



# **PROMOTING QUALITY OF LIFE THROUGH REHABILITATION RESEARCH, EDUCATION AND CROSS-SECTOR PARTNERSHIPS**

**STRATEGIC PLAN 2006 – 2009**

**Canadian Working Group on HIV and Rehabilitation**

**May 2006**



# TABLE OF CONTENTS

EXECUTIVE SUMMARY .....	i
MISSION, VISION AND SUMMARY OF OBJECTIVES .....	ii
BACKGROUND .....	1
Introduction .....	1
The Strategic Planning Process .....	1
CWGHR History and Structure .....	3
CWGHR's Approach to HIV, Disability, Active Living and Rehabilitation .....	3
CWGHR's Environment .....	5
CWGHR'S STRENGTHS AND ACHIEVEMENTS .....	7
CWGHR'S CHALLENGES .....	9
LOOKING FORWARD: 2006 – 2009 .....	11
CWGHR's Mission .....	11
CWGHR's Vision .....	11
CWGHR's Strategic Objectives .....	11
APPENDICES .....	16
Appendix A: Participants in the Strategic Planning Process .....	16
Appendix B: Descriptions of Rehabilitation Professionals Referenced in this Document .....	17
Appendix C: Other Emerging Issues Identified through the Consultation Process .....	18



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## EXECUTIVE SUMMARY

The Canadian Working Group on HIV and Rehabilitation (CWGHR) was formed in 1998 as a national, multi-sector, multi-disciplinary group working to address issues of disability and rehabilitation in the context of HIV.

In 2005-6 CWGHR undertook a comprehensive strategic planning process to identify our directions and priorities for the next 3-5 years. This process included a series of consultations with stakeholders in HIV and rehabilitation across Canada, including people living with HIV and AIDS. This process has been very important to CWGHR as it has provided opportunities to discuss our work on HIV and rehabilitation and obtain valuable input from a wide range of people to guide and focus our work. This strategic plan is also available electronically on the CWGHR web site at [www.hivandrehab.ca](http://www.hivandrehab.ca).

This plan highlights several key directions for CWGHR over the next 3-5 years. Outcomes of the consultation indicate that CWGHR will continue with its multi-disciplinary approach, current initiatives and priorities, with a focus on the following objectives:

- *promote and undertake further research on rehabilitation*
- *promote awareness among people living with HIV on the contribution that rehabilitation, as widely-defined, makes to increased participation in all aspects of life.*
- *increase capacity of rehabilitation professionals to work with and provide services for people living with HIV*
- *continue to work from a cross disability perspective related to episodic disabilities*
- *improve stakeholders' awareness and understanding of CWGHR as an organization and our work on rehabilitation*
- *broaden CWGHR's membership / participation base*
- *continue to promote CWGHR's broad understanding of rehabilitation while focusing on more "traditional" rehabilitation professions such as physiotherapy, occupational therapy, speech language therapy, mental health services and vocational rehabilitation counsellors as well as the role of physicians and nurses in rehabilitation*
- *continue to assess new or emerging issues as they arise and determine appropriate responses.*

This plan is a living document that CWGHR will review each year to determine progress and address challenges as we move forward. We encourage you to share this document with your colleagues. CWGHR would be happy to meet with you to discuss our work on rehabilitation and we welcome your input as we move forward to implement this plan over the next several years.

CWGHR acknowledges and appreciates the work of Glen Brown and Joan Anderson, who coordinated the strategic planning process, and the time and input of everyone who participated in the consultation process. Your ideas and insights are important in shaping the direction of our work.

CWGHR Board of Directors

May, 2006



# MISSION, VISION AND SUMMARY OF OBJECTIVES<sup>1</sup>



## **CWGHR's Mission**

***Promoting quality of life  
through rehabilitation  
research, education and  
cross-sector partnerships***



## **CWGHR's Vision**

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

### **CWGHR's Strategic Objectives**

The following areas are the priorities for CWGHR over the next several years. Our progress in meeting the objectives outlined below will be monitored and evaluated on a regular basis. CWGHR will report annually on work to date in achieving these objectives.

