



HIV AND DISABILITY

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Cover photo:

Koeut Chrel (38) from Cambodia lost his leg in a landmine explosion while serving in the army. He lost his job and was forced to start begging. He is HIV positive and receives antiretroviral (ARV) treatment from Medecins Sans Frontieres (MSF). He is now able to work, and sells books in Siem Reap town. He has three children. Two of them have tested negative for HIV, the youngest has yet to be tested.

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SUMMARY

Over one billion people – 15 percent of the world’s population - live with a disability significant enough to make a difference in their daily lives, and 80 percent of them live in the developing world.

It is often assumed that people with disabilities face lower risk of HIV than their non-disabled peers – because they are asexual, because they are less likely to use drugs or alcohol, and because they face lower risks of violence or sexual assault than others.

A growing body of research shows that these assumptions are wrong: persons with disabilities have the same rates of sexual activity and substance abuse as persons without disabilities. In fact, persons with disabilities may be more vulnerable to HIV because they are more likely to be abused, marginalized, discriminated against, illiterate, and poorer than the non-disabled population.

Yet people with disabilities have been largely ignored – and virtually invisible - in the response to HIV. They are rarely included in policy debates regarding HIV and are absent from the agenda of mainstream HIV organizations, international and domestic health organizations and government agencies. Governments and HIV organizations need to recognize the invisible problem of HIV among persons with disabilities and begin targeting this population before the epidemic spreads even further. Persons with disabilities also need to be included in the creation and development of programs meant to benefit them, honoring the principle of “Nothing about us without us.”

BARRIERS

People with disabilities face a wide range of barriers to HIV information and services that put them at risk of HIV and impede their access to treatment and care. These include:

- **Lack of access to sexual and reproductive health services, including HIV prevention, testing, treatment and counseling;**
- **Stigma and discrimination;**
- **High risk of violence and lack of legal protection; and**
- **Lack of education and information about sexual health**



“To live with a disability is to label yourself. To live with HIV is to label yourself. I just live. My wheelchair and my HIV status do not define me. It’s not a sentence to me.”

BILLY, A MAN WITH A PHYSICAL DISABILITY WHO HAS BEEN LIVING WITH HIV FOR 20 YEARS, NEW YORK

“I would have to crawl a long distance to get tested for HIV and sleep on the road on the way there, so I just live without knowing.”

CHARITY (PSEUDONYM), WOMAN WITH A PHYSICAL DISABILITY, AMURU DISTRICT, UGANDA

(above) People with physical disabilities living in remote places, like Filda, a woman in Uganda, have difficulty reaching HIV services, as well as entering them when they arrive.

