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What is this resource about and who is it for?

What is this resource about?

The aim of this e-module is to enhance knowledge about HIV care among rehabilitation providers in Sub-Saharan Africa to help address the needs of people living with HIV.

What do we mean by “rehabilitation”?

In this resource, **rehabilitation** is defined as any service or activity that addresses or prevents 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.

Who is this resource for?

This resource is primarily for rehabilitation providers practicing in Sub-Saharan Africa.

Rehabilitation providers include occupational therapists, physiotherapists, speech-language therapists, and psychiatrists.

Others who may benefit from this resource include:

- other health and social service providers;
- community rehabilitation workers, community health workers or home-based carers; and,
- people living with or affected by HIV

A description of the many people who can provide rehabilitation for individuals living with HIV is provided in [Section 1.5](#)

Why was the resource created?

Treatment advances have improved survival for people living with HIV who have access to care. HIV disease is now considered chronic and cyclical, with periods of wellness and illness^{2,3,4}

As many people with HIV in Sub-Saharan Africa are now living longer, they face a number of health challenges related to HIV, concurrent health conditions, and side effects of treatment.

A 2004 survey in Canada was the first to document the high prevalence of disablement among people living with HIV. At least 80% of respondents experienced a minimum of one impairment (e.g. fatigue, pain, memory problems), activity limitation (e.g. difficulty carrying out daily activities) or social participation restriction (e.g. employment, financial independence) in the previous month.⁵

More recently, research has been conducted in Sub-Saharan Africa that illustrates the various forms of disablement that may be experienced by adults and children living with HIV.^{6,7,8,9}

These findings highlight the role for rehabilitation to help people meet the challenges of living and aging with HIV.

How can the resource be used?

This resource is designed for use either:

- as a *whole* or
- by *section* depending on the specific learning needs of the user.

Each section can be used online or downloaded as a PDF file.

The online format allows readers to navigate around the resource to find specific content as needed. Links to additional resources are provided throughout so that readers can access further information.

Can this resource be used for teaching?

- Yes!
- This resource is designed to be used widely for teaching others, including:
 - Rehabilitation students
 - Practicing rehabilitation providers
 - Community rehabilitation workers, community health workers or home-based carers
 - Other health or social service providers
 - People living with HIV and their caregivers

This resource is copyrighted. Are permissions needed to use it?

This resource is intended to be shared with as broad a range of stakeholders as appropriate. Use of these materials is encouraged!

This resource may be reprinted and distributed in its entirety for non-commercial purposes without permission.

Permission must be obtained to excerpt and/or edit the content or to use the resource for commercial purposes. Use this form to request permission: <http://hivandrehab.ca/EN/resources/documents/Form.doc>

How is the resource organized?

The resource is divided into 5 sections as follows:

Section Title	Section Outline
<p><u>Section 1:</u> What is the role of rehabilitation in the context of HIV in SSA?</p>	<p>1.1 – How is “rehabilitation” defined in this resource?</p> <p>1.2 – How can rehabilitation help people living with HIV in SSA?</p> <p>1.3 – How can the World Health Organization's "ICF" help us think about rehabilitation for people living with HIV?</p> <p>1.4 – How can the Episodic Disability Model help us think about rehabilitation for people living with HIV?</p> <p>1.5 – Who provides rehabilitation for people living with HIV?</p> <p>1.6 – Do rehabilitation providers need special skills or training to care for people living with HIV? If so, what?</p> <p>1.7 – What roles do rehabilitation providers have related to HIV in SSA?</p> <p>1.8 – When is rehabilitation clinical intervention useful along the HIV care continuum?</p> <p>1.9 – What is the relationship between disability, poverty, HIV and rehabilitation?</p>
<p><u>Section 2:</u> What do rehabilitation providers need to know about HIV in SSA?</p>	<p>2.1 – What do rehabilitation providers need to know about the stages of HIV infection?</p> <p>2.2 – What do rehabilitation providers need to know about CD4 count and viral load?</p> <p>2.3 – What is the impact of HIV on body systems and why does this matter for rehabilitation providers?</p> <p>2.4 – Who might the patients be that rehabilitation providers treat in SSA?</p> <p>2.5 – What do rehabilitation providers need to know about ARTs in SSA?</p> <p>2.6 – What are the precautions that all rehabilitation providers should take regarding HIV and other related co-infections?</p>
<p><u>Section 3:</u> What are the rehabilitation interventions that can help people living with HIV in SSA?</p>	<p>3.1 – What are the rehabilitation interventions that address impairments common among people living with HIV?</p> <p>3.1.1 – Mental impairments</p> <p>3.1.2 – Sensory functions and pain</p>

