

# Pushing frontiers: Including the disabled in service provision



Photo: Courtesy of Enablement

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Education of deaf children in Nigeria

**People with disabilities (PWDs) are often excluded from HIV and AIDS education and care initiatives, partly due to the widespread perception that they are asexual. In reality they are just as sexually active as their non-disabled peers. At the same time, however, they are also often at much higher risk of sexual abuse from caregivers, partners and strangers who may see them as defenceless. Even where such abuse is reported, law enforcement officers and others in positions of authority tend to take it lightly.**

Gender inequality is a big issue regarding people with disabilities and HIV and AIDS. Not only is it driving the feminisation of the AIDS pandemic, but it is also leaving disabled women and girls more vulnerable to and more affected by physical and mental disabilities. Women and girls currently comprise 74 per cent of PWDs in low and middle-income countries yet they only receive 20 per cent of rehabilitation assistance worldwide.<sup>1</sup> The United Nations reports that “the combination of male preference in many countries and the universal devaluation of disability can be deadly for disabled females.”<sup>2</sup>

Despite the dire situation, there are innovative initiatives taking place on a local scale in Kenya and East Africa to address the impact of HIV and AIDS on people with disabilities. The Disability Programme at Liverpool VCT, Care and Treatment began with the provision of HIV services to deaf people through VCT centres in Kisumu, Mombasa and Nairobi in Kenya. At its inception as a programme for the deaf in 2003, it was the first major AIDS-related intervention for the hearing-impaired community in Kenya, and remains the only programme of its kind in Africa. It is run entirely by deaf counselling and administrative staff.

The key objectives of the programme are to raise awareness of HIV and AIDS among the deaf and people with disabilities, increase their access to VCT, care and treatment services and represent their needs at local, national and international policy conferences and fora.

The HIV services provided to the deaf and disabled people by deaf counsellors and peer educators meet the requirements of the national VCT quality assurance guidelines, which include measures to assess, monitor and improve the quality of both counselling and testing components of HIV testing and counselling (HTC) services.

## **The Liverpool way: breaking new ground**

The programme has provided confidential HIV testing and counselling to 12,000 clients with disabilities through its stand-alone clinics, as well as 200 mobile VCT service outreaches for people with disabilities between 2003 and 2008. The programme has also printed 500 copies of its manual, *Signs for Sexuality and Reproductive Health*, and trained 45 health care providers in Kenyan sign language.

The comprehensive nature of the initiatives of Liverpool Disability Programme and the way

they are embedded in Liverpool’s mainstream structure makes it a unique programme. Deaf project staff members are well integrated into the established, comprehensive structures of Liverpool’s main VCT, Care and Treatment programme, and the mainstream staff’s exposure to the Disability Programme helps to combat stigma at a systemic level. The disability programme does not discriminate against hearing people, since hearing clients attending the clinic work through an interpreter, inverting the norm of having deaf clients always needing to rely on an interpreter. This also contributes to dismantling the widespread ignorance and misunderstanding regarding the deaf community. The integrated nature of the Liverpool programme supports the deaf community and people with disabilities as they tackle HIV and AIDS issues and helps to reduce stigma both amongst health care workers and the broader community.

Recognising the specific challenges faced by women with various disabilities, the programme is also now addressing the issue of gender-based violence (GBV) within the deaf and disabled communities by providing support and referrals for survivors of GBV at their clinics. Gender-based violence within the deaf and disability communities generally has not been widely addressed and by taking it on, Liverpool VCT is, once again, breaking new ground.

## **Programme challenges**

Over the last five years, the Liverpool Disability Programme has demonstrated that deaf-to-deaf services are effective, efficient

and sustainable. Yet there are challenges. The 2007 Kenya National Survey for People with Disability revealed that the majority of people with disabilities live in rural areas, yet most VCT sites are located in urban areas. Reaching these rural communities requires more financial and technical support, time and creativity. Liverpool programme is trying to address this challenge through the expansion of their mobile outreach services, but is constrained by a lack of finance. The success of such initiatives and exchanges is, however, largely dependent on international support both in terms of policy and finances. The programme also still struggles to get mainstream AIDS service providers to deliver non-stigmatising, affirming and quality HIV services for all people with disabilities.

Liverpool Disability Programme encourages the replication of its model in other countries, and can serve as a source of information and support for others who wish to become more inclusive of people with disabilities but do not know where to start. The staff is willing to share its experience with other service providers and disabled people's organisations trying to bridge the gap between VCT services and people with disabilities.

### Recommendations and the way forward

Based on lessons learned in Kenya along with observation of other HIV and AIDS initiatives integrating people with disabilities in eastern and southern Africa, AIDS-Free World and Liverpool VCT recommend the

#### Lessons learned

- The mainstream staff's exposure to the Disability Programme helps to combat stigma at a systemic level.
- Hearing clients attending the clinic work through an interpreter and this contributes to dismantling the widespread ignorance and misunderstanding regarding the deaf community.
- The integrated nature of the Liverpool programme supports the deaf community and people with disabilities as they tackle HIV and AIDS issues and helps to reduce stigma both amongst health care workers and the broader community.

following for implementers looking to scale up the inclusion of persons with disabilities in their programmes:

#### 1. Including people with disabilities

- Promote access for people with disabilities to all mainstream health, legal, and police, and women's services.
- Conduct targeted services for people with disabilities if needed (such as home visits for those who cannot access health clinics, transportation services or outreach to rural areas).
- Budget organisational funds to support disability-specific programming.

#### 2. Research

- Collect disaggregated data on people with disabilities that use or access organisations' services.
- Conduct medical and social science research on HIV and AIDS and disability to further understand the overlap and how organisations can work to address it.
- Involve people with disabilities in the planning and implementation of this research.

#### 3. Combating Stigma

- Train and sensitise staff members to understand that disabled people have the same rights as everyone else in society. Sensitising police officers, lawyers, judges, doctors, community health workers, domestic violence shelters and women's rights organisations on the specific needs of disabled people will ensure that they interact with people with disabilities in affirming and non-stigmatising ways.
- Conduct campaigns to raise awareness about the Convention on the Rights of Persons with Disabilities.
- Disability institutions should provide a consistent and comprehensive sexual health/life skills package, of which HIV is one component.
- Disability institutions need to inform people with disabilities about abuse and exploitation.

#### 4. Advocate

- Ensure that organisations' advocacy positions in other areas, such as gender-based violence and access to

sexual and reproductive health, are inclusive of disability-related concerns.

- Reiterate the fact that disabled people have the same rights as everyone else in the society and that there is urgent need to include disabled people at local, national and international policy fora.
- Write and publish articles about disability and HIV and AIDS to encourage greater attention to the issue and feature them on organisational websites.
- Publicise success stories to provide models for other organisations to bridge the gap between HIV and disability.



Photo: Courtesy of Liverpool VCT

These recommendations may be useful to implementers who have the desire to better integrate people with disabilities into their work. For more ideas and guidelines, visit the AIDS-Free World website: [www.aids-free-world.org](http://www.aids-free-world.org). The website has a resource guide on HIV, AIDS and disability and is a good place to start a further investigation of the subject. ■

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2. United Nations Enable website, International Norms and Standards Relating to Disability, Rights of Women with Disabilities. Available at [www.un.org/esa/socdev/enable/comp504.htm](http://www.un.org/esa/socdev/enable/comp504.htm)