

THE YEAR OF

# THE LAUNCH

2011–12 ANNUAL REPORT



Canadian Working Group on  
HIV and Rehabilitation

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- » Human Resources Professionals Association of Ontario
- » The Ontario HIV Treatment Network
- » The Wellesley Institute

**Special thanks to CWGHR members, other committee members and volunteers who contribute so much of their time and expertise to CWGHR's activities throughout the year.**

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This report describes the activities of CWGHR from April 1, 2011 to March 31, 2012.

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# MESSAGE FROM

# THE CO-CHAIRS

MAY 2012

Dear fellow members, colleagues, funders and other CWGHR supporters:

2011–12 truly was a year of launches for CWGHR, with the introduction of several CWGHR resources and initiatives: online courses, new resources for people living with HIV and other chronic diseases as well as improving on the existing *EDEN (Episodic Disabilities Employment Network)* platform.

All the while, CWGHR has been continuing with other important ongoing activities: HIV and aging, long term care, HIV and mental health, and best practices for accommodations in the workplace.

On the international front CWGHR has been involved with a new initiative on HIV in the context of the UN Convention on the Rights of Persons with Disabilities (CRPD).

The Board would also like to recognize that CWGHR was selected as the recipient of the 2011 Citation Award with the Ontario Society of Occupational Therapists. CWGHR was nominated for its work on episodic disabilities and was recognized for its leadership and commitment to promoting partnerships as well as for its work raising awareness of the needs of people living with episodic disabilities.

In the coming year, the Board has two priority areas of focus for our work. Firstly, the Board will be using innovative and participatory evaluation tools to assess CWGHR's current Strategic Plan and prepare for development of the next Strategic Plan in 2013. Secondly, the Board is assessing current fundraising activities and developing new strategies to diversify our funding sources and ensure CWGHR's long term sustainability. To this end, we will continue to count on our members, other supporters and those who benefit from our innovative work.

On behalf of the entire CWGHR Board of Directors, we would like to thank our staff and executive director for once again going above and beyond the call of duty, and to everyone who has supported us in this work over the past year.

David Salter and Glyn Townson,  
*Co-Chairs*  
*Board of Directors*

# VISION

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

# MISSION

CWGHR is a leader and catalyst for improved rehabilitation services for people living with HIV through integrated research, education, policy and practice.

# MANDATE

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 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 **Canadian Working Group on HIV and Rehabilitation (CWGHR)** ([www.hivandrehab.ca](http://www.hivandrehab.ca)) is a national, multi-sector, multi-disciplinary organization, established in 1998 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 antiretroviral treatments, people also began to experience many of the disabling aspects of living with HIV and/or side effects of these life-saving treatments. The role for rehabilitation supports and services has correspondingly increased to address these disabling impacts of HIV.

CWGHR has a national voluntary Board of Directors that includes representation from diverse stakeholder groups and plays a strong and significant role in governance and leadership.

# PROGRAMS

2011 was an exciting and successful year for CWGHR — and a “Year of Launches”. This past year was pivotal, as several of our new initiatives and resources were launched. Over the year, CWGHR’s programs have continued to grow and develop based upon four pillars that are essential to developing and implementing effective, comprehensive and relevant rehabilitation policies and programs:

- » Fostering and advancing knowledge in HIV and rehabilitation (research)
- » Capacity building/knowledge exchange for strengthening rehabilitation as part of the continuum of care
- » Championing improvements in policy as it relates to HIV and rehabilitation
- » Promoting excellence in rehabilitation practice

Within these pillars, CWGHR’s activities may be understood as falling within three program or theme areas:

- » HIV, Disability and Rehabilitation
- » Integration between HIV and Other Episodic Disabilities
- » International Perspectives

While many activities fit within more than one of these areas, highlighted activities are described in this report under their primary area. All CWGHR activities involve partnerships with other HIV, disability and rehabilitation stakeholders. Educational activities and resource development are integral components of all of CWGHR’s programs.