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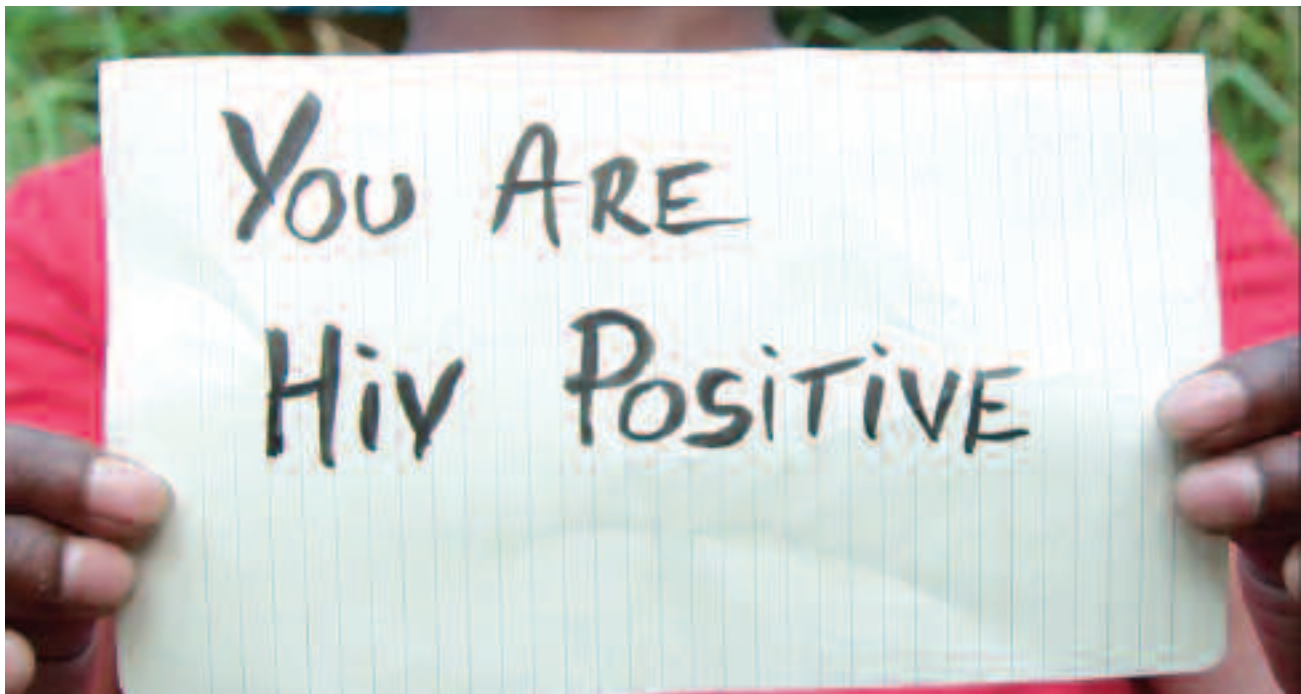


Lack of access to sexual and reproductive health services, including HIV prevention, testing, treatment and counseling

“If you have a wheelchair and you go to an AIDS service organization and the first thing you see...is a flight of stairs, you are immediately discouraged....So in the end, people don’t turn up.”

WINSTONE ZULU, HIV ADVOCATE, ZAMBIA

Persons with disabilities experience barriers to prevention, interventions and treatment for all sexual and reproductive health services, including HIV. For example, written HIV education materials are inaccessible for those with visual impairments; and the language used may be inappropriate for people with intellectual disabilities. People with physical disabilities may have difficulty reaching clinics, and once there, may not be able to enter, as they may be inaccessible, lacking ramps or elevators. Clinic staff may not be able to communicate effectively with deaf people, and their privacy may be at risk because a third party may be required to interpret. The cost of antiretroviral drugs or other related health care expenses may also be a barrier – in some cases, because families of people with disabilities may not consider them worth the investment.



John's Story

John Meletse is a deaf, gay, and HIV-positive South African man. When John went to get tested for HIV in 2001, the clinic staff could not communicate with him in sign language. The doctor took his blood, showed him a piece of paper that said, "YOU ARE HIV POSITIVE," and then asked him to leave.

John was shocked by this news. He struggled to understand what this meant for his life and how to cope with this situation. He did not receive any counseling about HIV or any information about ways to stay healthy.

At first, like many in the deaf community, John thought that HIV was a death sentence. However, he decided to turn his experience into an opportunity to educate and empower others in the deaf community to communicate openly about sex and sexuality. He has since become a leading voice of the HIV movement, advocating for people with disabilities to be included in HIV prevention efforts.



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"People look at disabled people and think, they don't have sex. But it doesn't matter if you are gay, straight or bisexual. We have sex. And we can be infected with HIV," he said.

John advocates that education, testing and counseling needs to be accessible not only for the deaf community, but for all people with disabilities. "We need to protect ourselves, because one billion people is a lot of people to forget."



This prevention poster developed by the Inter-American Institute on Disability and Inclusive Development (IIDi), reads, "AIDS does not discriminate: We all have a role in prevention".

Stigma and discrimination

"When I went to the hospital for HIV treatment, nurses and doctors thought that I didn't have the ability to speak for myself, make decisions for myself, just because I was in a wheelchair. You really have to sit down with a person with a disability and assess their cognitive and communication skills, find out what they want, direct your questions in a non-condescending manner so as not to alienate them from you."

