Viewpoint: A focus on disability is necessary to achieve HIV epidemic control

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Summary

In this viewpoint, we describe the adverse consequences of failing to provide inclusive services for achieving UNAIDS' 95:95:95 targets, including through generating models of testing and adherence data. Reaching vulnerable groups is critical for achieving the 95-95-95 targets by 2030. However, people with disabilities are often left behind. This gap is important because over one billion people worldwide have disabilities and at least a quarter of people living with HIV have disabilities. The link of HIV and disability is bi-directional: HIV can cause impairments and people with disabilities are at higher risk of acquiring HIV. People with disabilities also often have lower levels of access to and adherence with HIV treatment, as they face barriers at the supply-side (e.g. poor healthcare workers knowledge, inaccessibility of facilities), and demand-side (e.g. lack of autonomy and awareness of people with disabilities). Ultimately, these barriers arise from systems-level failures, including poor governance, leadership, financing and data on this issue. We outline good practice examples of how HIV services can be strengthened across components of the health system so that they also work for people with disabilities.

Reaching vulnerable groups is recognised as critical for achieving UNAIDS' 95-95-95 targets by 2030, but people with disabilities are often left behind.[1] This neglect is an important oversight as over one billion people worldwide have disabilities,[2] and at least a quarter of people living with HIV have disabilities.[3] The association of HIV and disability is bidirectional, arising both from the increased risk of acquiring HIV among people with disabilities, as well as the disabling effects of the virus itself, side-effects of ART and co-occurrent infections. People with disabilities are more likely to have lower levels of adherence to HIV treatment because of inaccessible services.[4,5] In this viewpoint, we elaborate on the adverse consequences of failing to provide inclusive services for achieving the 95:95:95 targets, and ways to strengthen HIV services to also work for people with disabilities.

HIV and disability

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

The relationship of HIV and disability is bi-directional as HIV may lead to disability, and people with disabilities are at higher risk of HIV infection (Figure 1). People living with HIV and disabilities therefore includes people with HIV-related impairments, as well as people with disabilities who acquired HIV.

HIV may lead to impairments and disability through different pathways. HIV itself may cause neuronal damage or trigger inflammation, leading to cognitive impairments, among others.[12] Opportunistic infections (e.g. toxoplasmosis, syphilis, CMV, herpes) may cause conditions such as meningitis or encephalitis that can result in sensorineural hearing loss and cognitive impairment.[12] Impairments may

also arise from drugs administered to treat co-infections such as TB (e.g. ototoxic drugs causing hearing loss[18]) and potentially from long-term use of ART (e.g. lower bone mineral content for TDF-based ART,[19] mixed evidence for cognitive impairments and ART use[12]). HIV-related disability is often described as being "episodic", as described in the Episodic Disability Framework, characterized by fluctuating periods of wellness and impairment over time, and influenced by contextual factors and life events.[20-23]

People with disabilities may also have a higher incidence of HIV infection.[6,7] This higher risk may result from proximal factors, such as higher frequency of paid sexual relationships, sexual violence, and STIs,[4,24,25] and more distal structural risk factors, including poverty and stigma.[4,7,25-27] People with disabilities often face barriers accessing HIV-prevention services, for example due to lack of funds, negative attitudes, and physical inaccessibility.[2,28-30] Adults with disabilities may have difficulties accessing sexual health services due to inappropriate assumptions that they are not sexually active.[24] Children with disabilities may not receive school-based education about HIV as their school may not be accessible, the pedagogy disability-inclusive, or because teachers are not confident teaching children with disabilities about sex and HIV.[31,32] As a consequence, people with disabilities on average have poorer knowledge about HIV and may exhibit riskier behaviour.[24,25,29,33,34]

Disability therefore needs to be a focus in HIV programming. People with disabilities need to be included in mainstream HIV-prevention services (e.g. by training healthcare workers to also communicate with people with disabilities) and may also benefit from targeted programmes (e.g. peer led counselling for people who are deaf).[35] People with HIV-related impairments will require linkages to rehabilitation and support services. People with disabilities are not a homogenous group, which will influence their risk and need for services. For instance, knowledge and awareness campaigns may need to particularly focus on women with disabilities,[7] or people with intellectual or hearing impairment. [4]

