People with disabilities, HIV and AIDS

KEY POINTS:

- There is growing evidence that people with disabilities are at higher risk of HIV infection than people who are not disabled.
- People with disabilities often experience increased risk factors associated with acquiring HIV including poverty, increased vulnerability to sexual violence and abuse, limited access to education and healthcare, and lack the information and resources needed to facilitate safer sex.
- People with disabilities are often overlooked in HIV sexual and reproductive health and rights programming and face increased barriers to accessing services.
- HIV and disability are also linked as people can develop disabilities as a result of the progression of HIV or due to the side-effects of antiretroviral treatment (ART).
- Tackling HIV among people with disabilities needs a rights-based approach, which tackles barriers holistically so that wider issues such as gender-inequality and violence are addressed.

Explore this page to find out more about why people with disabilities are at risk of HIV, whether HIV can cause disability, making HIV services accessible to people with disabilities and involving people with disabilities in HIV programming.

More than one billion people, 15% of the world’s population, live with a disability. Four out of five people with disabilities live in low- and middle-income countries. This includes between 150 - 200 million children and adolescents (aged 0 to 18 years).

People with disabilities are not a homogenous group with common needs facing common barriers. The UN Standard Rules on the Equalization of Opportunities for Persons With Disabilities note that
disability identifies a great number of different limitations ... People are disabled by physical, intellectual or sensory impairments, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.4

Issues relating to disability have moved up the global development agenda in the last decade. In 2006, the UN Convention on the Rights of Persons with Disabilities, which as of October 2017 has been ratified by 172 countries, stated that people with disabilities should be included in all global development and health initiatives. The Sustainable Development Goals also include people with disabilities within several targets.5

HIV and disability are linked in a number of ways. Although HIV-related data on people with disabilities is extremely limited, growing evidence suggests disabled people are more likely to experience factors that put them at higher risk of HIV infection than people who are not disabled. In addition, there is a misconception that people with disabilities are sexually inactive or unlikely to use drugs or alcohol, which means they have been left out of HIV programming.6

A number of studies have found HIV prevalence among people with disabilities to be nearly the same or higher when compared to people without disabilities.7 For example, a 2012 survey in South Africa reported an HIV prevalence among people with disabilities of 16.7%. The same study found that 78% of people with disabilities felt that they were at a low risk of acquiring HIV.8 This is clear evidence that HIV programmes need to ensure that people with disabilities can access their services.

Conversely, HIV and disability are linked as people can develop disabilities as a result of the progression of HIV or due to the side-effects of antiretroviral treatment (ART).9 With the rapid expansion of ART across the globe, this underexplored field is likely to become increasingly important, with an ever growing need to effectively integrate disability services (detecting and treating disabilities) within HIV programmes.

Why are people with disabilities at risk of HIV?

Exclusion from programming

People with disabilities are often overlooked in HIV prevention, testing and treatment programming and sexual and reproductive health and rights (SRHR) services and face increased barriers to accessing services.10

Often family, caregivers, employers and health-care providers fail to fully understand or appreciate the sexual and reproductive health needs of people with disabilities.11 In addition, many people with disabilities are unaware of their sexual and reproductive health and rights.

Intersecting vulnerabilities

People with disabilities experience all of the risk factors associated with acquiring HIV. They are often at an increased risk because of poverty, face severely limited access to education and
healthcare, and lack the information and resources needed to facilitate safer sex. Often, they lack legal protection and are vulnerable to abuse and stigma.12

In 2014, the prevalence of violence against people with disabilities — irrespective of the type of disability — was found to be 1.3 times higher than in the general population, 1.39 times higher among women with disabilities and 3.86 times higher among people with mental health conditions. Children with disabilities were found to be 3.7 times more likely than their non-disabled peers to be the victims of violence.13

Violence against young people with disabilities perpetrated by teachers, other staff and fellow students is common in educational settings. Students with disabilities often experience physical threats and abuse, verbal abuse and social isolation.14

