

INACCESSIBLE health services for people with disabilities (PWD), combined with social stigma and violence, contribute to high HIV risk - a gap that must be filled if the disabled are not to remain disproportionately vulnerable to HIV/AIDS, say health experts and activists.

"People with disabilities are at increased risk for exposure to HIV infection. HIV, in some cases in itself, can cause disability," said Jill Hanass-Hancock, a senior researcher at the Health Economics & HIV/AIDS Research Division (HEARD), a South African research institute.

Globally there are an estimated one billion people living with a mental or physical disability, according to the UN World Health Organization. Many live in low- or middle-income countries and have poorer health and little formal education compared to the general population.

"We cannot talk about reducing HIV and its co-morbidities if you exclude this 15 percent of the world's population," added Hanass-Hancock, speaking at the AIDS 2014 Conference, hosted by the International AIDS Society in Melbourne on 20-25 July.

Data are scarce; most national HIV monitoring or surveillance programmes do not specifically track incidence among people with disabilities.

An 2014 meta-analysis of data from Sub-Saharan

African countries showed that PWD are 1.3 times (1.48 for women) more at risk of contracting HIV than people without disabilities.

The 2014 "Gap Report" published by the Joint UN Programme on HIV/AIDS (UNAIDS) listed PWD as one of the key populations "left behind" in the global HIV response.

The no sex myth

Central to the struggle of PWD to gain inclusion in HIV response is breaking down the assumption that they are not sexually active and therefore do not need HIV services.

A 2014 Human Rights Watch (HRW) report on Zambia documented PWD describing how healthcare workers thought of them as "asexual".

"People with disabilities are people first. They have the same needs and desires when it comes to relationships and being sexually active," said Rosangela Berman Bheler, senior adviser at the UN Children's Fund (UNICEF).

Others caution that PWD are at greater HIV risk due to other factors.

"PWD are four times more vulnerable to sexual abuse and violence. This increases their risk for HIV infection," said Muriel Mac-Seing, HIV/AIDS protection technical adviser of Handicap International.

According to UNAIDS, "vulnerability, combined with a poor understanding and appreciation of their sexual and reproductive health



People with disabilities must be included in HIV response

needs, places people with disabilities at higher risk of HIV infection." A 2012 article in The Lancet showed that people with mental and intellectual disabilities were at particularly high risk of abuse and violence.

Access barriers

Betty Babirye Kwagala, a medical counsellor for The AIDS Support Organization

in Uganda, said the root of the heightened risk for people with disabilities can be seen in basic infrastructure.

"Services are not accessible - literally. Many health facilities do not have ramps or doors wide enough to accommodate people in wheelchairs," said Kwagala who has had a physical disability since a car accident when she was 19. Five years

ago she was diagnosed with HIV.

In her work as a medical counsellor, Kwagala has seen first-hand the lack of information and education materials suited for the needs of PWD, and a parallel lack of knowledge among health workers about how to communicate.

"How can a health worker who does not know how to

use sign language communicate with someone who is deaf? They usually use gestures. But you cannot use gestures when prescribing medication," said Kwagala.

Hanass-Hancock acknowledges bridging communication and understanding between health workers and PWD is critical to increasing the uptake of HIV services. But, she warns,

such interventions need to take social conditions into consideration.

“People with disabilities often depend on a care-giver. This has a great impact on getting information privately and confidentially,” said Hanass-Hancock, adding that strategies such as SMS outreach and counselling for hearing impaired people, or easy-to-understand picture books for people with intellectual disabilities need to be developed.

Data gap

HRW's research in Zambia, where one in 10 people has a disability, recommends a “twin-track approach starting with existing healthcare services more accommodating to PWD by simple things like widening doors”. PWD-specific interventions should be developed as well, they argue, and needs for either approach should be supported by improved data.

“We need to disaggregate the data to break it down by disability because all disabilities are different and will require different interventions. Then we can talk about creating tailor-fit services for them,” said Rashmi Chopra, a researcher on disability rights at HRW.

Lack of information - including about health and HIV - can leave PWD especially vulnerable in humanitarian emergencies.

The Sphere Standards, which set out best practice in the delivery of humanitarian

aid, encourage humanitarian actors to disaggregate data in their assessments, programming, and monitoring and evaluation tools by, among other things, noting if there is a disability involved.

However, Handicap International has critiqued the Sphere recommendation as insufficient to “mainstream a highly heterogeneous group such as [people with disabilities]”, and says recording the type of disability is crucial.

Despite the data gap, campaigners remain hopeful, saying the discussion has advanced from the days when the intersection between HIV and PWD was not even recognized.

“We must not forget that this is a dignity and human rights issue: most countries in the world - including donor countries - have ratified the UN convention on the rights of persons with disabilities (CRPD). It's time for them to be responsible for their disabled citizens,” said Muriel Mac-Seing, HIV and AIDS protection and technical adviser for Handicap International.

CRPD, which has been ratified by 147 countries, mandates that governments “provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.”(IRIN)