

HIV, AIDS and Disability

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1 Nicholas, Suite 726, Ottawa ON K1N 7B7
Telephone: (613) 233 7440 • Fax: (613) 233 8361
E-mail: info@icad-cisd.com • Web: www.icad-cisd.com

Introduction

There is a growing movement to address the need for increased collaboration in programming between those who advocate for the rights of people with disabilities (PWDs) and those involved in HIV education, prevention, care and treatment. Organizations dedicated to advocating for the rights of PWDs are beginning to develop and implement programming to effectively educate PWDs on HIV treatment and prevention techniques. Many of these individuals have been excluded from conventional HIV programming, despite having similar or increased rates of exposure to HIV risk factors. Unfortunately, the vast majority of HIV and AIDS programmes lack the training, resources and the commitment necessary to accommodate the needs of PWDs. However, numerous studies are being conducted to examine this gap, and explain what measures must be taken to provide the necessary accommodations. While many organizations advocating for the rights of PWDs are actively implementing HIV programming in their curriculum, there is an urgent need for existing HIV organizations to follow suit and modify their programming to better integrate the needs of people living with disabilities.

HIV and Disability – Links and Contributing Factors

The term “disability” indicates that an individual’s activities have been restricted because of obstacles imposed by the society in which they live. Should the opportunities and resources be available for an individual, a physical and/or mental impairment need not result in a “disability”. Whether born with a disability or disabled later in life, PWDs are just as likely to be exposed to all known HIV and AIDS risk factors as the population at large. However, many are not receiving the education in sexual health and HIV prevention techniques necessary to protect themselves.

Many PWDs are denied formal education because of discriminatory practices. Issues such as the inability to access transportation, school buildings, and materials, as well as parental unwillingness to “waste” money on the education of children with disabilities, often lead to high drop-out and illiteracy rates among PWDs. Due in part to the widespread misconception that PWDs are asexual, many are deprived of formal (at school) and informal (at home) education on sexual and reproductive health. This educational gap leaves PWDs in a vulnerable position, and can result in an inability to negotiate safer sex.

The combination of poverty and disability can make it very difficult to access health care. It is rarely affordable and, in the case of PWDs, accessible. For example, voluntary HIV testing may be delayed because of a lack of anonymity. Many PWDs rely on family members/friends for support (transportation and/or interpretation) and may not want to disclose personal details to them. Another barrier is the discrimination faced by PWDs from health care workers. PWDs are often ridiculed or dismissed when requesting reproductive health information, because they are perceived to be unattractive and/or asexual. Many women with disabilities (WWDs) fear forced sterilization if they seek out medical attention. In addition, there are few rehabilitation services in rural areas for people who acquire impairments later in life, which can greatly impact the ability to work and live after an injury. Finally, PWDs are often the last to receive care. Widespread social perceptions contribute to the assumption that PWDs will lead a lower quality of life and contribute far less economically and socially to a society. This devaluation of PWDs in the eyes of many health care providers contributes to unwillingness on the part of many PWDs to seek health care and testing for HIV.

Greater incidences of sexual violence and victimization against PWDs also place them at higher risk of HIV infection. A dependency on others for

daily needs, especially in institutionalized settings, leaves many PWDs vulnerable to abuse. Rates of sexual abuse are even higher in regions where belief in the traditional remedy of virgin cleansing is widespread. This practise involves engaging in sexual intercourse with a virgin in order to rid oneself of a sexually-transmitted infection. PWDs, seen as physically weak or unlikely to report attacks, are often targeted as they are assumed to be asexual and subsequently virgins.

The already uncertain future of a child orphaned by AIDS is further compounded if he or she has a disability. Caregivers in charge of multiple orphans do not have time to manage all the needs of a child with a disability. The situation is the same for adult children who are highly dependent on their parents. Without dedicated caregivers, PWDs are at a high risk of being institutionalized, neglected, abused, etc, all of which puts them at higher risk of contracting HIV.

To summarize, PWDs have an equal or greater chance of exposure to all known HIV risk factors. The costs of caring for an individual with a disability may deny caregivers HIV and AIDS training. Children with disabilities who are orphaned by AIDS may be especially vulnerable as they are at greater risk of being institutionalized. Lack of education can leave PWDs unaware of important HIV and sexual health information. Furthermore, insensitive, uncaring and inaccessible health systems deny PWDs access to reliable information, testing and care for and about HIV and AIDS. Greater incidences of sexual violence increase PWDs' exposure to HIV infection. All of these factors clearly illustrate the links between equal or greater exposure to all known HIV risk factors and disability.

Growing Awareness - International Studies and Advocacy

A number of publications and studies have been conducted amongst advocates for PWDs internationally in an attempt to identify appropriate strategies for addressing the needs of this subpopulation in HIV education and treatment programmes. These studies have been accompanied by a growing voice in local and national governments

advocating for legislation to protect and encourage the sexual rights of PWDs.