HIV service access by people with disabilities

People with disabilities also face a range of barriers in accessing HIV services, including testing, ART, treatment for co-infections and rehabilitation.[4,5,29,36-38] These

barriers arise for a number of reasons. People with disabilities are on average poorer and incur many disability-related costs, and consequently often face financial barriers. [4,7,37,39,40] Services are frequently physically inaccessible, and/or fail to provide information and communication in accessible formats.[37,41] Healthcare workers may lack knowledge and have negative attitudes about disability, and often face constraints in care-giving due to lack of equipment, resources and staff.[29,41-43] People with disabilities may lack family support or understanding/awareness about their condition and availability of services.[37,40] There is also often a lack of rehabilitation workforce and services,[2,44-46] particularly in the poorest settings. [46] For example, a study among paediatric HIV service users in Malawi showed that while 33% screened positive for disability, 67% of these children with disabilities had never received rehabilitation despite being enrolled in a clinical service.[17] Certain groups of people with disabilities may be particularly left behind, such as people with less education, mobility or hearing impairments, or more severe impairments.[26]

These barriers can be conceptualised from a health system perspective, as described in Figure 2. This health system framework was developed through literature review and expert consultation. [44] Barriers at the service delivery level occur on the demand side, from the perspective of the person with disabilities, in terms of issues with autonomy, knowledge and awareness, and affordability of services. Supply-side barriers can also exist from the perspective of the healthcare providers, including lack of disability awareness and skills among healthcare professionals, inaccessible health facilities, and lack of specialised services. These observable barriers occur due to underlying systems failures, such as lack of governance or political will (i.e. policies and laws), lack of leadership on disability within HIV programming, inadequate health financing to support provision of disability-inclusive services, and lack of data and evidence, including through routine information systems. The result of these barriers is that people with disabilities will have poorer outputs, such as a lower frequency of HIV testing,[26,47,48] and ART adherence.[8,21,49-51] Health outcomes will also be worse. Studies from the USA have shown higher mortality rates among people living with HIV who had disabilities,[52] or neurocognitive impairment.[53] A Malawian study reported that mortality rates from HIV were higher among people with disabilities, although without statistical significance.[54]

Health system failures will make 95:95:95 targets hard to reach

There are important negative consequences of these health systems failures for individuals, aside from the impact on mortality. People living with HIV and disabilities frequently experience worse quality of life, educational and social exclusion, and poorer mental health compared to those living with HIV alone.[5,55] Exclusion of people with disabilities will also hamper efforts to reach global targets such as the UNAIDS' 95:95:95 targets (by 2030, 95% of people living with HIV are aware of their status, of whom 95% are on ARTs, and 95% of people on treatment have suppressed viral load) . We can illustrate this point through simple models.

In 2020, approximately 83% of HIV-infected people living in Tanzania had been tested for HIV.[56] A reasonable estimate is that an average group of 1000 people living with HIV will include at least 250 people with disabilities (Figure 3).[3] The existing literature also indicates, conservatively, that people with disabilities are 10% less likely to be tested and therefore to know their status.[4,26] Therefore, for a hypothetical 1000 people living with HIV selected from the population, 830 will know their status, but this will be higher among the 750 people without disabilities (here, we assume 10% higher - 85%) than the 250 people with disabilities (77%). To reach 95% testing coverage by 2030, the testing prevalence will need to increase by 1.2% on average each year across the whole group. However, the model shows that in order to reach 95% testing coverage by 2030, 97% of people without disabilities will need to know their status to compensate for the fact that 88% of people with disabilities will have been tested. The model also shows that over time a growing proportion of those who remain untested will be people with disabilities and eventually they will make up the majority of those untested. This model is highly simplistic, not taking account of new HIV infections or deaths. However, it illustrates that it will be difficult to achieve HIV testing targets without including people with disabilities.

The situation may be even more stark for adherence. In a cohort of 1042 people living with HIV in Kwazulu Natal, 83% fully adhered to treatment[50] (higher than for South Africa overall[56]). In this study, 36% of participants had disabilities (indicated by functional limitations), and adherence was lower among people with disabilities (76%) compared to those without (86%). Undertaking a similar modelling as for

testing shows that reaching the 95% adherence target by 2030 will require 99% adherence among people without disabilities to compensate for adherence reaching 88% among people with disabilities (Figure 4). By 2030, 90% of those not adhering would be people with disabilities.

