

# *Promoting Inclusion*

## **Canadian Working Group on HIV and Rehabilitation**

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

### ***ANNUAL REPORT 2008–2009***

#### **CWGHR**

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Open Policy  
St. Michael's Hospital  
Shamba Foundation

**Special thanks to all CWGHR and committee members and other volunteers  
who contribute so much of their time and expertise to CWGHR's activities**

This report describes the activities of CWGHR from April 1, 2008 to March 31, 2009

This report was approved by CWGHR Board of Directors May 19, 2009

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## MESSAGE FROM THE CO-CHAIRS

May 2009

**D**ear CWGHR members, colleagues, funders, and other supporters:

It is our pleasure to present this Annual Report outlining the accomplishments of CWGHR over the past year, as well as many exciting ideas and directions for the future.

We would like to formally acknowledge the energy and skills of the CWGHR staff, under the leadership of our Executive Director, Elisse Zack, of our membership, and of our colleagues on the Board of Directors. We also acknowledge the contributions of so many others who have given countless hours and have brought diverse areas of expertise to our work on HIV and rehabilitation. 2008-2009 has been a year of much growth, as we have worked to bring life to the directions that have been established by CWGHR. From strengthening our voice on rehabilitation at the federal table as a national HIV partner organization, to expressing our new-found international voice, CWGHR's work continues to build in force and momentum.

Two of our primary areas, Labour Force Participation and Interprofessional Curriculum on HIV for Rehabilitation Professionals, have now moved into a new phase of work as we build on these important areas with new initiatives. From work to develop a research agenda on rehabilitation in the context of HIV and development of practice guidelines to a new HIV and rehabilitation mentorship program, a network on employment issues for people living with HIV and development of online educational resources, incredible energy and momentum have been built, promising to make 2009-2010 an exciting year of continued growth.

The ongoing growth of CWGHR continues to position us as the expert and champion in addressing the evolving area of rehabilitation in the context of HIV. Future opportunities and challenges will both require and benefit from the collective efforts and expertise of members, staff and other colleagues who work with us in so many important ways. Through our membership, individuals and organizations have many opportunities to participate in CWGHR's work to improve quality of life through rehabilitation research, education and cross-sector partnerships.

In closing, we extend our thanks to you for investing your own time and energy toward improving the lives of people living with HIV/AIDS. Together we CAN change the world.

Ken King and Peggy Proctor, Co-Chairs

Board of Directors

**T**he Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, multi-sector, multi-disciplinary organization, established to address the emerging need for a national comprehensive response to rehabilitation issues in the context of HIV. As many people living with HIV began to live longer, primarily due to new treatments, people also began to experience many of the disabling aspects of living with HIV and/or side effects of these life-saving treatments. Correspondingly, the role for rehabilitation supports and services has increased as well, to address these disabling impacts of HIV.

## Vision

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

## Mission and Mandate

Through research, education and cross-sector partnerships, CWGHR works to promote a comprehensive approach to HIV related disability and rehabilitation and improved quality of life of people living with HIV. Within its mission, CWGHR has three primary mandates:

a coordinating and advisory role on issues of disability and rehabilitation in the context of HIV

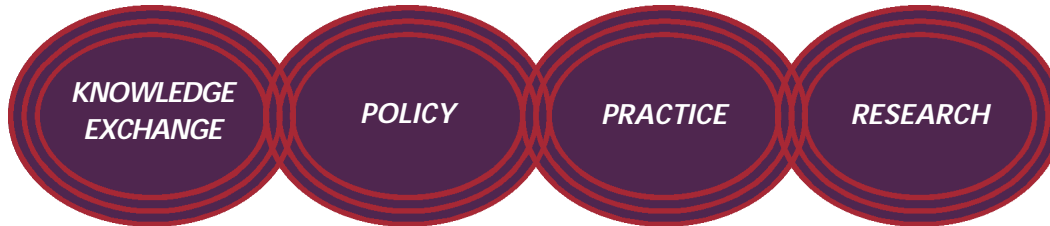
supporting and / or undertaking initiatives in rehabilitation in the context of HIV

encouraging pan-disease collaboration to address issues experienced by people living with HIV and those with other complex episodic or chronic diseases

The CWGHR Board of Directors, which includes representation from diverse stakeholder groups, plays a strong and significant role in governance and leadership.

