



Closing the equity gap: A call for policy and programmatic reforms to ensure inclusive and effective HIV prevention, treatment and care for persons with disabilities in Eastern and Southern Africa

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A B S T R A C T

In this paper, we explore the critical barriers that persons with disabilities face in accessing HIV services in the Eastern and Southern Africa (ESA) region, despite significant advancements in overall accessibility. We highlight the intersectional challenges experienced by individuals with disabilities, particularly women, and outline a comprehensive approach to bridge the existing gaps in policy and programmatic efforts. Specifically, we aim to address the exclusion of persons with disabilities from essential HIV prevention, treatment, and care services, a situation that has profound implications for their health, social inclusion, and economic productivity. In this discussion, we examine the current landscape, identify specific policy and programmatic hurdles, and propose targeted reforms, in an effort to contribute to the ongoing discourse on health equity and inclusivity.

1. Discussion

Eastern and Southern Africa (ESA) region has made significant strides in ensuring equitable access to Human Immunodeficiency Virus (HIV) services for all citizens. However, a critical segment of the population that continues to be left behind is persons with disabilities [1–3]. This exclusion violates their human rights, in particular their right to health, and has significant economic and social consequences on them and their families and impedes attaining their full potential as citizens. Persons with disabilities who are unable to access essential HIV prevention, treatment, and care services are more likely to experience poorer health outcomes, face increased social isolation, and contribute less to the overall economic productivity of their communities and nations [4].

Women with disabilities in the ESA region face disproportionate risks of sexual violence, HIV infection, and exclusion from healthcare due to intersecting vulnerabilities, harmful stereotypes, and inadequate disability-inclusive policies and interventions [5]. In this discussion

article, we explore the intersection of disability and HIV services in East and Southern Africa. We unpack the policy and programmatic hurdles that prevent persons with disabilities from accessing essential HIV services. We also discuss the potential of policy and programmatic reforms, targeted at resource mobilization and allocation, accessibility, assistive devices, training of healthcare providers on disability rights and active and meaningful participation of persons with disabilities in both policymaking and programming.

1.1. The landscape of disabilities in Eastern and Southern Africa and barriers to HIV prevention, care and treatment

The World Health Organization estimates a disability prevalence of 16 % of world population or more than 1,3 billion people [6]. Estimates point to the fact that 80 % of persons with disabilities live in developing countries and more than half of them are women. Current and reliable statistics on disability in Africa or regional statistics on Eastern and Southern Africa are hard to come by, but most nations draw from the

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United Nations (UN) measure and estimate that 15 % of their national populations consist of persons with disabilities. Further estimates suggest that a higher percentage of children aged 0 – 17 years (around 6.4 %) in ESA are children with disabilities compared to the global average (4.3 %) [7]. A 2023 United Nations Children’s Fund (UNICEF) report revealed that nearly 29 million children with disabilities live in East and Southern Africa [8]. The most commonly identified impairments are visual, hearing and physical [9]. However, access to formal disability screening, identification, assessment and determination systems remains limited [10]. The impact of armed conflict and displacement in some parts of Eastern and Southern Africa further exacerbates the prevalence of disability, in ways that create complex situations that require a multifaceted response [11].

The gap in access to healthcare by persons with disabilities extends far beyond HIV services [1,12]. Physical barriers like inaccessible infrastructure of healthcare facilities, inadequate, inaccessible and expensive public transportation options, and a lack of assistive devices such as wheelchairs, and crutches can significantly limit access to essential healthcare services, including HIV services by persons with disabilities. Furthermore, lack of information in appropriate formats such as Sign Language for person with a hearing disability or impairment and braille for those with visual impairments, and lack of healthcare providers trained in providing tailored healthcare for the diversity of persons with disabilities, can lead to delayed treatment, and ultimately poorer health and well-being outcomes. This highlights the urgent need for a more comprehensive and inclusive approach to healthcare, which takes cognizance of disability rights including in the HIV terrain across the region.