Developing inclusive HIV systems: good practice examples

Continuing to ignore disability and recognize it in HIV strategies and programming will make it difficult to reach HIV targets, and wellbeing of people with disabilities will suffer. A shift is needed in how HIV service delivery systems are constructed, supporting both better inclusion in HIV services and linkages to rehabilitation.[57] There is unlikely to be one magic bullet, and instead interventions will be needed across different components of the health system, informed by people with disabilities themselves. Some good practices are outlined below, corresponding to categories in the framework, showing how change is possible.

Systems level factors: Governance, leadership, financing and data:

Many current national policies now recognise the specific needs of people with disabilities.[58] Fourteen out of 18 of the National Strategic Plans (NSPs) of East and Southern Africa identified persons with disabilities as a vulnerable or marginalised population.[58] Thirteen proposed targeted programs for persons with disabilities. The South African NSP was the most disability-inclusive and could serve as an exemplar for other countries.[59] The importance of people with disabilities is also recognised in international HIV policy. Both 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 people with disabilities and their need for inclusion in services.[60,61] However, little mention of rehabilitation is made in the WHO guidelines, and it is absent from the UNAIDS political declaration. Further review and improvement in national and international policy to ensure disability inclusion will be important.[57]

Examples of disability-inclusive leadership are sparse; there is a specialist Advisor for Disability Health HIV at the South African National Department of Health, and Rehabilitation International train emerging leaders focussed on HIV and disability in

Tanzania and Mozambique.[62] There are also few examples of health financing investments to support inclusion of people living with HIV and disabilities, and funding agencies need to work harder to include disability in their programming. [57] The need for data and evidence generation is becoming recognised.[58] The South Africa NSP specifies the need for both disaggregation of HIV data by disability and disability-specific targets. [59] The results framework of the Zimbabwe NSP includes targets for the proportion of people with disabilities reached by HIV combination prevention and SRH programs.[63]

Demand-side factors: Autonomy, awareness and affordability

Improving awareness about HIV, and autonomy in decision making about care, can be achieved through education outreach, particularly if people with disabilities are included in development and delivery.[34] Delivery of Comprehensive Sexuality Education that is inclusive, such as the "Breaking the Silence Programme", is one approach likely to be effective.[64] Issues of affordability may be ameliorated through provision of social protection. Consequently, the NSPs of Lesotho and Uganda,[65,66] as examples, recognise the need to strengthen social protection for people with disabilities, and the South Africa NSP advocates for economic empowerment of people with disabilities.[59]

Supply-side factors: Human resources, health facilities, specialised services

The need for training on disability is recognised, including by healthcare workers,[43] and can help sensitize them around disability,[67] and improve their ability to communicate with people with a range of impairments. Designing accessible facilities from the start is more cost-effective than retrofitting inaccessible facilities. However, low cost interventions may be helpful to improve accessibility of existing services – such as implementing a disability desk to assist people with hearing, visual or intellectual impairment, or installing ramps to clinics.[67] Many people living with HIV and disabilities can benefit from community-based rehabilitation, rehabilitation, assistive technology and other specialised services.[37,68-73] Multi-disciplinary services are therefore needed, ideally near the community, to support the range of impairments connected to HIV. [38,40] However, these services are woefully lacking, particularly in Africa where HIV prevalence is highest, although efforts are underway to scale-up rehabilitation services at a global level.[74] Additional

innovative approaches may also be needed, such as the use of mobile technology, home-based rehabilitation or task-shifting. [27,37,73,75-77] 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.[40] This approach will require training of relevant healthcare and community care workers about disability screening.[40]

Conclusion

HIV policies and programmes need to increase their focus on disability. They must also strengthen links with rehabilitation services, so that people living with HIV and disabilities can thrive as well as 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.