3.1.3 – Voice and speech functions

3.1.4 – Functions of the cardiovascular, hematological, immunological and respiratory systems

3.1.5 – Functions of the digestive, metabolic and endocrine systems

3.1.6 – Genitourinary and reproductive functions

3.1.7 – Neuromuscular and movement related structures

3.1.8 – Functions of the skin and related structures

3.2 – What are the rehabilitation interventions that can address the activity limitations and participation restrictions common among people living with HIV?

3.3 – More information on rehabilitation interventions for people living with HIV in Sub-Saharan Africa?

3.4 – What do rehabilitation providers need to know about their patients' beliefs and use of traditional healers, spiritual leaders and alternative therapies outside the formal medical system?

Section 4:

What do rehabilitation providers need to know about caring for children and youth living with HIV in SSA?

4.1 – What is the role of rehabilitation for children and youth living with HIV and their families?

4.2 – What is the ICF-CY and how can it help us think about the role of rehabilitation for children and youth living with HIV?

4.3 – What are the rehabilitation interventions that address impairments common among children and youth living with HIV?

4.3.1 – Mental functions

4.3.2 – Sensory functions and pain

4.3.3 – Hearing

4.3.4 – Vision

4.3.5 – Sensation

4.3.6 – Voice and speech functions

4.3.7 – Functions of the cardiovascular, haematological, immunological and respiratory systems

4.3.8 – Respiratory Impairments

4.3.9 – Functions of the digestive, metabolic and endocrine systems

4.3.10 – Endocrine disorders

	<p>4.3.11 – Neuromusculoskeletal and movement-related functions</p> <p>4.3.12 – Functions of the skin and related structures</p> <p>4.4 – What are the rehabilitation interventions that can address the activity limitations and participation restrictions common among children and youth living with HIV?</p> <p>4.4.1 – Adolescents and Young Adults</p>
<p><u>Section 5:</u> What are the concepts and tools for measuring rehabilitation outcomes in HIV in SSA?</p>	<p>5.1 – What are outcome measures?</p> <p>5.2 – Why should rehabilitation providers use outcome measures?</p> <p>5.3 – How do rehabilitation providers know if an outcome measure will be useful in practice?</p> <p>5.4 – What are floor and ceiling effects in outcome measurement?</p> <p>5.5 – What is the difference between generic and HIV-specific outcome measures?</p> <p>5.6 – How should you decide which outcomes measure to use?</p> <p>5.7 – How do you access a copy of an outcome measure?</p> <p>5.8 – What are rehabilitation-related outcome measures that can be useful for people living with HIV in SSA?</p> <p>5.8.1 – Activities of Daily Living</p> <p>5.8.2 – Coping Response</p> <p>5.8.3 – Depression</p> <p>5.8.4 – Fatigue</p> <p>5.8.5 – Health-related quality of life</p> <p>5.8.6 – Presence and bothersome nature of symptoms</p> <p>5.8.7 – Self-management self-efficacy</p> <p>5.8.8 – Social Support</p> <p>5.8.9 – Stigma</p> <p>5.8.10 – Stress</p>

How was this resource developed?