**To access CWGHR’s educational resources, visit [www.cwghrcampus.hivandrehab.ca](http://www.cwghrcampus.hivandrehab.ca) or [www.hivandrehab.ca](http://www.hivandrehab.ca)**

# HIV, DISABILITY AND REHABILITATION

*While all of CWGHR's work relates to and impacts the lives of people living with HIV, some of our activities are undertaken from a cross-disability perspective and other work is undertaken with a more specific focus on issues related to HIV. This section highlights our work that begins with a focus on HIV.*

## HIGHLIGHTS

### IMPROVING ACCESS TO REHABILITATION

CWGHR aims to improve access to rehabilitation programs and services for people living with HIV and other related illnesses, through four key strategies or approaches:

- » Increasing awareness among health care providers and people living with HIV and other related illnesses of the role of rehabilitation in prevention of illness, maintenance and improvement of health and quality of life
- » Working to change policies that impede access to rehabilitation programs and services
- » Promoting and supporting program models that facilitate access to rehabilitation
- » Identifying and undertaking research to provide evidence-informed solutions

As barriers to accessing rehabilitation present challenges across Canada, CWGHR has continued to address barriers and to improve access to rehabilitation through this multi-faceted approach that requires collaboration with many other groups in the HIV, disability and rehabilitation fields.

### HIGHLIGHTS INCLUDE:

- » Follow-up from CWGHR's roundtable on access to rehabilitation, held in early 2011, to develop a Discussion Paper outlining key policy and program barriers and opportunities related to access to rehabilitation.
- » Participation in research to identify ways that people living with HIV are currently accessing rehabilitation, and related barriers and opportunities
- » Working with programs that are planning for and/or integrating rehabilitation programs into front line HIV care
- » Development of curriculum and other educational resources for rehabilitation and other health and social care providers and front line organizations working with people with HIV

## HIV AND AGING

Aging with HIV is an increasingly important field of research, policy and programming. CWGHR's work over the past year has built on current alliances and developed new partnerships to bridge experts in the field of aging and experts in HIV. We continued working with the Canadian Association on Gerontology and have developed new partnerships with the Canadian Homecare Association and Quality End-of-Life Care Coalition of Canada (QELCCC) to promote knowledge exchange and coordination of HIV and aging work across Canada. These new alliances are being integrated within current initiatives and have also created opportunities for new initiatives.

### KEY ACTIVITIES OVER THE PAST YEAR INCLUDE:

- » Coordinated national HIV and Aging Coordinating Committee, including three subcommittees: research, clinical practice and programs and services
- » Together with the national committee on HIV and Aging, CWGHR hosted a pre-conference session "Learning Across Borders: HIV and Other Complex Chronic Illnesses as We Age" at the 40th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology and the 4th Pan American Congress of the International Association of Gerontology and Geriatrics.
- » CWGHR hosted a 2011 national round table/think tank session on HIV and Aging to explore how the aging and HIV sectors can work together to meet the needs of people aging with HIV in Canada. One of the primary recommendations was to develop comprehensive multi-pronged strategies to address HIV and aging through cross-sector collaborations.

## MENTAL HEALTH

As mental health is a key component of effective rehabilitation, especially for people with HIV and other chronic and episodic conditions, CWGHR has recently undertaken several initiatives to integrate mental health issues into our work:

- » Interactive educational sessions across Canada on HIV and mental health with people working on the front lines in HIV, disabilities and rehabilitation, to bring a practical approach to assessing patients/clients for depression and other mental health issues, including evidence-based techniques to positively impact the mental health of people living with HIV and other disabilities
- » CWGHR's 2011 National Forum, "Keeping it Together: Mental Health Across the Continuum of Care", explored the commonalities between mental health issues in the context of HIV and other episodic disabilities. Caregivers' health and wellness were specifically identified as key to rehabilitation and an immediate issue to be further explored.

CWGHR is continuing to work on these issues and integrate them into our current and planned activities.

