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
- Often overlooked in HIV risk and programs
- Link between disability and HIV
HIV/AIDS and persons with disabilities in Uganda

• Uganda signed and ratified the Convention on the Rights of Persons with Disabilities* (2008)

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

• Uganda National Strategic Plan recognizes disability and details specific 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 (Kampala) and 1 rural/peri-urban (Jinja) areas

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

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<tr>
<th>Name</th>
<th>Organization</th>
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<tr>
<td>Mr. Edson Ngirabakunzi</td>
<td>National Union of Disabled Persons of Uganda</td>
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<td>Mrs. Rose Acayo</td>
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<td>Mrs. Robinah Alamboi</td>
<td>Mental Health Uganda</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 with potentially risky partners

  …we do not have choice or chance to get the real partners we want.
  …Most deaf people just have sex with anyone who comes because they think that’s their only chance to get a partner, and in that process they end up being infected.

  Female, deaf, HIV-positive, Uganda
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

  We go to some of these health centres to acquire services, for example condoms to protect ourselves. The attendants are shocked and comment “Even you a lame person, you want condoms!” At the end of the day, this makes us to feel small.

  Male, physically disabled, Uganda
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
  
  *You might find a girl in a rural area who can get like only 10,000 Uganda shillings in an entire year. And when a man who can give her the money … comes her way, she will go in to have sex with that man without any hesitation or caution to have protected sex.*
  
  Male, blind, Uganda
Facilities are not disability-friendly

- PWD 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 brailed and yet in the hospitals they don’t have any brailed system or communication to the blind.*

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

- Transport challenges; rampant discrimination
  These people who work in buses and taxis; when we are traveling, they don’t care about us at all. When you are boarding off, they just push you saying that you are delaying them, so we are mistreated by the people in transport system.
  
  Female, blind, HIV-positive, Uganda

- 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
Barriers to access to HIV and SRH services (2)

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

The problem for a blind woman comes when medication are given out because one needs assistance to differentiate the tablets. For instance, these health workers are writing on 1x3, 2x4 and so on and so forth on the medicine but you really cannot read, most of these health workers do not know how to prescribe medicine for the blind mothers.

Female, blind and physically disabled, Uganda
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
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
• Presented at ICASA (7 Dec)
• Study report will soon be available at:

  www.hivcore.org
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• 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