

Section 1: What is the role of rehabilitation in the context of HIV in SSA?

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1.1 – How is "rehabilitation" defined in this resource?

In this resource, **rehabilitation** is defined as any services or activities that address or prevent body impairments, activity limitations, and social participation restrictions experienced by an individual.¹ Rehabilitation is concerned not only with physical well-being, but also with mental and spiritual dimensions of health.

1.2 – How can rehabilitation help people living with HIV in SSA?

The medical community is getting very good at treating HIV disease. However, where is the focus on the impact of HIV and its related conditions on a person's *function* or *participation* in her/his community? This is the focus of rehabilitation.

A focus on function and participation is especially important now that many more people living with HIV are able to access life-extending antiretroviral therapy (ART). For many people on ART, HIV is becoming a chronic and cyclical disease with periods of wellness and illness.^{2,3,4}

Since 1995, antiretroviral therapy has averted 4.8 million deaths in sub-Saharan Africa. The greatest declines in AIDS-related deaths in sub-Saharan Africa (2008 – 2013) were in the following countries:

- Rwanda (76%)
- Eritrea (67%)
- Ethiopia (63%)
- Kenya (60%)
- Botswana (58%)
- Burkina Faso (58%)
- Zimbabwe (57%)
- Malawi (51%)
- South Africa (48%)
- Tanzania (44%)⁵

This success in reducing AIDS-related mortality is credited to the rapid increase in the number of people on ART.

Medicine is adding *years to life*. **Rehabilitation aims to add *life to one's years*** – by helping people living with HIV to continue to work, keep up parenting roles, go to school, participate in church, feel active and independent, or any other goal related to living life.

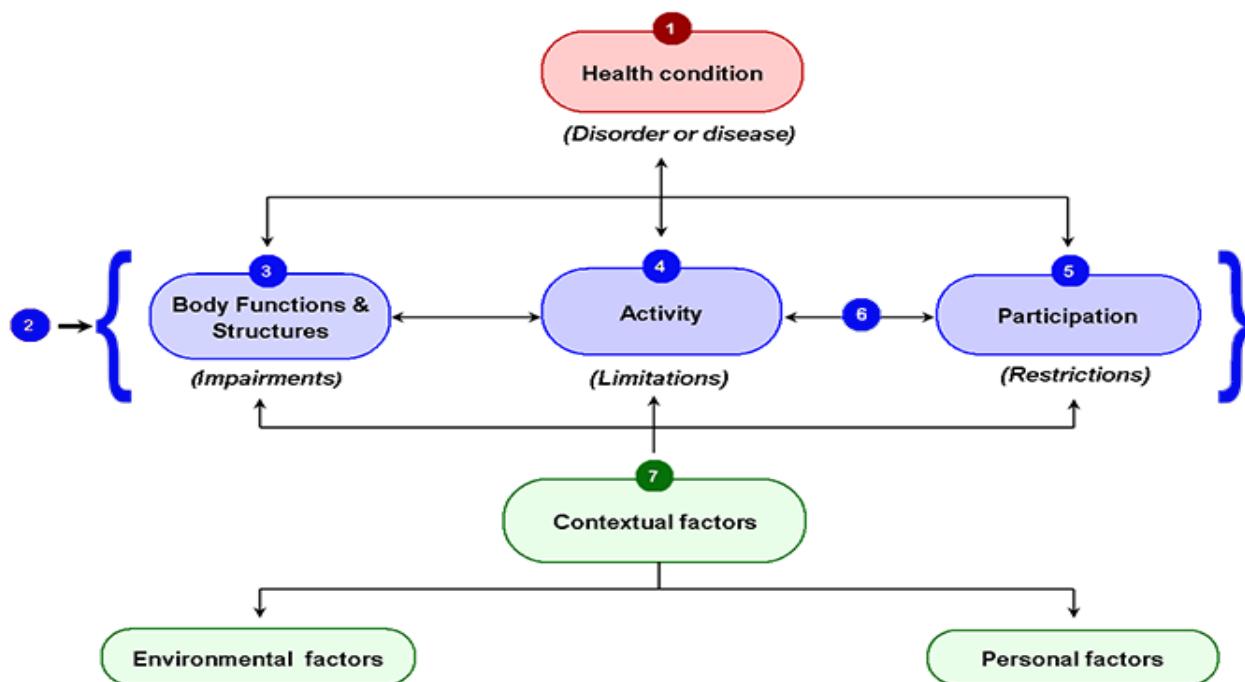
1.3 – How can the World Health Organization’s “ICF” help us think about rehabilitation for people living with HIV?

