

Disability and HIV



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Introduction

This report highlights existing key evidence on the relationship between disability and HIV. It discusses the concrete steps needed for a person-centred, disability-inclusive HIV response that allows for increased participation of people with disabilities and integrates rehabilitation within the continuum of HIV care.

Globally, it is estimated that 1 billion people (15% of the world's population) have a disability. Of those aged over 15 years, approximately 110–190 million (2.2–3.8%) experience significant disabilities (1). Disability is increasing in prevalence due to ageing populations, trauma, accidents and the increase in chronic health conditions, including HIV (1). Persistent discrimination against and exclusion of people with disabilities, in particular women and girls with disabilities, increases their vulnerability, including their risk of HIV infection.

While the Millennium Development Goals were silent on disability, the new Sustainable Development Goals feature a strong will to “leave no one behind”, including people with disabilities (2). Similarly, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (3) calls on state parties to ensure the rights of people with disabilities to participate and be included in all spheres of life, including specific articles relating to the right to access health services, including sexual and reproductive health, and rehabilitation services. CRPD also recognizes that “women and girls with disabilities are at greater risk” and need specific protection from negligence and violence.

What is “disability”?

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (3).

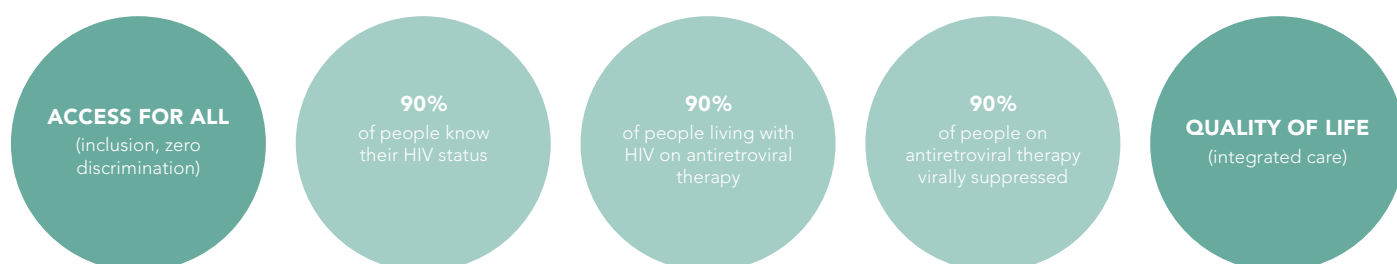
Disability results “from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (3).

Nevertheless, the United Nations Secretary-General's 2016 report on the Fast-Track to end the AIDS epidemic and the United Nations Political Declaration on Ending AIDS (4) recognize that people with disabilities, in particular women and girls with disabilities, experience barriers to accessing HIV services and are left behind in HIV policy-planning, programme development, service delivery and data collection. These documents also highlight that increased vulnerability and exclusion are linked to legal and economic

inequalities, gender-based violence and human rights violations against people with disabilities, including the provision of health care.

The UNAIDS 2016–2021 Strategy calls to Fast-Track the HIV response and to reach the people being left behind. The strategy highlights the bold effort needed to reach the 90–90–90 targets, to close the testing gap and to protect the health of the 22 million people living with HIV who are still not accessing treatment. To reach this goal requires zero discrimination, person-centred responses, equal access to health programmes and services, including sexual and reproductive health and rights, and integration of rehabilitation into HIV care to enhance quality of life (5) (Figure 1).

