those who would have assisted him.

On the other hand, communities themselves looked down upon PWD who had HIV/AIDS. Families in the rural areas hid them and isolated them from contact with the outside world. In rural areas, isolation was further compounded by poverty hence the targeted individuals were very difficult to access. Communities /families were known to hide disabled people with HIV/AIDS and leave them to die, or they would even hide ARV's and accessories meant to benefit the victims.

The solution to this was to work with the whole family and inform them about the positiveness of living with disability and AIDS. Those who had not been tested are encouraged to do so and come out and work within the support groups. If they work in groups it is easier for DPO's and ASO's to assist them in income generating project so that they get out of poverty and primarily live longer. Young visually impaired were the most vulnerable and they need to be educated in braille to make choices that do not risk their lives.

Service centres with support groups were encouraged to educate and communicate to the disadvantaged. The visually impaired were encouraged serve others as there was healing in helping others. Helping and working with others gives confidence and a sense of purpose which was very therapeutic. Support groups should have grants for food, transport and service centres where testimonies of hope would access the visually vulnerable and poor. His support group has now grown to 25.

## **TESTIMONY : DANIEL ( HEARING IMPAIRED)**

Daniel is hearing impaired and living with HIV/AIDS. He and his wife started taking ARV's in 2003. He came out public because of his will to survive b helping and identifying with others. What he has observed is that most service providers, doctors, nurses, counsellors,etc, don't know sign language. There was no communication on prescription and counselling after being identified as HIV positive. If there was information it was very difficult to get. Rape victims with hearing impairments are the most vulnerable where they can not effectively give evidence against the perpetrators.

There was need for a massive campaign through DPO's and ASO's, newspapers, TV's and radios to call for the hearing impaired to come out and be tested. Once they know their status they will be able to get assistance. It was pleasing to note that there is an increase in the number of DPO's who were now mainstreaming HIV/AIDS into their programmes and were assisting effectively.

There was need for a structure with an umbrella body like DHAT and NASCOH which should cascade down with DPO and ASO, to regional and district levels. These regional and district level would then have support centres which identify and work hand and glove with those who had HIV/AIDS whilst they are PWD's – blindness, deafness, physically challenged.

## **MINISTRY OF HEALTH**

### **DR. MUGUVUNGI**

A lot of consultations and workshops have been held. This workshop was now expected to spearhead practical action. In general, PWD and HIV/AIDS were stigmatised more than able bodied people. The National Aids Council ( NAC) had in Zimbabwe done a commendable job.

Surveys on the epidemic were conducted on pregnant women between the ages of 18-45 years. In year 2000, the prevalence of HIV/AIDS was very high. Statistics have shown a gradual decrease in the number of people with HIV/AIDS. The demographic health surveys of 2001 and 2006 show that HIV/AIDS was lower than anticipated. ARVs like any other drug had side effects.

Zimbabwe was not self sufficient in the provision of ARV's. It was therefore very difficult to hold clinical trial on drugs which are coming from outside. While HIV/AIDS was not considered as a disability. At a certain period during one's illness, where the effects of HIV/AIDS would disable one from doing certain functions would it be considered as a disability.

## **DAY 2:**

Participants summarized Tuesdays work with what they had learnt, Namely that going for HIV+AIDS testing was not life threatening, People had to be tested so that they make informed decisions on there health.

The mainstreaming of HIV+AIDS unite D.P.O's+ Disability into ASO was a helistic approach. It was a technique of ensuring that all strategic hey partners in the fight against the epidemic of HIV+AIDS came together and use their experience and resources effectively.

All drugs had side effects. Sign language had to be enriched so that the hearing improved could communicate the different between HIV+AIDS and the implication of being Positive and Negative.

Participants were then asked to intensive their expectations in view of initiating the material plan of action. The expectations were to be practical coming from problems / weaknesses and

## **ZWIDE : HIV AND AIDS AFFECTING DISABLED WOMEN**

ALL PROTOCOLS OBSERVED

The fight against HIV/AIDS has shown that the exclusion of women with disabilities is an influential vulnerability factor that may slow down prevention measures. Stigmatization and discrimination, generally associated with living with a disability, constitutes an important sexual vulnerability factor that adds to other inherent bio-psychosocial factors of disability. Research has constantly proved that PWD especially women and girls are victims of exclusion in the management of the health crisis generated by the AIDS pandemic

As indicated by a number of studies, most people assume that PWD especially girls and women with disabilities are asexual or less sexually active and that they are less exposed to such sexual risks as sexually transmitted infections (STIs) and HIV. On the same note, many non-governmental organization officials, programme directors and other influential people at the operational level rarely design projects with the thought of positioning women and girls



with disabilities at the centre of their interventions. Furthermore, there is very little evidence of the engagement of international donors in programmes that target people with disabilities especially women and girls. Thus, while considerable efforts have been made to reduce the dramatic and disabling effects of HIV/AIDS in the general population, there have been very few measures to build intervention programmes that minimize the impact of this disease on people with disabilities especially women with disabilities.

There is a growing need for increased collaboration in programming between those who advocate for the rights of people with disabilities (WWDs) and those involved in HIV education, prevention, care and treatment. Organizations dedicated to advocating for the rights of WWDs are beginning to develop and implement programming to effectively educate WWDs on HIV treatment and prevention techniques. Many of these individuals have been excluded from conventional HIV programming, despite having similar or increased rates of exposure to HIV risk factors. Unfortunately, the vast majority of HIV and AIDS programmes lack the training, resources and the commitment necessary to accommodate the needs of WWDs. While many organizations advocating for the rights of WWDs are actively implementing HIV programming in their curriculum, there is an urgent need for existing HIV organizations to follow suit and modify their programming to better integrate the needs of people living with disabilities. The combination of poverty and disability can make it very difficult to access health care. It is rarely affordable and, in the case of WWDs, accessible. For example, voluntary HIV testing may be delayed because of a lack of anonymity. Many WWDs rely on family members/friends for support (transportation and/or interpretation) and may not want to disclose personal details to them. Another barrier is the discrimination faced by WWDs from health care workers. WWDs are often ridiculed or dismissed when requesting reproductive health information, because they are perceived to be unattractive and/or asexual. Many women with disabilities (WWDs) fear forced sterilization if they seek out medical attention. In addition, there are few rehabilitation services in rural areas for people who acquire impairments later in life, which can greatly impact the ability to work and live after an injury. Finally, WWDs are often the last to receive care. Widespread social perceptions contribute to the assumption that WWDs will lead a lower quality of life and contribute far less economically and socially to a society. This devaluation of WWDs in the eyes of many health care providers contributes to unwillingness on the part of many WWDs to seek health care and testing for HIV to summarize, WWDs have an equal or greater chance