-BILLY, A MAN WITH A PHYSICAL DISABILITY WHO HAS BEEN LIVING WITH HIV FOR 20 YEARS, NEW YORK

Stereotypes, discriminatory attitudes, and myths abound regarding persons with disabilities and their sexuality. In the case of one woman with HIV in northern Uganda, for example, community members forbade her from bathing in the communal bath for fear that she would spread her HIV.

People with disabilities living with HIV often experience double discrimination: on the basis of their disability as well as their HIV positive status. They are also often considered asexual or incapable of becoming parents. Human Rights Watch documented cases in Argentina and northern Uganda where hospital staff asked women in wheelchairs how they could even have children, and questioned the ability of a blind woman to care for her own child.

Denial of education and information about sexual health

“Everything that has to do with sex [for persons with disabilities] is taboo.”

-SILVIA VALORI, DISABILITY RIGHTS ACTIVIST, ARGENTINA

People with disabilities are often shut out of education, including on sexual health. They are considered a distraction in schools, or incapable of learning. In many parts of the world, children with disabilities do not go to school because schools are physically inaccessible. The World Bank estimates that as many as 97 percent of all individuals with disabilities - and 99 percent of women with disabilities - are illiterate. It is commonly assumed that individuals with disabilities are not sexually active, but research shows that they are as likely to be as sexually active, and engage in the same kinds of sex (including homosexual sex) as their non-disabled peers. However, they are less likely to receive information about HIV prevention and safe sex, and are less likely to have access to prevention methods such as condoms.



Gay and Lesbian Memory in Action (GALA) in South Africa produced this comic to raise awareness of HIV among deaf people.

(below) Winstone Zulu, a champion for HIV prevention and treatment for vulnerable populations.

© Liz Marshall, Stephen Lewis Foundation




Winstone's Story

Winstone Zulu spent much of his life advocating for the rights of people whose marginalization put them at risk of HIV and tuberculosis, and kept them from getting the treatment and care they deserved: people with disabilities, orphans, grandmothers, as well as people already living with HIV and/or TB. Winstone had polio as a child, and used crutches or a wheelchair to get around. He was diagnosed with HIV in 1990, and soon after became the first Zambian to publicly acknowledge his HIV status. At the age of 47, he lost his battle to HIV, but his work lives on.

Throughout his life, Winstone faced discrimination because of his physical disability, including with respect to his sex life. In an interview with Human Rights Watch

in 2011, Winstone said, "People think if your leg is not working, it's a reflection of a general weakness for the whole of you. Perhaps this is the reason why they think that everything, including everything in your pants, is disabled. So you can't have sex." Recounting his experience while speaking at an AIDS conference, Winstone told us: "One woman [in the audience] said, 'How did you get it?' And I said, 'Sexually.' She looked at me, up and down, and said, 'But how?'"

Such attitudes also affect access to education for people with disabilities. "When information is being distributed in the community," Winstone explained, "[people with disabilities] are bypassed because everyone thinks, 'Why? Why give information about family planning to people who do not have sex anyway... or who shouldn't have sex.'"

A close-up, low-key photograph of a woman with dark skin and hair, wearing a red top, holding a baby wrapped in a grey blanket. The woman is looking down at the baby with a gentle expression. The background is dark, and the lighting highlights the contours of her face and the baby's head. The baby is wearing a small red headband. The woman is also wearing a thin necklace. The overall mood is intimate and tender.

“[My second child’s father] would just come at night, have sex, and leave in the morning. He lives around here, but has deserted me. When I went for antenatal care, then I came to know that I was HIV-positive. My older daughter takes me to the hospital to get [anti-retroviral drugs].”

EDNA (PSEUDONYM), A WOMAN WHO IS BLIND AND HEARING-IMPAIRED, NORTHERN UGANDA

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The Case of Uganda

In 2010, Human Rights Watch conducted research on discrimination and violence against women with disabilities in post-conflict northern Uganda. Over one-third of women with disabilities interviewed said that they had experienced some form of sexual or physical violence. One woman with a disability told Human Rights Watch that when she suggested to her partner that they undergo HIV testing before having sex, he agreed, but then under the guise of taking her to the health center, he took her to a friend's house and raped her. He then raped her three more times.