- » In early 2012, Health Canada held an international policy dialogue focusing on HIV and mental health. This was an ideal opportunity to meet with people from around the world who are working on these issues. CWGHR participated on the advisory committee for this event and presented on HIV, mental health and disability issues at the dialogue. Discussion at the dialogue identified areas for further research and issues such as links between mental health and addictions, housing and prisons that require education, policy and program responses.

*"Totally stunning. I was held captivated throughout all the days. It was relevant, very good interaction with teacher/students. It elicited thinking about lots of topics. Also it gave lots of validation and language and affirmation to what I'm already doing which for me is important to trust I am doing the right thing. Thank you so much! I am so impressed and feel lucky to have been present."*

*— Feedback from a participant in an interactive educational session on HIV and mental health*





# INTEGRATION BETWEEN HIV AND OTHER EPISODIC DISABILITIES

*While there are various issues that are unique to the experience of living with HIV, there are also increasing commonalities with other chronic illnesses, such as multiple sclerosis, lupus, diabetes, arthritis and some forms of cancer and mental illness. These conditions can often include an episodic component where people experience unpredictable and fluctuating states of health and illness/disability over time. Many Canadians are living with these types of illnesses and face challenges including employment participation, income security, community involvement, social inclusion and access to care and services in a comprehensive and integrated way at both the national and provincial levels.*

## HIGHLIGHTS

### EPISODIC DISABILITY WORK 2011–2012

In the past year CWGHR continued to play a leading role in addressing the challenges experienced by people living with a range of 'episodic disabilities'.

In addition to continuing to present workshops on episodic disabilities and employment issues for a broad range of employers and employees, and continuing

in a coordinating role in the Episodic Disabilities Network, CWGHR launched several episodic disability initiatives, including *Health Gateway*, an enhanced *Episodic Disability Employment Network (EDEN)* as well as the report *Evolving the Workplace: Identifying Opportunities to Support People with Episodic Disabilities in Employment*.



Left to right: Martine Mangion, CWGHR; The Honourable David Onley, Lieutenant Governor of Ontario; Susan Himel, Bridgepoint Health, at the Health Gateway Launch

## LAUNCHING HEALTH GATEWAY

Health Gateway ([www.healthgateway.ca](http://www.healthgateway.ca)) is an accessible web-based e-library for people living with complex chronic illnesses and episodic disabilities and their caregivers that connects them to the resources that meet their needs, wherever they are in their care journey. Health Gateway was officially launched at an event held at Bridgepoint Health in Toronto. The Honourable David C. Onley, Lieutenant Governor of Ontario, was our special guest.

*"It was very extensive and contained all of the things I might be looking for."*

*"A one-stop-shop that will make it easy for people to find what they need."*

*"The comprehensiveness of the site – it seemed to cover nearly all the topics that a person with a disability or caregiver would need."*

*—Feedback from Health Gateway users*

## LAUNCHING EVOLVING THE WORKPLACE: IDENTIFYING OPPORTUNITIES TO SUPPORT PEOPLE WITH EPISODIC DISABILITIES IN EMPLOYMENT

This report, developed and based on research undertaken by CWGHR, was launched at Scotiabank head office in Toronto to coincide with the 2011 International Day of Persons with Disabilities on December 3. CWGHR is working on some of the initiatives recommended in the report including:

- » Developing a business case to support the hiring of people with episodic disabilities
- » Training for managers and supervisors
- » Exploring opportunities to publicly celebrate companies doing well at accommodating people living with episodic disabilities
- » Developing an episodic disabilities and employment Human Resources Mentorship Program

## LAUNCHING NEW ONLINE COURSE ON EPISODIC DISABILITIES

*Accommodation Best Practices*, the second online course in the *Managing Episodic Disabilities* course series, launched in June 2011 to human resource (HR) practitioners across Canada. Course features include videos, interactive programming, additional resources and a course workbook. Partnerships to distribute the course include Human Resources professional associations and post-secondary academic institutions.