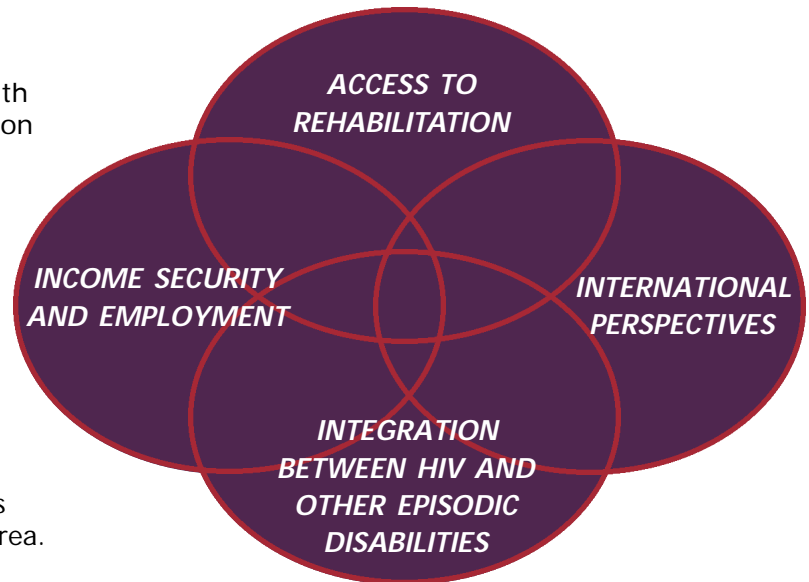
## PROGRAMS

**C**WGHR's programs are based upon four pillars that are essential to developing and implementing effective and relevant rehabilitation policies and programs:



All activities involve partnerships with other HIV, disability and rehabilitation stakeholders. Educational activities and resource development are integral components of all of CWGHR's programs.

CWGHR's activities may be understood within program areas. While many activities fall within more than one of these areas, highlighted activities are described under their primary area.



## Access to Rehabilitation

The four components illustrated below are critical to a comprehensive and coordinated approach to increasing access to rehabilitation programs and services.



**Interprofessional and interdisciplinary approaches** to rehabilitation are key principles within the learning, research and practice environments.

In early 2009, CWGHR hired its first **Director of Research and Education** to address the increasing need for new knowledge to advance this field. The Director will be leading and advancing CWGHR's research and education initiatives, including collaborations with other researchers and educators in the field of HIV and rehabilitation.

The overall work of CWGHR in this area is guided by CWGHR's Research, Education and Practice Advisory Committee (REPAC), as well as project-specific advisory committees.

## Highlights

**Building upon CWGHR's interprofessional learning (IPL) curriculum on HIV for rehabilitation providers, specifically:**

- Conducting the IPL course with universities and other partners**
- Adapting the IPL curriculum for other communities**
- Adapting the IPL curriculum for on-line e-learning access**

**Developing evidence-informed practice guidelines for rehabilitation and HIV**

**Writing the chapter on rehabilitation for the updated version of Managing Your Health (Canadian AIDS Treatment Information Exchange, 2009)**

**Developing a new HIV and rehabilitation mentorship program**

## Greg Downer



*In all the years I've been living with HIV, I was still unaware of the rehabilitation possibilities that were open to me and to fellow PHAs. I was also getting tired of hearing stories from people about the lack of services or of people who experienced stigmatization by someone in the healthcare field who did not want to work with them because they were living with HIV/AIDS. Thanks to the mentorship program that is going to change. I walk away from this experience enriched with knowledge that can open doors to our clients at The Toronto People With AIDS Foundation that before, I did not know existed. I also had the privilege to work with a group of rehabilitation specialists who wanted to gain knowledge and experience working with PHAs. Now these professionals can feel confident opening up their own practices and workplaces to PHAs. As a person living with HIV it is humbling to know that these folks now see me as 'just another patient' instead of 'that guy with HIV'.*

**M**entorship can be a wonderful way for people to share expertise and support each other. To promote opportunities for knowledge exchange and support in clinical practice on HIV and rehabilitation, CWGHR has developed a new interprofessional mentorship program. People living with HIV and rehabilitation professionals participate as co-mentors with rehabilitation professionals. CWGHR is looking forward to expanding the program in 2009-10, with plans to include other health and social care providers who currently, or would like to, work with people living with HIV.

