



# A focus on disability is necessary to achieve HIV epidemic control

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Provision of inclusive services and reaching marginalised groups are crucial to achieving the UNAIDS 95-95-95 targets by 2030. However, people with disabilities are often left behind. This gap in HIV care provision is important because more than 1 billion people worldwide have disabilities, including a quarter of people living with HIV. The association between HIV and disability is bidirectional: HIV can cause a range of physical, sensory, and cognitive impairments and people with disabilities are at higher risk of acquiring HIV. People with disabilities often have lower levels of access and adherence to HIV treatment due to barriers with regard to the provision of services (eg, inadequate knowledge among health-care workers and inaccessibility of facilities) and the demand for services (eg, absence of autonomy and awareness of people with disabilities of HIV care needs and service availability). Ultimately, these barriers arise from failures at the system level, including poor governance, leadership, financing, and paucity of data.

## Introduction

Reaching marginalised groups is crucial for achieving UNAIDS 95-95-95 targets by 2030 (by 2030, 95% of people living with HIV are aware of their status, of whom 95% are on antiretroviral therapy (ART), and 95% of people on treatment have suppressed viral load), but people with disabilities are often left behind.<sup>1</sup> This is an important oversight since more than 1 billion people worldwide have disabilities,<sup>2</sup> including at least a quarter of people living with HIV.<sup>3</sup> The association between HIV and disability is bidirectional, arising both from the increased risk of acquiring HIV among people with disabilities, and the disabling effects of the virus itself, side-effects of ART, and concurrent infections. People living with HIV and disabilities therefore includes people with HIV-related impairments, and people with disabilities who acquired HIV (figure 1). Adherence to HIV treatment is likely to be lower among people with disabilities than those without disabilities due to inaccessibility of services.<sup>4,5</sup>

## HIV and disability

The association between HIV and disability is well established.<sup>4-8</sup> A systematic review of 61 studies from sub-Saharan Africa showed that among people living with HIV, there was a high prevalence of physical impairment (median 25%), visual impairment (11%), hearing impairment (24%), cognitive impairment (40%), and developmental delay in children (68%).<sup>3</sup> Subsequent reviews confirmed the association between HIV and depression,<sup>9</sup> musculoskeletal conditions in children,<sup>10</sup> cognitive impairment,<sup>10-13</sup> hearing impairment,<sup>14,15</sup> and developmental delays.<sup>10,16,17</sup> People with disabilities are a diverse group, including people from different geographical regions, people in different demographic groups, and people with different impairment types. HIV risk might be particularly high among certain groups, such as women, people living in poverty, and people with intellectual or hearing impairments.<sup>4,6,7</sup>

HIV might lead to impairments and disability through different pathways. HIV can cause neuronal damage or trigger inflammation, leading to cognitive impairments,

as one example.<sup>12</sup> Opportunistic infections in people with HIV (eg, toxoplasmosis, syphilis, cytomegalovirus, and herpes) might cause conditions such as meningitis or encephalitis that can result in sensorineural hearing loss and cognitive impairment.<sup>12</sup> Impairments could also arise from drugs administered to treat co-infections such as tuberculosis (eg, ototoxic drugs, such as aminoglycosides, can cause hearing loss<sup>18</sup>) and potentially from long-term use of ART (eg, lower bone mineral content as a result of treatment with tenofovir disoproxil fumarate-based ART;<sup>19</sup> mixed evidence for the association between cognitive impairments and ART<sup>12</sup>). As described in the Episodic Disability Framework, HIV-related disability is often considered episodic, characterised by fluctuating periods of wellness and impairment over time and influenced by contextual factors and life events.<sup>20-23</sup>

People with disabilities might also have a higher incidence of HIV infection than people without disabilities.<sup>6,7</sup> This increased risk could result from direct factors, such as higher frequency of transactional sexual relationships, sexual violence, and sexually transmitted infections,<sup>4,24,25</sup> and more indirect structural risk factors, such as poverty and stigma.<sup>4,7,25-27</sup> People with disabilities often face barriers accessing HIV prevention