Despite international, and national commitments to the rights of persons with disabilities, HIV strategies in ESA often fall short [13,14]. While many National HIV Strategic Plans acknowledge vulnerability of people with disabilities, concrete actions like targeted budgeting, training, and monitoring are scarce [2,13,15]. Moreover, specific needs of subgroups, such as those with diverse sexual orientations or gender identities, are largely ignored. This lack of detail hinders effective implementation and equitable access to HIV care for people with disabilities [2].

Persons with disabilities face a multitude of barriers to accessing HIV prevention, care, and treatment services. For instance, transportation challenges are particularly acute for persons with physical disabilities, who may struggle to reach distant healthcare facilities due to a lack of accessible public transport or financial constraints [2,16]. In some instances, public transport operators demand additional payment for assistive devices such as wheelchairs and for accompanying assistants. Communication barriers arising from a lack of healthcare workers who are trained in alternative communication methods can hinder effective consultations and understanding of diagnostic and treatment options [17]. Additionally, social stigma and discrimination, both within healthcare settings, families and communities, can discourage persons with disabilities from seeking healthcare. For example, healthcare workers may hold unconscious biases about the sexual health of persons with disabilities and may consequently not provide condoms or additional HIV prevention methods, or family and community members may view persons with disabilities as less capable of adhering to complex treatment regimens [18,19], and may not even try to provide them with the support they may require to access HIV services.

Harmful traditional beliefs and practices that are prevalent in many African contexts aggravate the vulnerability of persons with disabilities to HIV infection. For instance, in some regions, religious and traditional healers prescribe sex with women or girls with disabilities as a “cure for HIV” or a means of acquiring wealth [20]. These harmful practices heighten the risk of HIV infection among women and girls with disabilities, who become more vulnerable to sexual abuse as men scramble to adhere to the prescriptions of the healers and to reap the associated benefits. Furthermore, persons with disabilities living with HIV are more likely to experience poorer health outcomes and higher mortality rates

compared to the general population, due to all these challenges.

1.2. Bridging the gap through a multi-pronged approach

Despite progress in some countries, significant disparities exist across ESA regarding access to HIV services by persons with disabilities. Countries like South Africa have incorporated disability inclusion into their national HIV strategies, with dedicated budget allocations and training programs for healthcare workers [21,22]. Similarly, Kenya’s past AIDS strategic framework [23] includes a focus on persons with disabilities, which directs the development of training manuals for healthcare workers and integration of disability into monitoring and evaluation frameworks, highlighting the potential for targeted interventions. However, many countries in East and Southern regions of Africa lack concrete costed plans, and those with disability inclusive policies struggle to translate the policies into action, as persons with disabilities are often least priority in their healthcare vision. A project implemented in Kenya offered disability inclusive HIV information and services, with a particular focus on persons with visual impairment. The project designed information, education, and communication (IEC) materials that met the needs of persons with visual impairment and effectively conveyed HIV-related messages to them. The materials were produced in large print, Braille and audio messaging. Radio talk shows were also organized. A committee that included persons with disabilities, including persons with visual impairment, oversaw the project. This project resulted in almost 9,000 persons with visual impairment being reached with HIV information on prevention, treatment, and care. About a third of the people reached went for counselling and testing [24].

A Zimbabwean project improved the sexual and reproductive health of youth with disabilities in rural and urban areas. Organizations of persons with disabilities (OPDs) collaborated with sexual and reproductive health and rights (SRHR) and HIV organizations, and ensured regular participation of school educators, policymakers, parents, and caregivers of persons with disabilities. Youth with disabilities reported good HIV prevention practices and contraception after the project. The project also enhanced access to HIV treatment information, education, and awareness among youth with disabilities. Counselling services were offered by teachers on SRHR issues, and OPDs collaborated with institutions that specialize in HIV counselling, testing, and treatment. The significance of early involvement of youth with disabilities and parents to achieve positive results, including addressing negative healthcare provider attitudes was highlighted [25]. These examples showcase the power of a multi-pronged approach involving policy reform, healthcare worker training, collaboration with OPDs, and the active and meaningful participation of persons with disabilities in seeking to ensure equitable access to essential HIV services throughout Eastern and Southern Africa.

