Understanding and Addressing HIV and Disability-Related Stigma

Great East Hotel
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Convened collaboratively by:

Virginia Bond, ZAMBART, Zambia
Chipo Chiiya, Mutale Chonta and Sue Clay, 3C Regional Consultants, Zambia
Jill Hanass-Hancock, Health Economics and HIV/AIDS Research Division (HEARD), South Africa
Stephanie Nixon, International Centre for Disability and Rehabilitation, University of Toronto, Canada
Phillimon Simwaba, Disability HIV and AIDS Trust (DHAT), Zimbabwe
Patty Solomon, McMaster University, Canada

Why a meeting on HIV and disability-related stigma?

The Sepo Study (2009-2011) explored the experiences of persons with a disability who live with HIV.[1] A key finding from this study was the extraordinary level of stigma and discrimination experienced by persons with disabilities who are HIV+.[2] This meeting was convened to further explore and begin to address stigma and discrimination experienced by persons with disabilities who are living with HIV.

Who participated in this 3-day meeting?

Days 1 and 2 brought together 22 people including women, men and youth with disabilities, people living with HIV, persons with disabilities who live with HIV, and activist-oriented researchers, health care providers and community workers to address these issues. Days 1 and 2 involved participatory workshop activities designed to explore and share the experiences and expertise of members of affected communities.

Day 3 involved these same participants plus additional stakeholders from government, donor agencies, and other organizations mandated to address HIV and/or disability issues including the Zambian Human Rights Commission, Zambian National AIDS Council, UNICEF, DfID, CIDRZ, Zambia-led Prevention Initiative and Steven Lewis Foundation. The focus of Day 3 was to share lessons learned during Days 1 and 2 and to explore the way forward together.

Please see the Appendix for a list of participants.

Workshop participants unpacking causes and effects of stigma.

What were the meeting highlights?

'A ground-breaking workshop': This comment from a participant reflected that this was a landmark meeting and a first for Zambia.

High level of active participation: The active participation of such a wide range of disability and HIV organizations meant significant and meaningful cross-learning for all involved – an example of *inclusion* in action.

Rich content based on the expertise of affected communities: This meeting privileged the voices of women and men who have disabilities and/or live with HIV, resulting in a rich tapestry of stories to inform future stigma reduction tools.

Connecting affected communities with decision-makers: The energetic participation of stakeholders from government, research and funding worlds on Day 3 added to the impact of the meeting by increasing awareness and tapping new expertise to identify recommendations for action.

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[1] We take our definition of "disability" from the Convention on the Rights of Persons With Disabilities as follows: "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." http://www.un.org/disabilities/convention/conventionfull.shtml

[2] For more information about the Sepo Study, please contact Stephanie Nixon at stephanie.nixon@utoronto.ca.

Where is HIV and disability-related stigma?

Stigma can and does happen anywhere. In particular, participants noted experiences of HIV and disability-related stigma taking place in the contexts of their families, communities, health clinics, workplaces, school, with the police or judicial system, and in places of worship.

Workshop participants exchanging insights.

Case Study: HIV and disability in the family

"Mabvuto" is a woman who cannot walk. She reveals to her older sister that she is HIV+, but that her husband is HIV-. Instead of providing love and support, Mabvuto's sister's first concern is assigning blame. She scolds Mabvuto for having left the home to marry, saying, "This is something a woman with a disability should never do!" Meanwhile, Mabvuto's husband has disclosed to his brother that Mabvuto is HIV+. Instead of responding with support, the brother reacts with outrage, saying, "We told you never to marry a disabled woman. She is nothing more than a burden! And now with HIV, she is a double burden for our family!" Despite the discrimination from both sides of their family, Mabvuto and her husband band together, seeking treatment of Mabvuto and couples' counselling about how to prevent HIV transmission to Mabvuto's husband. Two years later, Mabvuto has put on weight and is doing well. Her children are flourishing in a happy household. They have taught an important lesson to the in-laws about care and support.

Box 1. Workshop participants were asked:

If you were made President of Zambia tomorrow, what would be the first thing you would do to change stigma around disability and HIV?