The World Health Organization's International Classification of Functioning, Disability and Health (known as the ICF)⁶ is helpful for thinking about the role of rehabilitation in HIV.^{7,8,9}

Health conditions (the top box) are often the focus of HIV care and treatment, whereas the ICF calls attention to the wide range of the **life-related** challenges resulting from health conditions that can be addressed by rehabilitation (boxes 3-5).

The model was designed for all types of diseases and functioning, not just HIV. It offers a common language for clinicians, managers, policy makers or others interested in HIV models of care.

Figure 1.3: The ICF Model



The ICF Model (Figure 1.3) Explained

1

This box describes the medical diagnoses, diseases or injuries that a person can experience. For a *person living with HIV*, this could be any combination of:

- HIV (e.g., the virus directly targeting the immune or neurological systems)
- HIV-related conditions (e.g., TB, pneumocystis carinii pneumonia, Kaposi's sarcoma)
- Diagnoses related to ART (e.g., peripheral neuropathy)
- Diagnoses unrelated to HIV (e.g., multiple sclerosis, trauma resulting from a motor

	vehicle accident)
2	This row describes the life-related impacts that result from health conditions. Rehabilitation addresses these impacts.
3	Impairments are problems in body function (physiological or psychological functions of body systems) or structure (anatomical body parts), e.g., weak abdominal muscles, memory loss, right-sided hypertonicity, congested lungs
4	Activity limitations are problems executing a task or action (e.g., getting dressed, walking to a clinic, carrying one's child, communicating with a neighbor)
5	Participation restrictions are problems an individual may experience with involvement in life situations (e.g., being excluded from school, difficulty participating with one's church, feeling stigmatized at work, challenges with parenting)
6	<p>Note the arrows are bi-directional. This means that a challenge at one level can affect any other level. For example:</p> <ul style="list-style-type: none"> Peripheral neuropathy (health condition) causing bilateral leg pain (impairment) can limit one's ability to walk to one's bank (activity limitation) which in turn can limit one's ability to manage her/his household finances (participation restriction). Stigmatization for being HIV-positive can result in being excluded from one's football team (participation restriction) which results in less physical activity (activity limitation) which results in decreased endurance and strength (impairments)
7	<p>Contextual factors influence or shape people's experiences with these life-related impacts of health conditions.</p> <ul style="list-style-type: none"> Environmental factors are the physical, social and attitudinal environment in which people live and conduct their lives (e.g., stigmatizing attitudes about HIV, stairs vs. ramp outside a health clinic, laws that criminalize certain HIV-related behaviors). These contextual factors include the social determinants of health¹⁰(e.g., housing, food security, access to employment). Personal factors are internal to each individual (e.g., gender, age, coping styles, education, past medical history).

1.4 – How can the Episodic Disability Model help us think about rehabilitation for people living with HIV?

