



**HIV, DISABILITY AND REHABILITATION:
PROMOTING QUALITY OF LIFE THROUGH RESEARCH,
EDUCATION AND CROSS-SECTOR PARTNERSHIPS**

Strategic Plan: 2010-2013

Canadian Working Group on HIV and Rehabilitation

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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Canadian Working Group on HIV and Rehabilitation (CWGHR)

Strategic Plan

2010-2013

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 services for people living with HIV through integrated research, education, policy and practice.

Introduction

The Canadian Working Group on HIV and Rehabilitation (CWGHR) www.hivandrehab.ca is a national, multi-sectoral, multi-disciplinary organization that works to address issues of disability and rehabilitation in the context of living with HIV.

CWGHR has updated our strategic plan to help guide our work for the next three years.¹ This updated plan builds upon CWGHR's history, highlights current initiatives and indicates new priorities for the future.

The previous plan (2006-2009) emerged from an extensive strategic planning process undertaken in 2005-2006. The goal of this updated version of the strategic plan was to refine CWGHR's strategic directions until 2013. The process for this update included a one-day consultation with CWGHR Board members in February 2009, consultation with CWGHR membership at the Annual General Meeting in June 2009 and subsequent consultations amongst CWGHR's strategic planning committee and Board between June 2009 and March 2010. During this process, members of the Board consolidated CWGHR's values and principles, strategic directions, and example activities in each area. We circulated this revised strategic plan to members for their feedback in April 2010. We considered the feedback in this final version of the strategic plan that was approved by the Board on May 31, 2010.

¹ CWGHR Strategic Plan 2006-2009: http://www.hivandrehab.ca/EN/about_us/documents/Strat_Plan_2006-2009.pdf

Background

Formed in 1998, CWGHR is a national charitable non-profit organization promoting innovation and excellence in rehabilitation in the context of HIV disease. 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.

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.

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 long-term 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, unpredictable, episodic disability².

CWGHR considers the social determinants of health such as housing, income security, employment, access to education and health care in their work, and adopted a broad conceptualization of **disability** and **rehabilitation**³ which includes a wide range of 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.

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/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.

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

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.⁴

- **Body impairments** include any problems with body function or structure. Examples include pain, fatigue, diarrhea and numbness.
- **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 fulfilling 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).⁴ These contextual factors are consistent with the health policy framework of the “social determinants of health.”⁴

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.

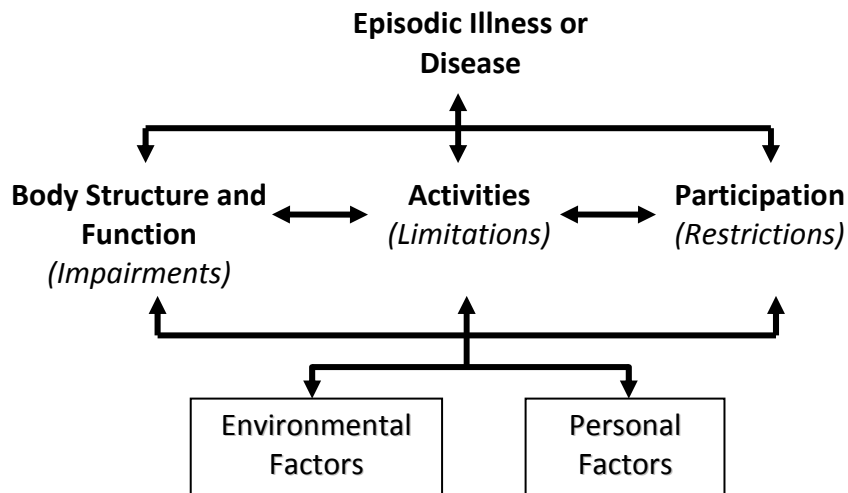


Figure 1: Components of the ICF Framework. Adapted From: World Health Organization International Classification of Functioning, Disability and Health (2001).

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

⁴ 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/oi-ar/index-eng.php>

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

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 nutrition
- Social supports such as friends, family, 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), complementary and alternative therapies
- Practical services such as referrals, advocacy, training and employment counselling
- Psycho-social supports such as mental health professionals, counsellors and peer groups

Values and Principles

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

- 1) CWGHR recognizes rehabilitation as an integral component of the HIV care and treatment continuum and must be addressed through 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 people living with HIV.
- 3) CWGHR recognizes the value of working in partnership 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 has four main strategic directions that encompass the four key areas of research, education, policy and practice.

