



> Managing Editor

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## AIDS programming with disabled people in mind

A global survey on HIV and AIDS and disability conducted by the World Bank and Yale University found that people with disabilities (PWDs) were not yet factored in the HIV sector, despite being vulnerable to a variety of known risk factors. Similarly, the authoritative medical journal, *The Lancet*, has reported that PWDs generally have limited access to health services and that care can be expensive and physically inaccessible. Barriers include restrictive cultural norms, lack of mobility aids, lack of communication skills by service staff, marginalisation in the community, illiteracy, lack of education and gender inequality.

Illiteracy makes communicating HIV messages more difficult. Sex-education programmes for PWDs are rare, and few HIV and AIDS campaigns target (or include) disabled populations. Electronic media campaigns further marginalise the hearing-impaired and the visually-impaired, respectively. The need to design messages with all kinds of disabilities in mind is paramount.

Research reveals that the negative attitudes PWDs often face within healthcare facilities discourages them from seeking help about their sexual health. Cost-effective technologies to enhance PWDs' access to information on HIV, including the production of materials in Braille and the repackaging of existing materials to target PWDs is needed.

Clearly, the need to mainstream the HIV and AIDS needs of PWDs into national policies for effective handling is urgent. Governments and donors should seek to support innovative projects initiated by PWDs that address their specific needs.

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### Signing "Know your HIV status"

Photo: Courtesy of Liverpool VCT



### A teacher in a regular primary school in Nigeria

Photo: Courtesy of Enablement

## Equalise it: Agenda setting in HIV and AIDS for people with disabilities

**The HIV and AIDS pandemic is negatively affecting people in Africa as a whole and in sub-Saharan Africa in particular. According to the Joint United Nations Programme on HIV and AIDS (UNAIDS), one adult in 16 in the region is living with HIV. In some African countries, the number of people living with HIV is as high as one adult in three. Despite these statistics, people with disabilities remain marginalised and excluded from HIV information, education and communication (IEC). They are also often left out of treatment, care and support programmes.**

There are an estimated 650 million people, or 10 per cent of the world's population, who are disabled<sup>1</sup>. Although this represents a significant segment of the population, the relationship between HIV and disability has not received due attention to date. Moreover, a growing number of people with HIV are also living with new impairments as a result of HIV-related illnesses and the side-effects of medications. Additionally, persons with disabilities are part and parcel of the community and also experience the same, if not more, HIV risks as others in the community. Therefore, there is an urgent need to further investigate the vulnerabilities of people with disabilities to HIV infection.

### A grim global picture of disability and exclusion

According to UN estimates, 30 per cent of people with disabilities worldwide live in

industrialised countries, while the rest are believed to live in developing countries. Approximately 25 per cent of households worldwide care for a member with a disability. Recent World Bank estimates indicate that people with disabilities account for as many as one in five of the world's poorest people, meaning, of the estimated 1.3 billion individuals living in poverty, about 260 million may have a disability.

Recent UNESCO studies suggest that only one-to-two per cent of children with disabilities in developing countries receive basic education. Boys with disabilities attend school more frequently than girls in similar situations. Some 40 to 70 per cent of girls and 15 to 20 per cent of boys with intellectual disabilities are sexually abused before the age of 18. Families of disabled boys and girls report that adolescence, a time for building social networks and

friendships, is often instead consumed by the need to just “get by”, resulting in fewer mechanisms for support and limited social capital<sup>2</sup>.

The social exclusion framework is a useful tool in understanding the conceptualisation of disability. This conceptualisation must be adapted to the social model, which removes the responsibility of disability from the individual to society. Society is, therefore, required to make appropriate adaptations in order to enable persons with disabilities to enjoy the same rights and privileges as other persons.

Governments, international agencies, non-governmental organisations, community and faith-based organisations have initiated numerous programmes and services

addressing HIV prevention, treatment, care, support and reproductive health issues. The inclusion and participation of persons with disabilities in such programmes, however, is still negligible and many disabled persons in need of such services still find themselves left out<sup>3</sup>. Moreover, most HIV IEC strategies are not provided in accessible formats such as Braille, large print and audio for blind persons, or in sign language for the hearing-impaired. This lack of IEC in accessible formats means that disabled people often have little HIV-related knowledge, including how to prevent transmission of HIV, how to live positively if one becomes infected and how to care for others living with the disease.