Figure 1. Inclusion and integrated care as a necessity to end AIDS



Disability and HIV

Access to HIV services

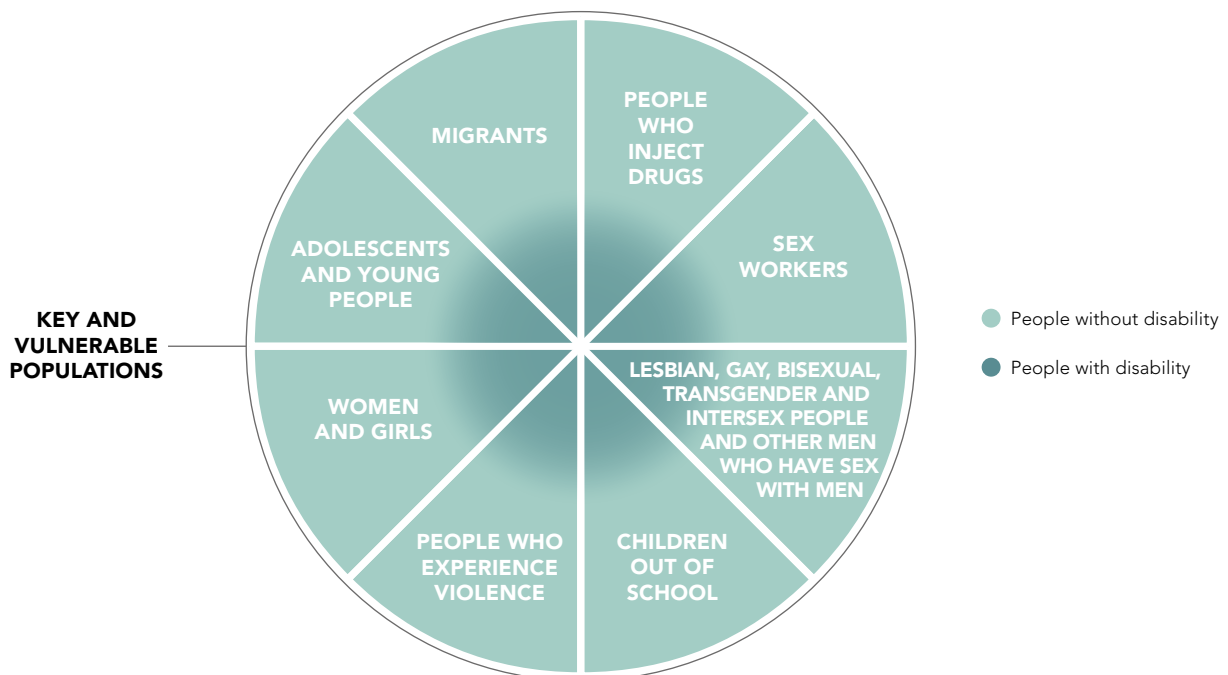
People with disabilities have been excluded and neglected in all of the sectors responding to HIV. HIV prevalence data among people with disabilities are scarce. Data from sub-Saharan Africa suggest an increased risk of HIV infection of 1.48 times in men with disabilities and 2.21 times in women with disabilities compared with men without disabilities (6, 7). Access to HIV prevention, care, treatment and support and sexual and reproductive health and rights services is equally important, and in some cases even more important, for people with disabilities compared with their peers without disabilities. This access is hindered by several factors, such as the following:

- Stigma and discrimination: people with disabilities, in particular women and girls, may be turned away from sexual and reproductive health and rights and HIV services (8, 9), may be considered a low priority, or may not be provided with accessible education and information material (10, 11). People with disabilities are found in all key and vulnerable populations, including people who inject drugs; sex workers; lesbian, gay, bisexual and transgender people; men who have sex with men; children out of school; people experiencing violence; women and girls; adolescents; and migrants (Figure 2). They may therefore experience multiple forms of stigma and discrimination in all spheres of life, including health, education, work and the justice system. This applies particularly to women and girls with disabilities who experience discrimination based on gender and disability.
- Exclusion from violence prevention: people with disabilities are 1.3 times more likely to experience sexual, physical and emotional violence than their peers without disabilities (12). In particular, women, girls and people with mental and intellectual impairments are two to eight times more likely to experience sexual violence than their non-disabled peers (12–15), and yet they are mostly forgotten in data collection and gender-based violence programmes (15). As a result, these people are less likely to report violence, seek care or access justice.
- Inaccessibility: health and education services are often not physically accessible and lack support for alternative modes of communication, such as sign language, Braille, and simplified easy-to-read and adapted tools (9, 16, 17). In the context of HIV and sexual and reproductive health and rights, people with disabilities may experience attitudinal barriers relating to the expectation that they are not sexually active and therefore not in need of such services (9). Any person with a disability may be sexually active and in need of services; women and girls with disabilities may need such services even more, as they have less decision-making power and autonomy to negotiate safer sex. The combination of discrimination based on disability, gender, sexual orientation and HIV may compromise access to services.
- Exclusion from sexuality education: young people with disabilities may be sexually active and may engage in behaviours that put them at risk of acquiring HIV, but they may have little knowledge about HIV and sexuality (18). Children with disabilities are

2–10 times more likely to be out of school than their peers without disabilities (19–21); those who are at school may lack access to comprehensive sexuality education if their educators hold negative beliefs about their need for sexuality education and lack the skills and tools to accommodate people with diverse learning needs. Evidence suggests that educators may avoid discussing sexuality and use an abstinence-driven teaching approach when they experience cultural barriers or struggle with increased incidence of sexual violence among their learners (10, 11, 22–24).