of exposure to all known HIV risk factors. The costs of caring for an individual with a disability may deny caregivers HIV and AIDS training. Lack of education. Furthermore, insensitive, uncaring and inaccessible health systems deny WWDs access to reliable information, testing and care for and about HIV and AIDS. Greater incidences of sexual violence increase WWDs' exposure to HIV infection. All of these factors clearly illustrate the links between equal or greater exposure to all known HIV risk factors and disability.

ZWIDE having taken into consideration all the above factors which exposes women and girls with disabilities to HIV AND AIDS would like to suggest and recommend the implementation of the following strategies.

HIV and AIDS service organizations to adopt a twin track approach to inclusion-including the women with disabilities in mainstream HIV programmes while at the same time, targeting the disability movement and sector

Inclusion is only achievable by proactive engagement-formal and informal partnerships and joint ventures between the disability and HIV sectors to develop and maintain disability and HIV perspectives in the respective sectors.

Ring-fencing a fixed percentage of annual budgets of both government agencies and NGOs working on HIV for joint- disability –disability-HIV initiatives with a special bias to women and girls with disabilities also identify and select disability organization and train them as nodal agencies to provide awareness, training and support on HIV to other disability organizations.

In conclusion, in order to monitor whether disabled people in general are accessing services and being included in HIV programmes, add an extra box to be ticked along side sex is a simple and low cost method to collect information. I would like also to take this opportunity to call for diversity and creativity in the development and packaging of HIV IEC materials and communication techniques.

ZWIDE forms part of the equation to success in fighting against HIV and AIDS in Zimbabwe

THANK YOU

**SUMMARY**

Children who were disabled women were at high risk of being affected by HIV+AIDS because they are vulnerable. Disabled women with HIV+AIDS should be educated and empowered so that they live positively with HIV+AIDS.

The worst vulnerable group was in the rural areas where they were not going to school/

### **N.G.H.H : HIV AND AIDS AFFECTING THE HEARING IMPAIRED**

- The Forgotten People By Lincoln Matongo (DEAF), :National Meeting on Disability and HIV & AIDS
- Signing Hands
- What is Deafness? : Clinically it means unable to hear.
- Deaf disability is language based disability in most parts of Zimbabwe it is based on English Language, except in Masvingo where it is Shona based. (shoe/shangu)
- Deaf People according to experience:

Deaf people we are a people who are misunderstood by the hearing people and in turn we misunderstands you as well.

No information is passed to us, there is complete BLACKOUT!!

#### **HIV & AIDS**

- To Deaf people these terms are the same
- The positive and negative terms are always confused.
- Literally
  - positive means good or okay
  - Negative means bad or not okay
- An HIV positive person is okay than an HIV negative one in Deaf community.

#### **The Deaf and VCTs**

- Deaf people shun VCTs due to a variety of reasons
  - Counsellors do not know sign language.
  - Lack of privacy when we bring along a relative to interpret for us.

- Lack of funds to hire an interpreter.
- No meaningful counselling session between the Deaf and VCT counsellors due to lack of communication

● **Deaf People: Experiences**

**Njalo** - He said his wife has got AIDS because of her previous sexual encounters.

What could you have done, go ahead marry her without getting tested or what?

He said “he and baby do not have AIDS”

Now his wife is sick again and he sent her to her rural areas.

Does this person understands HIV & AIDS

He wants to divorce his wife in the near future.

He is currently on the look for another girl to marry, not a town girl but an SRB.

Even though he claim he was tested but surely he was not counselled.

● **Zvanyadza’s Story**

Was impregnated in South Africa and gave birth to a baby boy.

She came to me requesting assistance to attain a passport so that she go to S. A. for birth certificate.

She neglected her baby and the baby died

Now she has another baby by a Zambian

● **Dadiso’s Story**

Was impregnated by a hearing man whom she claim to have been in love with but does not know his name or address.

Luck enough she had a miscarriage.

Now she is impregnated again by another unknown man.

What about the use of female condom?

There is lack of information concerning HIV & AIDS.

● **My wife**

Before we got married she was asked to go for tests at Ruwa Rehab.

It was not done voluntarily but all students were requested to be tested.

No pre or post-counselling services were done yet it is the norm because she and others were Deaf.

Deaf people are treated differently when they choose to go for tests.

- **Experience at Pari Hospital**

Attended ante-natal clinic for 6 months with my wife every time expecting mothers were talked to go for HIV test but we were left out because of Deafness.

During our last visit a different person used paper and pencil to invite us to get tested and why it was important to be tested.

Whilst it was ok for paper and pen for me it was not for my wife, i had to translate to sign language.

What of the JARGON: window period, discordance in results.

Non-issues concerning Deaf

Sign language discrepancies is not an excuse for neglecting us.

We have Shona and Ndebele in different dialects yet it never is an issue.

Some people think Deaf people are asexual, which acts as a magnet to attract people who believe in muti and AIDS cure by having sexual intercourse with virgins.

- **Real issues**

- Deaf inclusion in AIDS awareness campaigns is the starting point.
- Training of Deaf counsellors is long over due.
- Opening of VCTs centered on people with Disabilities manned by Disabled persons including the Deaf is called for.
- What has been done: NCHH
- Created a sign language poster with KGIV (BYO) and ASSOD.
- In the process of making a Sign Language dictionary to include such terms as Discrimination, oppression.
- Sign Language training for hospital personnel with Ministry of Health (Hre 8-12 Nov, Byo 15-19 Nov 2010)
- What can be done: ALL

- You are here today, You have the power to do something
- Taura ,Khuluma ,Speak
- Implement Action Plan
- Deaf life becomes easier.
- Thank you for being here!!