For people who can access and tolerate ART, HIV is becoming a chronic and cyclical disease. These cycles of wellness and illness over time are not well captured in the ICF. Therefore, the Episodic Disability Model was developed with adults in Canada to describe the unpredictable nature of living with HIV.^{11,12}

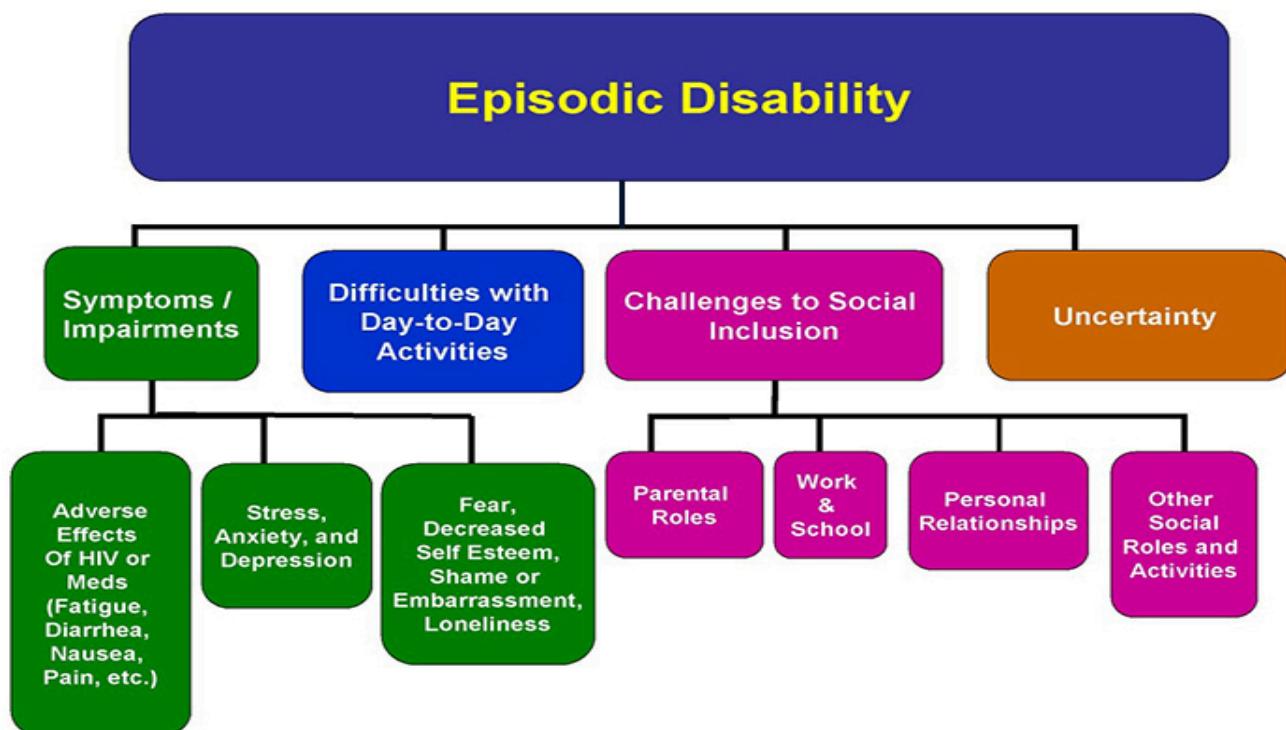
There is reason to expect that women, men and children on ART in sub-Saharan Africa will also experience episodes of wellness and illness related to their HIV.

The framework recognizes that each individual with HIV has her/his own disease course.

The Episodic Disability Model has 3 features:

