

DISABILITY HIV AND AIDS TRUST (DHAT)

Presentation Paper

on

**Role of DPO's in Mainstreaming HIV/AIDS
14th April 2008 – Kagisong Centre, Botswana**

Presented by

Godfrey Mwewa

Role of DPOs in mainstreaming HIV and AIDS

Ladies and gentlemen, before I go into presenting my paper I would like us to first of all explain some of the words in the title.

DPO stands for **Disabled Peoples Organizations**

These are organization of people with disabilities. People with disabilities have organized themselves into their own organizations. Disabled people's organizations are therefore, those organizations controlled by people with disabilities themselves.

The role of these organizations includes providing a voice of their own, identifying needs for their members, expressing views on priorities, evaluating services and advocating change and public awareness.

HIV stands *Human Immunodeficiency Virus*.

It a virus that attack our white blood cells, causing our body defense system to be weakened against any infections.

Once HIV enters the body it attaches itself to the white blood cells. These blood cells are our defenses; they attack and usually kill infections so that we can not fall ill. What the HIV virus does is attach itself onto the white blood cell and then use it as a factory to reproduce itself. Then when the white blood cell goes to attack an infection, instead of it doing that, it is held back by HIV and then burst spilling out all the HIV virus that have been inside it.

Therefore, people who are HIV+ are prone to infections that people with healthy immune systems (defense) can fight off.

AIDS stands for *Acquired Immune Deficiency Syndrome*. AIDS refers to a group of illnesses caused by HIV and is at last stage of the infection. AIDS itself is not a disease but a term used when the HIV virus has broken down the immune system to such a degree that the body is unable to fight off infection. The term AIDS is used for the collection of diseases and infections the person has, due to the effect of HIV. Over the years the virus weakens the body's abilities to fight off illnesses and finally leads to the collapse of the immune system and ultimately death.

MAINSTREAMING HIV AND AIDS IN AN ORGANIZATION

When you talk of the word “mainstreaming”, it has two parts:

1. AIDS work

This means adding work which is directly focused on preventing HIV/AIDS, care, treatment or support for those who are infected or affected. This could be work which is distinct from other existing development and humanitarian work. For example efforts to change peoples behavior.

2. Modifying the ways in which the organization functions: E.g. in terms of workforce planning & budgeting. I can give an example of a company which has integrated AIDS work but has not mainstreamed HIV/AIDS: A company with a policy on funeral grants, medical benefits for those who are infected and affected by HIV virus, but no one has considered how AIDS may affect the organization in future.

You could look at:

- ❑ Staff absenteeism
- ❑ Medical Costs
- ❑ Benefits Paid

The strategy aims at ensuring that the organization can survive the financial impacts of AIDS.

Mainstreaming is therefore, concerned with viewing things at a different perspective and making alterations as appropriate.

WHY mainstream HIV and AIDS into DPOs

Because HIV affects everyone. People with disabilities are vulnerable to HIV; therefore, organizations that deal with disabilities should be concerned with HIV/AIDS, especially with the future of the youth with disabilities and are HIV positive.

This group of people needs access to HIV/AIDS care, e.g. medical, counseling, rehabilitation, legal and inclusive policies on HIV/AIDS.

WHO IS A LEADER IN HIV/AIDS MAINSTREAMING?

What is leadership?

Leadership is a process by which a person influences others to accomplish an objective and directs the organization in a way that makes it more cohesive and coherent.

OR

A leader is a person who makes followers want to achieve high goals.

A leader in HIV/AIDS mainstreaming is a person who wants to work together with young people or members of the organization/community through sharing ideas, giving skills and supporting positive behaviors. Leaders are people who have a greater positive influence with others from the different age groups. Encouraging people of the same group (peer) to easily mix with one another and share ideas because of their similar interests. For example, peer pressure is beneficial when friends influence each other in a positive way, but it can have negative effects if peers pressurize one another in drug abuse, early sexual intercourse, unruly behavior and other unhealthy behaviors.

CHALLENGES IN MAINSTREAMING HIV/AIDS

There are many challenges faced by leaders in mainstreaming HIV/AIDS into DPOs. Some of these challenges are:

- Lack of Financial and Material Resources
- Lack of information on HIV/AIDS, prevention, care, and access to drugs and vaccine
- Exclusion from HIV/AIDS response strategies by Governments and community
- Public perception that PWDs often are seen as people without a sex life and therefore, are not affected by HIV/AIDS
- Lack of access to education, for instance, No material printed in Braille and also lack of trained interpreters for the hearing impaired.
- Lack of awareness of rights PWDs possess.
- Lack of access to HIV and AIDS related services (DPOs should advocate/register with voluntary testing centre or district health teams in order to receive an adequate supply of condoms and other related services for their members)
- Lack of a statistics/database to establish PWDs who are positive
- Lack of commitment of Leaders (DPOs should conduct appraisals of leaders to ensure their active and positive participation on HIV/AIDS issues)

WHY IS IT NECESSARY TO INVOLVE LEADERS IN MAINSTREAMING HIV/AIDS?