## **SUMMARY**

Education was the panacea to the vulnerability of those who can't hear. The government should increase the number of schools of the deaf where sign language can be taught.

The Zimbabwe Open University and university of Zimbabwe had a program for sign language. The areas which needed research were;

- Learning sign language to assist the reading of sign language.

Sign language is best taught through exposure and communication with the deaf. There was for advocacy alternatively from the Radio and TV.

There was need for material language which would be betrothed upon strategically planned sign language in interpreters in civil sounding / in situations i.e. police, court, clinics, etc.

## **V.S.O - THE ROLE OF V.S.O in HIV/AIDS And DISABILITY by FOSTER MUTSATSA**

The voluntary service overseas is a Non –governmental Organisation planning Volunteers in areas of participating skills. The main objective was to share skills and to change lives. In Zimbabwe V.S.O had a number of programmes with the of Health and Child Welfare, mainly of education to maintain a few. The Material Volunteering Programmes was an exchange of skills from different materials. V.S.O identified areas that needed specialist skills and sought expert volunteers to fill in and contribute, Zimbabwe though did not have deficiency of skills.

V.S.O had a Regional AIDS initiative in Southern Africa. The objective was to prevent the spreading of HIV+AIDS. It had a number of strategic plans to prevent care, and treat HIV+AIDS. This workshop was very critical in that all effort had been based on HIV+AIDS and not on Disability. The integrated approach where HIV+AIDS was being streamlined into Disabled people's organizations and disability into Aids Service Organizations was very commendable.

V.S.O was willing and contributed significantly in view of this workshop where a National Framework of Action would map out a concrete plan which would identify priority areas and steps which would be taken.

There was need for a situation analysis on how to have foreword concretely. Workshop of consultations of seminars comes short of having tangible results. Information should be disseminated to critical areas where access of data is needed. Areas of which needed attention in training should be identified and institutions established. There was need to carry a survey on training needs and Training of trainees of National Levels. People in D.P.O+ASO should be experts in HIV+AIDS as it relates to disability. To date there is no data on how many such experts we have and how many we needed in reality for such programmes to succeed.

The best was to this approach was to start small, implement, mention and then evaluate , V.S.O had a 2 week training of trainees workshop in only December 2011 where trainees of training were coming from Aids service Organisation and Disabled People's Organisation. V.S.O was working with groups of visually ampered in identifying critical areas of need. The aim was to teach on how Braille could affectively inform the visually improved HIV+AIDS. Trainees would be equipped with tools to deal with Disability, HIV+AIDS in concrete itemized areas of concern.

V.S.O was taking a leading role in streamlining HIV+AIDS into Disabled People's Organizations there are partners with and disability with Aids Services Organizations they have successfully been working with i.e. the National Aids Council.

V.S.O was interiorizing tangible results where pilots Projects for Disabled People,s Organisations and Aids Service Organisations and Aids and start income generating projects. The projects would enabled the PWD+AIDS to live positively while at the same time accessing the poor and vulnerable with terminal illness. Some would be the basis of successful home based care

V.S.O was willing to contribute the resource sourcing and filling gaps for the Ministry of Health and Child Welfare and Ministry of Public and Social Welfare.

An area of concern was the Disability Act was not very effective. There was need for review and research to improve it.

Zimbabwe should move towards a disability allowances. The division of responsibility between the MOH and the Ministry of Social Welfare was very bureaucratic and doing very little to help the disabled. There was need to advocate for one institution under one ministry to cater for the disabled. Donors and other well wishers had difficulty in channelling their resources or alternatively, did not know who was responsible for what, whom and where. There was need to really siphon all strategic partners including the Vice President, Danhiko Trust, etc.

## **RESEARCH ON DISABILITY, HIV AND AIDS**

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NCDPZ and FACT in collaboration did a research on HIV and Aids in 2004 in Manicaland.

### **Introduction**

Disabled people are vulnerable to HIV and Aids in the same way as anyone else. They also have families, they care for the sick therefore they are vulnerable to HIV infection.

The research demonstrated large gaps in meaningful involvement and participation of disabled people in HIV and Aids programmes.

- DP were not seen as sexually active
- ASOs did not pay much attention to meeting the needs of disabled people
- Prevention and treatment information were not available in formats that are accessible to visually, hearing and speech impaired e.g. not in braille
- DP were not involved in HIV and Aids programmes
- Access to buildings where HIV services are offered were physically inaccessible, there were no sign language interpreters
- Women and children were extremely vulnerable to HIV since they are --- to rape and sexual abuse and people with learning disabilities

### **Recommendations:**

- DPOs to lobby and advocate for the inclusion of disabled people in mainstream HIV and Aids programmes
- To develop strategic alliances with Aids Service Organisations
- To mainstream disability in HIV and Aids programmes



- DPOs to scale up awareness on HIV and Aids prevention, support care and mitigation to disabled people
- HBC programmes should involve caring of terminally ill disabled people

| Programme Area          | Target group  | Planned Coverage      | Actual Coverage | Remarks |
|-------------------------|---|-----------------------|-----------------|---------|
| Home Bases Care Support | <ul style="list-style-type: none"> <li>• Home based Care Clients 100</li> <li>• Primary Home based Care Givers 100</li> <li>• Secondary Care Givers 30</li> <li>• Support groups and groups of PLWAs</li> </ul> | Ward 13<br>Mabuthweni | 100%            |         |

**Planned Activities:**

| Activities  | Target | Achieved |
|---|--------|----------|
| Refresher Course for Secondary Care Give on Home Based Care | 30     | 30       |
| Training of Primary Care Givers on Basic Nursing Skills     | 100    | 100      |
| Training of Programme staff,                                | 25     | 22       |

|   |            |            |
|---|------------|------------|
| <b>stakeholders and Community Leaders on Palliative Care</b>                      |            |            |
| <b>Training of Trainers on Palliative Care</b>                                    | <b>4</b>   | <b>3</b>   |
| <b>Distribution of Home Based Kits to Secondary Care Givers</b>                   | <b>30</b>  | <b>30</b>  |
| <b>Distribution of Home Based Care Kits to clients/patient on home based Care</b> | <b>100</b> | <b>100</b> |
| <b>Income Generating Activities to Support groups and PLWAs</b>                   | <b>4</b>   | <b>4</b>   |

## **DISCUSSION**

NCDPZ had 89 branches and 25 support groups. Its activities include;

- Lobbying and advocacy
- Sourcing for scholarships
- Training – leadership, economic empowerment
- Women’s development programmes
- Youth development

### **New Programmes**

NCDPZ was very receptive to the effects of DHAT to mainstream HIV/AIDS into DPO and disability in ASO. Aids service organization historically had not paid attention to meeting the needs of disabled people with aids. DPO’s did not link the vulnerability of PWD to HIV/AIDS.