Health practitioners also often lack the necessary skills for dealing with disabled persons. They may stigmatise and discriminate against them due to their own negative attitudes against the disabled. Moreover, counselling, testing and support services are rarely modified to suit the needs of the visually-impaired. If a disabled person is infected with HIV, there is little support from the community due to social stigma. This may accelerate immunity deficiency and reduce life expectancy.

“Imagine for a moment that I am pregnant and going to seek prenatal services at my local health care clinic for the first time. I have a loving and caring partner and we are both overjoyed with the pregnancy but when I reach the clinic I am only met with disdain and pity from the nursing staff. “Shame!” they say... “Sorry!” “She’s disabled and now this...how will she manage?” they whisper...or even worse... “to think that someone should do this to her in her condition?”... With these degrading attitudes, we begin to see how easy it is for a young disabled woman to lose confidence in her local health care providers and to be discouraged from returning”<sup>4</sup>.

The exclusion of persons with disabilities is worsened by beliefs and myths that presume disabled persons to be asexual and at no risk of HIV infection. The reality, however, is that persons with disabilities have sexual desires just as do persons

without disabilities, but they are often denied the privacy to express their sexuality because of society’s belief that they need constant supervision. The disabled are, therefore, at higher risk of HIV transmission and infection because, firstly, they are deprived of their right to HIV and AIDS IEC. Secondly, the mere fact of being disabled puts a woman in double jeopardy. For example, cultural practices such as having sex with a disabled woman in the belief that someone will get cured of HIV exposes many women to the risks of HIV infection<sup>5</sup>.

### Initiatives and achievements

Despite the many challenges disabled people face in terms of access to HIV programmes, we must recognise that disabled people’s organisations (DPOs) in many countries have taken the lead in empowering their members to increase their

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knowledge on the pandemic through awareness training. Also, there has been some level of advocacy within some DPOs to sensitise AIDS service organisations (ASOs) on how to make their programmes more accessible. One example is that of the African Union of the Blind (AFUB) — an umbrella body for organisations and associations of blind and partially-sighted persons in Africa<sup>6</sup>.

Through its HIV and AIDS programme targeting visually-impaired persons in Cameroon, Ethiopia, Ghana, Kenya, Lesotho, Malawi, Rwanda, South Africa, Tanzania and Zambia; AFUB has trained visually-impaired peer educators who impart HIV and AIDS knowledge to other visually-impaired persons in their communities. In these countries, there are also lobby committees which include mainstream ASOs. These committees aim at sensitising mainstream AIDS service providers on how they can make their programmes and services more accessible to visually-impaired persons.



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Photo: Courtesy of Enablement



A disabled women at a meeting

Another important initiative is the formation of the African Campaign on Disability and HIV and AIDS. This was launched in January 2007 in Cape Town, South Africa and brings together DPOs, mainstream AIDS service providers, development agencies and civil society, with the aim of creating global awareness of the vulnerability of persons with disabilities on the impact of HIV and AIDS. The campaign also seeks to ensure equal access to HIV prevention, treatment, care and support services for PWDs and promote a coordinated response involving PWDs in African countries to achieve inclusive national HIV and AIDS policies and programmes. In March 2008 in Kampala, Uganda, the third Africa Campaign Conference brought together 170 delegates representing more than 20 African countries and 10 from outside the continent. Key achievements at this meeting were the creation of an important forum through which delegates shared their experiences, as well as different tools they had developed and resources on how to mainstream disability issues.

Another key achievement was the 'Kampala Declaration'. This communiqué is a call to governments, HIV and AIDS prevention specialists and service providers, the African Union AIDS portfolio, Africa AIDS Watch and DPOs to take up certain key roles and responsibilities to ensure equal inclusion and participation of disabled

persons in HIV and AIDS issues. Others enjoined in the communiqué were UNAIDS and its composite UN agencies — the UN High Commission for Refugees, the UN Children's Fund, the World Food Programme, the UN Development Programme, the UN Population Fund, United Nations Office on Drugs and Crime (UNODC), the International Labour Organisation, UN Education, Scientific and Cultural Organisation, World Health Organisation and the World Bank, funding agencies and development partners, independent research agencies and academic institutions.

