

SHARING THE BURDEN:

MOVING THE NEEDLE IN ENDING HIV AMONG PERSONS WITH DISABILITY (PWD) LIVING WITH HIV

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After an extended break, we are back with the Blood:Water Technical eUpdates, our now quarterly virtual newsletter designed to bring our community deeper into the ever-evolving technical landscape of health and development. Our goal is to keep you up to date with the latest in research and practices, to keep your teams up to date with our constantly expanding sector.

In this, our 30th volume of the e-newsletter, we will spark conversation and raise awareness on the intersection between HIV and Disability. Primarily we will focus on how underserved this sub-population within communities of persons living with HIV (PLHIV) is and how the success to breaking the cycle of infection requires intentionally engaging caregivers of People with Disability (PWD) Living with HIV.

AN ESTIMATED 1.3 BILLION PEOPLE EXPERIENCE SIGNIFICANT DISABILITY. THIS REPRESENTS 16% OF THE WORLD'S POPULATION, OR 1 IN 6 OF US AND AROUND 80 PERCENT OF THEM IN DEVELOPING COUNTRIES.

Disability varies widely according to age, sex, stage of life, exposure to environmental risks, socioeconomic status, and culture. In low income areas, despite existing social economic challenges, households that include people with disabilities (PWD) experience poorer social and economic outcomes compared to individuals and households without disabilities.

This is due to the additional cost of care the household incurs to achieve a standard of living that is equivalent to that of people without disabilities. In low-awareness contexts, disability is predominantly addressed as a medical concern, which is true to an extent due to rehabilitation needs. However, there is a growing realization that the greatest problems faced by households and PWD are social inequality, poverty and lack of human rights-issues that a medical facility cannot address.

ACCORDING TO THE UNITED NATIONS IN 2018, MORE THAN 80 MILLION AFRICANS WERE DISABLED.

A hallmark of the HIV/AIDS epidemic has been its disproportionate impact on vulnerable populations, including sex workers and their clients, intravenous drug users (IDUs), men who have sex with men (MSM), orphans, prisoners, and others. Surprisingly, one of the world's most vulnerable populations - individuals who live with a permanent physical, sensory (deafness, blindness), intellectual, or mental health disability - has been almost entirely overlooked despite the fact that they are at equal or increased risk of exposure to all known risk factors for HIV. This lack of intentional engagement of PWDs is commonly driven by the assumption that PWDs are at low risk of HIV infection.

PEOPLE WITH DISABILITIES ARE LESS LIKELY TO HAVE ACCESS TO INFORMATION AND SERVICES, SINCE IT IS ASSUMED THAT THEY ARE NOT SEXUALLY ACTIVE.

¹ Groce, N. E. (2005, January the President and Fellows of Harvard College.). HIV/AIDS AND INDIVIDUALS WITH DISABILITY. HIV/AIDS AND INDIVIDUALS WITH DISABILITY, Unknown(Unknown), Unknown. <https://www.hsph.harvard.edu/wp-content/uploads/sites/2469/2013/07/18-Groce.pdf>

This gap in HIV care provision is important because more than 1 billion people worldwide have disabilities, 25% of which are people living with HIV. When sampling data on sub-Saharan Africa on 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%).

THE VISION OF THE GLOBAL HIV RESPONSE IS TO ACHIEVE THREE ZEROS: ZERO NEW HIV INFECTIONS, ZERO AIDS-RELATED DEATHS AND ZERO DISCRIMINATION.

The Sustainable Development Goals (SDGs) highlight the need to “leave no one behind.” Therefore, Inclusion of people with disabilities, which represents an average of 17% of the global population, is essential to drive HIV prevention and to achieve the 95–95–95 targets. The most ignored determinant for these targets among PWD is often the caregivers of PWD; caregivers that spend the most time with them. In low-income areas, caregivers over and above being uncompensated are equally under equipped to not only provide the medical care and support but also the psychosocial support.

IN LOW INCOME REGIONS, CARE FOR PWDS IS PROVIDED PRIMARILY BY FAMILY MEMBERS; PRIMARILY MOTHERS OR ANY OTHER FEMALE GUARDIAN.