NCDPZ had projects where disability had been mainstreamed with developmental projects. If disabled people with HIV/AIDS work on income generating projects they become self sufficient and cut the vicious cycle of their vulnerability through poverty. Disabled women and children were the most vulnerable. Social protection where the programmes, projects and activities were membership driven will go a long way in eradicating povert and sustaining the initiatives.

Communities/societies should be the owners of the projects where they should allow PWD, HIV/AIDS advocacy through information on HIV/AIDS prevention, mitigation, care and support. Home based care support groups ensure that issues were being addressed adequately,

resources focused on priority needs and that at the end of the day, the rightful people benefit from the projects /programmes.

DPO's and ASO's, in view of the mainstreaming approach have to be very innovative and ensure developmental programmes with hand and glove with their target groups. Mainstreaming disability, HIV/AIDS with developmental programmes ensured that service provision was customer oriented. DHAT, NASCOH, USAID, DPO, ASO could only lead over the sustenance of projects to the community at large and get the USAID in its poverty reduction programme to assist financially by building synergies with strategic partners. Beneficiaries would get money for school fees, in the form of block grants, psycho-social assistance, wheel chair manufacturing, sourcing of Braille printing machines and audio visual technologies, etc.

Mainstreaming opened up a lot of opportunities where infighting within DPO's would negatively affect resource funding. DPO's and ASO's had to work in a coordinated and harmonized approach, and avoid inter /intra fighting.

**JILL HARNASS ( HANCOCH(PHD)**

Disability and HIV - Situation Analysis from a Research Perspective

**HEARD**

**(Health Economics and HIV/AIDS Research Division)**

**University of KwaZulu-Natal**

“We call on all African Governments to include disability in its diversity as a crosscutting issue in ALL poverty reduction strategies.....”

**Kampala Declaration of the Africa Campaign on Disability and HIV March 2008**

Historical Background

2003 Disability and HIV/AIDS was raised as an issue

2004 Global survey on HIV/AIDS and disability (Yale University)

2004 First Symposia on HIV/AIDS and disability in Germany and Namibia

2007 Launch of the Africa Campaign on HIV/AIDS and disability

2008 Disability was first presented at the World AIDS Conference and at ICASA

2009 UNAIDS releases policy brief on disability and HIV

2010 Disability was included in satellite sessions and in the Global Village of the World AIDS Conference

**Published Research (in numbers per year)**

Geographical Focus (2000-2008)

Summary of Results of Studies

People with sensory or intellectual disability have less knowledge about HIV

PWD experience barriers to HIV prevention interventions, VCT services and AIDS treatment

Social construction of disability marginalizes and stigmatizes PWD

Non-medical representations are connected to vulnerability of PWD

Disabled orphans are particularly vulnerable

Summary of Results of Studies

Data on sexuality and relationships:

Sexual Activity (**76% Malawi, 80% Cameroon**)

Pregnancy rates (**77%, Uganda**)

Engagement in multiple partners (**45%, Cameroon**)

Women abandoned if disabled child is born (**60%, Zimbabwe**)

PWD become victims of sexual abuse or exploitation (**17% Malawi, 22% Uganda**)

Summary of Results of Studies

Prevention:

PWD perceive themselves as particularly vulnerable to contract HIV (**55% Uganda, 75% Zimbabwe, 95% Kenya**)

VCT testing is low (**6% Uganda, 10% Malawi, 53% Kenya**)

Knowledge of how to use a condom is low (**42%, Malawi**)

Condom use is low (**10%–24% Uganda, 47% Cameroon**)

STDs are experienced but not always treated (**38%, Uganda**)

Radio main source of information (except for deafness)

Zimbabwe's evidence

Banda, Irene. "**Disability, Poverty and HIV and AIDS.**" Disabled People International, 2005.

CASS Centre for Approved Social Science, Rekopantswe, M. "**Understanding the Livelihoods of Children with Disabilities and Their Families in Zimbabwe.**" UNICEF, 2007.

Nganzi, P, Matonhodze G:. "**Disability and HIV & AIDS; a Participatory Rapid Assessment of the Vulnerability, Impact, and Coping Mechanisms of Parents of Disabled Children.**" Bulawayo Zimbabwe Parents of Handicapped Children, 2004.

Choruma, T. "**The Forgotten Tribe: People with Disabilities in Zimbabwe.**" progressio report 2006.

Charowa ,G.: **Body blows: In the thick of Zimbabwe`s current Turmoil, Women with Disabilities face hellish Prejudice, Hunger and Rape.** New Internationalist, 2005

Research Gaps

Prevalence data on disability and HIV

KAP Survey´s or cross-sectional surveys in regards to PWD

KAP Survey´s or cross-sectional surveys in regards to educators or health service providers

Qualitative data on the Experience of disability and HIV

Qualitative and quantitative data on the disabling effects of HIV

Evaluations of grassroot projects

Statistics on sexual abuse of PWD

.....

Zimbabwe´s NSP (2006-2010)

Recongnises PWD as a vulnerable group

Does not include disability in situation analyis

It is not clear if PWD are included as a group in the mulitsectorial response to HIV and AIDS (NAC)

The NSP addresses stigma and improvement of livelihoods, yet does not include PWD

Prevention approach mentions PWD

Treatment, care and support is silent on disability

Disability is not included in M&E struktures

## **Summary**

Zimbabwe was not alone in the fight against the HIV/AIDS epidemic vis a' vis PWD. There were many conceptions and cultural beliefs. Scientific research had adopted the mainstream approach as it intergrated all aspects of disability and HIV/AIDS. This presentation was an ear from outside.