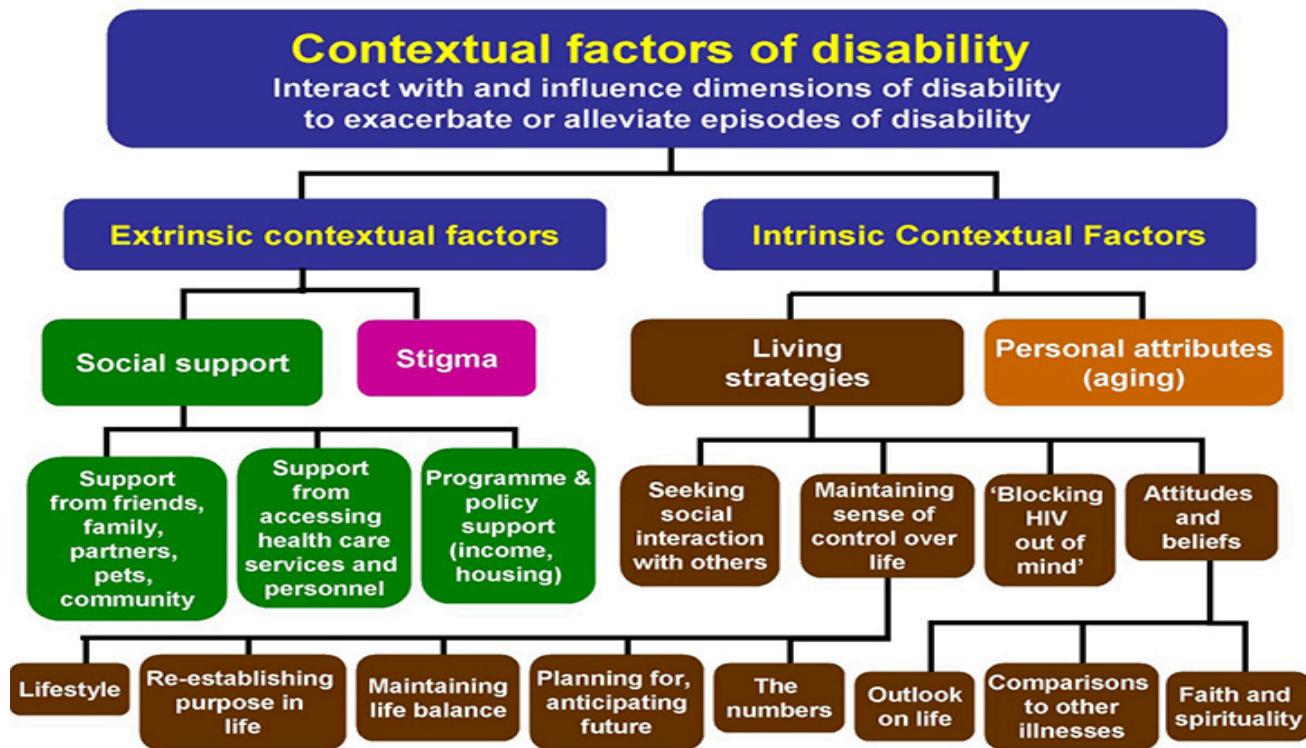
- **Dimensions of episodic disability** which describe four dimensions of episodic disability and their sub-components that may be experienced by adults living with HIV (see [Figure 1.4.1](#))
- **Contextual factors of disability** which describe the context in which disability is experienced. Extrinsic and intrinsic contextual factors could exacerbate or alleviate each of the four dimensions of disability for adults living with HIV (see [Figure 1.4.2](#))
- **Triggers** or life events that can mark a major episode of disability (e.g., first receiving an HIV diagnosis, starting or changing medications, suffering the loss of a family member or friend) (see [Figure 1.4.3](#))

Figure 1.4.1: Dimensions of Episodic Disability



O'Brien et al. *Health and Quality of Life Outcomes* 2008 6:76 doi:10.1186/1477-7525-6-76

Figure 1.4.2: Contextual factors of disability



O'Brien et al. *Journal of the International AIDS Society* 2009 12:30 doi:10.1186/1758-2652-12-30

Figure 1.4.3: Triggers

Triggers that Can Initiate Major or Momentous Episodes of Disability (Examples include)



O'Brien et al. *Health and Quality of Life Outcomes* 2008 6:76 doi:10.1186/1477-7525-6-76

Why is it helpful to think about HIV as an episodic disability?