## LAUNCHING EDEN

The enhanced *EDEN* ([www.edencanada.ca](http://www.edencanada.ca)), an employment social network website for people with episodic disabilities, includes forums, blogs and information resources on employment rights, accommodations, disclosure in the workplace, stigma and discrimination and work/life balance, etc.

*"It's great. I just found it – it's exactly what I'm struggling with. I just had the worst day because of issues related to work and accommodation, and here was this lovely answer to all my problems in my inbox."*

*–Feedback from EDEN website user*

## EDN AND OEDN

CWGHR continued to coordinate the national and Ontario Episodic Disabilities Networks (EDN and OEDN), made up of HIV and other disability related organizations working together to address the challenges facing people living with episodic disabilities. The networks collaborate on cross-disability research and engage in initiatives to advance public policy change to promote broad based integration to strengthen episodic disabilities initiatives in Canada. The vision for the future is for Canada to develop a National Episodic Disabilities Strategy to promote overall coordination and governance among disability support programs that impact the lives of Canadians living with episodic disabilities.

## HIGHLIGHTS OF EDN ACTIVITIES

- » Submitted a brief for the 2011 federal pre-budget consultations on changes to disability income support policies and programs in Canada to better support people living with episodic disabilities
- » Participated in the Policy Forum on Episodic Disabilities and Employment: Challenges and Solutions, organised by Human Resources and Skills Development Canada (HRSDC), Office for Disability Issues. The focus was to bring cross-disability and cross-sector stakeholders together to discuss the workplace challenges facing people living with episodic disabilities and highlight solutions to address these challenges. We hope this forum will begin to chart a path forward for addressing episodic disabilities and employment in Canada.
- » Participated in HRSDC's Stakeholder Engagement Meeting on Employment Barriers for Canadians with Disabilities in February 2012. This was a wonderful opportunity for stakeholders and community organizations to get together and advise HRSDC on disability and employment in Canada. One of the main recommendations made was for Canada to develop a five year strategy on disability and employment.

# INTERNATIONAL PERSPECTIVES

*HIV, disability and rehabilitation issues are continuing to gain recognition and significance, both in Canada and internationally. Over the past year, there have been several developments in this area. CWGHR has been working with other HIV and disability organizations to promote and strengthen collaborative initiatives among HIV, disability and human rights groups.*

## HIGHLIGHTS

- » A new initiative on HIV in the context of in the context of the *UN Convention on the Rights of Persons with Disabilities (CRPD)*. This work began with an environmental scan to determine research and/or resources that has been and/or is being done in this area, in order to develop educational materials and workshops on HIV and disability in Canada and internationally.
- » Working with HIV and disability groups within Canada and internationally to develop resources and hold workshops to promote discussion on HIV, disability and the CRPD, and ways that the CRPD can be used to promote and protect human rights
- » Advancing these partnerships at the international level through participating in the annual Conference of States Parties to the CRPD at the United Nations in September 2011
- » Presenting on HIV, disability and mental health at Health Canada's International Policy Dialogue on HIV and Mental Health
- » Continuing work with the Global Contact Group on AIDS and Disability to promote knowledge exchange and planning at the international level

As the CRPD has been ratified in Canada and many other countries, there is a continued need to provide education and support for implementation of the Convention. In addition to our other workshops and educational resources, CWGHR is working with UNAIDS to plan and co-host a symposium on HIV and disability at the XIX International AIDS Conference in July 2012. This work will continue to grow as new partnerships are developed and more people around the world begin to recognize the linkages between HIV and disability.