- Increased economic vulnerability: people with disabilities and their families are economically more vulnerable due to exclusion and discrimination in the labour market, lower employment rates and lower household incomes. They also experience higher out-of-pocket costs than the general population due to additional disability-related costs (25–27). In addition, women with disabilities experience additional gender-based inequalities that leave them with even less access to economic resources, further decreasing their ability to access health and education (26, 28). In some countries, the lack of labour market inclusion has been associated with risky sexual behaviour, such as sexual favours or sex work in order to gain income (29). Most HIV-related policies, programmes (30) and key programmatic responses (31), such as gender-based violence, sexual and reproductive health and rights and economic development (32), do not consider the needs of people with disabilities. Similarly, disability-focused programmes may neglect the need to address sexual and reproductive health and rights and HIV.

Figure 2. Examples of people with a disability being part of all key and vulnerable populations



Quality of life and living with HIV

Through increased access to antiretroviral therapy, AIDS-related deaths have declined, leading to an improvement in life expectancy (33, 34). Living longer with chronic HIV, however, may occur alongside other co-morbidities and the risk of disability (34–36). In addition, antiretroviral medicine regimens may cause adverse effects (37), potentially causing long-term damage to bodily functions.

Diverse aspects of disability are experienced by a high number of people living with HIV, including those on antiretroviral therapy (34, 38). These include impairments (e.g. sensory, musculoskeletal, cardiovascular, mental), activity limitations (e.g. mobility, daily activities) and participation restrictions (e.g. work, social life). Consequently, clinicians and front-line health-care workers are now expected to manage the increased complexity of chronic HIV (33, 38).

In resource-poor settings, families and communities often carry out care work. The unpaid care work related to disability or HIV is done mainly by women, which reduces opportunities and increases gender inequality. Health-care systems in many countries are still designed to provide acute HIV care and lack integration with rehabilitation services that strive towards preventing or mitigating impairment and ensuring participation and quality of life.

The health-care needs of living long term with chronic HIV therefore require new skills from health-care staff and a reshaping of health systems towards more integrated and comprehensive care that provides for disability and rehabilitation services (33, 39, 40). It also requires the development of equitable social protection mechanisms in terms of economic and human resources.

Disability as a cross-cutting issue

Including disability in the HIV response requires commitment to counteract underlying inequality and discrimination across all sectors and a shift towards integrating HIV with disability and rehabilitation services. Disability as a cross-cutting issue in the response to HIV also calls for broader social, cultural and economic development that is person-centred, is disability-inclusive (41) and addresses the unique barriers that face people with disabilities, in particular women and girls with disabilities, and people living with HIV. In most countries, disability-inclusive development is a new concept. Therefore, regional, national or organizational strategies to improve disability inclusion will be a necessary first step for all sectors.

Countries and organizations that have advanced the inclusion of people with disabilities across sectors often use a twin-track or three-track approach (41, 42). The twin-track approach addresses disability across all areas of development. It promotes two concurrent actions: disability-specific activities targeted directly at people with disabilities and mainstreaming disability across all sector responses (overcoming barriers and promoting inclusive environments). The twin-track approach also includes the authentic participation and active involvement of people with disabilities in all elements of programmes, such as design and planning, a supporting policy environment, implementation, and monitoring and evaluation.

The three-track approach adds the need to include political will and funding to facilitate the inclusion of people with disabilities. This takes into account the need to develop disability-inclusive policies, programmes and implementation strategies that ensure appropriate funding and resources. In order to plan for disability inclusion using the three-track approach, data and research are essential. Advocacy for this approach can make use of the UNAIDS and Global Health Workforce Alliance Agenda for Zero Discrimination in Health Care (43), which provides a platform for collaboration between countries, the United Nations, intergovernmental organizations, professional health-care associations, civil society, academics and others to take coordinated and coherent action for achieving zero discrimination in health-care settings. The associated action plan includes priorities for investing in evidence, knowledge-sharing and frameworks for accountability; addressing legal and policy barriers to eliminate discrimination in health-care settings; setting standards; empowering clients and communities to claim discrimination-free health care; strengthening leadership of professional health-care associations; and increasing funding support.

