



Canadian Working Group on HIV and Rehabilitation
Groupe de travail canadien sur le VIH et la réinsertion sociale

Advancing HIV, Disability and Rehabilitation

Canadian Working Group on HIV and Rehabilitation (CWGHR)

Strategic Plan

2014-2017

Date Last Revised: April 2nd, 2014

The **Canadian Working Group on HIV and Rehabilitation** (CWGHR) is a national charitable organization, working to improve the quality of life of people living with HIV through rehabilitation research, education, and cross-sector partnerships. CWGHR members include people living with HIV, members of community-based HIV organizations, national associations of health professionals, government agencies, private businesses and the employment sector.

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What is CWGHR?

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, charitable, organization that addresses issues of disability and rehabilitation in the context of HIV and related conditions (www.hivandrehab.ca).

Formed in 1998, CWGHR promotes innovation and excellence in rehabilitation in the context of HIV. In order to promote a comprehensive approach to rehabilitation in the context of HIV, CWGHR is multi-sectoral and multi-disciplinary in its membership and activities.

CWGHR members come from across Canada, as well as other countries, and include people living with HIV, members of community-based HIV and disability organizations, national associations of health professionals, government agencies, private businesses, and the employment sector. Members elect a nine-person Board of Directors to guide the organization.

Introducing the 2014 – 2017 Strategic Plan

In 2013, CWGHR celebrated its 15th anniversary. CWGHR has achieved great success since the launch of the 2010-2013 strategic plan with achievements spanning areas of research, education, policy and practice.¹ This 2014-2017 strategic plan builds upon CWGHR's history and accomplishments; highlights current initiatives; and indicates new priorities for the future. The goal of this strategic plan is to revise CWGHR's strategic directions for the next three years.

The process for this strategic plan renewal involved a three year multi-staged consultative and refinement process. The development of this strategic plan was a result of three consultations with CWGHR Board members between June 2012 and 2013, consultations with CWGHR membership at the Annual General Meetings in June 2012 and 2013, consultation with eleven CWGHR key stakeholders in December 2013, and on-going consultation among members of CWGHR's Strategic Planning Committee and Board between 2010 and January 2014. During this process, members of the Board consolidated CWGHR's mission to better reflect its work as it relates to people living with HIV and other related chronic conditions. CWGHR also identified four strategic directions that highlight areas on which to focus and maximize our impact on the health of people living with HIV and related conditions. The strategic plan was approved by the Board on April 14th, 2014 and circulated to the membership in June 2014.

CWGHR's Approach to HIV, Active Living and Rehabilitation

CWGHR's approach to HIV and rehabilitation is central to its vision, mission, and strategic directions. This approach, combined with a multi-sector model that encourages dialogue and collaboration between and among diverse communities and professions, helps shape this strategic plan, our strategic directions, and activities.

¹ CWGHR Strategic Plan 2010-2013. http://www.hivandrehab.ca/EN/about_us/documents/CWGHRStrategicPlanFinal.pdf

For many people living with HIV who have access to antiretroviral treatment, HIV is no longer considered imminently fatal. While there is currently no cure for HIV, for some people, HIV has become a life-long chronic condition.

For many, living with HIV can cause health-related challenges whereby periods of relative health may be interrupted by periods of illness, with little predictability as to when this will occur or for how long. Thus, for some people living with HIV, HIV can be described as a chronic and episodic illness².

CWGHR adopted a broad conceptualization of **disability** and **rehabilitation**³ which includes a wide range of facilitators and barriers to meaningful active living.

CWGHR recognizes that the language used to describe the health and health-related challenges that people living with HIV may experience is very contextual and may vary depending on the clinical, social or political context in which it is used. For example, in the context of employment insurance, disability may be defined in relation to a person's ability to work, while in the context of health care, disability may be defined as a person's physical ability to carry out a life-related task or daily activity.