1. To foster and advance knowledge in HIV and rehabilitation

- Participating in new and ongoing research addressing the top six research priorities⁵ in HIV and rehabilitation.
- Responding to new and emerging issues in HIV and rehabilitation research.
- Establishing and promoting an evidence-informed approach to HIV rehabilitation care, treatment and support.
- Engaging in various partnerships to conduct research.
- Facilitating the transfer of research knowledge to all relevant communities.

Example Activities:

- Engaging in new and ongoing research based on the 2007 Scoping Study⁵ which may address areas including, but not limited to, episodic disability, concurrent health conditions, aging with HIV, labour force participation and income support, access to and impact of rehabilitation services, and measurement. Examples of specific research activities include:
 - Developing evidence-informed recommendations for older adults living with HIV;
 - Developing a framework of barriers and facilitators to labour force participation for people living with HIV;
 - Evaluating the impact of a mentorship program for rehabilitation professionals on HIV/AIDS.
- Participating in disseminating new knowledge to multiple stakeholders in the form of reports, publications, skills building symposia, and conference proceedings (e.g. the Annual Ontario HIV Treatment Network (OHTN) Research Conference, the Annual Canadian Conference on HIV Research (CAHR), the Canadian Physiotherapy Association Congress).
- Engaging in the development of evidence-informed recommendations for best practice in HIV and rehabilitation (e.g. development of information sheets for care providers and people living with HIV, updating the original “*Module 7: Rehabilitation Services – A Comprehensive Guide for the Care of Persons with HIV Disease.*”⁶
- Engaging in ongoing research collaborations and partnerships, domestically and internationally, with researchers, clinicians, people living with HIV, and government stakeholders to advance the field of HIV and rehabilitation knowledge (e.g. Canada-United Kingdom Research Collaborative).
- Engaging in research on rehabilitation as prevention of the spread of HIV infection and its related disability.

⁵ O'Brien K, Wilkins A, Zack E, Solomon P. Scoping the Field: Identifying Key Research Priorities in HIV and Rehabilitation. *AIDS and Behavior*. 2010; 14:2: 448-58

⁶ Health Canada and Wellesley Central Hospital, 1998 (part of a series of modules on the care of people living with HIV)

2. To build capacity among health and other social care providers and the HIV community for strengthening rehabilitation as part of the continuum of care

- 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 for rehabilitation in the context of HIV.
- Responding to new and emerging learning needs in HIV and rehabilitation education, mentorship and professional development.

Example Activities:

- Developing, implementing and evaluating a mentorship program for rehabilitation professionals on HIV/AIDS.
- Developing new and innovative methods of curriculum delivery, including but not limited to, the online learning course for health professionals, online module HIV/AIDS course, interprofessional workshops and skills building symposia.
- Engaging in ongoing collaborations and partnerships with stakeholders to continually educate and promote capacity building among stakeholders (people living with HIV, current and future rehabilitation professionals, other health and social service providers, government, and employment sector) about the role for rehabilitation.
- Supporting the development of the Employment Network for people with episodic disabilities, including people with HIV.
- Recognizing and honouring leadership and excellence in HIV and rehabilitation through CWGHR's Annual Award of Excellence.

3. To champion improvements in policy and practice as they relate to HIV and rehabilitation

- Developing and supporting cross-disability linkages.
- Sustaining existing and building new inter-sectoral partnerships among individuals, organizations and government who share similar disability issues and concerns.
- Educating government decision-makers and health care program managers (stakeholders) on the role for rehabilitation in the context of HIV to inform the development of program and policy.
- Translating research and education knowledge about HIV and rehabilitation into useful tools to inform program and policy development.
- Linking HIV rehabilitation issues to broader population health and social policy initiatives.⁷

Example Activities:

- Fostering initiatives of the Episodic Disability Network (EDN) and the Ontario Episodic Disability Network (OEDN).
- Fostering linkages with government stakeholders to translate research knowledge and build capacity to enhance program and policy.
- Engaging in international partnerships to share knowledge and experience.
- Working with government and other national HIV and disability organizations on issues of HIV and disability, such as a discussion paper on the inclusion of HIV within the interpretation and application of the UN Convention on the Rights of Persons with Disabilities, and coordination of international policy dialogues among HIV and disability groups to inform policy and practice.
- Educating employers, insurance companies, government and other policy makers for more flexible income and employment policies to accommodate people living with episodic disabilities.
- Working with the National HIV Partners and other disability/rehabilitation colleagues to work towards achieving and sustaining adequate funding to respond to HIV, disability and rehabilitation.

