



Disability and HIV/AIDS

at a glance

Disability and Development: What is the Link?

Disabled people are among the poorest, most stigmatized and most marginalized of all the world's citizens.

Disability and poverty form a vicious circle. Conditions of poverty such as poor nutrition and lack of access to health services or safe living and working conditions create disabilities that can occur from birth to old age. After the onset of a disability, barriers to health and rehabilitation services, education, employment, and other aspects of economic and social life can trap people in a cycle of poverty (Elwan 1999).

One person in ten—as many as 600 million people worldwide—live with a physical, sensory (deafness, blindness), intellectual, or mental health impairment significant enough to make a difference in their daily lives (UN 1993). Eighty percent of these live in the developing world (Helander 1999). Disability also significantly impacts the lives of disabled people's family members and communities.

Are disabled people at risk of HIV infection?

Too often, individuals with disability have not been included in HIV prevention and AIDS outreach efforts because it is assumed that they are not sexually active and at little or no risk for HIV infection. The Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank has proven this assumption wrong. Individuals with disability have equal or greater exposure to all known risk factors for HIV infection. For example, adolescents and adults with disability are as likely as their non-disabled peers to be sexually active. Homosexuality and bisexuality appear to occur at the same rate among individuals with disability as among the non-disabled. Individuals with disability are as likely as non-disabled people to use drugs and alcohol (UNICEF 1999). Men and women with disabilities are even more likely to be victims of violence or rape, although they are less likely to be able to obtain police intervention, legal protection or prophylactic care (Groce and Trasi 2004).

Can disabled people be reached by HIV prevention and care services?

Reaching disabled individuals with HIV and AIDS messages, clinical care and reproductive health services presents unique challenges. Even when AIDS messages do reach disabled populations, low literacy rates and limited education levels complicate comprehension of these messages. The global literacy rate for adults with disability is as low as 3%, and 1% for women with disability (Helander 1998). Literacy is vital to understanding HIV messages and translating them into individual behavior change. But even literacy may not overcome all obstacles; HIV messages and communication are often inaccessible to people who are blind or deaf, and health service facilities are often not accessible to people with physical disabilities. There are few rehabilitation services, especially in rural areas. It is estimated that only 3% of all disabled individuals get the rehabilitation services they need (UNICEF 1999).

Finally, disabled individuals in many countries report being turned away when they are able to reach HIV testing centers or AIDS clinics. Frequently, disabled people report that they are told to go home by clinical staff, who assure them that disabled people "cannot get AIDS". Where AIDS medications are scarce and where services and support for individuals with HIV or AIDS are limited, individuals with pre-existing disabilities report being placed last on the list of those entitled to care.

Exclusion of disabled people from HIV/AIDS prevention and care is shortsighted. Given the size of the global disabled population (an estimated 10% of the world's citizens), the AIDS crisis cannot be addressed successfully unless individuals with disability are routinely included in all AIDS outreach efforts.

Can countries effectively fight HIV/AIDS in disabled people?

Yes. An increasing number of countries have begun to develop HIV prevention, AIDS treatment and impact alleviation approaches that include individuals with disability and disabled populations. Pilot programs in Uganda, South Africa, Thailand and the United States have successfully included individuals with disability, but many more are needed.

To reach disabled people:

- **Contact local disability advocacy organizations for help and guidance.**
- Make sure that local disability organizations are on your distribution list so that they receive the same materials that are sent to local HIV and AIDS organizations.
- Invite disabled people to join HIV and AIDS training groups and have training materials ready in an accessible format.
- Make sure that disabled people are depicted as members of the general population in posters, billboards or other materials about HIV and AIDS.
- Make sure HIV testing centers and AIDS care services are accessible. Different types of adaptations will be needed for different types of disabilities, but most adaptations can be easily anticipated. For example, ramps for those with physical impairments, sign language interpreters for those who are deaf, AIDS talks for those with intellectual impairments that are simple, straightforward and that emphasize repetition of key themes, talks for those who are blind that allow them to actually feel condoms rather than simply having someone in the front of the room hold one up.
- The nature of these services will depend on the individual disability, but ramps, sign language interpretation, and more verbal presentation and demonstration for blind people are some common measures that can easily be taken.
- Bear in mind that people with disabilities also engage in behaviors such as unprotected sex and drug injection with contaminated needles that place them in traditional groups at higher risk of HIV exposure.
- Train AIDS educators, outreach workers, clinic and social service staff on disability issues. When recruiting volunteers and paid employees, make sure that disabled people are considered and hired for these positions.
- Train police, lawyers and judges on disability issues related to protecting the safety and human rights of disabled people.
- Currently, there are virtually no data on the impact of HIV and AIDS on disabled populations. This means there is strikingly little information on the impact of the AIDS epidemic on 10% of the world's population and their families. Make sure to include a disability component when collecting data on HIV and AIDS.
- Be opportunistic – funding might be available in places other than mainstream projects and programs. Be persistent in looking for alternative funding.

Dos and Don'ts

Do expect controversy. In many societies, individuals with disability are viewed as being innocent or childlike. Many people are uncomfortable discussing difficult social issues in relation to disability, such as sexuality and rape. Nonetheless, such issues are very real in the lives of many individuals with disability and cannot be ignored. **Don't**

assume that disabled people are not at risk of being infected with HIV.

Don't wait. Historically, the medical, social and economic needs of individuals with a disability have often been placed last on a long list of competing social priorities. It is not unusual to have policy makers suggest that time, energy and resources should first be devoted to non-disabled populations, with the assumption that disabled populations will receive attention as soon as the problems with the non-disabled population are solved. This is unacceptable. The lives of individuals with disability are no less valuable than the lives of those who are not disabled - there is no reason why the millions who live with a disability should delay or deny their needs and wait for an unspecified point in the future. This is not only a human rights issue. Individuals with disability make up 10% of all populations. The AIDS epidemic will never be conquered unless individuals with disability are part of the general solution.

Do involve disabled people, disability advocacy groups and NGOs. "Nothing about us without us" - disabled people need to be involved in order to identify needs properly and decide how to address these needs appropriately. Also organizations "of" rather than "for" people with disabilities can be strong allies in the struggle against AIDS. The leaders and members of these organizations are often very familiar with the local disabled population and the medical, legal and socio-economic struggles they face. Such organizations are important resources that can expedite efforts to reach the general disabled population and recognize the specific requirements of particular disability subgroups. It is also imperative that members of these groups not only receive HIV information and AIDS care services, but also be trained as AIDS educators and advocates to better serve their own communities.

Do keep in mind that there is a wide range of disabilities. Disability varies both in severity and the way it influences the life of the individual living with the disability. Also remember that a disability that may have less significant implications in a life lived in a developed country may make a huge difference for a disabled individual in a developing country, especially if supporting equipment –hearing aids, wheelchairs– are unavailable or unaffordable.

Do address gender inequality. Being a disabled woman is an additional risk factor. Disabled women face unique challenges in preventing HIV infection, because of their heightened risk of gender-based violence, lack of access to reproductive health care services and low awareness of mother-to-child HIV transmission. Women with disability, compared with non-disabled women and with men with disability, are more likely to be illiterate, unemployed or marginally employed. Because of prejudice and stigma, these women are more likely to live in a series of unstable relationships than to marry. These social and economic factors make women with disability harder to reach with HIV messages and reduce their ability to negotiate safer sex.