To bridge the gap in access to HIV services by persons with disabilities in Eastern and Southern Africa, a multi-pronged approach is essential. At policy level, national and regional policymakers must prioritize disability inclusion in HIV strategies, including the involvement of persons with disabilities in policy-making spaces, decision making processes, given that they are the “experts” of their own experiences. To translate policies into practice, there is a need for resource mobilization and allocation to programs that address the needs and concerns of persons with disabilities, and their active and meaningful participation in developing, implementing and evaluating these programs must be ensured. Additionally, investments should focus on creating accessible healthcare facilities. These facilities should have physical infrastructure that is inclusive of people with disabilities. Information should be accessible to everyone, regardless of their disability. Essential assistive devices, such as wheelchairs, crutches, hearing aids, and vision aids, should be provided. Moreover, training programs for healthcare workers should focus on delivering disability-inclusive services. This training should be offered both during studentship and as part of in-continuous

professional development for qualified staff.

Empowering persons with disabilities is also central to achieving equitable access to healthcare. This involves supporting OPDs through capacity-building which enables them to among other things demand national costed workplans and disability inclusive healthcare budget allocations. Collaboration of OPDs with government and development partners also needs to be fostered. Furthermore, promoting self-advocacy skills through training programs and workshops can equip persons with disabilities with the knowledge and confidence that enable them to advocate for their healthcare needs [26]. This could include training on communication techniques, assertiveness, and advocacy for the realization of the rights of persons with disabilities in healthcare. Including persons with disabilities in data collection and research efforts related to HIV is also paramount, not just as research subjects but as researchers and users of the evidence gathered. This allows for a deeper understanding of their life worlds in ways that will ultimately inform policy and practice.

To achieve equitable access to HIV services by persons with disabilities in ESA, international donors and community mobilization efforts must also play a complementary role. International donors often bridge the funding gap by allocating resources to national HIV/AIDS programs that are inclusive of persons with disabilities [27]. Additionally, technical assistance from donors can provide valuable expertise to governments and civil society organizations. In addition, sharing best practices, facilitating knowledge exchange, and seconding experts for capacity building can significantly strengthen the response. By strategically aligning donor support with national priorities, resources can be maximized for the greatest impact.

However, a top-down approach of international donors and national governments may not yield much. As directed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and as stated earlier, the active and meaningful participation of persons with disabilities at all levels from planning, implementation, and right through to monitoring and evaluation is essential in efforts to tackle stigma, raise awareness, and ensure services are responsive to the needs of persons with disabilities and their families. Supporting OPDs through strengthening their capacity to hold governments accountable in HIV policy and legislative-making processes and programming is important [28]. Furthermore, community outreach through education campaigns that challenge stigma and promote understanding can create a more inclusive environment. Accessible information and communication in appropriate methods, partnering with faith-based organizations, and engaging traditional leaders are all crucial aspects of effective community outreach. ESA can create a more equitable and inclusive environment where persons with disabilities have full access to essential HIV services by combining government commitment with international donor support and strong community mobilization efforts which uphold the principle of active and meaningful participation of persons with disabilities.

2. Conclusion

Bridging the HIV healthcare gap for people with disabilities in ESA requires concrete actions including increased funding, accessible infrastructure, trained healthcare workers, and meaningful involvement of people with disabilities.

CRedit authorship contribution statement

Tafadzwa Dzinamarira: Writing – original draft, Conceptualization. **Christine Peta:** Writing – review & editing. **Enos Moyo:** Writing – review & editing. **Roda Madziva:** Writing – review & editing. **Rouzeh Eghtessadi:** Writing – review & editing. **Tatenda Makoni:** Writing – review & editing. **Godfrey Musuka:** Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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