Making equal access and participation in HIV programmes a reality

CRPD (3) clearly lays out the rights of people with disabilities to equality and non-discrimination (Article 5); equal access to education, including HIV information and comprehensive sexuality education (Articles 9 and 24); justice (Articles 12 and 13); health, including sexual and reproductive health, HIV services and rehabilitation (Articles 25 and 26); and the right to freedom from exploitation, violence and abuse (Article 16). CRPD-

compliant services include the concept of universal design (accessibility for diverse people) and reasonable accommodation (special adjustments such as sign language, Braille and simplified tools).

Leadership, inclusion and participation of people with disabilities are integral to these rights. Several innovations have advanced inclusion in HIV-related programmatic areas and hold potential for adaptations in other contexts.

Disability-inclusive policies and programmes

National strategic plans or frameworks on HIV set out the response of countries to the epidemic (30, 44). Two reviews, one focusing on national strategic plans on HIV (45) and the other on legislation in eastern and southern Africa (46), reveal that only a few countries have acknowledged the need to include people with disabilities, and none have included disability comprehensively. Legal frameworks provide for the rights of people with disabilities to some extent and yet fall short on providing guidance for implementation. Experience from Handicap International can inform efforts on how to improve disability inclusion at the policy and programme level (44). The new South African National Strategic Plan on HIV, TB and STIs 2017–2022 can be used as an example of disability inclusion in the context of HIV.

Including people with disabilities in other key programmatic areas

People with disabilities need to be included in other key programmatic areas, such as gender-based violence (31) and social protection. The vulnerability of people with disabilities is linked to social and structural drivers, such as increased risk of gender-based violence and multidimensional poverty. The Making it Work methodology developed by Handicap International documents “good practices on inclusion of persons with disabilities and analysing how these positive changes could be replicated or sustained” (31). The methods presented have been developed and implemented in more than 25 countries by more than 60 different organizations. They include topics such as gender-based violence, legal capacity, accessibility, inclusive governance and access to health, education, employment, water and sanitation.

Adjusting the workplace for people living with HIV and disability

The economic empowerment of people with disabilities is crucial to address social and structural factors that increase vulnerability to HIV. This includes people living with HIV who have disabilities. The International Labour Organization Vocational Rehabilitation and Employment (Disabled Persons) Convention (No. 159) and Recommendation (No. 168) promote “decent work for persons with disabilities based on the principles of equal opportunity, equal treatment, mainstreaming, and community involvement” (47). This includes the principles of non-discrimination and participation. The e-module of the Canadian Working Group on HIV and Rehabilitation provides a practical application for the context of HIV, including guidance on vocational rehabilitation and accommodation in the workplace (48).

Good practice example: reaching people with disabilities with gender-based violence and HIV services in Cambodia

This project was embedded into a regional initiative in Cambodia, Viet Nam and the Lao People's Democratic Republic that aimed to improve access to HIV prevention, care and support over 2008–2012. Using a twin-track approach implemented by Handicap International, the project provided support to specific initiatives empowering people with disabilities and their organizations and built capacity for HIV service providers to deliver accessible disability- and gender-sensitive information and services.

In Cambodia, the project focused on women with hearing impairment in the Kampong Cham and Battambang provinces who had identified the need to address sexual violence and disability rights in the context of HIV. Key successes were the development of a common set of Cambodian signs for discussing issues around HIV prevention, human rights, sexual violence and disability rights, and their dissemination through awareness-raising activities. After the completion of the initial project, the Deaf Development Programme of Maryknoll adapted training on HIV and sexual and reproductive health and rights for women and men with hearing impairment, which they continue to provide in their language and life skills centres. This transfer of skills to one of the project partners was a clear sign of project ownership and sustainability.

Disaggregating national HIV surveys via sex, age and disability

Data and research on disability are crucial to inform disability-inclusive programming. The need to improve routine data collection and focused research on disability has been highlighted in several documents. National surveys, including those on HIV, need to include disability indicators that can be disaggregated. A global analysis of disability data can be accessed through Plan International's global survey and analysis of data (19) and the World Report on Disability (1). Inclusive surveys or disability-focused research that provide a comparison to national averages are still rare in the context of HIV. Where efforts are made to provide disability data, however, they highlight the increased vulnerability of people with disabilities. For instance, in South Africa disability indicators have been included in the National HIV Prevalence, Incidence, Behaviour and Communication Survey since 2008, indicating a higher prevalence of HIV among this population compared with the national average (49). A survey in Cameroon revealed that people with disabilities have "higher exposure to HIV infection" than people without disabilities, and this is linked to higher risk of sexual violence and sex work, particularly among women with disabilities (50).