The UN had a policy on disability and HIV/AIDS. Zimbabwe had to sign the convention but was already adhering to it. All the literature in Zimbabwe in HIV/AIDS and disabilities was not scientifically gathered and empirically presented. There was need for a scientific research meeting international scientific data compilation and presentation standards.

Of all the disabilities, the intellectual disability was the most neglected and almost forgotten about. There were no statistics on PWD and HIV/AIDS. This was true to all forms of disabilities. PWD had a high prevalence of HIV/AIDS. It had to be ascertained whether this could be attributed to the side effects of drugs and the disabling effects of HIV/AIDS on the body.

There was need for a strategic plan of action mainstreaming HIV/AIDS and disability with the objective to have tangible projects suited for the direct needs. There was need to explore further the concept of universal designs of disability technology and designs. Research was needed from different countries and communities on whether there could be a universal standards of designing buildings so that they could be accessed the same the world over. The same research was being spread on to Braille, sign language, wheelchairs, etc.

There were many research gaps which identified the donor community. Many researchers were required. Alternative ways of funding research projects had to be explored in view of the difficulty in discussing overseas money.

DHAT, VSO, USAID should work very closely in view of this. With the advent of ARVs, research should move away from the focus on home based care to community based rehabilitation. Research should also explore the functions of ASO when the cure to HIV/AIDS is found.

Zimbabwe needed to effectively mainstream HIV/AIDS with DPO's and disability into ASO vis a' vis community based rehabilitation. Mainstreaming was part and parcel of the national rehabilitation strategy. A pilot study was needed to formulate research to address how effectively community based rehabilitation could intergrate the mainstreamed approach to HIV/AIDS and disability with a view to have projects which eradicate poverty by generating income. By generating income there is guarantee that the projects will be sustainable. The main objective was to have PWD and HIV/AIDS live positively and enjoy their lives.

## **MINISTRY OF HEALTH & CHILD WELFARE – REHABILITATION PROGRAMME**

Ministry of Health and Child Welfare response to support Persons with Disabilities (PWD)

Cecilia Nleya - Acting Deputy Director, Rehabilitation Department, Ministry of Health and Child Welfare

22 November, 2010

cjonleya@yahoo.co.uk

Format

Ministry of Health and child Welfare –

Vision

Disability Prevention and Rehabilitation Department –

Objectives

Types of disability

Current Disability Prevention and Rehabilitation programmes

- Hospital based (Treatment and Care)
- Outreach and Community Based Rehab (CBR)
- Children's Rehabilitation – 'AT RISK'

Format Continued...

Why current focus on Disability, HIV and AIDS



## Way Forward

MOH&CW

### VISION

To have the highest possible level of health and quality of life for all citizens of Zimbabwe

MOH&CW

### MISSION:

To ensure the provision of quality health services and to promote healthy lifestyles

- Equitable
- Appropriate
- Accessible
- Affordable
- Acceptable

### Rehabilitation

Increased access to quality and comprehensive rehabilitation services

- To improve the functionality, independence and quality of life for Persons with disabilities

### Rehabilitation

- Provision to PWD of health services required because of that disability, including:

services designed to prevent or minimize any further disability

For most people with disabilities, access to adequate (re)habilitation is a pre-condition for integration into society and participation in the communities in which they live.

### Definition

“The UN Convention on the Rights of Persons with Disabilities :

*“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.*

### Strategies

Survey to determine magnitude, consequences and types of disabilities in the country - disability burden of HIV and AIDS

Disability and Rehabilitation Advocacy, Community Awareness and Education

Scaling up screening and referral mechanisms for children 'At Risk' of disabilities , including monitoring of HIV positive children for developmental disabilities

CBR

Research

Linkages and Collaboration

Rehabilitation and habilitation go far beyond the health field and embrace a wide range of issues including education, social counseling, vocational training, transportation, accessibility and assistive technology, etc

-Sectors, Partners, PWD, families, community

Terms of Reference

Zimbabwe Disability Act (1992)

Standard rules for the Equalisation of Opportunities (1994)

United Nations Convention on the Rights of Persons with Disabilities (2006)

United Nations Convention on the Rights of the Child -particular reference Article 23

The National Health Strategy of Zimbabwe (2009 – 2013)

The Disabled Person's Act- Health Related Objectives

Persons with disabilities (PWD) are provided with ACCESS to general health care services and facilities

PWD have access to the same range and standard of affordable health services as provided to other persons, including maternal and child health services, sexual and reproductive health services, TB, HIV and AIDS services, rehabilitation ETC

In reality this.....

Requires health professionals to provide care of the same quality to PWD as to others, and on the basis of free and informed consent.

Definition 1.....

The UN Convention on the Rights of Persons with Disabilities :

*“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.*

Definition 2 .....

*any restriction or lack of ability to perform an activity in the manner or the range considered normal for a human being. Such restriction or lack of ability must be as a result of impairment”.*

WHO Classification

1980 – International Classification of Impairments, Disabilities and Handicaps (ICIDH)

2001 – International Classification of Functioning, Disability and Health (ICF)

“Shift” from medical model (impairment based to a system that focuses on limitations in activities and social participation

WHO Classification .....

An understanding of disability as defined by activity limitations and restrictions in participation

- Body function/structure
- Activity level
- Participation level

(Environmental + Personal factors)

Types of disability

Physical disability – movement restriction

- Speech and hearing disability
- Visual disability
- Learning disability – intellectual disability
- Epilepsy - fits
- Mental illness
- Albinism
- Multiple disability

# Causes of Disability

Source: National Health Profile

Injuries and accidents in the community

Accidents at work

Road Traffic Accidents

Disease

Congenital conditions

Other

Rehabilitation Services

Rehabilitation services available at all central, provincial and district hospitals

Hospital Based Services

Treatment of injuries/impairments

Provision of assistive devices

Training other health workers in disability issues

Programmes

“AT RISK” Programme for early detection and management of disability in children

Community Based Rehabilitation

Rehabilitation Villages

There is a special programme of training rehabilitation personnel in management of children with neurological /developmental disabilities – response to increase in HIV related developmental problems

What are the issues

Being disabled and having HIV or AIDS

HIV and AIDS causing disability

Complex issues – burden of illness

Increase in number of children referred with developmental problems

Developmental delay

- Cognitive

Demand on assistive devices

Current and Future Programmes

Sign Language Training programme for nurses and other health workers to improve access to information and services for the hearing impaired and Deaf

Consultations/process in place for mainstreaming disability in all health programmes (HIV and AIDS, Reproductive Health, Nutrition, )

Current and Future Initiatives.....