CWGHR uses the term 'disability' as broadly defined by the World Health Organization to refer to any body impairments, activity limitations or social participation restrictions experienced by an individual as a result of HIV, associated conditions, or treatments.^{3,4}

- **Body impairments** include any problems with body function or structure. Examples include physical (e.g. pain, fatigue, diarrhea), cognitive (e.g. difficulty remembering, focusing attention), and mental and emotional health (e.g. stress, anxiety, depression) impairments.
- **Activity limitations** include any difficulties an individual may have in carrying out a task or action. Examples include difficulty walking or climbing stairs, carrying groceries or carrying out self-care activities such as taking a bath or shower.
- **Participation restrictions** are problems an individual may experience with involvement in life situations. Examples include difficulty maintaining employment and education, personal relationships, and difficulty meaningfully engaging in community and social life, such as recreation, or leisure activities.

These components of disability may be influenced by contextual factors that can interact with and affect a person's health, including **environmental factors** (e.g. stigma, social structures or policy) and **personal factors** (e.g. gender, age, other health conditions). These contextual factors are consistent with the health policy framework of the "social determinants of health"⁵ which include housing, income security, employment, access to education and health care, all of which CWGHR considers in our work.

² Although we use the term "episodic" to describe many people's experience with HIV, that experience does not apply to all people living with HIV. By "episodic", we refer to fluctuating, or sometimes unpredictable periods, degrees and severity of illness and function. This is a working term and definition as we recognize that other terms (e.g. recurrent, cyclical, non-static) are also used and may be appropriate in different contexts. Other examples of episodic illnesses include multiple sclerosis, mental illness, lupus, arthritis and some forms of cancer .

³ Based on the World Health Organization International Classification of Functioning Disability and Health (ICF) 2001

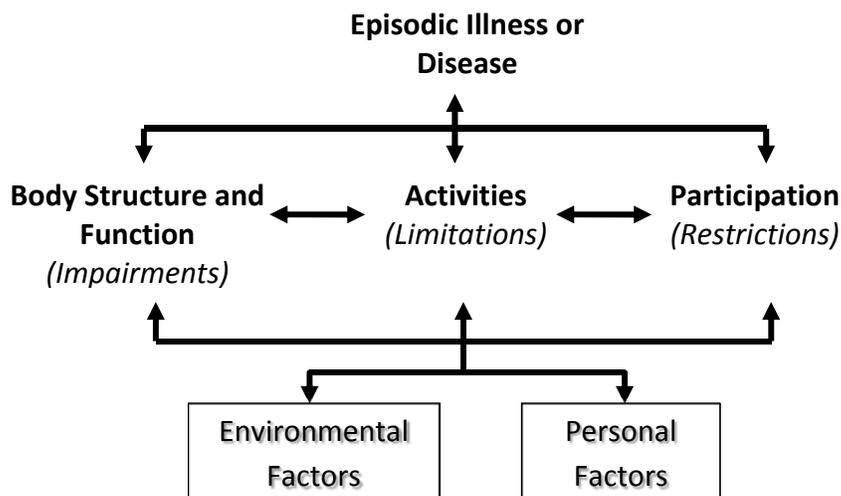
⁴ Worthington C, Myers T, O'Brien K, Nixon S, Cockerill R. *Rehabilitation and HIV/AIDS: Development of an expanded conceptual framework. AIDS Patient Care and STDs. 2005; 19(4):258-71.*

⁵ *Social determinants of health include factors such as income security, housing, access to appropriate employment, health care, education, nutrition/food security, psychosocial support, gender, social safety net, social inclusion*
<http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php>

Disability therefore, can include everything from a physical ailment to a lack of social support to a public policy that inhibits working or volunteering. All of these components have an impact on quality of life.

Figure 1: Components of the ICF Framework

Adapted From: World Health Organization International Classification of Functioning, Disability and Health (2001).



This broad conceptualization of disability forms the basis for an equally broad understanding of **rehabilitation**.

CWGHR defines rehabilitation as any services or activities that address or prevent body impairments, activity limitations, and social participation restrictions experienced by an individual.⁴

CWGHR understands that effective rehabilitation involves a continuum of rehabilitation policies, programs, and services for people living with HIV to maintain or return to meaningful active living. Rehabilitation supports can be both preventative (to prevent a decline in active living) and restorative (to support return to active living).