#### **1) Continue to Research, Analyze and Communicate the need, benefit, and availability of Rehabilitation Services**

CWGHR sees research as a key, integrated component of all our activities. Research is critical to provide “evidence-based” knowledge to inform other activities. In order to undertake effective work on rehabilitation, there are several areas of research that are important to address:

- a) More clearly identify and quantify the need, demand for, availability of and access to rehabilitation services for people living with HIV.
- b) Nurture a research climate, to promote more research in the field of HIV and rehabilitation.
- c) Continue research and advocacy to address public / workplace policies and social inclusion barriers to active living related to HIV.

CWGHR will also continue to engage directly in community-based research and develop partnerships to conduct research to advance opportunities for active living for people living with HIV.

#### **2) Continue to Increase Awareness Within the HIV Community of the Potential Benefits of Rehabilitation for Active Living**

Through this strategy, CWHGR will continue to educate people living with HIV and those who provide services to them about the potential benefits of rehabilitation services.

<sup>1</sup> Further details regarding these strategic objectives are provided beginning on page 11.



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**3) Continue to Increase Capacity of Rehabilitation Professionals to Provide Services to people living with HIV**

Through this strategy, CWGHR will continue to educate rehabilitation professionals and those who work with them about the potential benefits of rehabilitation services for people living with HIV.

**4) Continue to Develop and Support Cross-Disability Linkages**

CWGHR will continue to build and nurture relationships and partnerships with organizations and movements representing other disability issues, particularly those disabilities which are also episodic in nature. These links and partnerships will serve to identify common challenges and to facilitate collaboration on common approaches to those challenges.

**5) Improve Communications and Focus**

Through this strategy, CWGHR will continue to undertake activities to improve understanding of CWGHR as an organization and its key messages.

**6) Refine CWGHR's Focus**

Through this strategy, CWGHR will identify how it approaches different challenges along the broad spectrum of rehabilitation. CWGHR will continue to support and communicate a broad concept of disability and of rehabilitation. CWGHR understands rehabilitation to include a wide array of supports for people to maintain or return to meaningful active living. The bulk of CWGHR's strategies in education will focus on "traditional" rehabilitation professions (e.g. see **Appendix B**) with the recognition that physicians and nurses are often the gatekeepers in coordinating health care and referrals to other (e.g. rehabilitation) health care practitioners. Therefore, physicians and nurses are critical to include in rehabilitation education and capacity building activities. Research and advocacy efforts will also include workplace and related income support policy issues that inhibit or facilitate meaningful active living / workforce participation.

**7) Expand CWGHR's Membership and Base of Support**

Through this strategy, CWGHR will expand the number of members, advisors, supporters and 'champions' supporting the organization and its mission.

**8) Respond to Emerging Priorities**

From time to time, issues may emerge that require an immediate or priority response. CWGHR will identify a process to determine how and when to respond to these types of issues.

**9) Develop and Diversify Funding Opportunities**

CWGHR will continue to identify and develop a diverse and sustainable funding base. Specific strategies will relate to the objectives and initiatives identified in the strategic plan.





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# Canadian Working Group on HIV and Rehabilitation

## Strategic Plan

### 2006-2009

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## BACKGROUND

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### Introduction

The Canadian Working Group on HIV and Rehabilitation (CWGHR) was formed in 1998 as a national, multi-sector, multi-disciplinary group that works to address issues of disability and rehabilitation in the context of living with HIV.

CWGHR has developed a strategic plan that will help guide our work for the next 3 to 5 years. The strategic plan builds upon CWGHR's history and current initiatives, as well as setting new priorities for the future.

This report outlines key findings of the strategic planning process and proposed direction, strategies and action for the future.

### The Strategic Planning Process

CWGHR began a formal strategic planning exercise in February, 2005. The process began with a facilitated Board meeting to help design the strategic planning process, confirm the various stakeholders and forms of input into the process, and identify key issues to be explored.

Consultation tools were then designed, tested and refined, and a discussion paper was produced to help solicit further stakeholder input into the strategic planning process.

The consultants reviewed a wide array of internal and external documents in order to: shape an understanding of CWGHR's history and current role, and develop an analysis of the environment in which CWGHR operates.

A full-day consultation with the CWGHR membership (June 2005) provided an opportunity for member input regarding CWGHR strengths, challenges and possible future directions.