Some women with disabilities who were raped reported that they did not undergo HIV testing afterward because of long distances to health clinics or uncooperative hospital staff. Others found it especially difficult to get HIV post-exposure prophylaxis and other emergency care, such as emergency contraception.

Human Rights Watch also found that women with disabilities in northern Uganda were repeatedly abandoned by their partners, so many of them had multiple partners and were less empowered to negotiate safe sex, heightening risk of HIV infection.

High risk of violence and lack of legal protection

Individuals with disabilities are up to three times more likely to be victims of physical abuse, sexual abuse, and rape because they may not be able to easily flee from those perpetrating violence against them who may be their family members, neighbors, or caretakers, nor call for emergency assistance. People with disabilities also face additional barriers to sexual assault services, including psychosocial counseling and medical care to prevent HIV and pregnancy. In many countries, people with disabilities have little or no access to police, legal counsel, and courts for protection, even more so than others, because of physical, communication and attitudinal barriers.

“Where you have both HIV and disability, there’s a double stigma, and a double burden. We know that there’s very far to go. However, we know how to do it, and the way to do it is by working together. We’ve all got to work together: governments in North and South, civil society and in particular, people living with disabilities and people living with HIV.”

-JAN BEAGLE, UNAIDS DEPUTY EXECUTIVE DIRECTOR,
MANAGEMENT AND EXTERNAL RELATIONS

GOOD PRACTICES ON INCLUDING PEOPLE WITH DISABILITIES IN HIV OUTREACH AND SERVICES

While there is increasing awareness that people with disabilities face heightened HIV risk as well as barriers to HIV services, few organizations address the specific needs of people with disabilities in their programs. Including people with disabilities in HIV programs does not always require human or financial resources. It does require information and education about their needs, and commitment to ensure that all persons are guaranteed equal access to health information, treatment, and care. Following are some examples of mainstream HIV organizations and disability organizations across the world that actively engage with and offer services to persons with a range of disabilities.

KENYA

“We went to the local clinic and the district hospital to get tested as a couple, but they could not communicate in sign language and used gestures we could not understand. But today, because of Liverpool VCT, we are very happy that we know our status because we have been served in a language we clearly understand.”

LUCY AKINYI, 31, AND DANIEL JUMA, 33,
A DEAF COUPLE FROM BONDO, KENYA

Responding to the need for accessible HIV information and services, **Liverpool Voluntary Counseling and Testing (Liverpool VCT)** created a program for the more than one million Kenyans living with a disability. The Liverpool VCT disability program was originally designed for the deaf community, but has expanded to include all persons with disabilities, particularly those with physical and other sensory impairments. Liverpool VCT focuses on producing HIV information in accessible formats including audio, Braille and Kenyan Sign Lan-

(below) A hearing impaired counselor from Liverpool VCT educates the deaf community in Nairobi about HIV.



guage, and training service providers to work with persons with disabilities. Liverpool VCT has provided HIV testing and counseling to more than 35,000 persons with disabilities.

Kenya Society for the Mentally Handicapped (KSMH) has developed a home-based HIV prevention and treatment outreach program for people with intellectual disabilities in the Nairobi, Maragwa, and Thika districts of Kenya. As part of this project, it is developing an accessible radio program to inform HIV-positive people with intellectual disabilities about antiretroviral therapy. In Kenya, as in many countries, people with intellectual disabilities are often hidden in their homes, and effectively barred from HIV information and services. KSMH helps overcome these barriers by bringing the information to their homes, in person and by radio. In response to the high demand for these services for people with intellectual disabilities, KSMH intends to expand their work on a national level.



(above) The Kenya Society for the Mentally Handicapped is teaching Cecilia (right), a 35-year old woman with an intellectual disability, and her sister about HIV prevention.