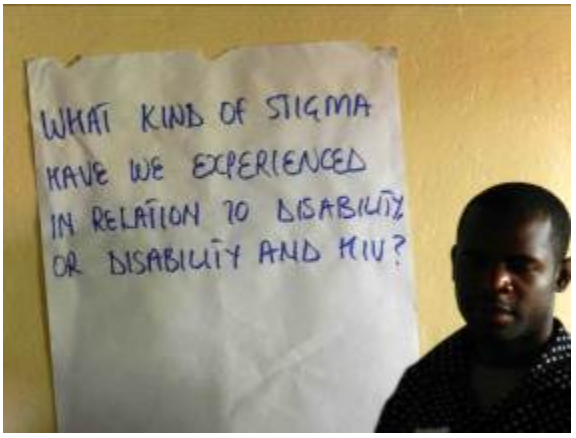
- I would enforce the laws to protect people with disabilities and HIV that already exist but have not been enacted.
- I would ensure there is more sensitisation in the communities and a more favourable transport system to assist persons with disabilities to get to HIV care.
- I would make sure the rights of persons with disabilities and HIV are respected.
- I would help communities to identify champions of change.
- I would ensure that children with disabilities who live in rural areas are taken care of as well as children with disabilities in cities.
- I would help families to understand and welcome persons with disabilities.
- I would bring sign language interpreters into all the institutions.
- I would make sure Zambia's National AIDS Council follows through on its commitments to include persons with disabilities in all HIV activities.
- I would speak to the public both in spoken and sign language.
- I would create social sectors where persons with disabilities are included in all activities (e.g., culture and sport).
- I would make integration of youth with disabilities a must for all schools.

Facilitator, Sue Clay, and sign language interpreter, Samson Mwale.

What kind of HIV and disability-related stigma have workshop participants experienced?

Discrimination by exclusion	• Barring persons with disabilities from participating in HIV prevention activities and/or sexual education • Persons with disabilities being hidden by families
Stigma linked to sexuality	• Greatly increased risk of sexual abuse and violence experienced by women and girls with disabilities • Persons with disabilities assumed to be asexual then treated with discrimination when seeking HIV testing (ie. "Why would you need an HIV test?")
Barriers to access	• HIV treatment facilities without ramps for people in wheelchairs • HIV information materials not available in Braille • No sign language interpreters
Exploitation due to vulnerability	• Illegal practice of "sexual cleansing" with girls with disabilities to "cure" HIV
Betrayal of confidentiality	• Health care workers not keeping information about HIV testing private
Using language to harm	• Cruel name-calling while in the ART queue • Calling someone *ifanfae avendo* (a moving coffin)

Sexuality, disability and stigma:
Because of the links between sexuality and HIV, disability and sexuality was a key issue explored with participants. Participants were thoughtful and candid, sharing a wide range of personal experiences of stigma from intimate relationships and having children, to sexual abuse because of disability. On a more positive note, there was much support for the idea that persons with disabilities have better sex than able-bodied people.



Teacher, Charles Mapulanga, who is visually-impaired, describes creative strategies for combatting stigma.

Box 2. What challenges related to *sexuality* are faced by persons with disabilities?

- Misconceptions and myths: asexual, hypersexual, sex with a virgin will cure HIV
- Stigmatizing expectations: not being sexually active
- Exclusion from sex education: at school, in preparation for marriage
- Sexual exploitation
- Need for creativity because of impairments: e.g., how to put on condom with only one arm
- Lack of confidence to approach others
- Lack of self-esteem to report abuse
- Overprotection of children with disabilities by parents: lack of socialization

Case Study: HIV and disability in the health clinic
Ngebe is a blind woman who is pregnant. She has not had an HIV test but has heard that there is treatment to prevent HIV from passing to her infant. She is afraid, but decides to go to the clinic for advice. While she waits in the queue, others make fun of her because they think she must be lost. They wonder why a blind woman would need HIV or pregnancy care. Ngebe endures this discrimination. But when she finally sees a health worker he acts the same way. He tells her, "Don't waste our time! There are many people who have a real reason for being here!" Ngebe is so discouraged that she never returns for HIV or pregnancy care again.