In addition, a series of focus groups and key informant interviews were conducted with a range of stakeholders over a period of several months. (See **Appendix A**)

A draft 'Strategic Plan' report was circulated and discussed at a CWGHR membership meeting (February, 2006). With this input, a subsequent draft of the report was prepared and considered by the CWGHR Board of Directors (March 2006).

The final version of the 'CWGHR Strategic Plan 2006-2009' was released in June, 2006.





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# CWGHR, HIV AND REHABILITATION

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## CWGHR History and Structure

CWGHR is a national charitable organization, formed in 1998, that promotes innovation and excellence in rehabilitation in the context of HIV disease. CWGHR is multi-sector and multi-disciplinary in its membership and its activities.

CWGHR members 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. CWGHR has thirteen organizational members, six individual members, and four associate (non-voting) members. The members elect a six-person board of directors to guide the organization.

## CWGHR's Approach to HIV, Disability, Active Living and Rehabilitation

CWGHR's approach to HIV and rehabilitation is central to its mission and goals. This approach, combined with a multi-sector model that encourages dialogue between diverse communities and professions, helps shape the strategic plan and objectives.

For many people living with HIV who have access to antiretroviral treatment, advances in treatments have meant that HIV is no longer considered imminently fatal. For some people living with HIV, HIV has become a long-term chronic condition (acknowledging that there is currently no cure for HIV).

For many people, living with HIV causes disabling conditions. A recent study of people living with HIV in British Columbia<sup>2</sup> concluded that 90% of respondents identified at least one limitation in their functioning due to HIV. Over one third identified more than ten limitations. For people living with HIV, periods of relative health are often interrupted by periods of relative disability, 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 disability**<sup>3</sup>.

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<sup>2</sup> Rusch M, Nixon S, Schilder A, Braitstein P, Chan K, Hogg RS. Impairments, activity limitations and participation restrictions: Prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health and Quality of Life Outcomes*. 2004; 2:46. <http://www.hqlo.com/content/2/1/46>.

<sup>3</sup> 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, some forms of cancer. .



CWGHR has adopted a broad concept of **disability** and rehabilitation <sup>4</sup> which includes a wide range of **barriers to meaningful active living**. These can include:

- **Body impairments**, whether from HIV itself or side effects of treatments (e.g. pain, fatigue, diarrhea, numbness)
- **Activity limitations** (e.g. difficulty walking or climbing stairs, carrying groceries or taking a bath or shower)
- **Participation restrictions** (e.g. stigma, discrimination, insufficient income support, unsupportive employment policies and other barriers to social activities, relationships, or volunteer or workforce participation)

Barriers to active living, therefore, can include everything from a physical ailment to a lack of social support to a public policy that inhibits working or volunteering.

A broad concept of disability forms the basis for a broad understanding of **rehabilitation**. CWGHR understands 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). This understanding is consistent with the health policy framework of “determinants of health.” <sup>5</sup>

**Supports** can include:

- 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, 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

CWGHR recognizes the critical role that physicians and nurses play in the care of, and coordination of services for, people living with HIV. While CWGHR addresses a wide range of rehabilitation services, supports and policies, it has a specific mandate to expand and enhance the potential for **rehabilitation capacity** in serving people living with HIV, including access to physiotherapists, occupational therapists,

<sup>4</sup> Based on the World Health Organization International Classification of Impairments, Activity Limitations and Participation restrictions – ICF 2001

<sup>5</sup> Determinants of health include factors such as income security, access to appropriate employment, health care, nutrition, psychosocial support, etc. – Health Canada and Wellesley Central Hospital, Module 7 - Rehabilitation Services: A comprehensive guide for the care of persons with HIV Disease, 1998



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speech-languages pathologists, psychiatrists, vocational counsellors, dieticians, mental health and social care workers, etc..

For a brief description of the role of some of these rehabilitation professions please see **Appendix B**.

