

HIV/AIDS AND INDIVIDUALS WITH DISABILITY

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A hallmark of the HIV/AIDS epidemic has been its impact on vulnerable populations. Surprisingly, one of the world's most vulnerable populations — individuals who live with a permanent physical, sensory (deafness, blindness), intellectual, or mental health disability — has been almost entirely overlooked despite the fact that they are at equal or increased risk of exposure to all known risk factors for HIV. It is commonly assumed that individuals with disability are at low risk of HIV infection.¹ They are incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol, and at less risk of violence or rape than their non-disabled peers. Individuals with mental illness have received more attention, but a focus on this group still lags behind that for the general population.²

Individuals with disability are among the most stigmatized, poorest, and least educated of all the world's citizens. One person in ten — 600 million individuals — lives with a disability significant enough to make a difference in their daily lives; 80% live in developing countries.³ Although disability is often addressed solely as a medical concern, the greatest problems facing individuals with disability are social inequity, poverty, and lack of human rights protection — not simply lack of access to medical care.⁴ Indeed, as stated by the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, one can be both disabled *and* healthy.⁵

Little is known about HIV/AIDS in populations with pre-existing disabilities. The handful of prevalence studies available raise serious concerns, however. For example, a

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small US study found that HIV rates among deaf individuals were double those of hearing populations.⁶ Another study published in 2001 revealed that AIDS was the leading cause of mortality among women with psychiatric illness in New York.⁷ Mulindwa, using sexually transmitted infections (STIs) as a proxy for potential HIV exposure, found that 38% of women and 35% of men with disability in her Ugandan study reported having had an STI.⁸ Anecdotes from disability advocates point to significantly underreported rates of HIV/AIDS infection, disease, and death.⁹ The extent of the problem in sub-Saharan Africa prompted Johnson to state that provision of rehabilitation services to disabled populations is “no longer possible” until HIV is addressed.¹⁰

This article is based on results drawn from the World Bank/Yale Global Survey on HIV/AIDS and Disability, a project at the Yale School of Public Health through the Center for Interdisciplinary Research on AIDS (CIRA) and co-sponsored by the World Bank’s Office of the Advisor on Disability and Development and the World Bank’s Global HIV/AIDS Program. The survey assessed the impact of the AIDS epidemic on disabled populations, and received over 1,000 responses from 57 countries. We sought to identify issues of access to HIV/AIDS knowledge, services, and care specific to individuals with disability over and above those confronted by members of the general population in resource-poor settings. We were particularly interested in identifying where individuals with disability shared common concerns with members of the general population around issues of HIV/AIDS and where they confronted disability-specific issues and concerns. Survey results found that AIDS is a looming problem for individuals with disability worldwide — a problem that is still largely unrecognized by both the AIDS and the disability advocacy communities.¹¹

Risk Factors for Disability and HIV Through the Life Cycle

Many of the established risk factors for HIV/AIDS — poverty, illiteracy, stigma, and marginalization — are identical to those for disability. For example, the global literacy rate for adults with disabilities is only 3%; for females with disability, it is as low as 1%.¹² Education, where it exists, is

often sub-standard, and dropout rates are double or triple those of non-disabled children.¹³ UNICEF estimates that globally, one-third of all street children are disabled.¹⁴ The millions who end up on the streets can easily become involved in crime, sex work, and drugs — frequently at the behest of others who see them as easy prey.

Links between disability, social marginalization, and HIV continue into adulthood, where unemployment often reaches 80%.¹⁵ The World Bank estimates that people with disability make up 20% of the world's poor. Routinely they are the poorest of the poor.¹⁶ Women with disability and disabled members of ethnic and minority communities face additional marginalization. This cycle of disability and poverty is profound. Worldwide, the most common form of employment for individuals with disability continues to be begging.¹⁷

At the same time, behavioral risk factors for HIV related to sexual activity among individuals with disability are identical to those for the general population. A US study of women with spinal cord injury found 67% sexually active after injury.¹⁸ In Mulindwa's Ugandan survey, 80% reported ever being sexually active.¹⁹ Adolescents with most types of disabilities reach puberty at the same age as non-disabled peers.²⁰ Disability status among adolescents, however, compounds many of the risks related to HIV transmission. For example, disabled adolescents are frequently excluded from social activities, limiting their opportunities to learn to set boundaries and, ultimately, lowering their sense of self-worth. This often compromises their ability to refuse when pressured to have sex or try drugs.²¹ Physically impaired French adolescents, for example, are reported to have higher rates of sexual intercourse than non-disabled peers, as well as more sexual partners.²²