Women with disabilities and HIV

The vulnerabilities that put people with disabilities at higher risk of HIV are amplified by gender inequality.15

Women and girls with disabilities face particularly severe discrimination. Evidence suggests women with disabilities fare worse than both women without disabilities and men with disabilities when it comes to poverty, education and vocational success.16

A study from sub-Saharan Africa revealed a gradient in the risk of HIV infection according to gender and disability status, with risk increasing for men with disabilities and even more so for women with disabilities when compared to non-disabled men.17

Risk of sexual abuse and exploitation

People with disabilities, particularly women and girls, are more vulnerable to sexual violence and abuse.18

Studies have found that the prevalence of sexual abuse experienced by people with disabilities is higher, especially for institutionalised men, women with intellectual disabilities, and adolescents.19 Disabled women and girls from low-income communities fare particularly badly as they are at heightened risk of sexual abuse yet experience extremely limited or non existent access to SRHR services, leading to unwanted pregnancies, HIV and other sexually transmitted infections (STIs).20

Several factors contribute to this higher risk. Some people with disabilities may need personal assistance with daily living, which may put them in a position of vulnerability. They may also have reduced physical and emotional defences and experience communication barriers, which hamper their ability to protect themselves or report abuse and violence. Disability-related stigma and discrimination also fuels acts of sexual violence or abuse against people with disabilities while at the same time preventing disabled people from feeling they are able to report it.21

Research has found the incidence of intimate partner violence experienced by people with disabilities to be high.22

Sexual violence, abuse and intimate partner violence experienced by people with disabilities is a significant public health and human rights issue which fuels this population’s vulnerability to HIV.23

CASE STUDY: Deaf women and sexual violence protection in rural Cambodia
This project, led by Handicap International, targeted deaf women and people with disabilities
in two rural provinces of Cambodia between 2008 and 2012.

Although awareness levels among people with physical impairments in these areas were found to be similar to the general population, people with disabilities were taking more risks in sexual relationships. In addition, respondents with sensory impairments reported having little or no access to sexual health services and messages. A starker reality also emerged: 40% of deaf women participants reported being survivors of sexual violence and/or of sexual abuse attempts.

Sign language classes and HIV and sexual violence prevention sessions were organised within the communities. A number of women who had taken part in the workshop were then trained to become future trainers and awareness-raising facilitators for other deaf women.

The fact that these activities were run in the communities where deaf women lived helped to build trust with parents and families. Capturing regular feedback from deaf women, their families and implementing partners during each part of the project also helped improve the quality of its implementation.24

Stigma and discrimination

People with disabilities often experience stigma and discrimination relating to their disability. This can lead to low self-esteem and social isolation – a pervasive experience of many people with disabilities – and can leave them open to violence and abuse.

Disabled people face the double burden of stigma and discrimination if they are also living with HIV. This is further compounded by reduced political and civic engagement and participation.25

Stigma and discrimination acts as a major barrier preventing people with disabilities from accessing the HIV and SRHR services they are entitled to. A study examining the experiences of a group of Zambian people with disabilities living with HIV revealed that stigma was apparent in a variety of settings, including while waiting for treatment, within interactions with healthcare providers, and within their communities. Not only did participants recount stories of internalised stigma but negative experiences also resulted in some participants admitting suicidal thoughts – one person said they preferred to “die quietly at home” rather than attempting to access ART.26

Similarly, the results of a study of 30 disabled adults from Mpumalanga Province, a rural area of South Africa, suggest that the barriers to HIV services that participants experienced extended far beyond physical obstacles. Many reported how experiences of discrimination, social exclusion and isolation stopped them from accessing services, underpinned by numerous context-specific experiences, including exposure to violence.27

Barriers when accessing healthcare

People with disabilities often face multiple barriers to accessing healthcare. This is, in part, because people with disabilities have not been included in the design and development of these services and hence have not been able to articulate their needs.28

Moreover, people with different types of impairments may experience different barriers when accessing healthcare. Logistical barriers include being reliant on someone else for mobility or communication, support in accessing clinic-based services, or lacking the financial means to travel to a clinic, especially if it is far way.