## **CWGHR's Environment**

The face of HIV has changed since the beginning of the epidemic. By virtue of its mandate, CWGHR operates in an extremely complex environment that spans multiple disciplines, stakeholders, funders, allies and competitors. The following points outline key shifts in the current environment that will impact on CWGHR's future directions:

- The number of people living with HIV in Canada continues to increase annually; infection trends are not slowing, and people with HIV are living longer.
- The epidemic is having a growing impact on marginalized people.
- The impact of HIV on communities and individuals varies widely. Biology, timing, gender, socio-economic status, geography, social inclusion/exclusion and other factors play as important a role as the virus itself. This complicates any strategies to provide services or supports.
- Increasing numbers of people living with HIV are aging and living with long-term side effects (physical and emotional) of living with HIV and the medication regimen.
- Knowledge of the potential role of rehabilitation services in supporting active living for people living with HIV is still very limited (though growing slowly) within the HIV community, thereby limiting demand for rehabilitation services.
- Knowledge of HIV issues is limited in rehabilitation professionals, thereby limiting supply of rehabilitation services.<sup>6</sup>
- Medical care providers (major gate-keepers for care and services for people living with HIV) rarely provide referrals to rehabilitation professionals.<sup>7</sup>
- Public funding for rehabilitation services has, in many jurisdictions, been restricted in recent years, thereby limiting access to rehabilitation services regardless of demand or supply.
- Health care restructuring, including regional coordination and renewed emphasis on primary care health teams/networks is accelerating in many jurisdictions. That provides both opportunities and threats for integration of rehabilitation services.

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<sup>6</sup> Evidence of this need is documented in the Canadian HIV and Rehabilitation Providers' Survey, Myers et al, University of Toronto, 2004

<sup>7</sup> *Ibid.*



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- Major shifts have occurred at the federal level in the funding and policy responses to HIV. Funding for the federal response has been doubled to \$84.4 million annually, with increases phased in over five years. Most responsibility for HIV funding and policy responses has been shifted to the recently-created Public Health Agency of Canada.
  - The “Federal Initiative to Address HIV in Canada”<sup>8</sup> outlines a new federal approach that includes developing discrete approaches to addressing the epidemic for different affected communities, increased inter-governmental collaboration, greater integration with other relevant diseases, and greater focus on determinants of health.
  - “Leading Together”<sup>9</sup>, a strategy intended to engage all stakeholders in a collaborative response to HIV in Canada, echoes similar themes as the “Federal Initiative”. It also calls for increased efforts at both the front-line and global levels.
  - The election of a new federal government (January 2006) may have an impact on the federal funding and policy environment; the impacts are difficult to predict at this time.
  - CWGHR is now recognized as a national HIV NGO partner, and participates in discussions at the national table. This creates both opportunities and additional expectations.

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<sup>8</sup> Government of Canada, Federal Initiative: Strengthening Federal Action in the Canadian Response to HIV/AIDS, 2004

<sup>9</sup> Leading Together: Canada Takes Action on AIDS (2005-2010) is a blueprint for Canada’s response to AIDS to 2010, was developed over several years and published in 2005 by non-government and government stakeholders who have a key role to play in the response to AIDS.



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## CWGHR'S STRENGTHS AND ACHIEVEMENTS

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A number of strengths and achievements for CWGHR have been identified through the strategic planning process. Among the key ones that CWGHR can build upon:

### 1) Unique Niche

CWGHR continues to occupy a unique niche within the HIV community and within the rehabilitation community, as the only organization to focus on the potential interrelationship between the two realms. CWGHR is the only national organization with a focus on the challenges and opportunities of rehabilitation and active living for people living with HIV.

### 2) Multi-Sector and Multi-Disciplinary Approach

CWGHR's approach and structure has allowed it to make connections with and between a broad range of sectors and disciplines within the HIV realm. Moreover, CWGHR has successfully developed relationships beyond the HIV realm, including other health groups, employers, government, labour, the insurance industry, and others.

### 3) Synergies with Government Policy Directions

CWGHR's mandate, activities and philosophies seem well matched with many government policy directions, as outlined in such documents as the *Federal Initiative* and *Leading Together*. Themes such as health determinants, connections between HIV and other health conditions, desire for multi-sector collaboration, and need for evidence-based decision making are examples of these common directions.

In addition, the emphasis on interprofessional education (IPE) and patient-centred practice, as well as recognition of the importance of interjurisdictional (e.g. federal/ provincial/ territorial) coordination of health and social policies and programs are compatible with CWGHR's interdisciplinary team approach and involvement with federal/provincial /territorial advisory bodies and should provide opportunities for growth and partnerships in the coming years.