Due to the duality of HIV and Disability there is clearly a significant impact of caregiving burden on caregivers with respect to their physical, psychological, and social wellbeing, and constraints on time and financial resources. To give more specific examples, there are noted issues when it comes to:

- Financial costs of caregiving in households already in poverty increases the risk of moving further into indigence.
- Gender biases where female caregivers bear the extra responsibilities of Disability and AIDS related care thus diverting their labour from productive work creating further household insecurity.
- Emotional stress/Psycho-social impacts of caregiving on carers of all ages and gender can result in social isolation.
- Lack of Access to external support and services such as training among many PWD living with HIV and their carers.
- Affiliate stigma which occurs when a person is closely associated with a stigmatized individual is quite common among caregivers of people with mental illnesses and or HIV, with more than half of caregivers experiencing it.

**ROSALYNN CARTER,
“THERE ARE ONLY FOUR KINDS OF PEOPLE IN THE WORLD. THOSE WHO HAVE BEEN CAREGIVERS. THOSE WHO ARE CURRENTLY CAREGIVERS. THOSE WHO WILL BE CAREGIVERS, AND THOSE WHO WILL NEED A CAREGIVER.”**

²Kuper ScD, H. (2022, April). A focus on disability is necessary to achieve HIV epidemic control. ScienceDirect, 9(4), e293-e298. <https://www.sciencedirect.com/science/article/abs/pii/S2352301821003453>

For projects/programmes that intend to implement Caregivers Inclusive/focused projects it is recommended to not only intentionally engage and include caregivers in designing interventions, but also target them with interventions specific to their needs and challenges. The push for this newsletter is to not only address the HIV and Disability home care needs but also to equip caregivers with the skills and tools to deal with the social, economic, and rights challenges. Beyond this, there needs to be systemic changes that:

- Recognise and value care work and its impact on women.
- Facilitate the greater involvement of men in caregiving roles and the equal sharing of care work between women and men.
- Promote women's rights and address broader gender inequalities including employment.
- Promote the participation and involvement of home-based care and caregivers in shaping national policies and solutions.
- Invest in operational research to better understand caregiving in the context of HIV and AIDS and Disability to generate strategic information to inform programming.
- Assessing the potential of livelihood programmes which focus on caregivers to reduce poverty;

HIV/AIDS and Disability as a development issue needs to be better understood through the lenses of the health, social and human rights perspective. This dual challenge acknowledges the need to break down socially discriminatory barriers - including those relating to all aspects of development, economic development, poverty reduction, access to basic needs, education, democratic governance, and access to health and rehabilitation. Once there is awareness and appreciation of these barriers, it becomes easier to identify and address human rights problems that impact persons with disabilities in the context of development.

REFERENCES

1. Policy Brief - [Inclusive and Integrated HIV and AIDS programming](#)

This is a policy brief by Handicap International on Why and How to HIV adopts a comprehensive, disability-inclusive programming approach that is also integrated to sexual and reproductive health and sexual and gender-based violence services. The policy Brief covers an HIV and AIDS project centred on four key areas of intervention; HIV prevention Treatment, care and support including different types of rehabilitation services, Integration with sexual and reproductive health (SRH) and Integration with gender-based violence (GBV).

2. Hand Book - [Preventing HIV/AIDS among persons with Disability](#)

This publication will help and guide policy makers, healthcare workers, NGOs, Caregivers and members of the public on how to integrate persons with disabilities in decision making programmes and activities that will help in reducing the spread and impact of HIV/AIDS among them.

3. Discussion Paper - [Caregiving in the context of HIV/AIDS](#)

This discussion paper presents key issues for discussion with on the burden of care on AIDS affected households, and in particular on women and girls, as a major concern in the AIDS-affected societies. It promotes the equal sharing of caregiving responsibilities between women and men paired with broader long term national strategies to reduce the overall impact of AIDS on affected households and communities as a pathway to alleviate the often debilitating burden of care at the household level.

4. Policy Document - [Inclusive and integrated HIV and AIDS programming](#)

This is a policy document by Handicap International that is aimed at providing an integrated and inclusive HIV policy document that can support an organization in shaping the scope of project activities; Provide technical guidance to programmes and projects which are implementing and/or intending to implement HIV and AIDS projects; Contribute to quality and coherence of work on HIV and AIDS and Promote results-based management in all projects on HIV and AIDS.

5. Paper - [HIV:AIDS and individuals with Disability](#)

This article is based on results drawn from the World Bank/Yale Global Survey on HIV/AIDS and Disability. The survey sought to identify issues of access to HIV/AIDS knowledge, services, and care specific to individuals with disability over and above those confronted by members of the general population in resource poor settings. The article identifies where individuals with disability shared common concerns with members of the general population around issues of HIV/AIDS and where they confronted disability-specific issues and concerns.