Assessing accessibility of HIV services through a disability audit

The accessibility of services, especially those for sexual and reproductive health and rights and HIV, is related to the social and structural barriers that people with disabilities may experience. Services need to implement the CRPD principles of universal design and reasonable accommodation. Simplified tools, such as a disability audit of services, can help to identify and then address issues of accessibility. The Closing the Gap pilot project in South Africa included such an audit in a training workshop on disability and HIV for health-care workers and people with disabilities. This training enabled participants to identify gaps and then discuss how to address them (16).

“‘Reasonable accommodation’ refers to necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure that persons with disabilities can enjoy or exercise, on an equal basis with others, all human rights and fundamental freedoms.

‘Universal design’ means the design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed” (3).

Evaluating HIV and sexual and reproductive health and rights interventions for people with disabilities

Evaluations of HIV and sexual and reproductive health and rights services in the context of resource-poor settings is still very scarce. Evaluations of a pilot project in this context show promising results, however, and highlight innovative approaches for implementation and evaluation. For instance, in Kenya, peer-led counselling has been tested and evaluated for people with hearing impairment (51, 52). In South Africa, a comprehensive sexuality education approach has been developed that includes methods on how to evaluate educators’ knowledge, attitudes and skills (23, 53).

Health-care workers are crucial to the provision of access to HIV and sexual and reproductive health and rights services. Training for health-care workers on the intersection of disability and HIV has been developed in South Africa (16) and can be requested through the Foundation for Professional Development. An e-module for rehabilitation staff has been developed and can be accessed online (54).

Training and supporting educators of people with disabilities to address misconceptions and strengthen access to comprehensive sexuality education

People with disabilities often lack access to comprehensive sexuality education due to negative attitudes and misconception about their sexuality, or due to a lack of skills and resources on how to provide comprehensive sexuality education in accessible formats. In South Africa, a comprehensive sexuality education approach has been developed that enables educators to address vulnerabilities and misconceptions and provide information in accessible formats to learners with more severe disabilities (23, 55). This can inspire similar work in other countries.

Adapting mainstream HIV and sexual and reproductive health and rights approaches to include people with disabilities

Including people with disabilities requires adaptation as well as rights awareness. For example, the Victor Pineda Foundation and the United Nations Children's Fund (UNICEF) have developed a simple guide on how to explain rights in simplified formats (56). Other tools have been developed to provide access to HIV counselling and testing for people with intellectual disabilities through a simplified picture book and guide (57).

Developing disability- and gender-sensitive approaches to identify and report violence

The inclusion of women and girls with disabilities in gender-based or other types of violence programmes is rare. A new initiative from Handicap International is currently collecting good practice examples that can inspire work across the world (31).

Empowering people with disabilities as agents of change by appointing them as leaders in inclusive HIV programmes

Initiatives that have successfully included people with disabilities in the response to HIV highlight the importance of leadership and the empowerment of people with disabilities and their organizations. For instance, the Christian Blind Mission report on disability-inclusive HIV policy and programme development in the United Republic of Tanzania provides an example on how leadership and participation promote inclusion at all levels (58).

Enabling peer education and support for people with disabilities

Some groups of people with disabilities are hard to reach. Peer-led or peer-supported programmes have been shown to overcome communication barriers such as those experienced by people with hearing impairment. Counselling by peers whose first language is sign language can overcome these barriers (51, 52, 58).

Training people with disabilities to strengthen legal literacy and rights awareness

People with disabilities can be advocates for their own rights. For example, training and simplified tools to enhance knowledge on CRPD have been made available by UNICEF (56).

Developing accessible information material in areas of rights protection for adults and children with disabilities, HIV information and HIV prevention and treatment

Information on HIV and sexual and reproductive health and rights has to be universally designed or, where this is not possible, reasonably accommodate access (56, 57, 59). The Gay and Lesbian Archives provide an interesting example of how to adapt information material to make it accessible for young people with hearing impairment (59).