The following are some the reasons why it's so important to involve leaders in mainstreaming HIV/AIDS:

- Leaders can mobilize members in their organization especially the youth who more vulnerable to HIV/AIDS. This can be done through AIDS clubs or other existing clubs.
- Leaders can also train youth as peer educators to organize youth groups to be involved in works like: Orphan care support, the care for the sick and other activities that support needy causes in their organizations/community.
- Leaders can advocate and influence participation of people with disabilities in the community and government programmes and policies.
- Leaders can mobilize resources to fight and mainstream HIV/AIDS into DPOs
- Leaders can advocate and lobby for inclusive policies; they can also identify the role of PWDs in the National AIDS policies.
- Leaders can identify strategies to respond to the HIV/AIDS pandemic by involving members of the organization. For example,

Leader can address issues of:

- ✓ Lack of access to medical and counseling (Inaccessibility of infrastructure)
- ✓ Lack of access to Education on HIV/AIDS & family health issues
- ✓ Lack of rehabilitation services
- ✓ Access to legal services in case of any abuse – rape or rights

In conclusion, there are many ways and methods of mainstreaming HIV/AIDS but there is need for DPOs to know their roles. Examples could be:

Formation of HIV/AIDS Policies in their organizations

DPOs are encouraged to develop HIV/AIDS policies in their organizations which can be a cross cutting tool applied to all programmes in the organization. Policies would guide the organization on HIV/AIDS issues that address the needs of their members.

Policy Advocacy and Lobbying

DPOs need to draw attention of policy makers, AIDS Service Organizations, governments, private sector and the community/public through public meetings and workshops to examine the issue of HIV/AIDS and Disability. Most national AIDS policies drawn by countries in Southern Africa were silent on the issue of disability and HIV/AIDS and did not recognize the disabled people as vulnerable groups to HIV and AIDS.

Educational Awareness

DPOs must make sure that their members were well informed on HIV/AIDS issues. Relevant and important information is imparted through workshops for staff, leaders, people with disabilities and their families on various HIV/AIDS areas. Topics may include prevention, safer sex practices, care and treatment etc. There is need to work closely with relevant sectors by creating partnerships. There is need for adapting HIV/AIDS information into audio or visual tapes, Braille and other formats that recognize the various types of disability in the community.

Medical and Counseling

DPOs should recognize the importance and need of People with disabilities having access to medical and counseling services. PWDs infected with HIV should be able to access treatment and medicines for both opportunistic infections and HIV. People with disabilities should also have access to Counseling which involves building trust and creating relationship with someone. In relation to Disability and HIV/AIDS, counseling might be helpful for people who have suffered sudden impairment to deal with disability. Counseling could also help disabled people at different stages of their disability.

Rehabilitation

DPOs should through rehabilitation programmes involve a full range of measures to try and treat impairments and restore functions as much as possible. He said medical rehabilitation includes: physiotherapy, psychosocial support, occupational therapy, communication or speech therapy and may take place in hospital or a rehabilitation centre, in community or home. He told participants that HIV/AIDS component can be fused into the psychosocial element of rehabilitation and that psychosocial rehabilitation could help infected and affected individuals and their families to plan for the future.

Legal

DPOs to start providing legal information to disabled people who are vulnerable to sexual abuse as chances of a perpetrator being brought to book are slimmer than the one abused person was without disability. People with disabilities are usually not aware of their rights and violations,

and when they were, they might not have the capacity to fight for their rights. Attention should be drawn to the lack of legal and social frameworks in society protecting the disabled and creating an environment conducive for protecting a disabled person within the context of HIV/AIDS and reproductive health.

HOW SHOULD A LEADER RESPOND TO HIV/AIDS

CASE STUDY – XY ORGANIZATION

Imagine that, XY is a DPO organization and that it was formed in 2005. Since its inception, it has seen itself recruiting leaders almost after every six (6) months due to deaths caused by HIV/AIDS. Members are also dying everyday. The organization is loosing a lot of finances through giving medical benefits, funeral grants to those infected or affected and buys coffins for everyone dies.

QUESTIONS

What do you think will happen to this organization as time goes by?

What do you think is a problem with this organization?

In groups, come up with ways in which leaders in your organization can respond to HIV/AIDS for their members in terms of:

- ✓ PREVENTION
- ✓ MITIGATION
- ✓ SUPPORT
- ✓ CARE
- ✓ TREATMENT