Rehabilitation supports can include, but are not limited to:

- Basic supports such as income, housing and nutritious food;
- Social supports such as friends, family, community, cultural and religious organizations;
- Supports and policies to encourage work or volunteer activities;
- Policies and practices to reduce stigma;
- Health care services and treatments, including rehabilitation services (e.g. physical therapy, occupational therapy, speech-language pathology), as well as complementary and alternative therapies;
- Practical services such as referrals, advocacy, training and employment counselling; and
- Psycho-social supports such as mental health programming, counselling and peer groups.

CWGHR outlines the following as their vision and mission for the next three years.

Vision

The daily lives of people living with HIV are improved in direct and meaningful ways by rehabilitation care, support and services.

Mission

The Canadian Working Group on HIV and Rehabilitation is a leader and catalyst for improved rehabilitation for people living with HIV and related conditions through integrated research, education, policy and practice.

Values

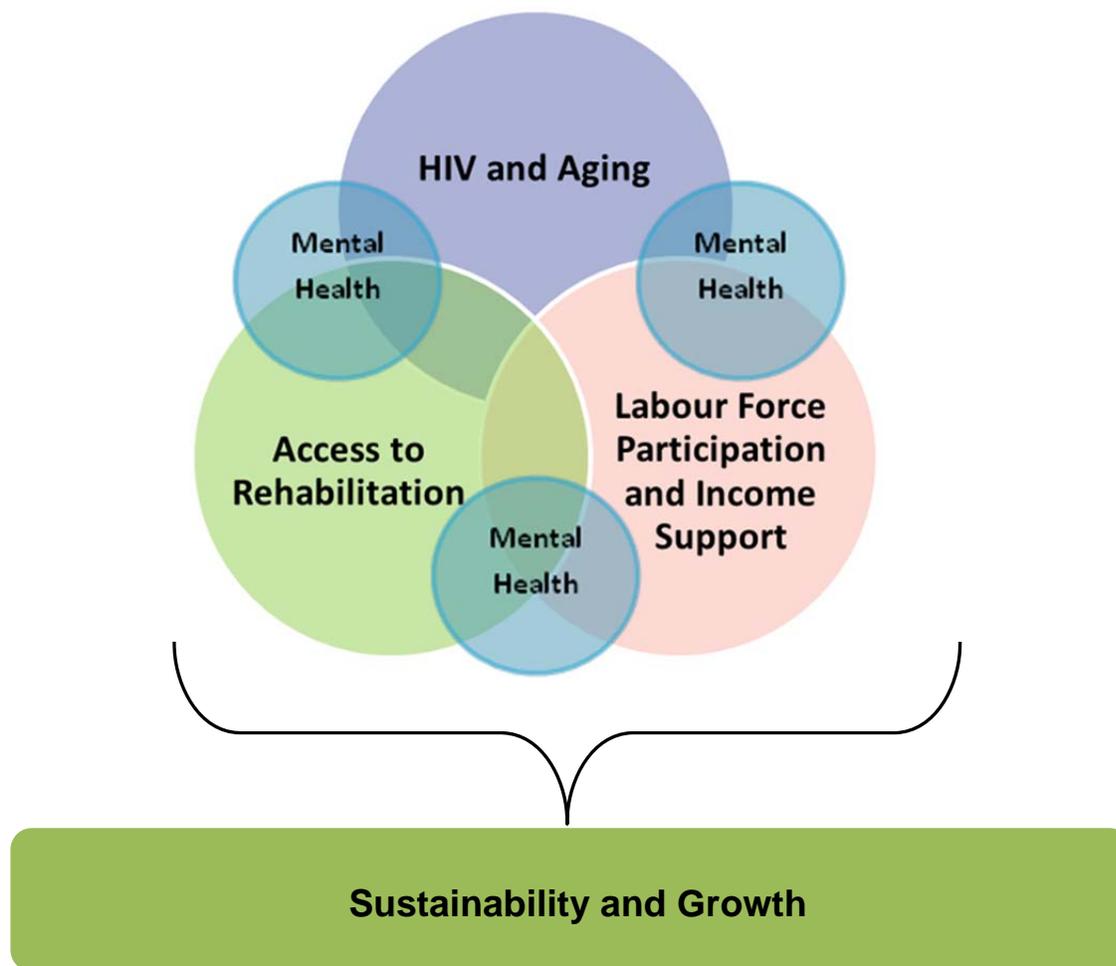
While CWGHR shares many of the same values and principles as our partners in the HIV and disability communities, CWGHR uses the following core values and principles to carry out its mission and vision.