A study by Human Rights Watch on the barriers to HIV treatment for people with disabilities in
Zambia described how being reliant on others often jeopardised adherence for disabled people. When third-party support was not available, respondents reported being forced to miss scheduled appointments. However, rather than being allowed to reschedule or given longer courses of antiretrovirals (ARVs) to reduce the number of times they needed to attend the clinic, health workers often labelled them as ‘defaulters’. This required them to have more frequent appointments and limited their supply of medicine, and increased the overall likelihood their treatment would fail.29

For people with disabilities who are able to attend a clinic, a further set of practical barriers may stop them accessing effective HIV services. For instance, many HIV testing and counselling programmes provide limited counselling in sign language for people with hearing impairment or the counselling given may be incomprehensible to people with intellectual impairment.30

Many people with disabilities also experience a lack of confidentiality when testing for HIV because of communication barriers and the need to involve a third person for interpretation.31

In addition, many health workers lack the necessary knowledge, skills and resources to provide these accessible, appropriate services. As a result, people with disabilities may also be put-off from seeking healthcare because of bad treatment.32 Globally, more than 10% of women and 23% of men living with a disability reported not returning to seek healthcare because they were treated badly during a previous visit. 33

...the doctor was surprised at me. He had laughed at me saying, “Can you also have HIV?” I then answered him that, “Doctor, I’m human. I also have the same feelings that you have. It’s only that the legs are the ones that differentiate us”... A disease that an able-bodied person can have, even me I can have it.

-A disabled person living with HIV in Zambia34

Exclusion from education and sex education

Knowledge about HIV among people with disabilities is generally low, due in part to difficulties in accessing any kind of HIV education. Information materials and approaches to disseminating information are rarely adapted to the diverse communication and physical needs of people with disabilities. The lack of appropriate information is thought to limit the ability of people with disabilities to access and understand safer sex messages or to negotiate safer sexual behaviours.35 For example, the Zambian study mentioned above, people with sensory or physical impairments reported experiencing difficulties in being instructed on how to use condoms correctly, in a way that would take their disability into account.36

Because physical and communication barriers mean people with disabilities are often isolated from their own communities, they are often also excluded from community-based awareness raising activities about HIV prevention and sexual health.37

An analysis of Uganda’s 2011 Demographic and Health Survey found people with disabilities reported significantly higher rates of sexually transmitted infections (STI), despite reporting comparable knowledge of the need for safer sex practices and greater knowledge than those
without disabilities about the need to use condoms to reduce risk of HIV. This suggests that, even in contexts where levels of knowledge among people with disabilities are comparable to people without disabilities, disabled people are less able to engage in safer sex, for instance through the use of condoms. This may be due to a lack of accessible places to buy condoms, embarrassment or harassment while buying condoms or being unable to afford them. It may also point to lack of ability to negotiate safer sex practices, regardless of knowledge.38

The right of people with disabilities to access information is denied at a young age. Adolescents with disabilities are far more likely to be excluded from sex education programmes than other adolescents due to communication barriers, discomfort about sexuality and disability, concerns about appropriate content of sexuality education and fear of promoting sexual activities.39

A study among 12 to 19-year-olds in Oyo State, Nigeria, found significantly more people with mild/moderate intellectual disabilities reported having sexual experience compared to those without intellectual disabilities (62.2% vs 37.8%), yet intellectual impairment was significantly associated with lower knowledge of HIV transmission. In addition, when compared with non-disabled participants, those with mild/moderate intellectual disabilities were significantly more likely to have reported inconsistent condom use and non-use of condom during last sexual activity.40

Can HIV cause disability?