Homosexual and bisexual identity among disabled populations appear at rates comparable to those within the general population.²³ As is the case with heterosexuals, homosexual and bisexual individuals with disability are vulnerable to being pressured into sex because of their need for social acceptance and inclusion. For example, a British study of men with intellectual disabilities having unprotected sex

with non-disabled men in public restrooms found that the men with disabilities did not consider themselves gay but participated in these activities because they were lonely and anxious to please their new "friends."²⁴

Women with disability, while often thought of as potential sexual partners, are nonetheless often considered unmarriageable.²⁵ In some countries, women with certain disabilities cannot obtain marriage licenses and may have no options other than to live in unstable relationships with a series of sexual partners.²⁶ With few prospects for employment or marriage, these women have a limited ability to negotiate safer sex.²⁷ Extreme poverty associated with disability status is also a factor forcing some into sex work. The survey on which this article is based obtained evidence of Thai families selling deaf daughters to brothel operators who are reported to be keen to buy them because, confined to brothels where no one speaks sign language, these girls are unable to call for help from the authorities or discuss their situation with people in the surrounding community.²⁸

Women with disability are up to three times more likely to be raped than non-disabled women; boys and men with disability may face equal risk of rape and sexual abuse as these disabled women.²⁹ Many people with disabilities are physically unable to defend themselves; others must delegate part or all physical care to attendants who may see them as easy victims. Hundreds of thousands of individuals worldwide live in institutions where physical, psychological, and sexual abuse from staff, visitors, and fellow patients is known to be common. In communities, outside of institution settings, individuals with disability are frequent targets of physical and sexual assault.³⁰

Additionally, the widespread belief in certain societies that an HIV-positive man can rid himself of the infection by having intercourse with a virgin places those with disability at increased risk. Reports from Africa and Asia indicate that both females and males with disability, who are assumed to be asexual and therefore virgins, are being raped by non-disabled individuals desperate to rid themselves of the virus.³¹ A variant is reported from West African communities where widows must remarry to maintain inheritance

rights. Widows of husbands who recently died from AIDS have been reported to seek out disabled men — especially deaf or intellectually disabled individuals — assuming that, because of communications barriers or their inability to understand how AIDS spreads, these men may be more willing to take a wife who is HIV-positive.³²

In many countries, there are few legal consequences for those who abuse people with disabilities. Police, judges, and social workers often attribute accounts of abuse or rape of individuals with disability to “confusion” or “misunderstandings.” In many countries, individuals with disability cannot submit police reports or give testimony.³³ Legal counsel is unaffordable for many people with disability, and law offices, police stations, and courts often lack ramps, sign language interpreters, or provisions to explain proceedings in simpler terms for individuals with intellectual disabilities. Having no police protection or legal recourse is an invitation for abuse. Disability status compounds other HIV-related risk factors. Drug and alcohol abuse, considered in some countries to be disabling conditions in themselves, further compounds the risk of HIV-exposure in people with physical, sensory, intellectual, and mental health conditions, which is of particular concern for socially isolated disabled youth.³⁴ In the US, Peinkoff estimates that 1 in 7 deaf adults has substance abuse problems — verses 1 in 10 hearing adults.³⁵ Li et al. found significantly higher rates of marijuana and crack cocaine use among disabled women than among non-disabled peers.³⁶ Interestingly, no studies have yet linked disabled populations, with the exception of hemophiliacs, with medically acquired HIV infections. Surgeries or medications administered by needle could place some at increased risk; however, from a population perspective this may be counterbalanced because individuals with disability are significantly less likely to receive medical care — disability-related or otherwise — than non-disabled individuals.³⁷ One additional implication of the AIDS epidemic must be noted. Many people with disability are dependent on parents and other family members for assistance with dressing, eating, and toileting, as well as for social, psychological, and economic support. When caregivers within a

family die from AIDS, the person with the disability — already in a vulnerable group — is at even greater risk. Caregivers with several orphaned children may have little time for the disabled child who needs extra help eating or toileting. AIDS orphaned children with disability face increased risk of neglect, institutionalization, and death.³⁸

Reaching Disabled Populations

Reaching disabled populations with AIDS messages is complicated. High illiteracy rates are a factor. Even where AIDS education is available, however, students with disabilities may be often excused from such instruction because teachers assume that they will not need the information.³⁹

