



HIV, DISABILITY AND REHABILITATION

Considerations for Policy and Practise



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The UNAIDS, WHO and OHCHR Policy Brief on Disability and HIV (2009) recognises the interrelations between HIV and disability, and emphasises that this issue has not received sufficient attention [1]. It presses the point that people with disabilities are one of the key populations at higher risk of exposure to HIV. It also emphasises that people living with HIV may develop impairments and disabilities as a result of the disease and side effects of the treatments.



The experience of disablement among people living with HIV has been a topic of concern since the advent of effective treatment in the mid-1990's [2]. Now, as HIV treatments are becoming available in Southern and East Africa where the prevalence of HIV is relatively high, we can expect to see similar issues of disability arise. The result is likely to be more and more people in need of access to rehabilitation services and financial grants. However, health systems in resource poor settings are already stretched and often ill-equipped to meet the rising demand for rehabilitation. As such, innovative ways of providing rehabilitation services are needed. This issue brief addresses these issues with focus on:

- Issues regarding the definition of "disability"
- Implications for rehabilitation services
- Considerations for "disability" grants

Issues regarding the definition of 'disability'

The UNAIDS, WHO and OHCHR Policy Brief was written in line with UN Convention on the Rights of Persons with Disabilities [3]. It calls on all

governments to ratify and incorporate into national law instruments that protect and promote the human rights of people with disabilities. The definition of disability (and therefore, who will be regarded as having a disability) is of crucial importance for the development of policy and law, and subsequent resource allocation (e.g. grants, health services).

The UN Convention states: "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" [1].

As noted in the UNAIDS, WHO and OHCHR Policy Brief, however, disablement challenges experienced by people living with HIV may be "on a temporary, episodic or permanent basis" [1]. We note that the definition in the UN Convention requires that disability be "long-term", but does not require impairments to be "permanent". As such, this definition may also be interpreted to include the experience of long-term episodic disability reported by many people living with HIV [4].

While permanent impairments may be easier to identify and measure, episodic impairments are emerging as an important reality for many people living with HIV [5]. However, episodic impairments and the resulting disability can be difficult to understand and challenging to address using policies designed to meet the needs of people with more predictable experiences of disability.

Implications for rehabilitation services

The UNAIDS, WHO and OHCHR Policy Brief emphasises the need for accessibility of services in two directions: (i) rehabilitation services for people living with HIV, and (ii) HIV services for people with disabilities. Here we focus on the first challenge in particular. With the life-prolonging effects of HIV

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treatments, people living with HIV can expect to begin encountering an array of impairments, activity limitations and participation restrictions that can benefit from a wide range of rehabilitation services.

For good reason, attention in resource poor settings has largely focused on scaling up antiretroviral therapy and the medical management of HIV and its secondary diagnoses. However, attention now needs to be paid to quality of life and the consequences of *living* with HIV as well. Rehabilitation services to address such needs are based on a multidisciplinary approach that may include physical, occupational or speech-language therapy, mental health interventions, access to assistive devices (e.g. walking aids, hearing aids) and other supports.

Although evidence for the effectiveness of particular rehabilitation interventions in people living with HIV was first established in North America and Europe [6], new evidence is emerging from resource-limited settings [7,8]. As the epidemic shifts in high-prevalence countries, plans for rehabilitation services need to be embedded in National Strategic Plans on HIV and AIDS.

	Community-Based Rehabilitation	Home-Based Care
Focus	rehabilitation, equalisation of opportunities, and social integration of all people with disabilities community empowerment and participation	care and support for people infected and affected by HIV in their homes and communities community empowerment and participation
Target Group	people with disabilities	people with HIV and AIDS
Setting	resource limited settings	resource limited settings

Table 1: Contrasting Approaches of Community-Based Rehabilitation and Home-Based Care

The practical implementation of rehabilitation services is a particular challenge in resource limited settings. Indeed, to impose yet another demand on already stretched HIV programmes is daunting. However, synergy may be found with the existing field of Community-Based Rehabilitation, or CBR, which has well-developed models of care provision. An approach to broader service provision might be found through scaling up and bridging existing services in Community-Based Rehabilitation programmes with HIV-focused Home-Based Care services.

Both approaches have been developed for use in resource limited settings, one for people with

disabilities and the other for people affected by HIV. The bridging of these two approaches could provide additional resources to largely under-resourced Community-Based Rehabilitation programmes while connecting Home-Based Care to rehabilitation services and networks that already exist in hard-to-reach areas.

Considerations for ‘disability’ grants

“Disability grants” (i.e., public income support grants for people that fit particular definitions of “disability”) are a key component of the social safety net in a range of countries, many of which are dealing with significant HIV epidemics. The current discussion of disability definitions is of crucial importance for people living with HIV. As such, we encourage policy makers to consider both the many dimensions of disability as well as the multi-faceted experience of living with HIV.

Decisions around allocation of grants should consider the extent to which a condition restricts activity and participation in society. Temporary activity limitations caused by HIV-related diagnoses may be resolved with appropriate intervention. However, long-term disability (both permanent and episodic) can limit full, effective and equal participation in society in a way that compromises a person’s ability to support her/himself. These impacts at the individual, family, community and societal levels ought to be taken into account when allocating disability support grants.

Conclusion

The drive to provide universal access to *HIV treatment and care for all* is in motion. We now need to broaden our understanding of “care” to include rehabilitation, and our understanding of “all” to include people with disabilities.

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