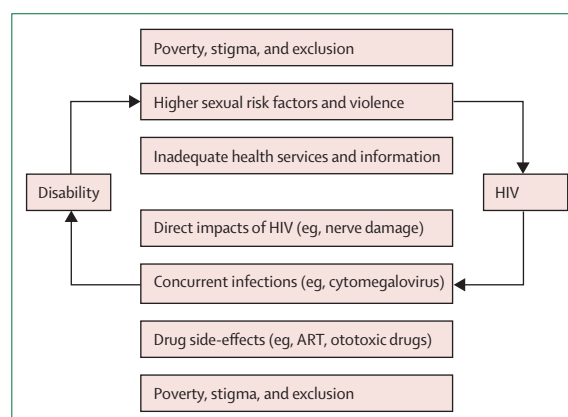


Figure 1: Association of HIV and disability  
ART=antiretroviral therapy.

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services—eg, due to insufficient funds, negative attitudes, and physical inaccessibility.<sup>2,28–30</sup> Adults with disabilities might have difficulties accessing sexual health services due to incorrect assumptions that they are not sexually active.<sup>24</sup> Children with disabilities might not receive school-based education about HIV as they are frequently excluded from school, the pedagogy might not be inclusive of disability, or teachers might not be confident teaching children with disabilities about sex and HIV.<sup>31,32</sup> Consequently, people with disabilities in general have less awareness of HIV and thus might exhibit more high-risk behaviour than those without disabilities.<sup>24,25,29,33,34</sup>

Disability therefore needs to be a focus of HIV programmes. People with disabilities need to be included in mainstream HIV prevention services (eg, training for health-care workers on how to communicate with people with disabilities), and might also benefit from targeted programmes (eg, peer-led counselling for people who are deaf).<sup>35</sup> People with HIV-related impairments will require referral to rehabilitation and support services. People with disabilities are not a homogeneous group, which will influence their risk of HIV acquisition and need for HIV prevention services and rehabilitation. Campaigns to increase knowledge and awareness might need a particular focus on women with disabilities,<sup>7</sup> or people with intellectual or hearing impairments.<sup>4</sup>

### HIV service access by people with disabilities

People with disabilities face a range of barriers in accessing HIV services, including testing, ART, treatment for co-infections, and rehabilitation.<sup>4,5,29,36–38</sup> These barriers arise for several reasons. People with disabilities are on average poorer than people without disabilities and incur many disability-associated costs, and consequently often face financial barriers.<sup>4,7,37,39,40</sup> Health-care services are frequently physically inaccessible, or do not provide information in accessible formats.<sup>37,41</sup> Health-care workers might have scarce knowledge on disability, and negative attitudes about disability, and often face constraints in caregiving

due to scarcity of equipment, resources, and staff.<sup>29,41–43</sup> People with disabilities might have insufficient family support or understanding, and awareness, about their condition and availability of services.<sup>37,40</sup> Rehabilitation workforces and services are often scarce,<sup>2,44–46</sup> particularly in resource-poor settings.<sup>46</sup> A study among paediatric HIV service users in Malawi showed that, although 33% of service users screened positive for disability, 67% had never received rehabilitation despite being enrolled in a clinical service.<sup>17</sup> Certain groups of people with disabilities might be more at risk of being left behind, such as people with a lower level of education, mobility or hearing impairments, or more severe impairments.<sup>26</sup>