The rapid expansion of ART has seen millions more people on treatment in recent years. This has resulted in a significant decline in AIDS-related deaths. However, as HIV becomes a chronic long-term illness, evidence on HIV-related disabilities is emerging. Further research, as well as specific policies and services, are needed to ensure people are given the right support and healthcare to prevent HIV-related disability and cope with it if it happens.

HIV-related disability can be short-term, fluctuating or permanent. Indeed, the fact that HIV can cause temporary loss of function has led to campaigners to call for health-related rehabilitation to be better integrated into the HIV care continuum, making referrals easier. This would not only address pre-existing disabilities but also impairments relating to HIV.41

HIV-related disabilities may stem from secondary conditions relating to HIV, particularly in cases where people are not on treatment or where treatment is failing. This highlights the need for people living with HIV to be on effective treatment so that they are able to achieve viral suppression, which is when the level of HIV in someone’s body is so low it will not affect their health.

HIV-related disability may also stem from side effects relating to ART, although these have lessened as ARVs have been developed.42 As people living with HIV are at high risk of developing a disability, disability screening and services should be integrated within HIV services to help counter this risk.

Some HIV-related disabilities are described below.

HIV-associated neurocognitive disorders (HAND)

HIV-associated neurocognitive disorders (HAND) affects brain functioning. HAND is generally characterised as mild, moderate or severe, the latter of which is known as HIV-associated dementia. This is the most debilitating type of HAND, which typically occurs after years of HIV and is associated with advanced stages of HIV. The main features are disabling cognitive impairment accompanied by motor dysfunction, speech problems, and behavioural change.43
Evidence from high-income countries suggests severe forms of cognitive impairment appear to be on the decline, but prevalence of mild impairment is largely unchanged and may even be increasing.44

The largest ever study on the relationship between HAND and aging suggests that people living with HIV face a heightened risk of developing neurocognitive impairment when getting older, even if they are on ART and are virally suppressed.45 With 50% of people living with HIV now over the age 50, and 30% over the age of 60, studies such as this are increasingly important.46

**HIV-associated peripheral neuropathy**

This is a disease of the peripheral nervous system, associated with pain, weakness, and sensations such as burning and numbness. It can lead to nerve damage and can reduce quality of life. The condition is generally irreversible and sometimes requires aggressive pain management, including the use of narcotics. More advanced HIV and older age are associated with increased frequency of this disability.47

**Lipodystrophy**

Sometimes known as ‘fat wasting’, this refers to the reduction of body fat, particularly in the face and distal extremities, such as the arms and feet. Although less disabling, increases in body fat, known as lipohypertrophy, can also occur. These disorders are mainly cosmetic, but in rare instances they can result in permanent disfigurement and pain, or both, and can reduce a person’s ability to walk, stand or sit. Importantly, they can also affect the quality of someone’s life due to depression, fears of stigma, and social isolation. This is particularly true if the disorder occurs in the face.48

**HIV-related disabilities in low- and middle-income countries**

People living with HIV in low- and middle-income countries often face factors that might put them at greater risk of developing HIV-related disabilities and OIs such as malnutrition and irregular access to ART. As a result, the poorest countries in the world carry the greatest burden of HIV-related disability.

The magnitude and scope of HIV-related disabilities in sub-Saharan Africa was indicated by a 2015 systematic evidence review. This found HIV-related disability to be common in the region, affecting individuals of all ages and a wide range of impairments. In 73% of comparative studies, significantly lower levels of functioning in people living with HIV across a range of impairment types were reported. Developmental delay stood out as most strongly linked to HIV, with prevalence as high as 78% in children with HIV in one study and a significant factor in 15 of 17 studies analysed. Overall, around half (48%) of studies that analysed HIV progression found a statistically significant relationship between worsening HIV and the presence of a disability.49

Another systematic review found around one in four people living with HIV in low- and middle-income countries suffered hearing loss, a much higher prevalence compared to people without HIV.50