Figure 1: Association of HIV and disability

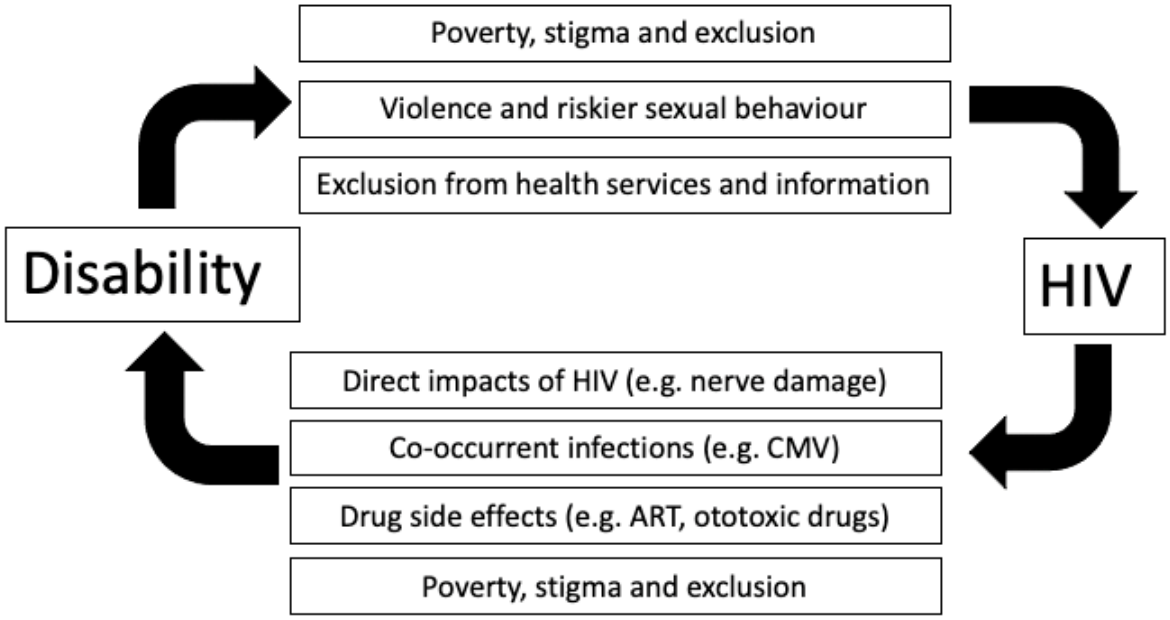

Figure 2: Framework of inclusive health systems

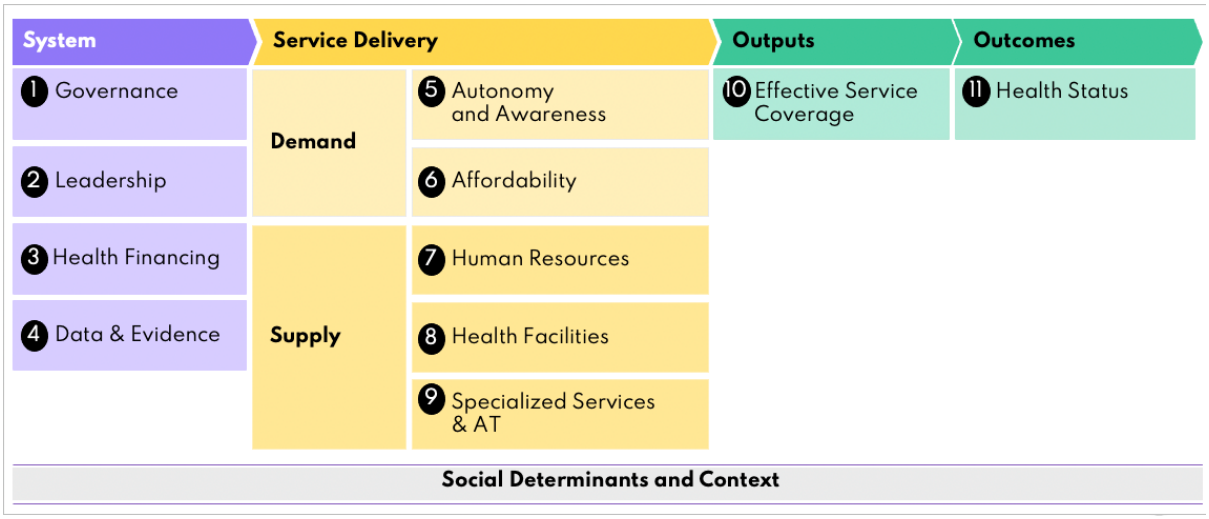

Figure 3a) Extrapolation of the percentage of people living with HIV who know their status 2019-2030, by disability. Tanzania*

