

# HIV and Disability Research and Advocacy Planning Meeting March 15-16, 2010

## Co-organized by:

Disability HIV & AIDS Trust (DHAT), Zambia  
Frontline Development Trust (*Frontline*), Zambia  
Health Economics and HIV/AIDS Research Division (HEARD), South Africa  
International Centre for Disability and Rehabilitation (ICDR), Canada

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This meeting was supported by a grant from the Ontario HIV Treatment Network (OHTN), and by the Health Economics and HIV/AIDS Research Division (HEARD), as well as in kind contributions from Disability HIV & AIDS Trust (DHAT) and Frontline Development Trust.

## Meeting Overview

This two-day gathering was co-hosted by The Quartet, a four-part collaboration between Disability HIV & AIDS Trust (DHAT), Zambia; Frontline Development Trust, Zambia; Health Economics and HIV/AIDS Research Division (HEARD), South Africa; and, International Centre for Disability and Rehabilitation (ICDR) at the University of Toronto, Canada.

The Quartet brought together experts from the advocacy and research communities to identify pressing issues in HIV and disability in Zambia and opportunities for addressing these priorities through advocacy and research (see Appendix A). Together, we developed a platform of advocacy and research activities that we believe will advance the HIV and disability movement in Zambia and, in some cases, the Southern African region.



Photo 1. Susan Mshoka and Samson Mwale communicating in sign language.

## **Meeting Outcomes**

Seven priority areas were identified along with corresponding directions for advocacy and research (see below). The meeting concluded with identification of the following three actions:

### **ACTION 1: Advancing the Advocacy Directions:**

- Mr. John Miyato, President of Zambia Federation of Disability Organisations (ZAFOD), will seek approval from ZAFOD to take a leadership role in convening a 90-minute meeting of the relevant workshop participants to review these proceedings and plan for how to move forward on the advocacy directions. Participants will self-fund their involvement in this first meeting.

### **ACTION 2: Advancing the Research Directions:**

- Dr. Stephanie Nixon, Academic Director of the International Centre for Disability and Rehabilitation, will take responsibility for engaging the relevant workshop participants in planning for how to move forward on the research directions.



Photo 2. Samson Mwale, John Miyato and Susan Mshoka

### **ACTION 3: Advancing the HIV and disability movement in Zambia:**

- All meeting participants pledged to review these proceedings to identify actions that fall within their mandate and means, and to share these directions for advocacy and research with other contacts who may be able to advance these agendas.

## **Priority Issues and HIV and Disability**

### **1. Insufficient data and statistics on people with disabilities (PWDs) and HIV**

#### **The issue:**

There is a lack of data and statistics on the prevalence of disability in general, and on HIV prevalence rates among people with disabilities in particular. This information is imperative for (a) justifying the need for investment in interventions by government and other stakeholders, and (b) better planning for interventions. Various groups can contribute to the effort of developing the statistics and data. For example, Jill Hanass-Hancock reports that the HSRC in South Africa has worked on disability indicators for a prevalence study and that the DHS in SA may contain

disability questions to facilitate surveys. Furthermore, the Zambia Agency for Persons with Disabilities (ZAPD) has expressed interest in promoting this kind of research in Zambia, possibly in collaboration with the Demographic Health Survey (DHS) by the Zambian Central Statistical Office (CSO).



Photo 3. Dixon Phiri and Phillimon Simwaba

#### **Advocacy directions:**

- Advocate for the Central Statistics Office to acquire information on people with disabilities as follows:
  - o number of PWDs, disaggregated according to different disabilities
  - o how many PWDs (disaggregated) are living with HIV
  - o geographical distribution
  - o where PWDs are seeking care (HIV service utilization)
  - o proportion that are literate (education indicators)
  - o socio-economic status and other demographics

#### **Research directions:**

- Explore how disability is currently being measured in demographic health surveys (DHS) and other prevalence studies, and identify lessons for mainstreaming disability questions into existing demographic surveys.
- Promote inclusion of PWDs in HIV clinical trials

