Persons with Disabilities: A Neglected Group in HIV and Sexual & Reproductive Health Programming

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Background and rationale

- Persons with disabilities represent large minority group—15-20% of world’s population
  - WHO definition: Impairments, activity limitations, participation restrictions
  - Approximately 2.5 million in Zambia
- Often overlooked in HIV risk and programs
- Link between disability and HIV
HIV/AIDS and persons with disabilities in Zambia


- African Campaign on Disability and HIV/AIDS (2008) called on governments to make HIV policies and programs inclusive

- Zambia National Strategic Plan includes references to disability but does not detail steps to operationalize concerns of persons with disabilities

- With the increased recognition to make HIV programming inclusive, it is crucial to understand disabilities and HIV programming to provide evidence for program development and establish a baseline for future program evaluation

* Provides a framework to promote equal rights to health, including HIV/sexual and reproductive health
Study objectives

• Situation analysis in Ghana, Uganda, and Zambia to:
  – Identify factors affecting access to and use of HIV and sexual reproductive health (SRH) services
  – Identify and describe existing HIV/SRH services for people with disabilities
Methodology

- **Focus group discussions** with persons with disabilities and caregivers of people with intellectual/developmental disabilities
  - Total 321 participants: 68 visually impaired; 97 hearing impaired; 108 physically disabled; 50 caregivers
  - 76 were HIV positive persons with disabilities

- **Key informant interviews** with program managers of disabled persons organization and non-governmental organizations (NGOs), government

- **Inventory of services**: HIV/SRH services specifically serving persons with disabilities*

- Conducted in 1 urban (Lusaka) and 1 rural/peri-urban (Solwezi) areas

*These may be services that specifically target disabled persons or they may be inclusive services.
# Zambia investigators and community advisory board

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<tr>
<th>Name</th>
<th>Organization</th>
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<tr>
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<td>Ms. Milika Sakala</td>
<td>Zambia Federation of Disability Organisation</td>
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KEY FINDINGS
Greater sexual vulnerability to HIV

• Participants were emphatic that PWD are sexually active, but they do not have equal access to HIV prevention information, services, condoms

• Participants felt PWD had limited opportunities for sexual relationships and may end up not practicing safe sex

  …most women turndown our proposals. So if you are lucky that a woman accepts you, you will not even hesitate having sex with her and most of the time with no protection hence putting us at higher risk.

Male, blind, HIV-positive, Zambia
Limited access to condoms

- Most do not access condoms or in some cases know how to use it correctly

Some have never seen or even felt a condom. So a person really doesn’t imagine if I had an opportunity of having sex with a person who can see, how would I protect myself, how would I guide myself?

Male, blind, Uganda

Now for me just to move over to the counter and pick the condoms was a hard job for me. I felt shy and didn’t even pick the condoms due to the fact that “what will people think of me as a disabled person getting all those condoms”.

Male, blind, Zambia
Sexual vulnerabilities of women and girls

- Perception that PWD are HIV free or that sex with PWD can cure HIV
  
  *Some hearing men think that when they rape the sick deaf woman, they can be healed or cured of HIV.*
  
  Male, deaf, Zambia

- Vulnerable to sexual abuse
  
  *Disabled people are at a higher risk because we are more vulnerable to rape as we are not strong enough to defend ourselves.*
  
  Female, physically disabled, Zambia

- Survival sex: Financial dependency & poverty increases propensity to engage in risky sex
  
  *We the blind found on the street are at risk because there on the street, we are enticed and there after give in just to have means of survival. As a result of poverty, HIV is on the increase.*
  
  Female, blind, Zambia
Facilities are not disability-friendly

- Persons with disabilities seek HIV/SRH services from mainstream health clinics and hospitals, but few facilities are disability-friendly
  - No sign interpreters
  - No materials in Braille
  - No ramps
  - No accessible toilets

The blind can’t understand the family planning methods because they don’t see unless it is brailled and yet in the hospitals they don’t have any brailled system or communication to the blind.

Female, physically disabled, Uganda
Barriers to HIV and SRH services (1)

• Transport challenges; rampant discrimination
  
  Transportation is a problem especially us the physically challenged when boarding buses some bus operators deny us from boarding their buses saying that there is no space for our crutches/wheelchairs.

  Female, blind, Zambia

• Need for escort

• Long wait times at facilities
  – Providers gave priority to those without disabilities because staff could not communicate with the person or were concerned consultation would take too much time

• Lack of confidentiality
  
  …So you’ll find that the one who escorted you gets to know all your HIV status details and yet information is supposed to be confidential.

  Male, blind, HIV-positive, Zambia
**Barriers to HIV and SRH services (2)**

- Providers lack skills and positive attitude in working with persons with disabilities

  *At the hospital, they only diagnose the deaf, give the times to take medication that’s all. In the long run the deaf get sick then eventually die because of not accessing correct information.*

  Female, deaf, Zambia
Disability-related stigma

• One of the greatest barriers to HIV/SRH services
  – Disability-related stigma: PWD seen as less than human, cursed, useless
  – Expressed even by family members and health providers
  – Internalized stigma related to disability

*Like now me am blind, I will not go to the health center, people will laugh at me... Supposing I went and told this health worker now I have come for HIV services. The health workers will ask herself how I contracted HIV yet am blind. Therefore we still have very low esteem; we are not very confident. We stay back because we fear going out there....*

  Female, blind and physically disabled, Uganda

*We are seen as people who are not important.*

  Male, deaf, Zambia
Conclusion

- Persons with disabilities are at risk for HIV
- Persons with disabilities are essentially excluded from receiving health services
- Main barriers to services relate to infrastructure, human resource capacity, and stigma

- Results underscore barriers to services beyond HIV and SRH services
- Human rights imperative to address these issues
Recommendations

- Awareness-raising campaigns to reduce stigma
- Enable access to mainstream health services (ramps, sign interpreters, Braille materials)
- Provide services through outreach, peer education, home-based care
- Provider training: Skills and sensitization

- Critical research gaps:
  - Situation analysis in other countries
  - Prevalence of HIV in disabled population
  - Prevalence of disability in the population
Next steps

• Stakeholder discussions and dissemination
  – Next steps for programs
  – Use findings for advocacy

• ICASA presentation

• Study report will soon be available at:
  www.hivcore.org
Investigators and partners

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- National Union of Disabled Persons of Uganda
- Uganda National Association of the Deaf
- Mental Health Uganda
- Ghana Federation of the Disabled
- Ghana Association of the Blind
- Ghana Society of the Physically Disabled
- Mental Health Society of Ghana
- Ghana AIDS Commission
- Zambia Federation of Disability Organisation
- Mental Health Users Network of Zambia
- Zambia Agency for Persons with Disabilities
THANK YOU
Challenges of conducting research with people with disabilities

• Recruitment was difficult, particularly HIV-positive persons; community advisory board from DPOs critical
• Mobility and transport
• Ethical challenges of including people with intellectual disabilities
• Finding appropriate venue for interviews that would accommodate PWD
• Sensitization of staff necessary