The recently adopted UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which 130 UN member states are signatory, asserts that people with disabilities have the same human rights as everyone else. Providing people with disabilities with appropriate HIV services will also contribute to the goal of universal access to HIV prevention, treatment, care and support by 2010<sup>7</sup>, and to the millennium development goal of halting and beginning to reverse the spread of HIV by 2015.<sup>8</sup>

### The exclusion of persons with disabilities is worsened by beliefs and myths that presume disabled persons to be asexual and at no risk of HIV infection

Recently, UNAIDS and WHO have been working on a policy framework titled '*Disability and HIV& AIDS – UNAIDS and WHO policy brief*'. This document is still in its draft stages and different stakeholders from within and without the disability movement are giving their comments to enrich it.

It should be noted that for the first time, the International AIDS Conference included disability issues in its formal programme. Last year in Mexico, disability issues were part of the agenda and different players in the disability movement had a chance to share the concerns and needs of disabled persons with regard to HIV and

AIDS. Also, in December last year, the Africa Campaign on disability and HIV and AIDS made a presentation about disability and HIV and AIDS during the International Conference on AIDS and Sexually Transmitted Infections (ICASA) in Dakar, Senegal.

### Gaps and limitations

There are certain challenges, gaps and limitations in terms of equalising opportunities for disabled persons in as far as access to and participation in HIV and AIDS programmes and services are concerned. They include:

1. The coordinated integration of persons with disabilities (PWDs) and disability issues into UNAIDS, the International AIDS Society (IAS) and other high level international structures is yet to be realised.
2. Though international and national development agencies have well laid out policies at the central level, in many cases, these policies are not communicated properly and structures are not created nor resources clearly demarcated to ensure their implementation.
3. Although many organisations pursue a rights-based approach with gender and minorities in mind, when it comes to disability, it is still largely viewed as a social welfare issue. A distinct service delivery approach is adopted instead of mainstreaming the issues and concerns of people with disabilities into their main programmes<sup>9</sup>.

The following are some of the recommendations that will help push the campaign on disability and HIV to a higher level:

1. It is important that individuals with disability are reached by uniform HIV and AIDS education messages and services that serve other members of the general public. This need not require many resources.
  - For example, there are many posters, billboards and videos with AIDS messages, but these are not depicting individuals with disability (e.g. wheelchair users or blind individuals



as part of group scenes in AIDS IEC materials).

- HIV education, testing and service delivery programmes, as well as drug, alcohol and domestic violence programmes can be moved to accessible meeting places.
  - Making simple adaptations, such as allowing blind individuals to feel what a condom is and how it is used, rather than just talking to them about it.
  - Delivering simple AIDS messages, allowing intellectually-disabled individuals to hear safety messages often enough to allow them to memorise them.
  - Training AIDS educators, outreach workers and clinical and social service staff on disability issues.
  - Empowering disabled persons to be trainers. Individuals with disability should be trained as AIDS educators.
2. Adaptations should be made to AIDS outreach campaigns to ensure that individuals with disability are included as members of the general public. These may require a little more resources to effect and may include:
- Captioning of televised AIDS public service announcements for the deaf.
  - Making AIDS materials available for the blind, in inexpensive cassette formats.

- Building ramps at meeting halls or clinics (ramps can be made of mud, stone, bamboo, wood, etc.)
- Ensuring that HIV and AIDS information is disseminated in a variety of formats, such as radio and billboards to reach specific groups like the blind and deaf.
- Disability-specific adaptations should be made to existing materials and new materials should be developed to reach the disabled outside the bounds of the general public that target harder to reach individuals and populations.
- Having videos in sign language for the deaf.

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- Targeting schools and institutions serving disabled populations for special programmes to ensure that students and residents are informed.
  - Rewriting of training materials in simpler language and in easy-to-understand formats for those with intellectual impairments or for disabled individuals who are illiterate or have limited reading skills.
3. National HIV and AIDS strategic plans must recognise disability in its diversity and clearly allocate resources for disabled people.

### The way forward

From the studies carried out, and which have been referred to in this article, it has been established that HIV presents a significant threat to the disabled. Yet individuals with disability are rarely included in most HIV programmes. It is evident that the AIDS crisis cannot be adequately addressed without involving people with disabilities.

But all is not lost because some DPOs have taken steps in responding to HIV and AIDS through awareness creation, which has led to increased knowledge on the pandemic by the disabled. But a lot still needs to be done. However, more will be achieved if

stakeholders in the HIV field mainstream disability issues in their HIV and AIDS programmes.

Lastly, opportunities should be created for sharing experiences, success stories, innovations, challenges and lessons learned, as we strive towards reaching the disabled with effectively-targeted information on the HIV and AIDS pandemic - because disabled persons DO matter! ■

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Instructing the mother of a child with brain damage in Bangladesh