### 4) Increasing the Visibility of HIV and Rehabilitation Issues

CWGHR's efforts over the past several years have resulted in greater visibility and attention to HIV and Rehabilitation issues. Among the markers of that success:

- Many people have attended CWGHR workshops.
- There is now a rehabilitation stream at the biannual Canadian HIV Skills Building Conference.
- There is more research being conducted into HIV and Rehabilitation issues.



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- CWGHR has published a wide variety of papers and newsletters. It has also taken the lead role on distributing “Module 7: Rehabilitation Services for People Living with HIV” (see footnote 4) and will contribute to the next edition of CATIE’s “Managing Your Health”<sup>10</sup>.
  - The input of CWGHR helped to strengthen the content re: rehabilitation in the *Federal Initiative* and in *Leading Together*.
  - CWGHR has been instrumental in creating and supporting the Episodic Disabilities Network<sup>11</sup>.
  - CWGHR’s advocacy (in coalition with a range of partners) with the federal government has helped to create more flexibility within the Canada Pension Plan (Disability) policies and practices.

## 5) CWGHR’s Role at the National Level

CWGHR participates in national HIV partner discussions. As a result, CWGHR is able to bring the rehabilitation perspective to important deliberations, and to engage in more effective partnerships.

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<sup>10</sup> Canadian AIDS Treatment Information Exchange: Managing Your Health: A guide for people living with HIV or AIDS, 1999

<sup>11</sup> The Episodic Disabilities Network (EDN) is a cross-disability network of groups who work and/or live with episodic disabilities (see also footnote 3). The EDN was developed by CWGHR in 2003 to promote a coordinated response on episodic disability issues of common concern.



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## CWGHR'S CHALLENGES

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CWGHR faces a number of challenges as it looks forward to the coming three years. Among the key ones:

### **1) Demonstrating the Potential Value of Rehabilitation in the Lives of People Living with HIV**

People living with HIV have many issues and concerns that limit their full engagement in “active” daily living. However, many people living with HIV are unaware that rehabilitation specialists have skills and knowledge to help mitigate these issues and concerns. Thus many people living with HIV live an unnecessarily diminished quality of life. Conversely, many rehabilitation professionals are unaware of the need for rehabilitation services among people living with HIV. The barrier goes beyond a lack of awareness, to the challenge of bridging these two separate worlds or “cultures”.

### **2) Communication Challenges and Opportunities**

It appears that the messages about CWGHR as an organization and, more importantly, the messages about the potential benefits of rehabilitation services for people living with HIV have not reached beyond a relatively small audience. This speaks to the need and opportunity for a much greater emphasis on communication strategies and tactics to bring the CWGHR message to its targeted audiences. It may also speak to the need to re-examine the CWGHR name and “brand”.

### **3) Refining the CWGHR Focus**

Another challenge facing the organization over the coming years is the balance between addressing the full range of issues that could be considered under the banner of “active living” versus focusing on a narrower range of issues under a more traditional understanding of rehabilitation services.

### **4) Broadening the CWGHR Base**

A challenge related to #2 above is broadening the CWGHR base beyond the current number of members, advisors, supporters and ‘champions’ supporting the organization and its message.

### **5) A National Organization with a Provincial and Local Challenge**

Many of the health services and policy issues related to rehabilitation are delivered at either provincial or local levels. It is a challenge to engage those diverse communities and delivery mechanisms from the perspective of a national organization.



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## 6) Addressing the Diversity of the HIV Community

The challenges of active living vary widely, influenced by gender, sexual orientation, income, housing status, mental health, race and ethnicity, and many other factors. Strategies to address these challenges must also be diverse and flexible.

## 7) Funding Sustainability

Similar to other national HIV and other non-government organizations, the instability of funding and the trend towards project-based funding are ongoing challenges. Although the federal government has increased funding for HIV-related initiatives between 2005-2010, this funding is not long-term or secure. This presents challenges for long-range planning and organizational sustainability. Diversification of funding sources takes time and resources. Funding is most often project-based and is also dependent upon the changing priorities of various external funding bodies.