## **2. Inaccessible HIV services for people with disabilities, with special concern for confidentiality during provision of HIV services**

#### **The Issue:**

HIV services, including communication campaigns, are deemed to be largely inaccessible for people with disabilities. For example, physical obstacles for people with mobility impairments trying to seek care in buildings; lack of Braille versions of education materials for people who are blind or visually impaired; to lack of targeted education strategies for people with intellectual

impairments. A particular concern has been raised by people who are deaf, hard of hearing or hearing impaired regarding lack of confidentiality when a third person needs to be involved for interpretation during sensitive HIV services such as VCT.



Photo 4. Phillimon Simwaba and Stephanie Nixon

### **Advocacy directions:**

- Strongly advocate for inclusion of disability issues in the 2011-2015 National Strategic Framework currently being developed
- Develop a checklist of baseline expectations for accessibility of HIV services (physically, communication, etc).
- ZAFOD/Disabled Peoples Organisations (DPOs) and other organizations to systematically assess the accessibility of HIV services using the checklist. First support programmes to become more accessible. For programmes that do not comply, use stronger measures, including drawing on obligations in law.
- Clarify the existing commitments already in Zambian law requiring accessible services (is this already written into law?).
- The disability organizations should hold sensitization workshops on disability law, human rights and the UN Convention.
- Hold workshops on HIV services for PWDs to increase awareness of their right to demand accessible HIV services (also drawing on the UN Convention).
- Translate the disability act and other instruments (e.g. UN Convention) into local languages and disseminate to PWDs and others.
- Encourage HIV services providers to learn sign language.
- Advocate for every HIV centre to have at least one person who can use sign language, and for condoms manufacturers to include the expiry date in Braille.

### **Research directions:**

- Promote evaluation of programmes offering accessible HIV services to PWDs to develop a body of research on best practices
- Explore preferences and health seeking behaviours of PWDs regarding HIV services (e.g., private, public, traditional providers)

## **3. Need for attention on disability experienced by people living with HIV**

### **The Issue:**

Now that HIV anti-retroviral treatment (ART) is being scaled up in Zambia and the rest of Southern Africa, we can expect to see similar changes as was seen in the West upon the advent of HIV treatment in the late 1990's. That is, people will begin to live longer lives but may experience a range of new impairments, activity limitations and participation restrictions (see WHO International Classification on Functioning, Disability and Health [ICF], 2001) as a result of HIV, its secondary effects and side effects from treatment. Using a disability lens to examine the experience of living with HIV in this new era of ART can offer ways of thinking about policy and programme responses that do not come to light with a medical model. We also note that this reasoning applies to both able-bodied people and



Photo 5. Psalms Ndewe, Agnes Michelo Banda and Cathy Cameron

people with disabilities who become HIV-positive.

**Research directions:**

- Promote the need for a study that investigates the prevalence of disabilities (e.g., impairments, activity limitations, participation restrictions) being experienced by people living with HIV in Zambia/Southern Africa? Considerations:
  - o Ensure a control group since the prevalence of disability is high in the general population
  - o Consider links with on ART or not, adherence to ART, stress levels and well-being measures
- Consider advancing a qualitative study that explores the experience of living with HIV in this era of ART using a disability lens. Considerations:
  - o Consider comparing across countries, e.g., Zambia versus South Africa because of differences in provision of disability grants and other factors
  - o Consider role of food security and nutrition
  - o Also explore how the concept of “episodic disability” (identified by people living with HIV in Canada) plays out for people living with HIV in SSA.
  - o Consider how meanings are attached to impairments and disabilities in different cultural settings
  - o Explore other hidden costs related to treatment, e.g., liver function tests, transport costs
  - o For sampling, may wish to collaborate with a clinic and focus on their population
- Investigate the health seeking behaviours of people living with HIV for managing their disabilities, and different models of care for delivering services
- Investigate the role of nutrition in preventing/managing disabilities in people living with HIV who are on treatment, with particular attention to the prevailing context of poverty (and contrast with ART and nutrition research in rich countries)
- We also note that Anitha Menon is currently investigating neurocognitive changes among people living with HIV in Zambia



Photo 6. Ignatius Kayawe with sign language interpretation from Samson Mwale

#### 4. Poverty and vulnerability as the context for disability and HIV

**The Issue:**

We noted that all of the issues we discussed related to the needs of people with disabilities and people living with or vulnerable to HIV must be understood in the context of poverty.