This resource is a comprehensive adaptation of the [2014 version of the “e-Module for Evidence-Informed HIV Rehabilitation” \(e-Module\)](#),¹⁰ which was designed for *Canada*. This resource was adapted for rehabilitation providers in *Sub-Saharan Africa*.

What is the history of the 2014 version of the “e-Module for Evidence-Informed HIV Rehabilitation”?

In 1998, "*A Comprehensive Guide for the Care of Persons with HIV Disease (Module 7)*", was published by Health Canada and the Wellesley Central Hospital in Toronto, Canada.¹¹ This version was updated by the Canadian Working Group on HIV and Rehabilitation (CWGHR) in 2013 and 2014.

Founded in 1998, the Canadian Working Group on HIV and Rehabilitation is a national multi-sector, multi-disciplinary, charitable organization of stakeholders involved in rehabilitation in the context of HIV in Canada. CWGHR works to bridge the traditionally separate worlds of HIV, disability and rehabilitation to promote quality of life through research, education, and cross-sector partnerships (www.hivandrehab.ca).

In 2013, the 1998 ‘Module 7’ was updated to address the changing profile, emerging issues and new evidence related to HIV and rehabilitation.¹² The 2013 adaptation was led by CWGHR and was a collaboration among a dedicated team of authors, editors, and external reviewers including: people living with HIV, clinicians, researchers, and advocates representing fields spanning medicine (family medicine and psychiatry), nursing, occupational therapy, psychology, physical therapy, speech-language pathology, social work, pediatrics, midwifery, and policy.

In 2014, the resource was further updated by a large team of volunteers who participated as content experts, advisory committee members, writers and reviewers. The final resource was called the 2014 version “*e-Module for Evidence-Informed HIV Rehabilitation*”.¹⁰

How was the Canadian 2014 e-Module adapted for Sub-Saharan Africa?

This current resource is a comprehensive adaptation of the 2014 Canadian e-Module for rehabilitation providers in Sub-Saharan Africa. This adaptation was led by collaborators at:

- Canadian Working Group on HIV and Rehabilitation (Canada)
- Disability Service Programme (Kenya)
- International Centre for Disability and Rehabilitation at the University of Toronto (Canada)
- University of Zambia (Zambia)

Adaptation involved input from a range of individuals with rehabilitation, disability and/or HIV experience from 5 countries in Sub-Saharan Africa. The adaptation process involved 7 steps:

- 1) The **2013 e-Module** was carefully reviewed by individuals with experience in HIV and/or disability and/or rehabilitation in Sub-Saharan Africa.
- 2) Reviewers’ feedback was consolidated and an outline for the adapted resource was developed.
- 3) Content for the adapted resource was developed by drawing on text from the 2014 e-Module and new writing.

- 4) Drafts were reviewed by all collaborators.
- 5) The adapted resource was pilot tested with rehabilitation providers and rehabilitation students in Kenya and Zambia.
- 6) Changes were made to the resource based on feedback from the pilot.
- 7) The final resource was made available for free in online, mobile and downloadable PDF versions.

Who funded the development of this resource?

Financial support for this current online resource adapted for Sub-Saharan Africa was provided through a grant by [Grand Challenges Canada](http://www.grandchallenges.ca). Grand Challenges Canada is funded by the Government of Canada and is dedicated to supporting Bold Ideas with Big Impact in global health. For more information visit <http://www.grandchallenges.ca>.

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Who contributed to writing and reviewing this adapted resource?

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Acknowledgement of pilot participants

Thanks to the rehabilitation providers and students who contributed their time and expertise to provide feedback on the draft resource during the pilot testing phase in Kenya and Zambia.

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ssa.hivandrehab.ca

Disclaimer

While the content of this resource is, to the best of our knowledge, current and reliable, information is not a substitute for actual health care and treatment. The opinions expressed in this resource do not necessarily reflect the official policy of CWGHR or any of the sponsoring organizations.

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