**CWGHR's Mission**

*Promoting quality of life  
through rehabilitation  
research, education and  
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**CWGHR's Vision**

*The daily lives of people  
living with HIV are  
improved in direct and  
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**CWGHR's Strategic Objectives**

The following areas are the priorities for CWGHR over the next several years. Our progress in meeting the objectives outlined below will be monitored and evaluated on a regular basis. CWGHR will report annually on work to date in achieving these objectives.

**1) Continue to Research, Analyze and Communicate the need, benefit, and availability of Rehabilitation Services.**

CWGHR sees research as a key, integrated component of all our activities. Research is critical to provide “evidence-based” knowledge to inform other activities. In order to undertake effective work on rehabilitation, there are several areas of research that are important to address:

- a) **More clearly identify and quantify the need, demand for, availability of and access to rehabilitation services for people living with HIV.** Some examples of strategies and activities:
  - A comprehensive needs assessment surveying people living with HIV and their service providers on the need, desire, demand and access to rehabilitation services
  - Pilot projects promoting and providing access to rehabilitation services for identified populations of people living with HIV, measuring both uptake and impact.
  - Literature reviews comparing people living with HIV activity restrictions and available rehabilitation services
  
- b) **Nurture a research climate, to promote more research in the field of HIV and rehabilitation.** Examples include:
  - Building relationships with funding bodies (CIHR, OHTN etc) to determine their current awareness / funding opportunities related to rehabilitation
  - Advising relevant researchers of funding opportunities related to rehabilitation and HIV



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- Identify rehabilitation research priorities to include in calls for proposals, etc, and highlight research priorities for both funding bodies and researchers.
- c) **Continue research and advocacy to address public / workforce policy and social inclusion barriers to active living related to HIV.** Examples include:
- Policy analysis and promotion of policies and strategic alliances that promote employment opportunities and accommodation for people living with HIV
  - Support networks of people living with HIV related to employment
  - Longitudinal employment projects

**CWGHR will also continue to engage directly in community-based research and develop partnerships to conduct research to advance opportunities for active living for people living with HIV.**

## **2) Continue to Increase Awareness Within the HIV Community of the Potential Benefits of Rehabilitation for Active Living**

**Through this strategy, CWGHR will continue to educate people living with HIV and those who provide services to them about the potential benefits of rehabilitation services.**

Some examples of strategies and activities:

- Provide workshops at national and regional gatherings of AIDS Service Organizations (ASO)
- Publish newsletters, website publications, etc.
- Clarify and communicate CWGHR's advisory/referral role for ASOs facing rehabilitation questions
- Integrate rehabilitation information into treatment information services, in partnership with relevant treatment information organizations.
- Develop information for people living with HIV and HIV care providers to increase awareness of rehabilitation services
- Create opportunities for rehabilitation special interest groups within HIV organizations/groups
- Link people living with HIV with members of other disability networks for mutual learning and knowledge exchange

Some examples of success outcomes:

- More individuals and organizations from Rehabilitation and HIV worlds across Canada are involved in CWGHR
- In every province/territory people living with HIV, with CWGHR's support, are pressing their governments to enhance rehabilitation services and policies
- Champions understand the link between HIV, disability and rehabilitation



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- Clinics are linked to and make referrals to rehabilitation services
  - Newly diagnosed people living with HIV have information about and access to rehabilitation
  - People living with HIV have ongoing say in CWGHR, with mechanisms to be included and involved

### **3) Continue to Increase Capacity of Rehabilitation Professionals to Provide Services to People living with HIV**

**Through this strategy, CWGHR will continue to educate rehabilitation professionals and those who work with them about the potential benefits of rehabilitation services for people living with HIV.**

Some examples of strategies and activities:

- Support for interdisciplinary groups and initiatives
- Education before entry to practice and continuing professional development
- Increased curriculum addressing issues such as stigma, discrimination and working with marginalized and vulnerable populations
- A national HIV and rehabilitation mentorship program including people living with HIV, HIV and rehabilitation service providers
- Workshops at national and regional rehabilitation and health care gatherings
- Newsletters, website publications, etc.
- Inter-professional learning opportunities on HIV issues for rehabilitation professionals
- Development of educational resources for family physicians and nurses regarding HIV and rehabilitation issues
- Opportunities for HIV special interest groups within rehabilitation organizations
- Addressing issues of people living with HIV access to rehabilitation services through provincial/territorial health care organizations and policies.
- Expanding the understanding of rehabilitation professionals to include mental health workers, social workers, nutritionists, and other relevant professions.
- Participating in knowledge exchange and partnership opportunities to share with and learn from HIV and rehabilitation organizations and individuals internationally