- 1) CWGHR recognizes rehabilitation as an integral component of the HIV care and treatment continuum which must be addressed with consideration for its various overlapping dimensions such as episodic disability, chronic illness, aging with a life-long condition, etc.
- 2) CWGHR values the diversity of experience, expertise and participation of all its stakeholders, including the meaningful participation of the people living with HIV.
- 3) CWGHR recognizes the value of working in partnership and collaboration with others to advance our common goals.
- 4) CWGHR embraces a comprehensive approach to HIV and rehabilitation practice, research, education and policy. All of these are informed by scientific and experiential evidence and values and preferences of people living with HIV.

Strategic Directions

CWGHR engages in a multitude of endeavours related to HIV, disability and rehabilitation. In this strategic plan, CWGHR focuses on the following five strategic directions: aging, access to rehabilitation, labour force and income support, mental health, and sustainability and growth. These areas may converge resulting in intersecting activities whereby CWGHR addresses multiple priorities. For example, CWGHR approaches healthy aging with HIV by promoting increased access to rehabilitation to address disability and enhance health promotion; or CWGHR addresses issues of mental health for those aging with HIV and works to improve the transition into retirement from the labour force for older adults with HIV and other related conditions. The greater the extent to which the strategic directions converge, the greater the potential for CWGHR to have an impact. Sustainability and growth remains a core foundation of CWGHR's work in order to strengthen the capacity for CWGHR to successfully achieve its mission throughout these areas.

Figure 2 – Overview of CWGHR’s Strategic Directions



❖ **HIV and Aging**

CWGHR will promote healthy aging and improved quality of life for people aging with HIV and related conditions by:

- Connecting the aging, HIV and rehabilitation sectors to foster a coordinated response to HIV and aging.
- Responding to new and emerging issues in HIV, aging and comorbidities.
- Considering the multi-dimensional nature of disability including the physical, cognitive, mental, emotional, and social health challenges experienced by people aging with HIV across the lifespan.
- Developing and disseminating knowledge on the health-related challenges associated with HIV and aging, and living strategies and interventions that will address disability and enhance the health of people aging with HIV.
- Engaging in policy and health systems change that will enhance healthy aging among people living with HIV.
- Supporting the use of evidence-informed palliative and end-of-life care approaches for people living with HIV and related conditions.

❖ **Access to Rehabilitation**

CWGHR will work to enhance access to rehabilitation services for people living with HIV and related conditions by:

- Increasing knowledge and awareness among the HIV community of the role of rehabilitation to prevent or address disabilities among people living with HIV.
- Educating current and future rehabilitation professionals, and other referring health and social care providers about the role of rehabilitation in the context of HIV.
- Responding to new and emerging learning needs in HIV and rehabilitation education, mentorship and professional development.
- Developing innovative rehabilitation service delivery models and evaluating their ability to effectively address disability and enhance the health of people living with HIV and related conditions.
- Fostering partnerships across chronic illness sectors to promote a coordinated clinical, programmatic, and policy response to access to rehabilitation.
- Engaging in opportunities to better integrate rehabilitation as a component of primary care by liaising with local, provincial, or national level decision-makers.

❖ **Labour Force Participation and Income Support**

CWGHR will work to enhance the income security and participation of people living with HIV and related conditions in (and out of) the labour force by:

- Engaging with employers, insurers, rehabilitation providers, and government to promote adaptable policies and programs to enhance recruitment and retention of people living with HIV and related conditions in the work place.
- Considering the mental, emotional, social, and financial health challenges experienced by people living with HIV and other related conditions across the lifespan, e.g. people aging with HIV who may be transitioning out of the work force, as well as, youth living with HIV and other related conditions about to enter/recently joining the labour force.
- Educating employers, insurers, human resource professionals, frontline managers and supervisors about the labour force participation and income security challenges of people living with HIV and related conditions i.e. hiring, retention and return to work.
- Fostering partnerships across chronic illness community organizations to promote awareness of effective workplace interventions that facilitate labour force participation by people living with HIV and other related conditions.
- Creating a knowledge hub of expertise on labour force participation and income support of people living with HIV and other related conditions to respond to new and emerging needs of these groups in these areas.