The most comprehensive international study on the topic of HIV and PWDs was published by the Yale School of Public Health and the World Bank in 2004. "*HIV and Disability: Capturing Hidden Voices. Global Survey on HIV/AIDS and Disability*" concludes that HIV represents a significant threat to individuals with disabilities around the globe.

Uganda has demonstrated progressive thinking in their inclusion of members of the population with disabilities in educational programmes and government decision-making processes. A situational analysis of HIV and young PWDs in Rwanda and Uganda examines the reality that many are not being included in safe-sex conversations, and outlines what steps must be taken towards further integration. In addition, the Disability Stakeholder's HIV/AIDS Committee in Uganda, a Coalition of over 15 Disabled Persons' Organisations, met with a Parliamentary HIV/AIDS Standing Committee to discuss the inclusion of disability into national strategies and policies. As a result of the meeting, the community of individuals with disabilities will be accorded a Self Coordinating Entity (SCE) status, meaning that they will be represented at the highest national HIV/AIDS Committee - the Partnership Committee - to participate in HIV policy formulation and programme implementation at the national level.

On March 12 2008, "The Kampala Declaration on Disability and HIV" was signed by all participants of the second meeting of the *Africa Campaign on Disability and HIV/AIDS*. The Declaration calls on all stakeholders, including African governments, HIV service providers and International Organizations to recognize the vulnerability of PWDs to HIV infection and implement the accommodations necessary to address the issue. The signatories were also called upon to engage members of the disabled population in subsequent decision-making processes.

Programming Initiatives

As a response to the increased awareness of linkages between disability and vulnerability to HIV, a number of groundbreaking programming initiatives have emerged throughout the developing world. This document focuses on programmes found on the African continent, as well as some that have been

established across parts of Asia. Some programmes have modified existing resources and programming for PWDs to address HIV, while others have adopted new resources and toolkits to create innovative programming.

• AFRICA

The official launch of “*The Africa Campaign on Disability and HIV/AIDS*” in January 2007 is a further step towards the integration of PWDs into the international HIV and AIDS response. A collection of organizations advocating for the rights of PWDs, organizations of people living with HIV/AIDS, non-governmental organizations, AIDS services organizations, researchers, activists, and other citizens, the Africa Campaign was initiated to fulfill a variety of objectives. Members have agreed to address issues of equal access to HIV information/services, and to coordinate a response to achieve inclusive national HIV and AIDS policies and programmes.

African Union of the Blind (AFUB) (pan-Africa)

Through funding from the Canadian International Development Agency (CIDA) and the Canadian National Institute for the Blind (CNIB), the African Union of the Blind (AFUB) launched the “HIV&AIDS Awareness and Training project for Blind and partially sighted persons in Africa”, in 2005. Six African countries (Cameroon, Ghana, Kenya, Malawi, Rwanda and Tanzania) were tasked with the following objectives: mainstreaming HIV awareness in their programming; establishing national lobby committees to advocate for greater access to programmes and raise awareness; developing specially formatted training and resource materials; and ensuring the participation of blind/partially sighted women as advocates, educators and beneficiaries. Peer counsellors were trained on various topics related to HIV including transmission methods, counselling and testing, where and how to obtain health services, life skills, anti-retroviral therapy, sexually transmitted infections and home-based care.

Norwegian Church Aid (NCA) and National Council of Churches in Kenya (NCCK) (Kenya)

The NCA and NCCK have initiated programming to address HIV education for PWDs, and have prioritised the development of materials and

messages in sign language, Braille and audio formats to meet the needs of individuals with disabilities. In the belief that self-sustainability contributes to the decrease of stigma and the ability to protect oneself against sexually-transmitted infections, NCCK has also supported income-generating activities including tailoring, shoemaking, beadwork, art and crafts, carpentry and vegetable/fruit vending by PWDs.

Handicap International (HI) (pan-Africa)

Teams involved with community health education from Handicap International in Morocco, Kenya, Mozambique and Burundi, have included HIV prevention messages through a variety of means in their programming. The recent assignment of an HIV/AIDS Medical Advisor to the East Africa Region has resulted in the training of numerous health care workers on disability issues. HI is in the process of launching a project that will enable access to legal and health services for victims of sexual abuse with disabilities. The HI programme in Togo will introduce HIV prevention information into pre-existing rehabilitation projects, with the ultimate aim of reducing vulnerability and stigma against individuals who have disabilities and are HIV positive.