Where sex education is taught within the home, people with disabilities often receive little information because it is believed that they do not need such knowledge or will become promiscuous if it is provided.⁴⁰ This lack of information increases the risk of acquiring HIV infection and STIs — as well as for unintended pregnancies — for many individuals with disability. While both girls and boys are at risk, in many societies disabled girls may be instructed in appropriate sexual behavior, as well as management of menstruation. It is assumed, however, that boys will acquire the information informally. Studies of disabled adolescents in Japan and Sweden found that intellectually disabled boys received much less sexual education than girls. This was problematic, in part, because these boys found it difficult to tie together stray comments and jokes into a coherent understanding of sexuality and safer sex.⁴¹

There are further complications. Where HIV/AIDS campaigns are run through newspapers and billboards, blind individuals are at distinct disadvantage; where HIV/AIDS campaigns have concentrated on radio, deaf individuals are often uninformed. Such public campaigns are likewise confusing to those with intellectual disabilities who have difficulty sorting through too much information. Conversely, euphemisms such as "safer sex" and "protection" are too vague. The complexity of such communication is illustrated by Robertson, who describes the difficulty of explaining AIDS to a woman with intellectual disability who did not fully understand the concept of death.⁴²

Also striking is the lack of awareness of some of these issues on the part of AIDS advocates. Only a handful of outreach efforts to disabled populations by AIDS organizations exist at any level, from grassroots to global.⁴³ The importance of including individuals with disability in general AIDS campaigns or designing disability-specific interventions is largely unrecognized. This gap is well illustrated in a comment from a South African disability activist: "I see AIDS educators going door-to-door, inviting all adults to AIDS meetings. They walk by and wave to the woman sitting in her doorway in a wheelchair watching her children, but they do not invite her to come."⁴⁴

People with disability themselves often know little about AIDS. In some societies, individuals with disability believe that, since they have one disease, God would not give them another. In deaf communities, widespread misinformation about HIV/AIDS is reported, due to a lack of accessible media and inaccurate information passed between sign language users. For example, some deaf individuals believe that "HIV+" is a good thing" because the word "positive" indicates a good outcome.⁴⁵

Access to Health Care

Unfortunately, should individuals with disability become infected with HIV, the inequities continue. In many countries, HIV testing centers and clinics are physically inaccessible, lack sign language interpretation, and do not address the needs of the individuals with intellectual or mental health impairments.⁴⁶ Among those living in extreme poverty, persons with disability are often unable to afford transportation to testing sites, let alone the cost of testing or medical care. Many health professionals, unaware that individuals with disability may be sexually active, do not offer to test them or provide services, under the assumption that they are not at risk.

The result is that many individuals with disability are not reached with HIV/AIDS messages, are unaware of the symptoms of HIV/AIDS, and do not understand the implications of these symptoms, should they appear. Many who depend on others for transportation or sign language inter-

pretation report delaying seeking testing or care even after symptoms appear because of reluctance to disclose personal sexual histories.⁴⁷ There is anecdotal evidence from many countries of individuals with disability coming to clinics with full-blown AIDS only days before death; many others die without diagnosis or care. Beyond this, accessing medical, social, or legal services is often beyond the capability of ailing individuals with disability who lack education, communication skills, and support networks. Finally, where access to AIDS medications or health services are not sensitive to human rights considerations and are prioritized in terms of "quality of life" or "contribution to society," individuals with disability are too often placed at the bottom of the list.⁴⁸

Where to Now?

In responses to our survey, disability advocates, programs, and institutions from 57 countries reported overwhelmingly (87%) that HIV/AIDS is of immediate concern to the disabled populations that they serve.⁴⁹ They further reported that outreach is needed on every level of research, policy, and funding. For example, epidemiological data are needed both on HIV infection rates among individuals with disability in general and for distinct disability groups. Virtually nothing is known about how disabled populations can best be reached as part of general HIV/AIDS outreach efforts or through disability-specific programs. Currently, interventions that include individuals with disability are rare, most are short-term, and almost all lack monitoring or evaluation.⁵⁰ Disabled groups report that requests for funding for HIV/AIDS programs are routinely denied by funders, which justify this by stating that money is in short supply even for non-disabled populations — as if the lives of those with disability are of lesser value.⁵¹

In 2000, the UN Committee on Economic, Social and Cultural Rights specifically noted the need for the right to equal access to health care for persons with disability as a major component in their General Comment on The Right to the Highest Attainable Standard of Health.⁵² In light of

this statement, the issue of the impact of the HIV/AIDS epidemic on individuals with disability could not be more timely, or more significant.

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