Integrating sexual and reproductive health and rights and HIV services into disability-focused programmes and the work of disabled people's organizations

Disability-focused initiatives and organizations need to include sexual and reproductive health and rights and HIV elements within their programmes. Examples from disabled people's organizations that have advanced the integration of HIV and sexual and reproductive health and rights into work focusing on people with disabilities can be accessed (60).

Developing integrated and comprehensive HIV services

The World Health Organization (WHO) guidelines on antiretroviral treatment advocate building integrated chronic HIV care services (39). These guidelines build on the WHO Global Strategy on People-Centred and Integrated Health Services, which present a fundamental shift in the way health services should be funded, managed and delivered (61). The concept of integrated health services includes the idea that health services "are managed and delivered in a way that ensures that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services ... according to their needs and throughout their whole life" (61). Current HIV policy and programmes provide little guidance, however, on how to integrate the rehabilitation aspect. Several innovative approaches can inform the needed shift.

Approaches to integrating disability screening into routine chronic care

The identification of functional limitations and disability is the first step in linking people to care. In many countries, however, health-care workers are not trained in and cannot use simple screening tools to identify people with potential disabilities. The Centre for Global Mental Health (62) and the Canadian Working Group on AIDS and Rehabilitation (48) provide examples and tools to identify functional limitations and disabilities in the context of HIV.

New models of integrated HIV and rehabilitation care

Integrating rehabilitation into chronic care requires a shift in chronic care models towards more integration. Current models may integrate some aspects of rehabilitation, such as mental health, but this must be widened to include other aspects. Chetty's model of integrating HIV and rehabilitation care can provide guidance on how to analyse existing care, identify opportunities for integration on all levels and highlight the variety of disabling effects that people living with HIV may experience (63).

Good practice example: from evidence to action—integrated care in the context of chronic HIV

Tucked away in a semi-urban area of KwaZulu-Natal, South Africa, a group of researchers and their local partners developed a comprehensive integrated model of HIV care that includes feasible approaches to rehabilitation. The project site includes a 200-bed public hospital serving a population of 750 000 people, of whom more than 250 000 are living with HIV. Through a series of consultative workshops and research projects, the group identified that people living with HIV in the long term may experience a diverse set of functional limitations that increase their risk of disability and negative livelihood outcomes.

The working group of researchers, implementers and people with disabilities adopted a learning-in-action approach that aimed to understand disability in the context of HIV in resource-poor settings, to build capacity among health-care workers and people with disabilities and to develop feasible approaches towards integrated HIV care that include rehabilitation. The project provided first evidence on the complexity and nature of functional limitations experienced by people on long-term antiretroviral therapy and identified opportunities and challenges in developing comprehensive and integrated services in the context of HIV. It provided evidence on the safety and potential of alternative approaches, such as home-based rehabilitation, for people living with HIV who experience mobility limitation. The project developed a training module for health-care workers on the intersection of disability and HIV. The project strengthened local capacity by involving volunteers and final-year physiotherapy students in local services, and by strengthening the capacity of nongovernmental organizations and disabled people's organizations to raise funds for necessary assistive devices and support. Using a twin-track approach to policy development, this work is currently informing South Africa's efforts to strengthen integrated care through its new National Strategic Plan on HIV and AIDS (2017) and its new Framework and Strategy on Disability and Rehabilitation Services (2015).

Training of rehabilitation professionals or health-care workers to provide mitigating or rehabilitative services in the context of HIV

Integrating rehabilitation services and chronic HIV care requires a better understanding of the intersection of disability and HIV and the feasible approaches to delivering rehabilitation interventions. Training tools such as the Closing the Gap approach (16) and the e-Tool for Evidence-Informed Rehabilitation Practice for People Living with HIV in Sub-Saharan Africa (54) can guide the needed training and sensitization of a variety of health-care staff.

Providing information to and supporting people living with HIV to actively engage in their own care management to prevent and mitigate impairment

People living with HIV need to develop health-promoting practices that can help to prevent or mitigate impairment over time. Pilot projects using health information and home-based exercises have shown promise in reducing the risk of co-morbidities, such as ischaemic heart disease and mobility limitations (64–66).