Top 10 Priority Actions to Address HIV and Disability-related Stigma in Zambia

1. Train HIV health workers to reduce anti-disability stigma:

- Much of the stigma reported in both the Sepo Study and the 3-day workshop took place in health facilities. Reducing stigmatizing attitudes among health staff through training could have an immediate impact. See Boxes 3 and 4 for easy starting points.

2. Enhance the capacity of DPOs to address HIV and disability stigma:

- Disabled People's Organizations (DPOs) called for cooperation and mutual support in mounting anti-stigma efforts and avoiding the potential divisions that can arise from competition for limited funds. Building the capacity of DPOs is crucial for managing programming and funding. DPOs should also develop and review HIV policies within their organizations.

3. Identify "quick wins" for donors to address HIV and disability stigma:

- Stakeholders at the workshop expressed willingness to help support interventions, but called for easy entry points for starting work in this area. Examples may include supporting anti-stigma workshops based on successful HIV models (see #4 below), supporting HIV health services to become more accessible (see Boxes 3 and 4), or developing and reviewing disability policies at their own organizations.

4. Adapt and expand existing HIV stigma tools for disability:

- Several tools from the Toolkit "Understanding and Challenging HIV Stigma: Toolkit for Action" were piloted during the workshop with great success. Rather than starting from scratch, efforts should build on existing tools. A key component will involve training people with disabilities and allies in the disability community to become training facilitators and to champion these activities.

Box 3. What kind of messages should HIV prevention programmes promote for persons with disabilities?

Use a "twin track" approach. This means making sure *all* information and services are accessible to persons with disabilities ("mainstreaming"), and at the same time recognizing when persons with disabilities have specific needs that also need to be met ("targeting"). Here is an example of what a "twin track" approach could mean in HIV prevention:

Mainstreaming: <u>All the same</u> HIV education that able-bodied people receive should also be delivered to persons with disabilities in ways that they can access – e.g., in Braille, large print or pictures for those with vision impairments.

and

Targeting: In addition to these common messages, there are <u>special issues</u> that need to be emphasized when working with persons with disabilities:

- Addressing myths about sexuality, such as "sexual cleansing" and the added risk of exploitation faced by women and girls with disabilities
- Emphasizing that persons with disabilities have the right to make their own sexual decisions
- Supporting persons with disabilities in reporting abuse

5. Implement existing policies and laws that protect the rights of people with disabilities and HIV:

- Zambia has ratified the Convention on the Rights of Person with Disabilities (CRPD) and has HIV built into the National HIV Strategic Plan. Advocacy for inclusion of disability within these policies has been successful. Now it is time to make the ideas in these policies a reality.

6. Develop expertise within the media:

- Educate and sensitize key people in media regarding issues of HIV and disability. This includes developing media literacy on the further intersections of HIV and disability with other crucial issues like gender.

7. Cultivate compelling champions:

- Given the success of champions in reducing HIV stigma, we should identify local, national and international women and men who are champions to tackle HIV and disability-related stigma.

8. Ensure that Zambia's National HIV/AIDS Council (NAC) addresses issues on disability and inclusion within the NSP:

- Zambia's disability and HIV communities need to develop a mechanism for holding accountable the NAC to ensure that the disability dimensions of the NSP are applied in practice.

9. Provide sensitization and support for families that include children, women or men with disabilities:

- Parents should be taught about the destructive effects of stigma and how to counteract them in the household and community. Mabvuto's case study illustrates stigma within families and the need for sensitization at the household and community levels.

10. Use HIV prevention for persons with disabilities as an opportunity to learn about a "twin track" approach:

- A "twin track" approach calls for making all services and information that are available for able-bodied people also accessible for people with disabilities (because it is their right), plus identifying unique issues that need special targeting. This approach has proven successful in addressing other disability-related issues and can easily be applied to HIV (see Box 3).

Box 4. How can HIV health services provide better quality care to persons with disabilities?