CANADA

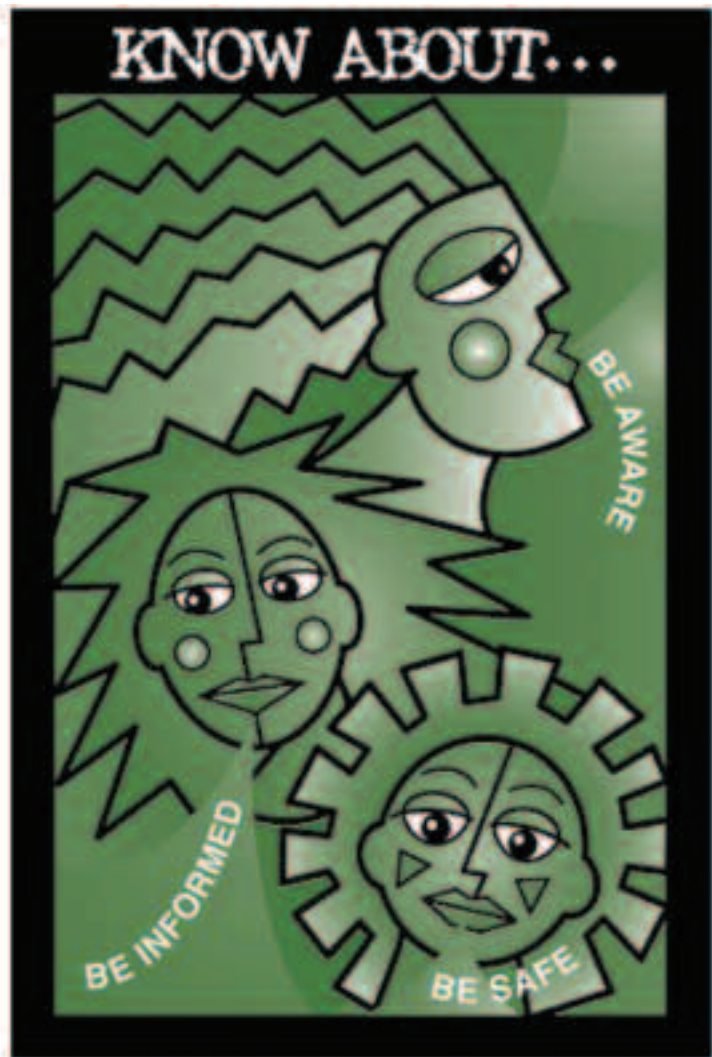
“The thread that connects all the work we’ve done at the AIDS & Disability Action Program is the basic right to accessible information and the right to speak for ourselves. Sadly stigma and judgment continue to limit our capacity for health and participation.”

SHELLEY HOURSTON,
PROGRAM DIRECTOR, ADAP

In 1988, the British Columbia Coalition of People with Disabilities launched its AIDS & Disability Action Program (ADAP), which has collected and created HIV/AIDS education materials for people with all types of disabilities. They have developed booklets on how to use a condom, sexual abuse, and HIV among older persons with disabilities, which are available in high and low literacy formats, Braille and audio tapes. These resources were developed with input from people with disabilities themselves. In 2010, ADAP began developing resources for people living with HIV and mental health issues. They now create training resources to support frontline staff and to increase resilience and wellness among people living with HIV and depression.

ZAMBIA

The **Strengthening the AIDS Response Zambia (STARZ)** program ran from 2004-2009, and successfully advocated for the inclusion of people with disabilities into the national HIV response. By partnering with disabled people’s organizations, STARZ was able to understand the specific challenges in accessing HIV education and services for each disability. As a result, disability is now specifically addressed in the national agenda, such as in Zambia’s Fifth National Development Plan. STARZ also forged partnerships between local disabled persons’ organizations and the Zambian government to ensure that people with disabilities remain in the national HIV discussion.



HIV and AIDS

AIDS & Disability Action Program

This booklet has information and drawings about sex.

The British Columbia Coalition of People with Disabilities has produced a series of publications, like this one, to educate people with disabilities about HIV prevention.