**Research directions:**

- Advocate to researchers already doing HIV/poverty/vulnerability research to also consider

- disability in their studies, e.g., in the context of food security research
- Consider exploring how households manage disability in the context of poverty and HIV

## 5. Limited participation of people with disabilities in HIV planning and service delivery

### The Issue:

The disability movement is grounded in the philosophy of “nothing about us without us”. However, to date there has been little involvement of PWDs in planning for HIV strategies or delivery of HIV services. The HIV community has a parallel philosophy called “GIPA”, which stand for the greater involvement of people living with HIV and AIDS, which suggests that their will be an openness to including PWDs in HIV efforts as the need is made clear.

### Advocacy directions:

- Encourage HIV planners and service providers to recognize the talents and potential contribution of PWDs to the HIV effort.
- Advocate for the involvement of PWDs at centralized and decentralized levels of committees on HIV/AIDS, especially National Strategic Frameworks
- Develop a checklist of “prerequisites for an accessible meetings and initiatives”
- Use this checklist to educate the HIV community and others on how to host a meeting or an initiative that is accessible for PWDs
- Advocate for including a budget line for ‘accessibility costs’ in HIV meeting/initiative budgets to enable participation of PWDs



Photo 7. Margaret Maimbolwa and McKenzie Mbewe

## 6. Sexual abuse experienced by people with disabilities

### The issue:

It is well documented that rates of sexual abuse among PWDs, especially women and girls, far exceeds the general population. Yet services for prevention or care are under-developed, and the judicial system is vastly inaccessible for PWDs.

### Advocacy directions:

- Advocate for awareness and sensitization to the unacceptably high rates of sexual abuse among PWDs and the resulting links to HIV infection.

- Link with and build capacity of sexual abuse organizations to better address the needs of PWDs.
- DPOs to build on the capacity of the psychosocial care providers and institutions regarding needs of PWDs
- Advocate for accessibility to courts by PWDs, noting that the judiciary system is viewed as highly unfriendly to PWDs

**Research directions:**

- Explore opportunities for research on sexual abuse among PWDs.  
 Considerations:
  - a. A potential funder is UNICEF, which is interested in research on sexual abuse involving children, youth and mothers
  - b. Consider partnering with a group already working in care for people who are sexually abused
  - c. Research may focus on myths and attitudes regarding PWDs and HIV, lack of sexual education among PWDs regarding their rights, operations research accessible services in the judicial system

**7. The double stigma of HIV and disability**



Photo 8. Jill Hanass-Hancock and Ginny Bond

**The Issue:**

PWDs describe the double stigma experienced when becoming HIV-positive. Stigma research has considered epilepsy, mental health, TB and HIV, but there has been little specific work done on disability and HIV, particularly in a Zambian context.

**Advocacy directions:**

- Partner with Susan Clay of the Alliance Zamia (formerly AIDS Alliance) to develop a module on disability for their anti-stigma training tool kit.

**Research directions:**

- Explore tools and indicators to measure the impact of HIV on PWDs, noting that there are indicators for HIV and mental health but disability is unclear.

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## **Appendix. Participants:**

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Photo 9. Back row: Stephanie Nixon, Samson Mwale, Phillimon Simwaba, Susan Mshoka, Jill Hanass-Hancock, Ignatius Kayawe, Cathy Cameron, Dixson Phiri. Front row: Psalms Ndewe, Abigail Speller, McKenzie Mbewe, Agnes Michelo Banda, John Miyato, James Kapembwa. (Absent: Ginny Bond, Margaret Maimbolwa, Anitha Menon)