As people with access to ART live longer, the long-term impacts of HIV and its treatments (in combination with aging itself) may lead to increased prevalence of concurrent conditions, such as arthritis, fractures from osteoporosis, diabetes, some forms of cancer, and depression or other mental illnesses.¹³

- The common feature of these other conditions is that they can all be **episodic** both in nature and impact.
- As such, people living with HIV may experience several episodic conditions concurrently, all with different fluctuations in their functioning and health.
- Thus, the need for rehabilitation is expanding to prevent or manage such disabling impacts and promote quality of life.

This approach also helps to identify policy models that promote more flexible employment or school programs that enable people with episodic illnesses to participate when their health permits without losing the opportunity when they get sick again.

1.5 – Who provides rehabilitation for people living with HIV?

Rehabilitation is defined as any service or activity that addresses or prevents body impairments, activity limitations, and social participation restrictions experienced by an individual. This includes physical, mental and spiritual dimensions of health.¹⁴ Therefore, there are *many* people who can provide rehabilitation for people living with HIV, including:

- Rehabilitation professionals, such as physiotherapists, occupational therapists, speech-language therapists and psychiatrists¹⁵
- People providing rehabilitation in the community, including community rehabilitation workers, other community-based rehabilitation (CBR) workers, HIV home-based care workers, or family/friends focused on improving an individual's function and participation
- Doctors, nurses, social workers, psychologists, nutritionists or others working in health care who are focused on enhancing an individual's function and participation
- Complementary therapies focused on function and participation, including the work of chiropractors and massage therapists
- Traditional healers and spiritual leaders may also contribute to rehabilitation when they promote function and social participation (see [Section 3.4](#))
- Anyone else in the multidisciplinary team who is focused on improving the function and participation of a person living with HIV

1.6 – Do rehabilitation providers need special skills or training to care for people living with HIV? If so, what?

Most rehabilitation providers **already** have the clinical skills they need to help people living with HIV (e.g., rehabilitation assessment of patients and treatment techniques that are used for musculoskeletal, cardiorespiratory and neurological conditions).

Many diseases affect only one body system. However, HIV and its related conditions can affect every body system (e.g., neurological, musculoskeletal, cardiorespiratory). While the underlying HIV-related pathology may be new, the resulting *impairments* (e.g., muscle weakness, impaired memory), *activity limitations* (e.g., difficulty climbing stairs or getting dressed) and *participation restrictions* (e.g., being able to work, participating in a community group) tend to be the same as other conditions.

The rehabilitation assessment and treatment techniques for these challenges also tend to be the same.

Examples

- A pneumonia may result from HIV, but the chest physiotherapy assessment and treatment techniques are the same as other pneumonias.
- A stroke may result from HIV, but the rehabilitation assessment and treatment techniques are the same as other patients with stroke
- Cognitive dysfunction may occur as a result of HIV, but the rehabilitation assessment and treatment techniques for assisting that individual to cope with daily tasks are the same as other patients with cognitive decline

However, there is *some* new information that rehabilitation providers need to know about HIV, including:

- That HIV can simultaneously affect multiple body systems
- The side effects of HIV treatments that may cause disability
- The unique forms of HIV-related stigma that may disable people as much as the virus itself
- Psychosocial aspects of living with HIV and where to refer for counselling

Another concern is that rehabilitation providers may not feel skilled enough to care for people living with HIV.^{16,17,18} This is the primary purpose of this resource: to equip rehabilitation providers with guidance on the care of people living with HIV, in order to improve quality of life.

1.7 – What roles do rehabilitation providers have related to HIV in SSA?