Family AIDS Caring Trust (FACT), Harare (Zimbabwe)

FACT, an organization dedicated to mitigating the impact of HIV in Zimbabwe, has begun training members with disabilities on the “Stepping Stones” programme, in order to address the ongoing lack of information and communication. “Stepping Stones” is a life skills behaviour change communication training methodology on HIV/AIDS, promoting gender equity, intergenerational respect and solidarity with people who are HIV positive.

• ASIA

The Ho Chi Minh City Deaf Club, Ho Chi Minh City (southern Vietnam)

This project, “STI/HIV Prevention for Deaf and Hearing Impaired Young Persons of HCM Deaf Club”, focussed on Club members (thirty youth and four adult), advisors, and other allies from orphanages and special schools for deaf children. Peer education was employed by facilitators to create more self-sufficiency and self-reliance in HIV programming and information dissemination within

the deaf community. The goal of the project was to increase the percentage of HCMC Deaf Club youth members who practice and promote STI/HIV prevention, and consequently improve deaf and hearing-impaired youths' knowledge of the subject.

Nethrajothi, Chennai (southern India)

This organization has been working on HIV programming for visually impaired people since 1992 and is cited as the earliest known example of disability and HIV and AIDS programming in India. Nethrajothi began by translating HIV prevention information into Braille and working closely with HIV and AIDS organizations. Currently, the organization conducts awareness programmes in schools for the blind while continuing to maintain peer support programmes. Due to funding issues, Nethrajothi has only been able to work inconsistently and irregularly. The most significant lesson to take from this example is the importance of using a range of techniques (Braille, audio-cassette, talks/presentations, engagement with other sectors, both disability and HIV and AIDS focussed, the use of a peer support system to reach visually impaired people in the community at large) to achieve greater inclusion.

Deaf Way, Delhi (northern India) and Hyderabad (southern India)

Founded in 2002, the primary focus of this organization is to deliver workshops covering all aspects of sexual and reproductive health. Workshops last four days and are conducted in Indian Sign Language (IES). The organization holds an average of three workshops per year in response to requests from other organizations for PWDs. To date, Deaf Way has conducted 15 workshops, training and educating 350 deaf people. Facilitators use a full range of techniques, including IES, local gestures, captioning, mime, role play etc. As with Nethrajothi, this diversity is shown to promote greater inclusion.

The Mumbai District AIDS Control Society (MDACS) and the Association for Blindness and Low Vision, Mumbai (western India)

This collaboration began in January 2005 when the Association approached the MDACS (a state-run organization) requesting that they translate their HIV information into Braille and large print. These materials were then sent to all schools for the blind and all known organizations for PWDs in the area.

This initiative demonstrated both the importance of an effective distribution and dissemination strategy as well as the value of engaging with existing state structures.

The Devnar Foundation for the Blind and the Andhra Pradesh State AIDS Control Society (APSACS), Hyderabad (Southern India)

The importance of collaboration between sectors is evident in this project. In 2006, after identifying a gap in the sexual and reproductive health education materials available for vision impaired youth, the Devnar Foundation approached the APSACS. The Foundation offered a joint solution: they would translate materials into Braille, while the APSACS would cover the cost of production and distribution.

Recommendations for inclusion of PWDs in HIV programming

To date, few suggestions have been put forward concerning the integration of people with disabilities into pre-existing HIV and AIDS programming. This process has been historically slow because of an overwhelming and paralyzing misconception; many outreach workers and organizers believe that the integration of people with disabilities into their programmes will be unattainably expensive. Emerging scholarship disputes this assumption.

Groce, Trasi, and Yousafzai propose guidelines for inclusion that operate on a continuum and are mindful of the limited finances available to most outreach programmes. This continuum is divided into three parts: part one proposes general inclusion of people with disabilities in outreach programmes and as part of society at large; part two explores the possibility of minor to moderate modifications to existing material and programmes in order to facilitate accessibility and inclusion; part three involves the development of disability-specific programming and materials, with a special focus on harder to reach individuals. While these suggestions clearly operate on an escalating cost scale, all should be within the reach of HIV and AIDS outreach organizations.

In addition, Groce, Trasi, and Yousafzai importantly point out that people with disabilities are a diverse group. It is unlikely that one of these suggestions on its own will facilitate inclusion of all people with

disabilities in any given area. A combination of these different suggestions will likely be needed.

Conclusion

HIV does not discriminate between gender, race, sexual preference or physical and mental capabilities. There is a fast-growing awareness that programmes which focus on HIV prevention, awareness and treatment must not discriminate either, and must

establish means of educating and servicing the population as a whole. Organizations dedicated to the rights and issues of persons living with disabilities have already begun their fights against HIV by using whatever resources available to educate members on sexual and reproductive health and the steps that can be taken to protect themselves. We have seen evidence of this in Africa, most notably with the recent formation of the Africa Campaign on Disability and HIV/AIDS, and in parts of Asia where rates of HIV transmission are also high.

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