To determine level of Accessibility of MOH&CW facilities

Research - to develop guidelines and checklists

Work with partners 'Training of Trainers' in Disability, HIV and AIDS

Way Forward

Provide an enabling environment through the

- Continuous audit of health facilities and programmes
- Continuous prioritization of corrective action measures
- Continuous training and Sensitization of staff in all sectors

Way Forward

All MOH personnel be sensitized to provision of services to PWD

Health workers to be trained in Basic Sign Language

All MOH & Child Welfare facilities to be upgraded to ensure full access to members of the disabled community

Implementation Special needs register for PWD in all RHcs and district hospitals

Way Forward

To develop and implement a Rehabilitation Policy that is designed for people with disabilities to provide equal opportunities in all aspect of life

-Special needs for women with disabilities

-special needs of children with disabilities

-specific needs e.g. Braille, sign language, physical access

#### Way Forward

- To ensure that Draft Policy and Plan of Action for screening and referral mechanism for children with disabilities is finalized for 2011 – includes monitoring and rehabilitation of HIV positive children
- Incorporation of the disability access guidelines into the hospital standards
- To provide technological innovations to assist PWD

The Ministry of Health and Child Welfare is committed to providing the highest quality of health care to all the people of Zimbabwe without discrimination

Thank You!

## **INTRODUCTION TO GROUP WORK**

PARTICIPANTS WERE DIVIDED INTO 4 GROUPS:

- |         |   |                          |
|---------|---|--------------------------|
| Group A | - | Policy                   |
| Group B | - | Programming              |
| Group C | - | Women, Youth, Children   |
| Group D | - | Information and research |

Participants were tasked to mainstream HIV/AIDS into DPO's and disability into ASO's. Identify ;

- What the issues were and identify the challenges,
- How to overcome these challenges,
- Who should do what, when and how.
- What issues for advocacy were to be addressed.

The solution to these tasks were to form the basics or pivots in formulating the national frame of action plan, mapping the way forward for 2013 – 2015.

### **DAY 3**

Participants continued their group activities and presented their work as below;

#### **Group A - Policy**

##### **Policy Issues**

1. Main streaming disabilities in HIV and AIDS programmes in Zimbabwe
2. HIV/AIDS Prevention strategy policies which are disability user friendly (e.g. appropriate condoms)
3. Creation of a specific ministry or department to address disability issues bringing administration of disability under one roof (health, welfare)
4. Free access to health services and education
5. HIV services/ programmes should be tailor made to suit and meet the needs and demands of people with disabilities
6. National HIV/ AIDS policy in relation to disability and HIV/AIDS-amend the current policy
7. Government to institute or commission research work on disability and HIV/AIDS
8. Equal opportunities policy in development for PWD including employment.

- Lobby the government to speed up the signing and ratification of the UN Convention on the rights of persons with disabilities.

#### Issues

- No disability policy
- DPA is shallow- need to audit the ACT.
- National HIV/AIDS Policy is disability blind.
- Non involvement and participation of PWD in policy formulation eg national HIV policy
- MOE to put in place a policy that supports children with disabilities by strengthening the School psychological services department.

| Policy  | Activities   | By Whom                                | By when |
|---|--|--|---------|
| Main streaming disabilities in HIV and AIDS programmes in Zimbabwe  | <ul style="list-style-type: none"> <li>Lobbying the Govt, ASOs, Pvt Sector, Civil Society, Donors to mainstream disability &amp; HIV/AIDS in their programmes</li> </ul> | NASCOH, DPOs, DHAT,                    |         |
| HIV/AIDS Prevention strategy policies which are disability user friendly (e.g. appropriate condoms)   | Lobby the ministry of health & HIV/AIDS service providers eg NAC, MAC and aid manufacturers to produce user friendly condoms.  | NASCOH, DPOs, DHAT,                    |         |
| Creation of a specific ministry or department to address disability issues bringing administration of disability under one roof (health, welfare) | Lobby the GVT to set an admin for disability issues  | NASCOH, DPOs, DHAT, MAC & NAC          |         |
| Free access to universal health services and education ( MDGs)  | Lobby the ministry of healthy & education  | NASCOH, DPOs, DHAT & service providers |         |



|  |                                   |  |  |
|--|-----------------------------------|--|--|
|  |                                   |  |  |
| HIV/AIDS services/ programmes should be tailor made to suit and meet the needs and demands of people with disabilities | Lobby the GVT & service providers | NASCOH, DPOs, DHAT & service providers |  |
| National HIV/ AIDS policy in relation to disability and HIV/AIDS-amend the current policy                              |                                   |  |  |
| Government to institute or commission research work on disability and HIV/AIDS   |                                   |  |  |
| Equal opportunities policy in development for PWD including employment.  |                                   |  |  |

### **Group B – Programming**

- ▶ Group Work
- ▶ Programming
- ▶ **Issues and Challenges faced by PWD**
- ▶ Current HIV and AIDS programs are not including PWDs
- ▶ Information gaps e.g. Prevention, Positive Health, Dignity and Prevention, Treatment Literacy, Mitigation.
- ▶ Information not being disseminated to PWDs;

- ▶ The information that is available is not user friendly, i.e. IEC material is for those who can see, no subtitles for the hard at hearing and deaf.
- ▶ Issues and Challenges faced by PWDs cont....
- ▶ **Health services**

- limited access to SRH services, VCT and other HIV and AIDS services

-staff not trained to offer these services to PWDs

- ▶ **Health centers**

- health centers not user friendly. Geographical distance for rural health centers is a hindrance to PWD.