❖ **Mental Health**

CWGHR will work to reduce disability and enhance the overall health of people living with HIV. CWGHR's work on mental health will specifically concentrate on areas in which mental health converges with aging, access to rehabilitation and labour force participation and income support by:

- Building awareness among health and social providers of the mental health challenges facing people living with HIV and related conditions so they may better recognize and respond to the rehabilitation needs of this population.
- Fostering partnerships among the clinical, academic, community-based service and rehabilitation sectors to address the complex health challenges experienced by people living with HIV and related conditions.
- Identifying, evaluating and building awareness of effective interventions to address disability experienced by people living with HIV and related conditions.
- Engaging in policy and health system change processes to enhance the health and social inclusion of people living with HIV and related conditions.

❖ Sustainability and Growth

CWGHR will cultivate and strengthen our resources for sustainability and growth by:

- Engaging in activities and relationships that will develop, utilize, broaden, and sustain CWGHR's internal expertise, capacity and resources.
- Integrating knowledge management and succession planning mechanisms.
- Building and expanding CWGHR's membership and base of supporters.
- Fostering ongoing and new collaborations with different sectors that share a common interest in improving the health and well-being of people living with HIV and related conditions.
- Creating new opportunities for income generation and sustainability.
- Developing and utilizing communication mechanisms and opportunities to strengthen CWGHR's profile.
- Integrating evaluation processes to monitor and enhance CWGHR's effectiveness, accountability and relevance.
- Participating in initiatives that help ensure sufficient resources for a sustainable societal response to HIV, disability and rehabilitation.

Guiding Principles

The following describe the processes CWGHR uses to do its work. These principles describe *how* CWGHR will achieve our mission through the above strategic directions.

- CWGHR will address the above priorities through integrated **research, education, policy and practice**. Activities will be dependent on the research priorities in HIV and rehabilitation,⁶ strategic directions, funding opportunities, partnerships and capacity.
- CWGHR will focus on the development, promotion, implementation and evaluation of **effective interventions** that will prevent or mitigate disability and improve the health of people living with HIV and related conditions.
- CWGHR will adopt either an **HIV-specific or cross-disability (episodic illness) linkage approach** in order to maximize the impact on a given strategic direction. For example, access to rehabilitation, labour force participation and income support may be addressed using a cross-

⁶ O'Brien K, Wilkins A, Zack E, Solomon P. Scoping the field: Identifying key research priorities in HIV and rehabilitation. *AIDS and Behavior*. April 2010, 14:2. 448-58. DOI 10.1007/s10461-009-9528-z

disability approach involving partnerships with other chronic illness organizations whereas certain issues specific to HIV and aging may be addressed using an HIV-specific approach. In all realms, CWHGR will sustain and build new inter-sectoral partnerships among individuals, organizations and government who share similar interest in addressing disability-related issues and concerns.

- CWGHR will assume a leadership role when our expertise and resources permit, and support others when they are the most appropriate leaders. The activity and terms of partnership will be considered. In some instances (for example, where our strategic directions converge) CWGHR may lead an initiative whereas at other times CWGHR may take on the role of collaborator.
 - CWGHR will focus on **knowledge transfer and exchange** across all priority areas by translating research evidence and adapting educational initiatives to create useful tools which inform program and policy development.
 - CWGHR will continually **evaluate** the nature and extent to which they address the priority areas by measuring impact of their work and sharing it with their members.
 - CWGHR will engage in activities with the potential to be transferable to people living with HIV **locally, nationally, and internationally** to maximize the impact of its work.
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Priority Outcomes

The following outcomes are based on the strategic directions which CWGHR will use to address our priority areas. Specific activities will be monitored and/or evaluated and used as indicators of progress toward these outcomes.