Integration and use of e-health tools advancing early identification of disability, linkage to care and learning tools

Advancing the integration of rehabilitation into HIV care through improving skills and knowledge can be accelerated through the use of Internet-based education, such as the Canadian e-module for rehabilitation professionals (48) and the development of new screening tools (67, 68). In recent years, app-based screening tools for resource-poor settings have been developed for vision, hearing and mobility. These can be used by lay health-care workers and include automated linkage to local rehabilitative care and support (67).

Delivery of affordable and appropriate assistive devices

The integration of rehabilitation into HIV care may include the need to provide assistive devices. These must be adapted to individual needs and can be costly. Decades of experience in providing affordable assistive devices in resource-poor settings can be accessed through existing national and international nongovernmental organizations that work with people with disabilities (68, 69).

Using alternative service delivery modes

Within the past decade, service delivery models that use a task-shifting approach to deliver rehabilitation services in resource-poor settings have been evaluated in the context of HIV. These approaches may be feasible alternatives in areas that lack skills in rehabilitation (70, 71).

Existing approaches such as home-based or community-based rehabilitation to reach people living with HIV, which have been widely applied in resource-poor settings outside the field of HIV, can be used to inform how rehabilitation can be delivered and integrated with HIV care in a feasible manner (54, 65, 70, 72).

Framework for action

CRPD commits state parties to “provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other people, including sexual and reproductive health and population based programmes” (Article 25), and to “organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in areas of health, employment, education and social service” (Article 26). It also calls to “ensure the full development, advancement and empowerment of women with disabilities” (Article 6). Hence, people with disabilities have equal right to access all services, including those for HIV. This requires a cross-cutting and multisectoral response.

The Sustainable Development Goals (SDGs) highlight the need to “leave no one behind”, including people with disabilities. Inclusion of people with disabilities (15% of the global population) is essential to drive HIV prevention and to achieve the 90–90–90 targets. The 2016 United Nations Political Declaration on Ending AIDS urges governments and funding agencies to “commit to ensure that the needs and human rights of persons with disabilities are taken into account in the formulation of all responses to HIV and that HIV prevention, treatment, care and support programmes as well as sexual and reproductive health-care services and information are made accessible to persons with disabilities”.

The WHO Global Strategy on People-Centred and Integrated Health Services and Consolidated Guidelines on Antiretroviral Treatment (39) includes an “approach to care that consciously adopts the perspectives of individuals, families and communities” and highlights the need to “access rehabilitation and palliative care” in the context of HIV. The Consolidated Guidelines highlight that “if an intervention is to achieve the desired health outcomes, it needs to be evidence-based and of high quality” (39). Hence, HIV services need to include disability-centred approaches and rehabilitation services that are evidence-based. Within this, appropriate measures need to be taken to reduce unpaid care work and promote equal sharing of responsibilities among women and men.

The three-track approach should be adopted to improve accessibility of HIV services and increase the participation of people with disabilities through mainstreaming disability in all sectors, funding specialized services that accommodate specific disability needs to overcome attitudinal, communicational, gender-related and structural barriers and developing disability-inclusive policy and programming.

Opportunities for action

People with disabilities were left behind in the previous developmental agenda, but the SDGs emphasize the need to “leave no one behind”, including people with disabilities. Over the past decade a number of documents have provided recommendations on how to advance inclusion of disability in the response to HIV, including the UNAIDS, Office of the United Nations High Commissioner for Refugees (UNHCR) and WHO policy brief on disability and HIV (73), the Kampala Declaration of the African Campaign on Disability and HIV (74), and the International Disability and Development Consortium Task Group on Disability and HIV discussion paper (75). All of these documents emphasize that advancing disability inclusion in the response to HIV and other sexual and reproductive health and rights services requires commitment from all sectors, including government, civil society, development partners and funders. Based on the 2009 UNAIDS policy brief (73) and continued engagement with the disability sector (5, 74–79), the following opportunities for actions have been compiled.

Action for governments

In order to inform disability-inclusive policies and programmes, data and information are needed. National surveys and surveillance studies need to collect and analyse sex-, age- and disability-disaggregated data. Gender-specific analyses need to be conducted to prioritize actions that will address the specific needs of women and girls with disabilities in the context of HIV. In addition, disability-specific research needs to advance our understanding of the intersection of disability and what works to reach those who have been left behind.

