National Response to Disability and HIV in Eastern & Southern Africa

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Introduction

The World Health Organisation (WHO) reports that there are about 650 million people with disabilities throughout the world, and that the number is increasing due to various factors including the rise in chronic diseases. Data shows that 80% of people with disabilities live in low-income countries, are poor and have limited or no access to basic services, including education and rehabilitation[1].

The United Nations Programme on HIV/AIDS (UNAIDS) recognises that vulnerable populations with limited access to their basic human rights are often at increased risk of exposure to HIV. The limited evidence available suggests that people with physical, intellectual, mental or sensory disabilities are as likely, if not more likely, to be at risk of HIV infection [1-5]. Additionally, there is a growing understanding that people living with HIV or AIDS (PLHIV) are also at risk of becoming disabled on a permanent or episodic basis as a result of their illness [6, 7].

Definition

The United Nations *Convention on the Rights of Persons with Disabilities*, 2009 says "disability results from the intersection between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others".

HIV and AIDS serves to exacerbate existing difficulties facing people with disabilities by, for example, increasing health, welfare and psycho-social needs, providing added fuel for stigma and discrimination and further limiting economic opportunities.

In addition, many Eastern and Southern African countries have signed international conventions around human rights, such as the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and are bound to provide services for people with disabilities, including HIV prevention, treatment, care and support.

Example

Services may be limited in various ways; for example, HIV and AIDS information may be inaccessible to people with visual impairments, health care services may be physically inaccessible to people with physical disabilities and people with disabilities may be marginalised due to the prejudices of inadequately trained health care providers.

Despite the significant intersection between HIV and disability, people with disabilities have been largely ignored within national responses to HIV and AIDS, and existing HIV prevention, treatment, care and support programmes generally fail to meet their specific needs. This increases the vulnerability of people with disabilities to HIV and AIDS, and increases the impact of HIV and AIDS on their lives.

Disability in National Strategic Plans

Recent research [8] shows that less than half of the NSPs in Eastern and Southern Africa recognise disability as an issue of concern, or

[1] http://www.who.int/nmh/a5817/en/, Accessed: 5 November 2009.

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recognise the vulnerability of people with disabilities, in their national response to HIV and AIDS. In Eastern and Southern African countries where disability is recognised as an issue, the most common response to an NSP is to provide for specialised prevention interventions for people with disabilities.

Significance of NSPs

NSPs set out a country's national response to HIV and AIDS, protecting those vulnerable to HIV and AIDS as well as providing for those affected by HIV and AIDS. NSPs are critical as they guide the national response and, furthermore, guide the allocation of funding, resources and human capacity for the various strategies outlined in the national response.

In most cases there is limited recognition of the need to include people with disabilities in multi-sectoral structures to manage the national response (see table 1) and consequently people with disabilities are seldom represented as a group within the national response to HIV and AIDS.

Similarly, only a few National Strategic Plans specifically mention the need to protect the rights of people with disabilities in the context of HIV and AIDS, and provide for accessible and appropriate HIV-related treatment, care and support. None of the Plans provides for PLHIV who become impaired or disabled through HIV and only two countries include disability within the national monitoring and evaluation frameworks for HIV and AIDS.

Furthermore, even where NSPs commit to targeted health care for people with disabilities, there is generally limited guidance on how health care services should be tailored to meet the specific needs of people with disabilities. The failure to increase understanding of and provide for the needs of people with disabilities in the context of HIV and AIDS results in their increasing marginalisation from current responses and compromises their human rights.

Table 1: Emerging responses within NSPs in Eastern and Southern Africa

	NSP fails to recognise disability as an issue in any way
	NSPs do not specifically indentify disability as an issue but nevertheless include some reference to disability within the response
	NSP identifies disability as an issue but fails to operationalise this concern
	NSP identifies disability as an issue and takes selective steps to operationalise this concern
	NSP identifies disability as an issue and takes extensive steps to operationalise the issue

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Recommendations

In general there are three major areas of focus to ensure the comprehensive integration of disability within a country's response to HIV and AIDS

- People with disabilities should be included at all levels within the national structures and framework responding to HIV and AIDS, including the levels of design, implementation, monitoring and evaluation
- The rights and specific needs of people with disabilities should be integrated within the national response to HIV and AIDS, to ensure that they are protected and provided for as a vulnerable group
- Monitoring and evaluation on disability, HIV and AIDS should be integrated in order to inform evidence-based national responses to HIV and AIDS.