These barriers to care can be conceptualised from a health system perspective (figure 2).<sup>44</sup> Barriers exist in relation to service demand, from the perspective of the person with disabilities, regarding issues with autonomy, knowledge and awareness, and affordability of services. Barriers regarding provision of services can also exist from the perspective of the health-care providers, including poor disability awareness and inadequate skills among health-care professionals, inaccessible health facilities, and scarcity of specialised services. These barriers occur due to underlying systems failures, such as inadequate governance or political will (ie, policies and laws), poor leadership on disability within HIV programming, inadequate health financing to support provision of disability-inclusive services, and scarcity of data and evidence, including a paucity of data obtained through routine information systems. These barriers result in a lower frequency of HIV testing<sup>26,47,48</sup> and ART adherence<sup>8,21,49–51</sup> among people with disabilities, and are likely to result in worse health outcomes. US studies have shown higher mortality rates among people living with HIV who had disabilities,<sup>52</sup> including neurocognitive impairment, than people living with HIV without disabilities or neurocognitive impairment.<sup>53</sup> A Malawian study reported that mortality rates from HIV were higher among people with disabilities than people without

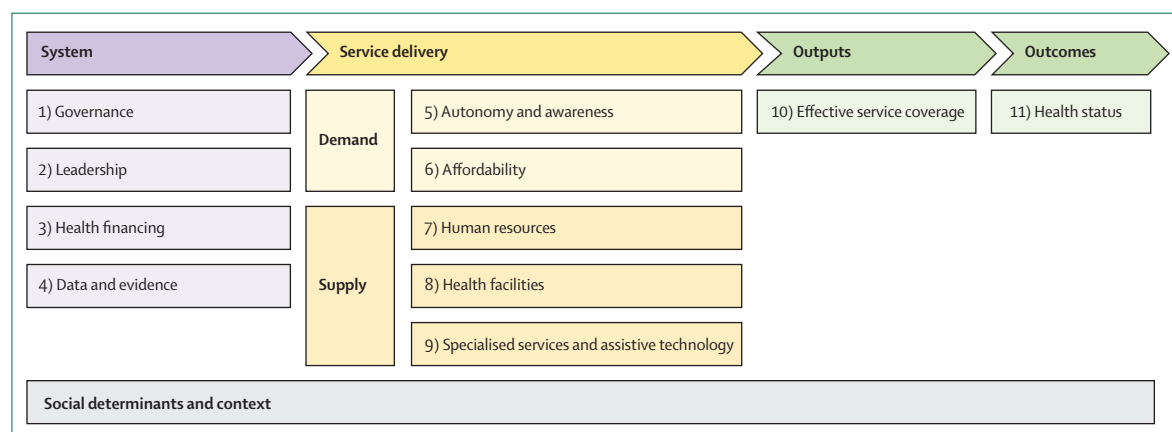


Figure 2: Framework of inclusive health systems

Developed through a literature review and expert consultation. Adapted from Kuper and Heydt.<sup>44</sup>

disabilities, although differences between groups were not statistically significant.<sup>54</sup>

### Consequences of health system failures

Health system failures have important negative consequences for individuals, aside from the effect on mortality. People living with HIV and disabilities frequently report worse quality of life, educational and social exclusion, and poorer mental health than those with HIV alone.<sup>5,55</sup> Exclusion of people with disabilities will also hamper efforts to reach global targets such as the UNAIDS 95-95-95 targets. This point can be illustrated through simple models.

In 2020, approximately 83% of people with HIV living in Tanzania had been tested for HIV.<sup>56</sup> A reasonable estimate is that a group of 1000 people living with HIV will include at least 250 people with disabilities (figure 3).<sup>3</sup> The existing literature also indicates, conservatively, that people with disabilities are 10% less likely to be tested and therefore to know their status than people without disabilities.<sup>4,26</sup> Therefore, for a hypothetical group of 1000 people living with HIV selected from the population (750 people without disabilities and 250 people with disabilities), 830 will know their status; however, we assumed this number would be 10% higher among the 750 people without disabilities (85% of people aware of their status) than the 250 people with disabilities (77% aware of their status). To reach 95% testing coverage by 2030, the prevalence of testing would need to increase by 1.2% each year across the whole group. However, the model shows that to reach 95% testing coverage by 2030, 97% of people without disabilities would need to know their status to compensate for the fact that only 88% of people with HIV with disabilities will have been tested. The model also shows that over time, a growing proportion of people who remain untested will be those with disabilities and eventually these individuals will represent the majority of untested individuals. This model is highly simplistic and does not account for new HIV infections or deaths. However, the model illustrates that it will be difficult to achieve HIV testing targets without the inclusion of people with disabilities.