Leadership and participation of people with disabilities is key to the development of disability-inclusive programmes. Therefore, governments and their agencies need to ensure that people with disabilities (particularly women), their advocates and researchers can actively participate in all stages of planning, implementation and evaluation of HIV policies and programmes. In collaboration with the disability sector, governments need to develop disability-inclusive policy frameworks. This includes signing, ratifying and domesticating CRPD, prohibiting all forms of discrimination based on disability and promoting equality through national legislation.

Disability inclusion requires the prohibition of discrimination based on disability, gender, real or perceived HIV status, related health needs and promotion of disability-relevant adjustment in the workplace. Disability inclusion also needs to be reflected in countries’ national strategic plans on HIV and to ensure that the right to equal access to all HIV and sexual and reproductive health and rights services is included across all sections of these plans.

Implementation of disability-inclusive policies and plans requires setting disability-specific targets and allocating sufficient funding towards their achievement. These targets need to promote accessibility of health, education and related services and include:

- Development of universal design in HIV and sexual and reproductive health and rights prevention and treatment services.
- Provision of reasonable accommodation in HIV and sexual and reproductive health and rights services through sign language interpretation, Braille or simplified formats.
- Inclusion of people with disabilities in key programmatic areas, such as behavioural and biomedical HIV prevention and treatment programmes, gender-based violence programmes and social protection.
- Enabling access to justice for people with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodation.
- Access to education, especially HIV and comprehensive sexuality education, to young people with disabilities in a gender-, age- and disability-sensitive manner.

Governments need to develop and strengthen the integration of HIV, sexual and reproductive health and rights and rehabilitation services. This includes the advancement of screening, referral and service provision and the need to address the issue of unpaid care work in the context of disability and HIV. In order to achieve this, training on HIV, sexual and reproductive health and rights, gender equality and disability needs to be integrated in professional-led training of medical and health-care workers, educators and rehabilitation staff.

Action for civil society

Both the mainstream and the disability sectors need to champion advocacy for a disability-inclusive approach and evidence-informed practice. By adopting a three-track approach, civil society can promote access to mainstream services, specific initiatives for people with disabilities and integration of disability into policy.

Civil society can promote inclusion by ensuring that people with disabilities and researchers are represented during the development of national strategic plans and country coordinating mechanisms. Such efforts can focus on the enhancement of participation and leadership of women with disabilities, including those living with HIV, in the development, implementation and monitoring of HIV policies and programmes.

Inclusion and participation can also be strengthened through collaboration between women's organizations, networks of women living with HIV and disabled people's organizations. Mainstream civil society organizations can often provide people with disabilities with opportunities to network and exchange information with diverse stakeholders, such as governments, funders, nongovernmental organizations, implementers and researchers.

Similarly, disabled people's organizations and nongovernmental organizations working for people with disabilities need to integrate HIV and sexual and reproductive health

and rights education into their programmes and establish collaborations with other key and vulnerable populations.

Action for development partners and funding agencies

Development partners often influence the response to HIV and sexual and reproductive health and rights through their role as advisers, collaborators or funders. This provides opportunities to ensure that disability inclusion and participation of people with disabilities is operationalized in all programmes, including HIV, health, rehabilitation, gender equality and sexual and reproductive health and rights. Similarly, development partners and funding agencies can ensure that the programmes in which they are involved are designed, implemented, monitored, reported on and evaluated with a focus on the specific needs and priorities of women and girls with disabilities, including those living with HIV.

Funders can ensure the inclusion of disability by including a compulsory section on disability inclusion in all calls for proposals. In addition, funders can support and invest in advocacy, capacity development and mobilization of people with disabilities, in particular women and girls with disabilities.

Considering the lack of data and research on disability and HIV, development partners and funding agencies need to support and fund research on disability, HIV and sexual and reproductive health and rights, in particular when local researchers, disability-focused nongovernmental organizations and disabled people's organizations lead the research. Such funding needs to include bridging projects with a focus on integrating disability and rehabilitation services into existing programmes and, where this is not possible, approaches for reasonable accommodation.

Action for all

Disability is a cross-cutting issue. Everybody holds responsibilities and opportunities to enhance the participation and representation of people with disabilities, particularly women and girls, their advocates and researchers, in all spheres of life, including programmatic areas relating to HIV, access to health, education and social protection.

Challenges around disability are often similar across countries and regions. The combined efforts of all can aim to develop regional and country-specific strategies to enhance the participation of people with disabilities in key priority areas, including the obligatory inclusion of disability in funding allocations.

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