- ▶ Stigma and discrimination e.g. How can PWD be HIV positive?.
- ▶ **How can these challenges be overcome?**
- ▶ Mainstreaming PWD issues and challenges into current HIV programming i.e. sign language, bigger font, Braille and subtitles to video presentations.
- ✓ PWD representatives be in already existing NAC structures i.e. in taskforces & TWGs for all thematic areas e.g. CHBC, Prevention, OVC, M&E, Gender, Youth.
- ▶ Build the capacity of ASOs so that they can be able to deal with issues of PWD & HIV.
- ▶ Networking with all ASOs.
- ▶ Research into the specific needs of men and women e.g. reproductive health needs of PWDs in order to map issues of PWDs.
- ▶ How can these challenges be overcome cont....
- ▶ Resource mobilization for PWD & HIV programs.
- ▶ Meaningful Involvement of PWD in HIV programming .
- ▶ Advocacy Work by DPOs
- ▶ Awareness raising by DPOs
- ▶ **Who should do What?**

**Government should:**

- ▶ Put in place policies that are pro-PWD.
- ▶ Ensure that these policies are fully implemented by putting in place an M&E system.

- ▶ Mobilize resources for programs in support of and specific to PWD issues.
- ▶ Capacitate strategically positioned staff.
- ▶ **Who should do what cont.....**

**DPOs should:**

- ▶ Advocate for the construction of infrastructure that is appropriate for PWD and
- ▶ Come up with HIV programs for PWD
- ▶ Set up Taskforce Committees from ward to national level.
- ▶ Mainstream HIV and AIDS issues into their programs.
- ▶ **Who should do what cont.....**

**AIDS Coordinating Bodies (ACBs) and ASOs should:**

- ▶ ACBs like NAC, ZAN, ZNNP+ should meaningfully involve PWDs in strategy formulation e.g. the ZNASP, BC strategy,
- ▶ Mainstream and integrate PWD into the already existing HIV and AIDS programs.
- ▶ Resource mobilize specifically for PWD & HIV programs e.g. IEC materials for the visually impaired, hard at hearing or deaf, Condom use for PWD.
- ▶ Build the capacity of DPOs on HIV and AIDS issues
- ▶ Advocacy Issues
- ▶ Elimination of stigma and discrimination
- ▶ Human Rights, equality and protection of PWDs
- ▶ Meaningful involvement of PWDs in formulation of policy, strategy and programs.

**Group C – Women , Youth, and Children,**

- DISABLED WOMEN, YOUTH AND CHILDREN
- `
- PROBLEMS
- ACCESSIBILITY
- ATTITUDES

- DISCLOSURE
- ACCESS TO PREVENTION,CARE ANMND TREATMENT
- EXCLUSION
- 
- Women in general have low economic status making them vulnerable to domestic violence resulting to HIV. Not empowered to negotiate for safe sex.
- Violation of women rights, unable to make decisions in regards to sexual reproductive health. Low uptake of female condom
- Parents hide children and health workers cannot access them
- Policy Ministry of Education – No child under 16year should be educated about sex
- Youth excluded and seen as immature (guardians not acknowledging that their children could be sexual active)

#### Accessibility:

- Physical: geographical setting, walking long distances to health facilities. Health facilities can be expensive. Health workers not trained to deal with the disabled.
- Hearing: lack of access to information sign language
- Visual: lack of access to information braille material and large font

#### Attitudes:

- Health workers ignorant of disability issues
- Negative attitude by the disabled themselves
- Issues of mental poverty and giving up
- Deaf children start sex early because they and speak language without adults beating them up like those children who hear.

#### Disclosure:

- Women and youth don't disclose their status, level of sharing are very low. Within disabled women issue of high and low class.
- DPOs not having HIV and AIDS programmes to support those who disclose.

#### Access to prevention, care and tratment

- VCTs ignorant of disabilities
- VCTs perched in high buildings
- Health workers attitude that the disabled don't need the services (myths and misconceptions)
- Negative attitude of health workers as they believe the disabled should not have or enjoy sex
- Forced sterilisation
- Issues and challenges

#### DEAF

- Discrimination first as a woman and then as a disabled women
- Communication barrier
- Low literacy rates
- Lack of knowledge on reproductive rights and health
- Lack/limited resources
- Low/no income
- Poverty – poor or destitute
- Lack of information and about basic health issues
- Health care services are expensive and too far

#### BLIND

- No brailled material available on health issues

#### INTELLECTUAL

- Stigma and discrimination

#### MULTIPLE

- Lack of understanding of disability by the community hence are left out on important issues
- No respect for disabled people
- Fear of disabled people, some people think they will also get a disability

## OVERALL

- Low economic status (cannot negotiate for safer sex)
- Violation of women's rights
- Culture and myths (belief that disabled are cursed or its a punishment from God or the ancestors.
- How to overcome challenges
- Women should unite together and fight for their rights in one name
- Government and community leaders to enforce laws and policies that protect disabled women, youth and children
- Women and youth to be given position with authority in government including Parliament
- Gender equity and equality for all
- Governments and civil society and communities at large should work together to crease a just society for the disabled women and youth
- What are the advocacy issues
- Education
- Gender equality
- Employment opportunities
- Discrimination and stigma
- Disability rights as human rights
- INTERVENTIONS

## WOMEN AND YOUTH

## MEDIA ADVOCACY

## SEXUAL AND HEALTH REPRODUCTIVE RIGTHS

## GENDER EQUALITY

## DOMESTIC VIOLENCE

## MAINSTREAMING OF YOUTH IN DPOs IN EXISTING PROJECTS

- CAPTIONS OF ROLE MODELS ON TV AND BANNERS

- JINGLES
- COMPETITION ON KNOWLEDGE PITTING RURAL AND URBAN
- WOMEN
- SENSITISATION OF DPOs
- STRENGTHENING OF YOUTH PROGRAMMES
- TASK FORCE ON WOMEN, DISABILITY AND HIV AND AIDS TASKFORCE BASED ON REAL LIFE TESTIMONIES
- SELF HELP GROUPS FOR EMPOWERMENT AND EASIER FOR ADVOCACY
- Lobby for policy to change to allow youths who are sexually active to be allowed preventive methods
- INTERVENTIONS
- INFORMATION AND NETWORKING
- ZEBRA TARGETING-REPRESENTATION OF RURAL AND URBAN WOMEN AND YOUTH AT EACH AND EVERY GATHERING CONSIDERING ALL DISABILITIES
- COLLABORATIVE OUTREACH PROGRAMMES(DPOs, ASOs and community reps)
- Education and training
- Instrument protecting women youth and children
- Skills training for youth and children
- Community dialogues with agents of change e.g community leaders, PASTORS AND TEACHERS
- WORKSHOPS
- FUNDS AVAILABILITY
- REVIVAL OF DISABILITY FRIENDLY CLUBS, CAMPS ETC
- PEER EDUCATION
- EDUTAINMENT
- INTERVENTIONS