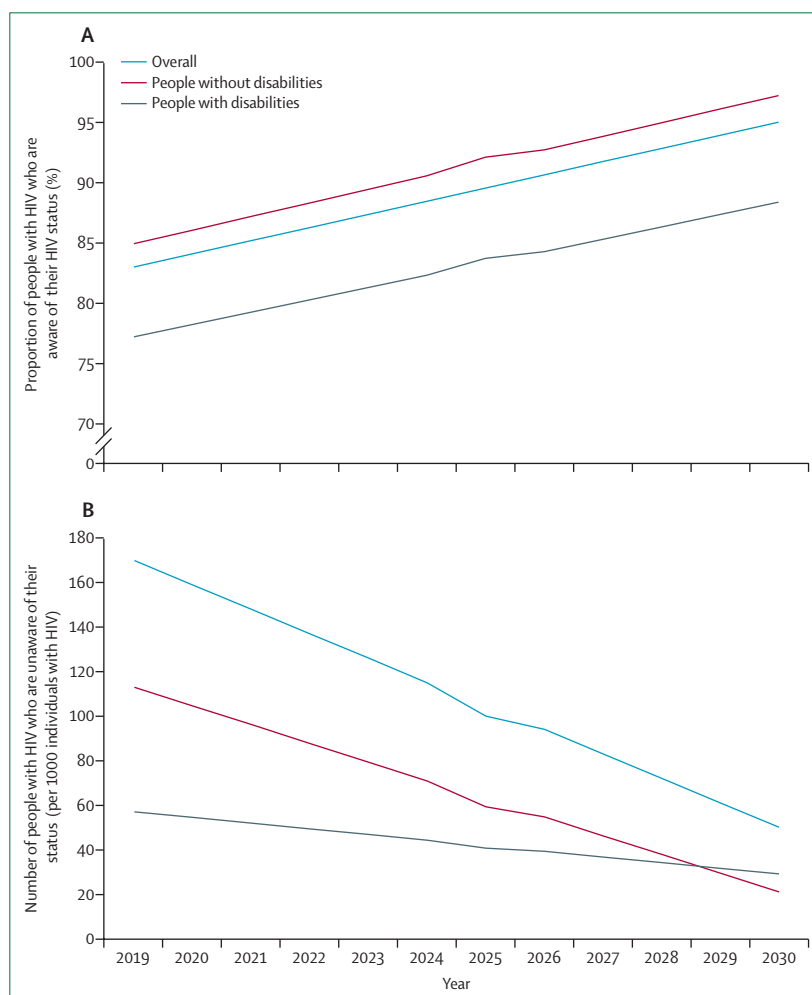
The situation might be even more stark for adherence to treatment. In a cohort of 1042 people living with HIV in Kwazulu Natal, 83% fully adhered to treatment,<sup>50</sup> which was higher than for people living with HIV in South Africa overall (68% in 2018).<sup>56</sup> In this study, 36% of participants had disabilities (indicated by functional limitations), and adherence was lower among people with disabilities (76%) than people without disabilities (86%). Using a similar modelling as that used for testing, to reach the 95% adherence target by 2030, 99% adherence among people without disabilities would be required to compensate for adherence reaching only 88% among people with disabilities (figure 4). By 2030, 90% of people not receiving treatment would be people with disabilities.