⁷ e.g. Social Determinants of Health <http://www.phac-aspc.gc.ca/ph-sp/oi-ar/index-eng.php>

4. To cultivate and strengthen CWGHR's resources for sustainability and growth

- Cultivating 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 with common interest in improving the health and wellbeing of people living with HIV.
- 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 to ensure sufficient resources for a sustainable societal response to HIV, disability and rehabilitation.

Example Activities:

- Promoting individual and organizational membership of CWGHR – expanding the number of members, advisors, supporters and champions supporting the organization and its mission.
- Promoting participation in the CWGHR Annual Forum on HIV and Rehabilitation (held in conjunction with the Annual General Meeting).
- Undertaking activities to improve understanding and to ensure the continued relevance of CWGHR as an organization including:
 - sharing information about CWGHR, its key messages and related activities
 - receiving and integrating input and feedback from partners and other stakeholders
 - keeping up-to-date on current and emerging issues on HIV and rehabilitation
- Actively pursuing partnerships with AIDS Service Organizations and other frontline AIDS organizations.
- Building upon the development of CWGHR's Case for Support.
- Continuing to identify and develop a diverse and sustainable funding base. Specific strategies will relate to the objectives and initiatives outlined in the strategic plan.
- Increasing opportunities to generate income through courses, workshops and other resources.

Priority Outcomes

The following outcomes are based on the strategic directions. Specific activities will be monitored and/or evaluated and used as markers for progress of these outcomes.

1. CWGHR will have partnerships, documents, research grants, and knowledge exchange activities to address the identified six research priorities, plus any new emerging issues for HIV and rehabilitation.
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 HIV and rehabilitation, for which CWGHR will have played a significant role.
4. CWGHR will be recognized as a leader in HIV and rehabilitation, and will have a stronger membership and financial base to continue its work.

The Board will monitor CWGHR's success in achieving the above outcomes as they relate to the strategic directions. This is in addition to evaluation that is embedded within CWGHR's specific activities.

Summary

Over the next three years, these sharpened strategic directions will provide a clearer direction for CWGHR to continue and build on the work set out in the 2006-2009 Strategic Plan.

Many thanks to all the members and partners who have contributed to the work of CWGHR during the 2006-2009 phase of the Plan. We look forward to the continued energy and participation during 2010-2013 for achieving the targets set out in this updated Plan.

Glossary

The following are operational working 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.

Case for support: (or Case Statements) is a written document(s) or presentation(s) that clearly express an organization's mission, vision, history and programs, while presenting a strong argument for the importance of the work done by the organization. The case for support acts as a tool to convince others to donate to the organization.

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

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, 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 from all the current and required stakeholders; with 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.

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

Knowledge exchange: the transfer of new knowledge to those people or processes which can have 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 as many of the steps and processes possible 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 enables the separate and shared knowledge and skills of multiple stakeholders and allows the issue with its many dimensions to be handled holistically.

National HIV partners: national non-government, voluntary sector organizations in Canada whose primary focus is HIV.

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

Partnerships: include coordination among and/or collaborations with stakeholders, organizations, specific individuals or institutions in order to address a particular initiative. Partnerships may be academic, community-based, policy and 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 (Worthington et al 2008).

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/oi-ar/index-eng.php>.

Acronyms

AIDS: Acquired Immune Deficiency Syndrome

CAHR: Canadian Association for HIV Research

CWGHR: Canadian Working Group on HIV and Rehabilitation

EDN: Episodic Disabilities Network

HIV: Human Immunodeficiency Virus

ICF: International Classification of Functioning, Disability and Health

OEDN: Ontario Episodic Disabilities Network

OHTN: Ontario HIV Treatment Network