## Lisa Trudelle



*I am a physiotherapist who is currently working in the community in Northumberland County. I became interested in participating as a mentee in the HIV/AIDS mentorship program because it seemed like such a valuable long-term learning opportunity. The part of the program that I most enjoyed was hearing the PHA mentors and speakers openly share their experiences with living with HIV and learning about the psychosocial implications of HIV. Topics addressed during the teleconferences were not pre-determined but were guided by the mentees' questions. This allowed a focussed discussion that met the mentees' specific learning objectives. The most valuable thing that the program has provided me is the contacts that I have made. I now have access to a multidisciplinary team of experts that I know will continue to provide guidance and support even though the program has formally ended. I would encourage any health professional who is interested in HIV to participate in this amazing opportunity, regardless of whether they are currently working with PHAs.*

## Income Security and Employment

Income security and employment are key determinants of health and important components of rehabilitation. These issues together are another priority program area for CWGHR, as we work to eliminate the employment barriers experienced by many people living with HIV. CWGHR undertakes much of this work from a cross-disability approach, as these issues are of primary importance not only to people with HIV but also to other disability groups, particularly people living with life-long or chronic and “episodic” conditions. CWGHR collaborates with other disability groups, and approaches the issues from several perspectives, including education of rehabilitation and other care providers, employers, government and other policy makers, private insurance, and people living with HIV and other episodic disabilities. CWGHR has been working to identify opportunities and mechanisms for increased communication and coordination among disability, income and employment programs, departments and services. Improved coordination of services for people living with HIV will benefit many other disability groups as well.

### Highlights

**Launching on-line course on episodic disabilities for Human Resources professionals**

**Undertaking research into barriers and facilitators to labour force participation**

**Undertaking research and education to improve coordination of disability income support programs**

**Developing a new network on employment issues for people living with HIV**

People living with HIV often face challenges related to employment, may be unsure about employment policies and processes, and / or concerned about discussing employment issues in certain contexts. CWGHR is working with people living with HIV to develop a **national network on employment issues**. This network will provide mechanisms (e.g. on-line, in-person communications, etc.) to facilitate and promote opportunities for discussion on employment issues among people living with HIV.

### Paul Curwin



*Hi, I'm Paul Curwin and I am on the steering committee for the HIV/AIDS Employment Issues*

*Network. I've been living with HIV for over 12 years and have been involved with CWGHR for the past 3 1/2 years. Work issues have always been important to me as an HIV + person living on a long term disability; so when CWGHR began to develop the Employment Network I was excited to be a part of it. Thanks to improved treatment options many of us are surviving longer and living healthier lives. I believe the work we are doing around employment issues will lead to policy changes that will help many HIV + people have the most complete lives possible. The Network will be an excellent way to bring people together to discuss the issues facing many of us today. I hope it helps you out too.*

## Integration between HIV and Other Episodic Disabilities

Increasingly, many conditions such as HIV are experienced and understood as chronic diseases with an episodic component e.g. Multiple Sclerosis (MS), mental health challenges, cancer, arthritis, diabetes, and HIV. CWGHR works to promote collaborative and integrated strategies on issues of mutual concern to people living with HIV and other episodic conditions.

### Highlights

**Coordinating the national Episodic Disabilities Network (EDN)**

**Promoting recognition and response by government to policy and program gaps on episodic disabilities**

**Working towards a national strategy on episodic disabilities**

Since 2003, CWGHR has developed and coordinated the **Episodic Disabilities Network** of over 25 organizations and individuals across Canada working and / or living with HIV or other episodic conditions. The EDN exchanges findings from research (e.g. workplace accommodation issues for people with arthritis to promote the ability to stay at or return to work), has developed briefs and presentations on government budgets and other policy issues related to disability income and labour force, and has held meetings with key staff working in these areas within the federal and provincial governments. Over the past year CWGHR has been working with other national disability organizations to identify, design and promote the most effective mechanisms for accomplishing this work.