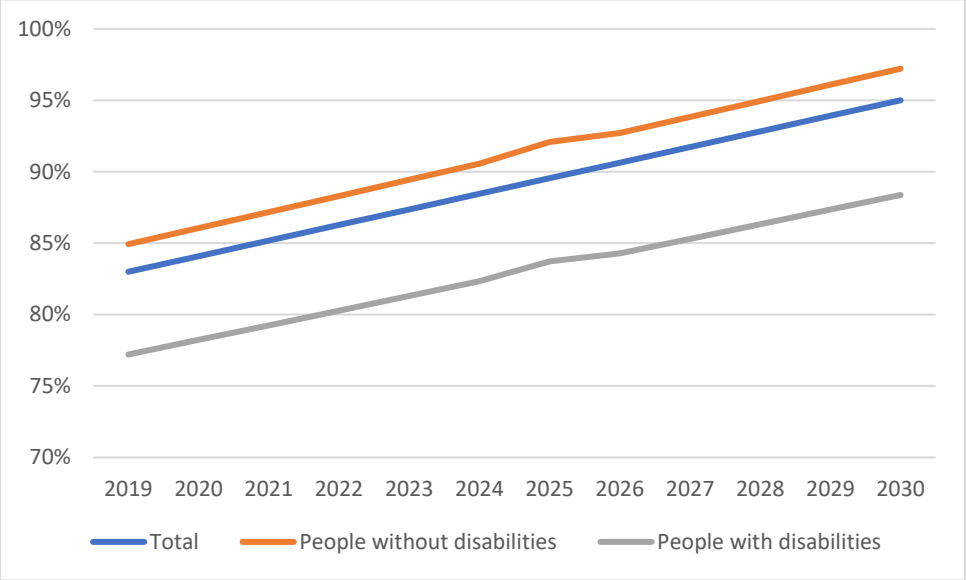

*Figure produced based upon a simple model on data on HIV in Tanzania,[56] prevalence of disability among people with disabilities,[3] and discrepancy in HIV testing by disability status.[4,26]

Figure 3b) Extrapolation of number per 1000 people living with HIV 2019-2030, who do not know their status, by disability. Tanzania*

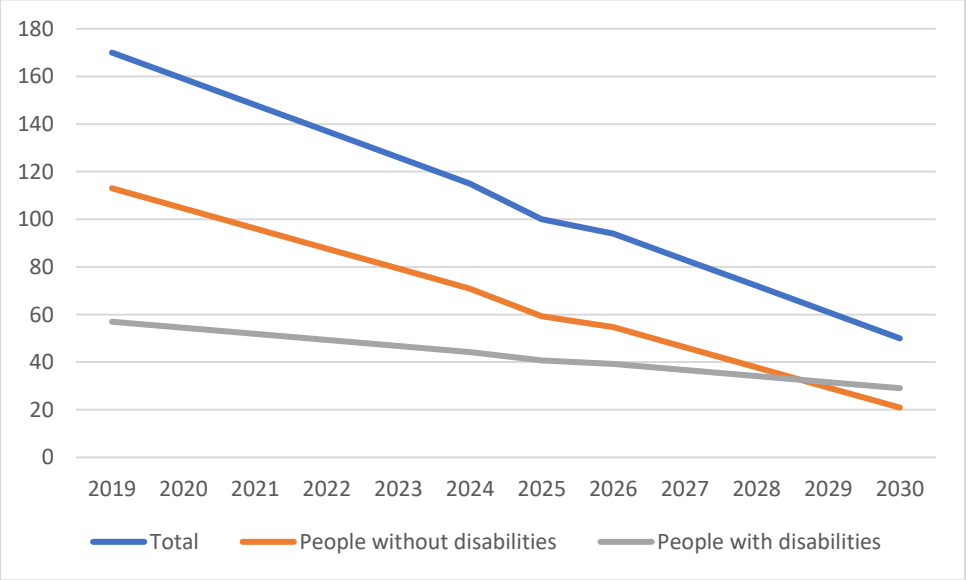

*Figure produced based upon a simple model on data on HIV in Tanzania,[56] prevalence of disability among people with disabilities,[3] and discrepancy in HIV testing by disability status.[4,26]

Figure 4a) Extrapolation of the percentage of people living with HIV who are on ART 2019-2030, by disability. South Africa*