**Making HIV services accessible to people with disabilities**

HIV programmes must be disability-responsive, which means they need to address the needs of people with disabilities and ensure that they are accessible. For example, a disability-responsive HIV prevention programme would address the lack of written information for people with visual...
impairment by providing information in a larger font or in Braille.\(^{51}\)

Not only should mainstream HIV services ensure access for people with disabilities, initiatives targeting people with disabilities through specific interventions and messages are needed to operate in conjunction. This is known as the twin track approach. \(^{52}\)

For this to happen, people with disabilities need to be fully included in national HIV responses, something UNAIDS called for in its 2014 GAP Report.\(^{53}\) However, the UNAIDS Fast Track Strategy 2016-2020 mentions disability only twice, and some in the global disability community have argued it is unclear how these inclusions can be operationalised. Major donors such as PEPFAR and the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) also have no disability focus.\(^{54}\)

South Africa and Uganda are among a handful of African countries to include people with disabilities in their national strategic plans (NSPs). Both are making progress towards inclusive programming and policies and more disability-friendly programmes and services are beginning to appear.\(^{55}\)

South Africa first included disabled people in its NSP in 2007-2011. As a result, issues relating to disability are included in the South Africa HIV Treatment Guidelines.

...it is only through involving disabled people themselves in their diversity that we will be successful in addressing HIV and AIDS in our country.

- Hendrietta Ipeleng Bogopane-Zulu, Deputy Minister of Social Development, South Africa \(^{56}\)

A number of disability organisations are now working on the HIV response. Some are helping increase access to treatment for people with disabilities, others have trained counsellors with disabilities to work in voluntary testing centres to counsel both disabled and non-disabled clients and free HIV testing is encouraged at disability meetings. In order to improve access to information and services for deaf people, sign language interpreters have been trained on issues relating to HIV and assigned to HIV clinics in many urban areas.\(^{57}\)

Handicap International has had several successes in getting disability integrated into HIV programming, funding strategies and national strategic plans. For instance, the organisation’s work in Senegal saw the inclusion of disability in the country’s 2011—2015 NSP. As part of this work, the government of Senegal has added people with disabilities to its official list of populations vulnerable to HIV infection. The NSP includes a focus on specific HIV prevention services for women and men with disabilities and allocates resources to support these services. They are also being included in nationwide epidemiological and behavioural surveys. This inclusion of, and sensitivity towards, disability issues in a West African country’s NSP is a significant breakthrough.\(^{58}\)

Similar work in Ethiopia has resulted in people with disabilities being successfully included in Ethiopia’s 2010/11—2014/15 NSP for the first time in the country’s history.\(^{59}\)
Before the peer educator taught me about HIV and AIDS, I did not have any information about it and I also never thought that my disability could make me vulnerable to HIV. I did not know that blind women had a high chance of getting raped.

- *Tsehay, a young blind woman in Addis Ababa, Ethiopia*

The Central American System of Social Integration has also adopted a declaration on disability and HIV, with clear recommendations. In line with international conventions, many central American governments have enacted laws and acts that provide for the rights and rehabilitation of people with disabilities.

Similarly, the Africa Campaign on HIV and Disability, advocates for the inclusion of people with disabilities in health-related matters. This campaign has brought together a number of African countries, including Algeria, Cameroon, Congo, Ethiopia, Kenya, Malawi, Namibia, Nigeria, Rwanda, South Africa, eSwatini, Uganda, the United Republic of Tanzania and Zimbabwe.

**The meaningful involvement of people with disabilities in HIV programming**

To be truly effective, HIV programmes for people with disabilities must be inclusive of a range of disabilities through, for example, the provision of information through multiple formats, aimed at people with different cognitive capacities.

Involving people with disabilities in the design and implementation of HIV programming is essential to ensuring the diverse needs of people with disabilities are met. Yet people with disabilities are often denied the opportunity to articulate their specific needs or be heard, owing to their marginalised position in society. Working with organisations led by people with disabilities, in order to build their capacity to deliver and support HIV services, is key to this.