Rosangela Berman Bieler, former Director of the International Institute on Disability and Development, shows a poster in Spanish on HIV prevention targeted at the deaf community in Central America.

CENTRAL AMERICA

Countries in Central America have joined together to create the **Central American Forum about HIV and disability**, which joins high-level officials, experts, and persons with disabilities from each country in the region to develop strategies to address HIV and disability. Each meeting of the forum is dedicated to a different topic, such as inclusive public policy, and monitoring national HIV programs to ensure that people with disabilities are included in the response. Countries throughout Central America have launched inclusive sexual education campaigns. The tagline, “EL SIDA NO DISCRIMINA,” translated, “AIDS does not discriminate,” combats the stigma and misconceptions that people with disabilities are not sexually active.

JAMAICA

Since 1991, **Jamaica AIDS Support for Life (JASL)** has been empowering vulnerable populations to reduce their risk of HIV infection, and promoting a human rights-based approach to the country’s HIV response. With support from amFAR, JASL created the hearing impaired project, which connects deaf men who have sex with men to health care services. This population is taught about safe sex methods, and also provided with medical and psychological treatment as needed.



With backing from UNAIDS, the **Jamaica Council of Persons with Disabilities (JCPD)** in the Ministry of Labour and Social Services launched the public education campaign, “Education and economic empowerment for persons with disabilities.” The program provides accessible HIV education, such as printed Braille pamphlets and sign language interpreters on televised HIV prevention messages. The program specifically targets Jamaican deaf women and girls, given their particular vulnerability to sexual violence. They are taught self-defense and economic skills to encourage financial independence. The program operates under the premise that empowering women reduces their vulnerability, thereby reducing their risk of HIV infection.

WHAT SHOULD BE DONE

GOVERNMENTS, UN AGENCIES AND HIV ORGANIZATIONS SHOULD:

- Learn more about the specific needs of persons with disabilities in the community.
- Ensure HIV services, including testing centers, care services, and teaching and training sessions are fully accessible to persons with different types of disabilities. This includes providing sign language interpretation, easy-to-understand information materials, Braille resources and ensuring that the services are physically accessible.
- Provide information about HIV and sexual health in formats tailored to people with different disabilities.
- Train staff of HIV organizations on disability issues and the disability community on HIV issues. Train persons with disabilities and especially HIV-positive persons with disabilities as peer support workers in HIV programs.
- Promote and fund research on HIV and disability, ensuring that persons with disabilities are included in the team designing, implementing and analyzing the research.
- Encourage governments to ratify and incorporate into national law instruments that protect the human rights of persons with disabilities, including the Convention on the Rights of Persons with Disabilities.
- Advocate for persons with disabilities to enjoy their full sexual and reproductive rights, access to harm reduction services, and to be free from physical and sexual abuse.

Resources

AIDS-Free World: Disability & HIV/AIDS, www.aids-freeworld.org/content/blogcategory/35/66/

AIDSLEX, <http://www.aidslex.org/english/Topics/Topic-Details/?rid=26>

British Columbia Coalition of People with Disabilities, <http://www.bccpd.bc.ca/health.htm>

Health Canada, http://data.unaids.org/pub/Report/2009/20091111_hiv_and_disability_en.pdf

Human Rights Watch: Disability Rights, <http://www.hrw.org/en/disability-rights>

Human Rights Watch, "As if We Weren't Human: Discrimination and Violence against Women with Disabilities in Northern Uganda," <http://www.hrw.org/en/reports/2010/08/24/if-we-weren-t-human>

Liverpool VCT, "A Handbook on Best Practices regarding HIV and AIDS for People with Disabilities" <http://www.liverpoolvct.org/images/downloadable/handbookonbestpractices.pdf>

WHO, World Report on Disability 2011, http://www.who.int/disabilities/world_report/2011/en/index.html

World Bank, <http://siteresources.worldbank.org/DISABILITY/Resources/Health-and-Welln...>

Yale University and World Bank Survey on HIV/AIDS and Disability, <http://cira.med.yale.edu/globalsurvey/>