### Development of inclusive HIV systems: good practice examples

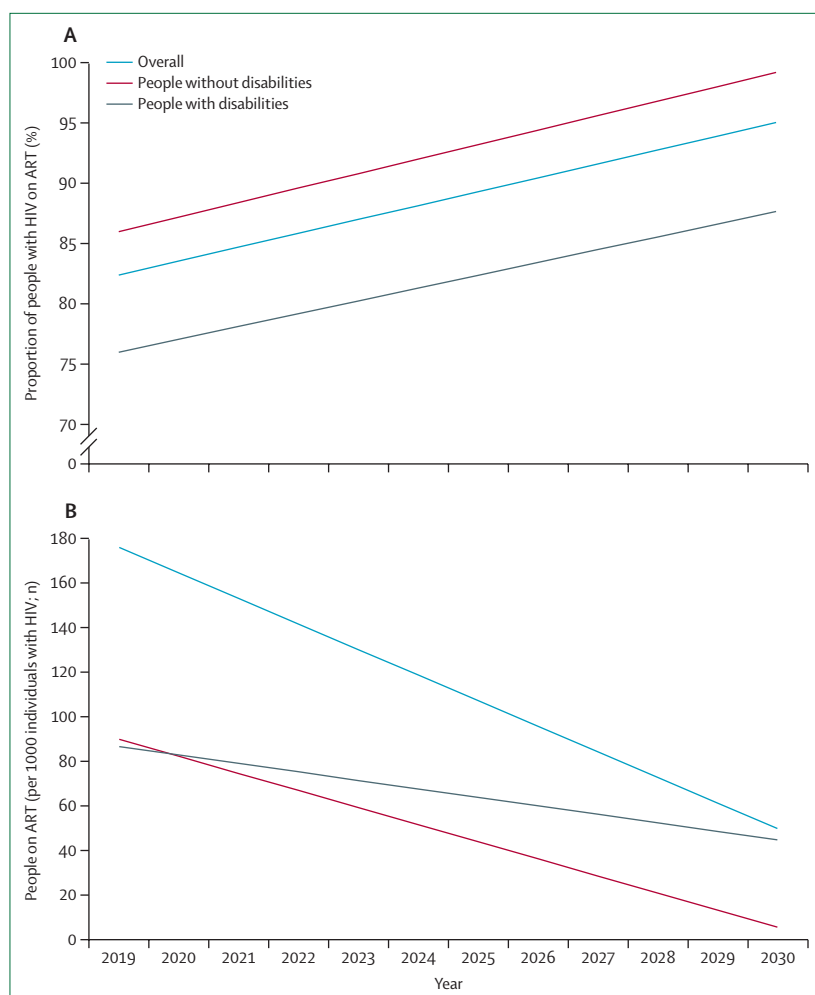
**System level factors: governance, leadership, financing, and data**

Continuing to ignore disability and failing to recognise it in HIV strategies and prevention programmes will make it difficult to reach HIV targets, and the wellbeing of people with disabilities will decline. A shift in how HIV service delivery systems are constructed is needed to enable improved disability inclusion in HIV services and linkage to rehabilitation.<sup>57</sup> There is unlikely to be a single solution, and instead interventions will be needed across different components of the health system, informed by people with disabilities.

Many national policies recognise the specific needs of people with disabilities.<sup>58</sup> 14 of 18 National Strategic Plans (NSPs), specifically for HIV programming, of eastern Africa and southern Africa identified people with disabilities as a high-risk or marginalised population.<sup>58</sup>



**Figure 3: Modelled estimates of the proportion of people living with HIV in Tanzania, by disability (2019–30)** (A) Proportion of people with HIV who are aware of their HIV status. (B) Number of people with HIV who are unaware of their HIV status per 1000 individuals with HIV. Data from Tanzania.



**Figure 4: Modelled estimates of the proportion of people living with HIV, by ART status and disability (2019–30) in South Africa**

(A) Proportion of people with HIV on ART. (B) Number of people not on ART (per 1000 people with HIV). Data from South Africa. ART=antiretroviral therapy.