Recommendations for Governments

States should consider the following measures in order to integrate disability within their national responses to HIV and AIDS:

- Include representatives of people with disabilities within their multi-sectoral frameworks to respond to HIV and AIDS, so that people with disabilities are able to interact on HIV and AIDS at national, provincial and district levels
- Consider the establishment of a disability task team consisting of people with disabilities as well as professionals, with or without disabilities, working in the field, to inform the integration of disability within the NSP as well as the development of a specific disability sector plan
- Ensure that NSPs identify and prioritise the rights and needs of vulnerable groups perceived to be at higher risk of becoming infected with HIV, or particularly vulnerable to the impact of HIV and AIDS on their lives. People with disabilities should be specifically recognised as a vulnerable group
- Integrate disability throughout an NSP with the inclusion of strategic objectives in all focus areas, as well as indicators to monitor and evaluate the impact of HIV and AIDS on people with disabilities and the national response to HIV and AIDS and
- Provide detailed guidance on how services should be tailored to meet the needs of people with disabilities within an NSP.

Advocacy opportunities for civil society

Many of the NSPs analysed are currently due for replacement. Advocacy opportunities will arise as countries prepare for the review and development of new NSPs, since almost all countries use a participatory and consultative process in the development of their NSPs. It is imperative that disabled people's organisations as well as disability service organisations advocate for their inclusion in strategic planning processes, ensure their representation on national decision-making forums and integrate the needs of people with disabilities and their service providers within all focus areas of the national response to HIV and AIDS. In order to ensure the full integration of disability, advocacy should include detailed guidance on the limits of existing health care services and recommendations for adaptation of services to meet the needs of people with disabilities. In relation to this, the disability movement could:

- Advocate for a rights-based approach, urging governments to ratify and comply with the UNCRPD
- Advocate for people with disabilities to become a recognised sector within the national framework to respond to HIV and AIDS
- Advocate for the establishment of a disability task group which focuses on the development of a disability sector plan
- Unify with the HIV-movement to raise awareness for the interrelations of HIV and disability.

Way forward for implementers

Many countries have signed the UN Convention on the Rights of Persons with Disabilities and are therefore obliged to ensure that services, such as education, health care and the judicial system, are inclusive of people with disabilities. Service providers need to ensure that they implement the provisions within an NSP and make services accessible for all sectors of the population. Research has shown that services are not accessible, and providers need to make

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necessary adaptations. In resource poor settings this may be challenging. Using suggestions from the World Survey on HIV/AIDS and Disability [1] the following adaptations could be seen as a way forward:

- Adaptations that require no extra resources:
  These adaptations focus on including people with disabilities within existing programmes. Service providers can develop working relationships with disabled people's service providers and NGOs and share resources, skills and best practices. Practically, service providers can improve the accessibility of facilities and install crucial services on the ground floor of buildings. Training of VCT counsellors can include sensitisation around disability issues, address misconceptions about people with disabilities and raise awareness for additional needs.

- Adaptations that require few resources:
  These refer to minor to moderate adaptations within already existing services. Recommended adaptations focus on structural changes to facilities, such as building ramps or providing mobile VCT clinics in tents as opposed to caravans. Similarly, these types of interventions make HIV-prevention material accessible for people with sensory disabilities through providing material in Braille, broadcasting HIV messages on TV with sign interpreters, and through including schools for children with special needs and insitutions for people with mental health problems in awareness campaigns.

- Adaptations that need substantial resources and long term planning:
  These are interventions for individuals that otherwise wouldn't be reached. Recommendations include the development of disability specific material such as sex and HIV education material for children with intellectual disabilities, training of sign interpreters for health services and the judicial system, and providing special psychological assistance and assessment in abuse cases. It also includes the extension of rehabilitative services through health centres or Community Based Rehabilitation (CBR) to make rehabilitative services available to the increasing number of PLHIV that experience disablement. Material of Good Practise can be found in the HEARD Good Practise Collection to be viewed at:

  www.heard.org.za/african-leadership/disability

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