1. CWGHR will have built partnerships, published resources, applied for research grants, and engaged in knowledge exchange activities to address critical issues facing individuals living with HIV and related conditions, including: aging, access to rehabilitation, and labour force participation and income support.
2. There will be an increased number of care providers and people within the HIV community who have the knowledge and skills to include rehabilitation as an integral part of the continuum of care.
3. There will be positive changes in policy and practice around access to rehabilitation for people living with HIV and related conditions, which CWGHR will have played a significant role in promoting.
4. People living with HIV will be more aware of, and will have the capacity to, seek out and navigate the health care system to access available rehabilitation services.
5. CWGHR will be recognized as a leader in HIV and rehabilitation, and will have a stronger membership and financial base to continue its work.

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6. There will be positive changes in the participation of people living with HIV and other related conditions in the labour force and improvements in the policy environment to facilitate greater income security for this group.

The Board will monitor CWGHR's success in achieving the above outcomes as they relate to the strategic directions. On-going evaluation is also embedded within CWGHR's specific activities.

Summary

Over the next three years, these sharpened strategic directions and processes with which to address them will provide a clear direction for CWGHR to continue to build on the work set out in the 2010-2013 Strategic Plan.

Thanks to all the members and partners who have contributed, and continue to contribute to the work of CWGHR. We look forward to your continued energy and participation during 2014-2017 as we work toward achieving the targets set out in this updated plan.

Glossary:

The following are operational definitions of some of the terms used in the CWGHR strategic plan.

Capacity/capacity building: providing knowledge, skills training, resources, access, support, etc. to enhance the meaningful participation of stakeholders.

Communities: may include (but are not limited to) people living with HIV and related conditions, and the various other identified target population groups, including: AIDS Service Organizations, current and future rehabilitation professionals, the academic sector, the employment sector, the insurance sector and governments.

Cross-disability: collaborative approaches that include HIV and other disabilities.

Disability: any body impairments, activity limitations or social participation restrictions experienced by an individual as a result of HIV, aging, associated conditions or treatments.

Diversity: includes not only individuals with varied backgrounds (cultural, sexual orientation, gender identity, ethnic/racial, geographic, ability, etc.) but also the wide and varied experience, expertise and participation of all the current and required stakeholders, achieved by having in place the appropriate supports and/or accommodations provided so that all can be involved in a meaningful way.

Episodic and chronic disability: although we use the term “episodic” to describe many people’s experience with HIV, that experience does not apply to all people living with HIV. By “episodic”, we refer to fluctuating/alternating, often unpredictable periods, degrees and severity of illness and functioning. This is a working term/definition as we recognize that other terms (e.g. recurrent, cyclical, non-static) are also used and may be appropriate in different contexts. Other examples of episodic disabilities include multiple sclerosis, mental illness, lupus, arthritis and some forms of cancer.⁷

Evidence: refers to knowledge emerging from research (e.g. published and grey literature), clinical and life experiences, as well as community values and preferences.

Knowledge exchange: the transfer of new knowledge to those people or processes which can influence a positive change in practice and/or policy.

Meaningful participation: encouraging and supporting individuals (and groups) most affected by HIV to be actively involved to the extent they desire in all stages of policy development, programming, research, advocacy, governance, etc. (for people living with HIV, this is often referred to as GIPA/MIPA; greater/meaningful involvement of people living with HIV/AIDS).

Multi-sectoral, multi-disciplinary, inter-professional: multiple (various) sectors, disciplines, professionals and stakeholders working and making decisions together – a process of communication and decision making that respects both the unique and shared knowledge and skills of multiple stakeholders and allows an issue with many dimensions to be handled holistically.

⁷ http://www.adelefurrie.ca/PDF/Dynamics_of_disability.pdf

Network: a formal or informal social structure made up of individuals and/or organizations which are connected for one or more purposes, such as common interest/beliefs, knowledge exchange, etc.

Partnerships: include coordination and/or collaboration among stakeholders, including organizations, individuals or institutions, in order to address a particular initiative of mutual interest. Partnerships may be academic, community-based, policy and/or peer-driven.

Practice: programs and services, including the ways in which services are provided. CWGHR understands practice as part of the four pillars of research, education, policy and practice.

Rehabilitation: any services or activities that address or prevent body impairments, activity limitations and social participation restrictions experienced by an individual.

Social determinants of health: social determinants of health include factors such as income security, housing, access to appropriate employment, health care, education, nutrition/food security, psychosocial support, gender, social safety net and social inclusion <http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php>.