### Louise Bergeron



*I have been involved with the Episodic Disabilities Network since 2005. As President of an arthritis*

*organization and as a person who lives with arthritis, I find it important to be involved in a network which addresses so many of the issues that affect people with episodic disabilities. I have seen how working together can be powerful and we have been able in so short a time make great strides in advancing the awareness and the issues surrounding episodic disabilities. With our continued partnership I believe that in the next five years there will policies in place for accommodation in disability benefits, employment insurance, and employment opportunities for all people affected by episodic disabilities.*

Louise Bergeron is President of the Canadian Arthritis Patient Alliance, a grass roots patient driven advocacy organization advocating for the rights of people with arthritis. She lives with Systemic Lupus Erythmatosus.

## International Perspectives

**H**IV, disability and rehabilitation issues have relevance both in Canada and internationally. In 2006, CWGHR began the development of a database of individuals and groups working on these issues around the world. Connections are being developed and collaborative initiatives among HIV, disability and rehabilitation groups are being strengthened.

**W**ith the 2007 signing of the UN Convention on the Rights of Persons with Disabilities, there are **opportunities to include HIV and promote protection of human rights** through the Convention. As people living with HIV often experience many of same vulnerabilities and human rights challenges as people with other disabilities, CWGHR has been working with the Canadian HIV/AIDS Legal Network to share a Discussion Paper on HIV in the context of the UN Convention. Written by the Legal Network in 2008, the discussion paper explores how HIV is recognized as a disability within various national and international contexts and how the UN

Convention can be a tool for promoting protection of the rights of people living with HIV. Over the past year, HIV and disability groups have begun to coordinate efforts to promote ratification of the Convention and the protections it provides.

In 2008, CWGHR's Annual General Meeting and skills building sessions were held in collaboration with two other national HIV partners, the Canadian HIV/AIDS Legal Network and the Interagency Coalition on AIDS and Development, on the theme of HIV, disability and human rights, a theme that is of relevance to all three organizations. Further collaboration on issues of HIV, disability and human rights has continued for other initiatives over the past year.

## Highlights

**Presenting at Asia-Pacific Economic Cooperation (APEC) workshop on HIV/AIDS as an Episodic Disability**

**Developing curriculum on HIV, disability and rehabilitation for a developing world context**

**Addressing HIV, disability and human rights**

The relationship between HIV and disability is increasingly being recognized as a critical issue that must be included in strategies, programs and policies at all levels. In March 2009, Health Canada, International Affairs Directorate, sponsored an international policy dialogue on HIV and disability issues. CWGHR participated on the planning committee for this important event which brought together many leaders within the HIV, disability and rehabilitation fields. In addition, UNAIDS has recently developed a Policy Brief on HIV and Disability that provides an overview and analysis of key issues and priorities related to HIV and disability research, policy, programs and practice.

## COMMUNICATIONS

Communication is a priority throughout all CWGHR initiatives, as we continue to exchange knowledge and ideas with other stakeholders in rehabilitation and HIV. CWGHR has a key role to play in helping people understand the role and benefits of rehabilitation in improving quality of life of people living with HIV.

Over the past year, CWGHR has strengthened our Communications Advisory Committee to guide and advise on communications strategies and activities, including media and government relations as well as membership and other stakeholder communications.

### Award of Excellence in HIV and Rehabilitation

In 2008, CWGHR launched its first annual **Award of Excellence in HIV and Rehabilitation**. CWGHR established this award to



*Dr. Greg Robinson*  
*2008 Award Recipient*

recognize a person or organization who/that has made an important contribution to advancing the field of HIV and rehabilitation. The 2008 recipient was Dr. Greg Robinson who has worked tirelessly to promote awareness, knowledge and engagement in this area.