### **4) Continue to Develop and Support Cross-Disability Linkages**

**CWGHR will continue to build and nurture relationships and partnerships with organizations and movements representing other disability issues, particularly those disabilities which are also episodic in nature. These links and partnerships will serve to identify common challenges and to facilitate collaboration on common approaches to those challenges.**



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## 5) Improve Communications and Focus

Through this strategy, CWGHR will continue to undertake activities to improve understanding of CWGHR as an organization and its key messages.

Some examples of strategies and activities:

- Change the organization's name to better reflect and communicate its mission
- Develop a communications strategy that identifies key messages, audiences, and communication vehicles
- Better communicate evidence of the need for rehabilitation services
- Identify staff resources to coordinate communication activities
- Develop concrete tools for CWGHR champions: power point presentations, template articles, key messages, etc.
- Continue to publish reports, newsletters and updates in print and online

Some examples of success outcomes:

- Policy is influenced
- Complex issues related to rehabilitation and HIV are more clearly understood
- Partnerships are created at the provincial level
- Key players are mobilized, with the HIV community demanding rehabilitation services
- CWGHR's work has shifted from the "conceptual" level to the "impact" level
- CWGHR is acknowledged as the primary national resource on rehabilitation in the context of HIV

## 6) Refine CWGHR's Focus

Through this strategy, CWGHR will identify how it approaches different challenges along the broad spectrum of rehabilitation. CWGHR will continue to support and communicate a broad concept of disability and of rehabilitation. CWGHR understands rehabilitation to include a wide array of supports for people to maintain or return to meaningful active living. The bulk of CWGHR's strategies in education will focus on "traditional" rehabilitation professions (e.g. see Appendix B) with the recognition that physicians and nurses are often the gatekeepers in coordinating health care and referrals to other (e.g. rehabilitation) health care practitioners. Therefore, physicians and nurses are critical to include in rehabilitation education and capacity building activities. Research and advocacy efforts will also include workplace and related income support policy issues that inhibit or facilitate meaningful active living / workforce participation.



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Some examples of success outcomes:

- CWGHR has developed processes and criteria for determining new priorities and initiatives
- Clearer communication of CWGHR's priorities.

## 7) Expand CWGHR's Membership and Base of Support

**Through this strategy, CWGHR will expand the number of members, advisors, supporters and 'champions' supporting the organization and its mission.**

Some examples of strategies and activities:

- Consider expanding membership opportunities to any person or organization supporting the organization's mission
- Re-examine the roles, responsibilities and commitments expected of members
- Create and support a national network of people living with HIV who support the mission, who will champion the rehabilitation message, and who will offer critical feedback to CWGHR
- Create and support a network of "HIV champions" within relevant medical and rehabilitation professional organizations
- Identify staff resources to coordinate outreach and engagement activities

Some examples of success outcomes:

- More people from rehabilitation and HIV worlds are involved in CWGHR
- People living with HIV in every province/territory, with CWGHR's support, are pressing their governments to enhance rehabilitation services and related policies
- There are new champions who understand the link between HIV, disability and rehabilitation
- There is an expanded base of people who feel connected to CWGHR and its programs
- More people living with HIV have a say in CWGHR's activities, with expanded opportunities and mechanisms for involvement.

## 8) Respond to Emerging Priorities

**From time to time, issues may emerge that require an immediate or priority response. CWGHR will identify a process to determine how and when to respond to these types of issues.** For examples of some emerging priorities, see **Appendix C**

## 9) Develop and Diversify Funding Opportunities

**CWGHR will continue to identify and develop a diverse and sustainable funding base. Specific strategies will relate to the objectives and initiatives identified in the strategic plan.**



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## APPENDICES

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### Appendix A: Participants in the Strategic Planning Process

We are grateful for the time and expertise offered by many people during the strategic planning process. In the interests of protecting anonymity, none of their comments have been recorded by name in the resulting documents.