Zimbabwe is one of a handful of countries in the world to implement a mainstream HIV and AIDS peer counselling training programme for people with disabilities. The 3-year programme (2014-2016), led by the National Association of Societies for the Care of the Handicapped with funding from the Global Fund, trained 1,500 people with disabilities as HIV and AIDS peer counsellors. Its results are expected in late 2017.

In Uganda, people with disabilities have been involved in the HIV response since 2005 when the Disabilities Stakeholders’ HIV/AIDS committee (DSHAC), a coalition of around 15 disabled persons’ organisations, was established. DSHAC has played a significant role in coordinating Uganda’s disability community around issues relating to HIV by ensuring disabled people are represented at Uganda’s highest national HIV/AIDS Committee. DSHAC has also organised participation of people with disabilities in the National AIDS Conference and in World AIDS Day activities; raised awareness of the marginalisation of people with disabilities in HIV programmes locally, nationally and internationally; participated in the development of Uganda’s HIV NSP to include people with disabilities, and developed a Disability National HIV/AIDS Strategic Plan.

**CASE STUDY: Empowering people with visual impairments in Kenya to access HIV**
This project, led by Handicap International, focused on increasing access to HIV information and services for people with visual impairments in Kenya. It was implemented in Nairobi, Kiambu and Machako in 2012.

A committee of people with disabilities and disability support organisations guided the project’s design and implementation.

Materials were produced in large print and Braille and audio messaging. Topics included HIV prevention, the challenges faced by people with visual impairments in disclosing their HIV status, multiple stigma faced by people with disabilities in relation to HIV, the challenges experienced by people with visual impairments in accessing testing and counselling services, and barriers to adhering to ART. (For instance, one challenge is that people could not use sight to distinguish the different ARVs they had to take.)

Radio talk shows were also organised so that people with visual impairments as well as non-disabled people could learn more about HIV, STIs and TB.

Community mobilisation and awareness-raising was carried out by disabled peer educators who also conducted home visits to help people with visual impairments learn how to use condoms in the privacy of their homes.

As a result, 8,800 people with visual impairments were reached with HIV information on prevention, treatment and care; 23 community discussion sessions were organised; and 3,000 people with visual impairments went for counselling and testing.

Putting rights at the heart of the HIV response

The fact that people with disabilities are highly vulnerable to HIV is indicative of the fact that marginalised, stigmatised communities with limited access to basic human rights are frequently at higher risk of HIV infection and feel the impact of HIV and AIDS more significantly than the general population.

For this reason, tackling HIV among people with disability needs a rights-based approach. This means tackling barriers holistically so that wider issues such as gender-inequality and violence are addressed. It also means recognising that people with disabilities are a hugely diverse group with a wide range of needs that can only be identified and addressed by enabling people with disabilities to lead the design and implementation of HIV programmes. Strengthening disabled people’s organisations is pivotal to this, as is strengthening the promotion and defence of disability rights in the global HIV response.

The way forward

For national HIV responses to genuinely address the unmet and diverse needs of people with disabilities, more research and evidence on HIV prevalence in people with disabilities, the factors that put them at risk of HIV, and the barriers they face to accessing services is needed. Evidence is also needed on effective ways to integrate screening for impairment and referral to rehabilitation within HIV programmes.

The lack of data relating to people with disabilities is a major issue throughout the world. The gathering of comprehensive data on disability, disaggregated by factors such as disability type, gender and socioeconomic status, will be the first step to convincing policy-makers and programme managers to change course and stop excluding people with disabilities from the HIV response. It is also the foundation on which inclusive programming must be built. Yet, despite some progress
within a handful of countries, epidemiological and behavioural data on HIV and people with disabilities is largely non-existent.72

The absence of data reflects an overall failure to recognise the SRHR needs of people with disabilities and a failure to develop services that will respond to these needs.73 Understanding the specific realities of people with disabilities better will help to remove barriers and improve the provision of HIV and other SRHR services.

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46. ibid


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