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
  - Approximately 5 million in Ghana
  - 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 Zambia

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

- Ghana ratified the **Convention on the Rights of Persons with Disabilities** *(2012)*.

- **Ghana National HIV Strategic Plan** does not include any reference to disability.

- However, with the increased international 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 (IDD)
  - 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 and 1 rural/peri-urban areas; however, in Ghana, only in Greater Accra

*These may be services that specifically target disabled persons or they may be inclusive services.
## Ghana Investigators and Community Advisory Board

<table>
<thead>
<tr>
<th>Name</th>
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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.

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

  *The drugstore operator will sell you the condoms alright but will look down upon you, “Someone who is crawling on the floor and buying a condom, what are you going to use it for?” When it happens like that, it is very painful.*

  Male, physically disabled, HIV positive, Ghana

*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
May engage in risky sex

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

...most women turn down 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

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Male, blind, 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 violence
  Yes, a lot of the disabled today are victims of abuse by people in the community because they know if they do anything to them they cannot run or speak because of their disability.
  Female, physically disabled, Ghana

- Survival sex: Financial dependency & poverty increases propensity to engage in risky sex
  We don’t have work to do. So a man can call the woman, “I will give you money, I will give you money”, and she will have sex with him so that [he will] do whatever he pleases with her.
  Female, blind, HIV positive, Ghana
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

But the hospitals and small clinics they build, they do not provide speed ramps so that the disabled can pass. It is steps so we can’t go … The way you will suffer to climb the stairs. 

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

- **Transport challenges**
  
  At times our situation is a little sad. I am a woman and I crawl on the floor with my knees and hands and I’m pregnant. Because I cannot walk, in my village there may not be a hospital or health centre where I can get the medicine. So unless I make the effort and little by little go a long way before I can get some of the medicine. When it happens that way, when I’m going, I don’t have anyone to take me so I won’t go.

  Female, physically disabled, Ghana

- **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

Sometime, when they [health care providers] observe that you are a deaf person, they sometime want to, maybe, ignore you because they say “ah o how can I communicate with you?”. If you want to go and see doctor you will realize that they find it difficult because they will be asking themselves what shall we do to be able to communicate with this deaf man.

Male, deaf, Ghana
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

*A deaf person will go, will meet the nurse, she will ask you, “What are you looking for?” She will not even smile, like she will frown the face. So you not even feel to tell him or her your problem. And also, you go and tell them, “I want to prevent my pregnancy” and they will laugh at you.*

Female, deaf, Ghana

*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
- Participation of persons with disabilities in policy making and programming

- 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
  – Population size estimates of persons with disabilities
Next steps

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

• Presented at ICASA

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

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- 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
What can [government, donors, DPO/NGO/CSOs] do to meet the HIV/SRH needs of persons with disabilities?