Table 1.7: Roles of Rehabilitation Providers

Roles of Rehabilitation Providers	Examples
Clinical care	<p>From promotion, to prevention, to referral, to acute care, to rehabilitation, to habilitation and to palliation.</p> <p>E.g., see Section 1.8 for details of clinical roles for rehabilitation.</p>
Advocacy	<p>Using one's knowledge and status in the community to advocate for change in support of the needs of people living with or at risk for HIV.</p> <p>E.g., advocating for inclusion of rehabilitation in HIV National Strategic Plans, advocating for HIV physicians to refer to rehabilitation, advocating for people living with HIV who are marginalized to receive equitable care, advocating for food security and feeding schemes.</p>
Capacity-building	<p>Providing training to others to enhance the inclusion and participation of people living with HIV in their communities.</p> <p>E.g., education to teachers about how to ensure inclusion of children living with HIV in their classrooms, education to employers about how to support employees living with HIV, education to parents or other family members about appropriate HIV precautions and how to combat HIV-related stigma, education of spiritual leaders and traditional healers about the importance of individuals living with HIV taking ARV</p>
Research	<p>Many rehabilitation researchers are leading the way conducting studies to better understand how to address HIV/ART-related disability.</p> <p>E.g., research to develop a tool to assess HIV-related disability,¹⁹ research on when and how people with disabilities may be excluded from HIV care and how to address this,²⁰ research on non-pharmacological treatment of peripheral neuropathy or lipodystrophy,^{21,22} research on rehabilitation with children living with HIV,²³ rehabilitation on pain management in HIV,²⁴ research on safe and effective exercise prescription for people living with HIV^{25, 26}</p>

1.8 – When is rehabilitation clinical intervention useful along the HIV care continuum?

Rehabilitation has important contributions to make throughout the care continuum. Although people often present for care late in their HIV disease, rehabilitation also has an important role to play in preventing disability when someone with HIV is feeling well and is asymptomatic.

Table 1.8: Rehabilitation along the HIV care continuum

Status of the person living with HIV					
	Feeling well, asymptomatic	Minor symptoms	Acute illness	Recovering from acute illness	Palliative
Goal of rehabilitation	Prehabilitation to prevent future disability	Address specific impairments with goal of optimizing function and participation in typical roles	Address acute cardiorespiratory, neurological, musculoskeletal or other impairments to recover from acute illness	Improve function and independence to return to typical function and participation	Pain management, maintaining function to optimize comfort
Settings for rehabilitation	Community, Work place, Home	Rehabilitation clinic, Community Home	Hospital, Home	Hospital, Rehabilitation clinic, Community	Home, Hospice, Hospital
Examples	Aerobic and progressive resistance exercise prescription	Interventions to help manage impairments related to peripheral neuropathy in feet	Chest physiotherapy	Stroke rehabilitation	Specific pain management techniques, providing adaptive equipment to assist with function while patient becomes weaker

1.9 – What is the relationship between disability, poverty, HIV and rehabilitation?

Disability, poverty and HIV are linked in a vicious cycle

People with disabilities are more likely to experience poverty, and people in poverty are more likely to develop disabilities. This also extends to the families of people in poverty.²⁷

HIV can also become part of this cycle – that is, HIV can result in disability, and HIV can also exacerbate poverty for many people.

Similarly, having a disability or being in poverty can make a person more vulnerable to HIV or AIDS.

Examples

For example, if a person living with HIV is the main breadwinner in a family, her/his illness and resulting disability can worsen the poverty of that household. Worsened poverty can result in poor nutrition for the entire family, and also for the person living with HIV – which can be especially challenging if that person is also taking medications that require good nutrition.

Most countries in sub-Saharan Africa do not have strong financial support systems to help people living with disabilities. This worsens the cycle.

Rehabilitation offers a strategy for breaking this cycle by reducing disability and supporting people to optimize their function, participation and independence. In addition to **clinical** roles, rehabilitation providers also have an **advocacy** role to play in addressing the wider determinants of health that can exacerbate disability.

Is HIV itself a disability?

The answer to this question depends on what you mean by disability. In this resource, we consider people with disabilities to 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.²⁸ This is the definition in the Convention on the Rights of Persons with Disabilities (CRPD) so we do not consider HIV to be a disability in this resource.

However, in certain social support systems, being HIV-positive may qualify people for a "disability grant" or other forms of financial benefit.^{29, 30} In these unique instances, people may consider HIV to count as itself a disability.

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