- Hire staff who have a disability: *inclusion* is the first step to addressing disability-related stigma.
- Remember a person with a disability has a *right* to access HIV testing, and treatment.
- Remember she/he is a human being like anyone else, e.g. sexual being, reproductive being
- Do not stigmatize because she/he has a disability.
- Have someone on staff who knows sign language.
- Have materials in Braille, large print and pictures.
- Make sure your building, treatment room and toilets are accessible for people in wheelchairs.
- Have height adjustable beds for persons with physical disabilities, especially for ante-natal care.
- Remember confidentiality is crucial, just like for anyone else.
- Provide anti-stigma training on HIV and disability for staff.
- Have referral systems in place for disability and rehabilitation services.

Appendix.

Participants for Day 1&2 - 19&20 March 2012

Name	Organization
Danny Apuleni	Saint Mulumba School, Zambia
Justine Bbakali	Zambia Federation of Disability Organizations (ZAFOD)
Ginny Bond	Zambia AIDS Related TB Project (ZAMBART)
Cathy Cameron	International Centre for Disability and Rehabilitation (ICDR), University of Toronto, Canada
Chipo Chiiya	3C Regional Consultants, Zambia
Mutale Martin Chonta	3C Regional Consultants, Zambia
Moses Chubili	Zambia National Association of the Deaf
Sue Clay	3C Regional Consultants, Zambia
Shaun Cleaver	International Centre for Disability and Rehabilitation (ICDR), University of Toronto, Canada
Jill Hanass-Hancock	Health Economics and HIV and AIDS Research Division (HEARD), South Africa
Chola Kaoma	Association of Sign Language Interpreters of Zambia (ASLIZ)
Bridget Kakuwa Kasongamulilo	Zambia-led Prevention Initiative (ZPI)
Mary Wendy Kateka	Zambia Disability HIV/AIDS Human Rights Programme
Precedece Gertrude Kapulisa	Community Based Intervention Association (CBIA), Zambia
Margaret Maimbolwa	University of Zambia, School of Medicine
Charles Mapulanga	Saint Mulumba School, Zambia
Susan Mshoka	Equippers Disabled Association, Petauke, Zambia
Brian Musonda	Zambia National Federation of the Blind (ZAMFOB)
Samson Mwale	Zambia National Association of Sign Language Interpreters (ZNASLI)
Charity Ndhlovu	Treatment Advocacy and Literacy Campaign (TALC), Zambia
Stephanie Nixon	International Centre for Disability and Rehabilitation (ICDR), University of Toronto, Canada
Scott Robertson	Zambia-Led Prevention Initiative (ZPI)
Josephine Shinaki	Zambia National Association of Disabled Women (ZNADWO)
Phillimon Simwaba	Disability HIV and AIDS Trust (DHAT), Zimbabwe
Patty Solomon	McMaster University, Canada
Marianne Stevens	International Centre for Disability and Rehabilitation (ICDR), University of Toronto, Canada
Yvonne Zimba	Zambia National Association of the Physically Handicapped (ZNAPH)

Additional Stakeholders Joining for Day 3 - 21 March 2012

Name	Organisation
Stable Basa	Centre for Infectious Disease Research in Zambia (CIDRZ)
Chad Rathner	Zambia-led Prevention Initiative (ZPI)
Themba Mazyopa	Zambian Human Rights Commission
Landry Tsague	UNICEF
Valerie Roberts	United Kingdom Department for International Development (DfID)
Mwilu Mumbi	Zambian National AIDS Council
Idah Mukuka	Stephen Lewis Foundation

For more information about this workshop or its outcomes, please contact any of the meeting co-hosts:

Name	Organization	Phone	Email
Virginia Bond	ZAMBART, Zambia	+260 211 254710	gbond@zambart.org.zm
Chipo Chiiya, Mutale Chonta, Sue Clay	3C Regional Consultants, Zambia		regionalconsultants3c@gmail.com
Jill Hanass-Hancock	Health Economics and HIV/AIDs Research Division, South Africa	+27 031 2603125	hanassj@ukzn.ac.za
Stephanie Nixon	International Centre for Disability and Rehabilitation, Canada	+ 1 416 946 3232	stephanie.nixon@utoronto.ca
Phillimon Simwaba	Disability HIV, and AIDs Trust, Zimbabwe	+263 4778565	simwaba@dhatregional.org
Patty Solomon	McMaster University, Canada	+1 905 525 9140	solomon@mcmaster.ca

Workshop participants hard at work identifying solutions.

Acknowledgements

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