13 of 18 NSPs proposed targeted programmes for people with disabilities. The South African NSP was the most disability-inclusive and could serve as an example for other countries.<sup>59</sup> The importance of people with disabilities is also recognised in international HIV policy. The 2021 UNAIDS Political Declaration on HIV and AIDS and the 2021 WHO consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring noted the high risk of HIV among people with disabilities and their need for inclusion in services.<sup>60,61</sup> However, rehabilitation is seldom included in the WHO guidelines, and has not been incorporated in the UNAIDS Political Declaration. Further review and improvements in national and international policies will be important to ensure disability inclusion.<sup>57</sup>

Examples of disability-inclusive leadership are sparse; there is a specialist adviser for Disability Health HIV at the South African National Department of Health, and

Rehabilitation International train emerging leaders focused on HIV and disability in Tanzania and Mozambique.<sup>62</sup> Few examples of health financing investments exist to support inclusion of people living with HIV and disabilities, and funding agencies need to work harder to include disability in their programmes.<sup>57</sup> The need for data and evidence generation is becoming recognised.<sup>58</sup> The South Africa NSP specifies the need for both disaggregation of HIV data by disability and disability-specific targets.<sup>59</sup> The results framework of the Zimbabwe NSP includes targets for the proportion of people with disabilities reached by combination HIV prevention and sexual and reproductive health and research programmes.<sup>63</sup>

#### **Factors affecting service demand: autonomy, awareness, and affordability**

Improving awareness about HIV, and autonomy in decision making about care, can be achieved through educational outreach, particularly if people with disabilities are included in development and delivery.<sup>34</sup> Delivery of comprehensive sexuality education that is inclusive, such as the Breaking the Silence Programme,<sup>64</sup> is one approach that is likely to be effective. Issues of affordability could be ameliorated through provision of social protection. Consequently, the NSPs, specific for HIV, of Lesotho and Uganda<sup>65,66</sup> recognise the need to strengthen social protection for people with disabilities, and the South African NSP advocates for economic empowerment of people with disabilities.<sup>59</sup>

#### **Factors affecting service provision: human resources, health facilities, and specialised services**

The need for training on disability is recognised, including by health-care workers,<sup>43</sup> and can help inform them about disability<sup>67</sup> and improve their ability to communicate with people with a range of impairments. Designing accessible facilities from the start is more cost-effective than adapting inaccessible facilities. However, low-cost interventions might be helpful to improve accessibility of existing services, such as implementing a disability desk to assist people with hearing, visual, or intellectual impairment, or by installing ramps at clinics.<sup>67</sup> Many people living with HIV and disabilities can benefit from community-based rehabilitation, rehabilitation, assistive technology, and other specialised services.<sup>37,68–73</sup> Multidisciplinary services are therefore needed, ideally near the community, to support the range of impairments associated with HIV.<sup>38,40</sup> However, these services are scarce, particularly in Africa where HIV prevalence is highest, although efforts are underway to scale up rehabilitation services at the global level.<sup>74</sup> Additional innovative approaches might also be needed, such as the use of mobile technology, home-based rehabilitation, or task-shifting.<sup>27,37,73,75–77</sup> Routine screening of people living with HIV for impairments, potentially integrated into their routine check-ups, could help in the identification of need and referral to these services.<sup>40</sup> This approach will require training of relevant health-care

workers and community-care workers about disability screening.<sup>40</sup>

## Conclusions

HIV policies and programmes need an increased focus on disability, and should also strengthen links with rehabilitation services, to enable people living with HIV and disabilities to thrive and survive, while also allowing global HIV control targets to be met. HIV programme implementers and donors need to start investing in analysis, data, and action on removing access barriers for people with disabilities in all areas of HIV programming.

### Contributors

All authors contributed to the conceptualisation of the paper. HK wrote the first draft and created the graphs. PH created figure 2. All authors read and approved the final version.

### Declaration of interests

We declare no competing interests.

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