In total, more than 60 people provided input into the strategic plan.

Among the contributors to this strategic planning exercise were:

1. CWGHR Board of Directors
2. CWGHR Members
3. CWGHR Staff
4. CWGHR's Income Support Committee
5. CWGHR's Education and Practice Advisory Committee
6. Three Executive Directors of other National HIV Organizations
7. Two staff members of other national HIV organizations
8. A representative of the Canadian Physiotherapy Association
9. A representative of the Canadian Association of Nurses in AIDS Care
10. A researcher active in HIV and rehabilitation Issues
11. A primary care physician active in HIV care
12. An executive director of a national consumer group representing another episodic disability
13. A health care activist representing a coalition of people with disabilities
14. A provincial government HIV leader representing the Federal/Provincial/Territorial AIDS group
15. A senior policy advisor with the Public Health Agency of Canada
16. An executive director of a provincial ASO representing people living with HIV
17. An executive director of an ASO representing women living with HIV
18. Three front-line ASO case managers/service providers working with people living with HIV
19. Four people living with HIV, who are not representing organizations



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## Appendix B: Descriptions of Rehabilitation Professionals Referenced in this Document

*Physiotherapists (Physical Therapists)* are university-educated experts who can help people achieve their highest level of physical functioning with a personalized treatment plan based on their specific needs.

Physiotherapists may provide:

- Assessment of movement, strength, endurance and other physical abilities;
- Assessment of the impact of an injury or disability on physical functioning;
- Assessment of physical preparation for work and sports;
- Program planning and education to restore movement and reduce pain;
- Individualized treatment of an injury or disability based on scientific knowledge, a thorough assessment of the condition, environmental factors and lifestyle.
- Individual and systemic advocacy and health promotion to address barriers to health.

*Occupational Therapists* are university-trained health professionals. Occupational Therapists work with people to identify difficult activities and help improve them. This can include:

- Learning new ways of doing things, like dressing or cooking with one arm or developing new ways to remember if memory is poor.
- Activities to help maintain or improve abilities, strength and confidence.
- Adapting material or equipment; for example, a specifically modified toilet or bath seat.
- Changes to the work or home environment; for example changing the home or office layout to make it more accessible or to prevent further injury.
- Developing new skills, abilities and interests in work and leisure time through job readiness programs, community programs, or social/recreational activities.

*Speech Language Pathologists* may work alone or as part of a team to help individuals of all ages to communicate effectively and to eat and swallow safely. The role of the S-LP is to identify, assess, evaluate, treat, manage, educate and help to prevent language, speech, voice, fluency, cognitive, and other related communication disorders as well as swallowing problems.

*Physiatrists* are physicians specializing in physical medicine and rehabilitation. Physiatrists treat a wide range of problems from sore shoulders to spinal cord injuries. They see patients in all age groups and treat problems that touch upon all the major systems in the body. These specialists focus on restoring function to people. Physiatrists treat acute and chronic pain and musculoskeletal disorders. Physiatrists also treat serious disorders of the musculoskeletal system that result in severe functional limitations. Physiatrists coordinate the long-term rehabilitation process for patients with spinal cord injuries, cancer, stroke or other neurological disorders, brain injuries, amputations, and multiple sclerosis.



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*Vocational Counsellors* help employees in the transitional process in starting or returning to the workforce.

*Mental Health and Social Care Workers* including social workers, counsellors, psychologists, and psychiatrists. These various professionals play key roles in helping people deal with conditions such as depression, fatigue, isolation, memory loss and other factors limiting their active living.

*Other Health Professionals* provide an array of complementary additional health therapies and services.

### **Appendix C: Other Emerging Issues Identified through the Consultation Process**

- Researching the impacts of aging on people living with HIV – both as its own phenomenon and as aging interrelates with the impact of HIV disease and treatments.
- Advocating for therapies and strategies to deal with the long-term side effects of treatments, including “cosmetic” effects such as facial wasting. Access to these therapies will be a key policy issue.
- Monitoring the impacts (and potential opportunities) of health care restructuring and health care reform initiatives on integrating rehabilitation services, and on access to those services.
- Developing alternative models for volunteer engagement, aimed at including marginalized people in society
- Developing partnerships with professional organizations to present joint educational materials and workshops.