Types of actions to include disabled people in HIV/AIDS prevention and care

Type of Action	Methods	Cost	Examples
Type I: Individuals with disability are reached by the same AIDS education messages and services as members of the general public	<p>Ensure that AIDS educational outreach and services available to the general population include individuals with disability.</p> <p>Use materials already available to the general public, incorporating simple adaptations to ensure accessibility by all.</p> <p>Train AIDS educators, outreach workers, clinical and social service staff on disability issues. Train individuals with disability to be AIDS educators. Include outreach to the disability community to recruit into these programs.</p>	Little or no additional cost (but keep in mind that the cost will rise with the level of tailoring to individual disabilities)	<p>AIDS posters and billboards depict individuals with disability (i.e. wheelchair users, blind and deaf individuals) as part of group scenes. Move AIDS education, testing and care service delivery programs, as well as drug, alcohol and domestic violence programs to accessible meeting places.</p> <p>Make simple adaptations such as allowing blind individuals to feel a condom, rather than just talking to them about it.</p> <p>Make simple and straightforward HIV messages to allow intellectually disabled individuals to understand and memorize the words.</p>
Type II: Adaptations are made to AIDS outreach campaigns to ensure that individuals with disability are included as members of the general public	<p>Adapt already existing HIV materials to ensure inclusion of disabled people.</p> <p>Make simple alternations to facilities to increase inclusion.</p> <p>During general training programs, train HIV and AIDS educators and clinicians about disability in general, and that there are differences in the needs of individuals with different types of disabilities.</p> <p>Train individuals with disability to be AIDS educators.</p>	Low to moderate additional cost	<p>Caption AIDS public service announcements on TV for deaf people.</p> <p>Make AIDS materials available for blind people in inexpensive cassette formats and in Braille.</p> <p>Build ramps into meeting halls or clinics (ramps can be made of mud, stone, bamboo, wood, etc).</p> <p>Ensure that HIV/AIDS information is disseminated in a variety of formats: radio, billboards, to ensure that specific groups (deaf, blind) do not miss out.</p>
Type III: Disability-specific adaptations of existing materials and development of new materials to reach individuals with disability outside the bounds of the general public, targeting harder to reach individuals and populations	<p>Develop disability-specific outreach efforts.</p> <p>Develop new materials to use in outreach efforts.</p> <p>Train AIDS educators, hire staff specializing in the issues related to serving the specific disabled population targeted; train disability advocates to be AIDS educators within the disability community as well as the overall community.</p>	Moderate to higher added cost	<p>Videos in Sign Language for Deaf</p> <p>Target schools, institutions and organizations serving populations of disabled people for special programs to ensure that students, residents or participating members have been informed.</p> <p>Rewrite training materials in simpler language/ easy to understand format for those with intellectual impairments, or for disabled individuals who are illiterate or low literacy.</p> <p>Have a Sign Language interpreter available at clinics/hospitals to explain complicated regimes of AIDS drugs and follow-up.</p> <p>Train HIV educators and service providers about disability issues.</p>

* This table is based on a similar table in the Yale/World Bank Global Survey on HIV/AIDS and Disability report, 2004

Do work cross-sectorally. In most countries, responsibility for the legal, socio-economic, educational and medical well-being of individuals with disability is divided among a number of different government agencies and ministries. Efforts to quickly and effectively address HIV and AIDS within disabled populations will

require a multi-sectoral approach that takes into account the many influences on individuals with disability that may increase, or decrease their risk of HIV infection, as well as expedite their access to HIV prevention, AIDS treatment and impact alleviation efforts.

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Key websites

<http://cira.med.yale.edu/globalsurvey>
Yale/World Bank Global Survey on HIV/AIDS and Disability. This site lists examples of interventions, studies, films etc, that have been implemented for populations with disability around issues of HIV/AIDS.

<http://www.worldbank.org/AIDS>
Global HIV/AIDS Program, World Bank Group. This site provides access to information, training materials, studies and policy on HIV/AIDS by the World Bank.

<http://www.worldbank.org/disability>
World Bank Disability Website. Information and World Bank studies on global disability advocacy, policy, economic development and education.

UNAIDS <http://www.unaids.org>
Data, studies, interventions and policy recommendations from UN AIDS and its affiliated organizations.

Expanded versions of the "at a glance" series, with e-linkages to resources and more information, are available on the World Bank Health-Nutrition-Population web site: www.worldbank.org/hnp