## ORGANIZATIONAL DEVELOPMENT

In all activities, a strong organizational infrastructure with clear directions is key to ensuring support, coordination and integration of programs and projects. CWGHR's Board of Directors and advisory committees play an important role in guiding and providing advice in planning, implementation and evaluation of CWGHR's work.

### Strategic Planning

CWGHR's work is guided by a strategic plan that was developed in 2006. The plan is reviewed on an annual basis as part of the planning process and implementation of new activities. At the same time, CWGHR continues to assess new or emerging issues as they arise and determine appropriate responses.

In 2009, CWGHR will be reviewing our current strategic plan and updating it to guide our work for the next three to five years.

### Membership Development

CWGHR's membership is open to organizations and individuals with an interest in HIV, disability and rehabilitation. Over the past year, CWGHR has continued to expand opportunities for people to participate in our activities. CWGHR has a broad reach in our initiatives to bridge the worlds of HIV, disability and rehabilitation and there is great potential for engaging people in our work. Membership information is available on our web site at [www.hivandrehab.ca](http://www.hivandrehab.ca).

CWGHR has a very busy agenda in 2009-10 as HIV and rehabilitation initiatives continue to gain momentum.

**Highlights of the coming year include:**

**Expanding the HIV and rehabilitation mentorship program**

CWGHR is looking forward to expanding the program in 2009-10, with plans to include other health and social care providers who currently, or would like to, work with people living with HIV.

**Updating Module 7**

CWGHR will be updating *A Comprehensive Guide for the Care of Persons with HIV Disease: Module 7: Rehabilitation Services*, originally developed in 1998 through funding from Health Canada as part of a series on the care of persons with HIV.

**Promoting a national strategy on episodic disabilities**

In early 2009, CWGHR developed a discussion paper on this proposed strategy and will be circulating it during 2009 to promote awareness, dialogue and future planning. We will also start work on a provincial episodic disabilities network and resource centre in Ontario which could serve as a model for other provinces in the future.

**Strategic Planning**

In 2009, CWGHR will be reviewing our current strategic plan and updating it to guide our work for the next three to five years.

**Expanding the HIV employment network and related activities**

CWGHR will be strengthening the employment network infrastructure and activities, including a series of workshops on HIV, employment and human rights to be held in locations across Canada during 2009.

**CWGHR Board of Directors 2008-9**

Ken King, Co-chair  
 Peggy Proctor, Co-chair  
 Larry Baxter  
 Jeremy Buchner  
 Deborah Randall-Wood (as of March 2009)  
 David Salter (as of November 2009)  
 Marina Sampson  
 Patty Solomon  
 Stephen Tattle (to February 2009)  
 Glyn Townson

**CWGHR Staff, Students and Consultants**Staff

Judy Gould, Director of Research and Education  
 (as of March 2009)  
 Julie Hard, Mentorship and Curriculum Coordinator  
 (as of June 2008)  
 Janet London, Administrative Assistant  
 Eileen McKee, Manager, Episodic Disabilities Initiatives  
 Catherine Nasije, Administrative Assistant  
 (as of September, 2008)  
 Fiona O'Connor, Administrative Assistant  
 (to August 2008)  
 Melissa Popiel, Project Coordinator, HIV and other  
 Episodic Disabilities  
 Ruth Pritchard, Communications Coordinator  
 Elisse Zack, Executive Director

Students

Myda Kavazanjian, Summer Student 2008  
 Jason Singh Mukhi, Student, Master of Social Work  
 practicum  
 Egeria Puka, Summer Student 2008

Project Consultants

Kate Cressman, Income support resource database  
 Myda Kavazanjian, HIV and Employment survey  
 Neil Kemp, Swift Fox Strategies,  
 Health / economic analysis  
 Cristina Mattison, Best Practices initiative  
 Samra Mian, Best Practices initiative  
 San Patten, Project evaluation  
 John Stapleton, Episodic disabilities initiatives  
 Chris Sulway, HIV and Rehabilitation Course  
 Anne Tweddle, Episodic disabilities initiatives  
 Pat Vandesompele, Web design  
 Annette Wilkins, Best Practices and  
 Research Priorities initiatives

IT Support

Joe Batista, Business Computer Solutions

Translation

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