- EMPOWERMENT
- INCLUSION IN DECISION MAKING
- SELF REDIRECTED EMPLOYMENT
- FORMAL EMPLOYMENT

INFORMATION SHARING

LIVELIHOODS

ENFORCEMENT OF QOUTA SYSTEM AND ITS INCENTIVES

**Group D INFORMATION AND RESEARCH GROUP**



# **National Disability and HIV and AIDS Workshop**

## **Information and Research Group Presentation**

### **Team**

**Fambaineni Magweva  
Robert Sinyinza  
Lincoln Hlatywalo  
Dr. Jill Hanass-Hancock**

## **GAPS-Research**

- ❖ **Evaluation of Best Practices**
  - **Design a Knowledge Attitude and Practices (KAP) survey, e.g. on sex education**
- ❖ **Experiences of disability and HIV and AIDS**
  - **e.g. from Studies from home based care**
- ❖ **Disabling effects of HIV and AIDS**

## **GAPS Research**

- ❖ **Lack of statistics**
  - **HIV Prevalence data on PWDs; carried out on the onset with National Demographic Health Surveys**
- ❖ **Lack of survey on disability demographics**
  - **Development of database on types of disability**
- ❖ **Sexual Abuse in Relation to Disability**
  - **Quantitative data is required**
  - **Focus on reported cases from parents and police**
  - **Information from PWDs themselves**

## **Gaps-Information**

- ❖ **Terminology in HIV and AIDS not simplified for PWDs**
  - Develop signs for new words in HIV/AIDS for HI
- ❖ **Inadequate Information on HIV and AIDS for the visually Impaired**
  - **Braille**
    - Development of software that recognizes voices
  - **Voice synthesizers for the blind**
  - **Jaws for the blind**
- ❖ **Lack of access to information for people with learning difficulties**
  - **Need to develop manuals for PWDs with intellectual disability**
    - E.g. Rebecca Jones developed a manual for intellectual disability and can be used as a teaching tool for health workers

## **Gaps-Information**

- ❖ **Lack of access to information by Hearing Impaired who are not literate**
  - **Use of family members in signing**

## **Priorities and Assignment of Tasks**

- ❖ **Disabling Effects of HIV and AIDS**  
DHAT, MoHCW, Research Institutions/UZ, DPOs, NASCOH
- ❖ **Sexual abuse in relation to disability**  
DHAT, Research Institutions/UZ, NASCOH
- ❖ **Evaluation of best practices**  
DHAT, Research Institutions/UZ, MoHCW, NASCOH

## **Priorities and Assignment of Tasks**

- ❖ **Disabling Effects of HIV and AIDS**  
DHAT, MoHCW, Research Institutions/UZ, DPOs, NASCOH  
Activities
  - **Preparation of Research Proposal**  
By Whom: DHAT, MoHCW and NASCOH  
By When: March 2011
  - **Fundraising**  
By Whom: DHAT and NASCOH  
By When: July 2011
  - **Research**  
By Whom: DHAT, MoHCW, Research Institutions/UZ, DPOs, NASCOH  
By When: October 2011

## **Priorities and Assignment of Tasks**

### **❖ Sexual abuse in relation to disability**

**DHAT, Research Institutions/UZ, NASCOH**

#### **Activities**

- **Preparation of Research Proposal**

**By Whom: DHAT, MoHCW and NASCOH**

**By When: March 2012**

- **Fundraising**

**By Whom: DHAT and NASCOH**

**By When: July 2012**

- **Research**

**By Whom: DHAT, MoHCW, Research**

**Institutions/UZ, DPOs, NASCOH**

**By When: October 2012**

## **Priorities and Assignment of Tasks**

### **❖ Evaluation of best practices**

**DHAT, Research Institutions/UZ, MoHCW, NASCOH**

#### **Activities**

- **Preparation of Research Proposal**

**By Whom: DHAT, MoHCW and NASCOH**

**By When: March 2013**

- **Fundraising**

**By Whom: DHAT and NASCOH**

**By When: July 2013**

- **Research**

**By Whom: DHAT, MoHCW, Research**

**Institutions/UZ, DPOs, NASCOH**

**By When: October 2013**

## **CLOSING REMARKS**

The workshop was officially closed by Phillimon Simwaba – DHAT Executive Director. In view of the participants who attended the 3 day workshop, Dhat had succeeded in creating and establishing the critical working relationship which was pivotal with strategic partners in mainstreaming HIV/AIDS with DPO's, disability with ASO's. Contributions from all DPO's and ASO's were received with gratitude.

The participation from USAID, VSO, Ministry of Health and Child Welfare, and Hamida for organizing the workshop and all the strategic partners has built confidence and brought hope that with the national action plan in hand, the set goals would start a long journey with willing partners.

He pleaded for partners to walk together in harmony with perseverance to accomplish the goals set. Mainstreaming is a wide concept with a lot of room for other players to come in and contribute. DPO should allow and give room to be assisted by able bodied people. There should not be any cause to discriminate the deaf from the physically handicapped, the visually challenged and mentally challenged. Inter and intra organizational conflict based on personalities or intercepts should be avoided. Cooperation and harmony are the solution, conflict was decapacitating.

Mainstreaming should begin within our own organization before we go out and start advocating for it. Donor community was very ready to work with DHAT, NASCOH, DPO's and ASO not mentoring at this workshop USAID and VSO.

A mainstreamed approach to the donor community will enable strategic sourcing of not only money but skill, i.e. in research, etc.

Donors are willing to assist in mainstreaming issues as they relate to disability, HIV/AIDS. The aim was to make life to those with HIV/AIDS be positive and longer while paying particular attention to the vulnerable groups as the disabled young children, girls, women and the elderly who are poor and isolated.

The contacts which have been made and the follow up meetings in implementing the national plan of action will have made this workshop a success.