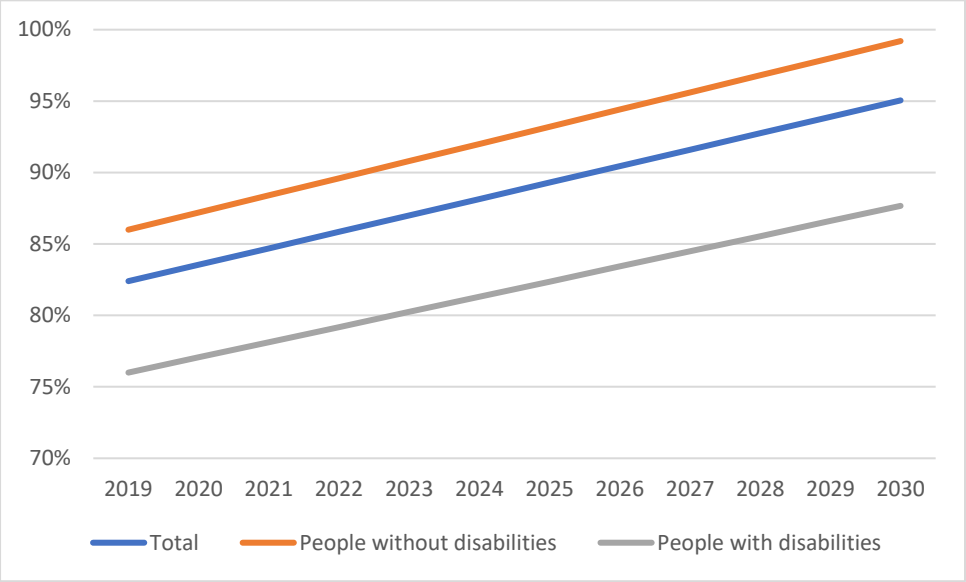

*Figure produced based upon a simple model on data on HIV in South Africa, prevalence of disability among people with disabilities, and discrepancy in adherence by disability status.[50]

Figure 4b) Extrapolation of number per 1000 people living with HIV, who do not receive ART 2019-2030, by disability. South Africa*

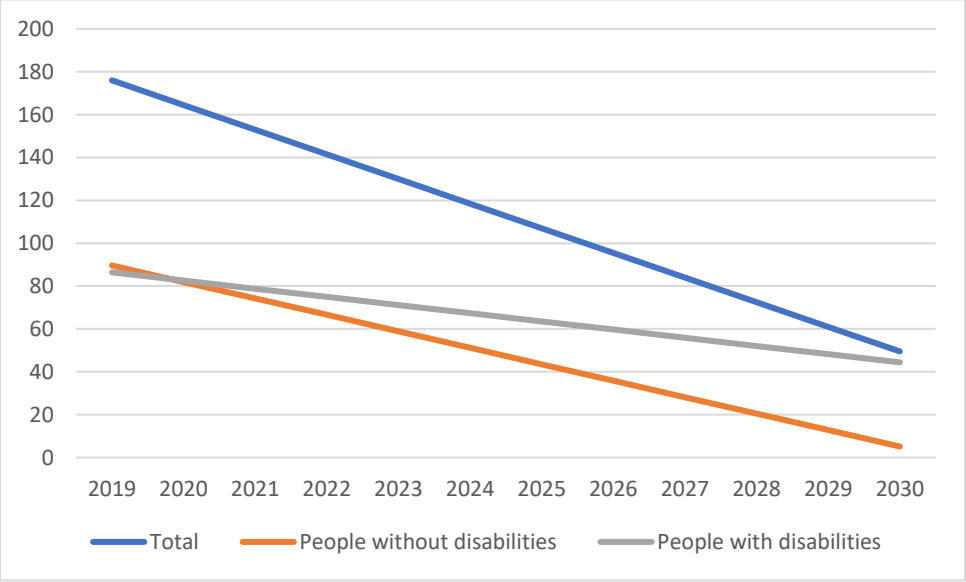

*Figure produced based upon a simple model on data on HIV in South Africa, prevalence of disability among people with disabilities, and discrepancy in adherence by disability status.[50]

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Authors' contributions

HK, PH and CD all 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 interest

The authors have no conflicts of interest.