DR. MARY PETTY, recipient of the 2011 Award of Excellence

# 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 recognize a person or organization who/that has made an important contribution to advancing the field of HIV and rehabilitation. In 2011, the 4<sup>th</sup> Annual Award recipient was Dr. Mary Petty. A knowledgeable and impactful social worker and a great advocate, Mary is widely known and respected in the community at large for the work she does on behalf of people living with HIV/AIDS. The award was presented at a reception and dinner held in conjunction with CWGHR's national Forum and Annual General Meeting in June 2011.*

# ORGANIZATIONAL DEVELOPMENT

*A strong organizational infrastructure with clear direction is key to ensuring not only coordination and integration of programs and activities, but also promoting sustainability and growth of CWGHR's work as a whole. CWGHR's Board of Directors and advisory committees play an important role in guiding and providing advice for planning, implementation and evaluation of CWGHR's work.*

## HIGHLIGHTS

### STRATEGIC PLANNING

In 2010, after a consultation process with CWGHR's membership and other stakeholders, CWGHR developed its strategic plan for 2010–13. This plan builds upon the previous plan with a focus on four primary directions:

- » Advancing and fostering knowledge in HIV and rehabilitation
- » Building capacity among health and social care providers and the HIV community to strengthen rehabilitation as part of the continuum of care
- » Championing improvements in policy and practice related to HIV and rehabilitation
- » Cultivating and strengthening CWGHR's resources for sustainability and growth

In 2011, we explored a range of evaluation mechanisms for the current strategic plan and other strategies to prepare for development of the next strategic plan in 2013.

### DEVELOPMENT STRATEGY

CWGHR's Development Committee has continued to develop and implement the development strategy that guides CWGHR's work in the area of promoting organizational sustainability and growth. This strategy provides a framework for advancing knowledge- and resource-based collaborations and initiatives for the next five years, as a key component of CWGHR's strategic plan.

### MEMBERSHIP DEVELOPMENT – EXPANDING OUR MEMBERSHIP BASE

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 and there is great potential for engaging people in our work. Membership information is available on our web site at [www.hivandrehab.ca/EN/get\\_involved/become\\_member.php](http://www.hivandrehab.ca/EN/get_involved/become_member.php)

# LOOKING AHEAD

# 2012–13 AND BEYOND

***CWGHR has a very busy agenda in 2012–13 as we continue to build upon and expand the scope of our work in HIV, disability and rehabilitation in Canada and internationally. Highlights of the coming year include:***

- » Building on the foundation of *The Discussion Paper on Access to Rehabilitation* to work with a broad range of partners to increase access to rehabilitation services, especially for people with HIV and other related or chronic diseases
- » Continuing to review and update CWGHR resources such as the *E-module on Evidence-Informed HIV Rehabilitation* and the interprofessional HIV and rehabilitation course to ensure that they remain current and relevant
- » Expanding the online version of CWGHR's interprofessional curriculum on HIV, disability and rehabilitation in partnership with academic and health institutions, including a new module on HIV and aging
- » Developing curriculum for a third online course for front line managers on employment related accommodations related to people living with episodic disabilities
- » Expanding the reach of educational sessions on HIV, other episodic disabilities and mental health in collaboration with post secondary institutions
- » Continuing the development and coordination of the Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC), including current and upcoming research initiatives and strategies to promote international dissemination and knowledge exchange on HIV and rehabilitation
- » Continuing to coordinate national and provincial episodic disabilities networks for research, education and policy advancement
- » Working with Canadian episodic disabilities groups, government and other stakeholders to promote a national strategy on episodic disabilities
- » Expanding the *Episodic Disabilities Employment Network* and related educational activities
- » Furthering work on the initiatives recommended in *Evolving the Workplace: Identifying Opportunities to Support People with Episodic Disabilities in Employment*
- » Expanding *Health Gateway*
- » Coordinating research and educational initiatives on HIV and aging, including new collaborations between the fields of HIV and aging
- » Expanding curriculum and educational opportunities on HIV in the context of the *UN Convention on the Rights of Persons with Disabilities*
- » Participating in global networking among HIV, disability and human rights groups via the Global Contact Group on AIDS and Disability and the Conference of States Parties to the UN Convention on the Rights of Persons with Disabilities (New York, September 2012)
- » Participating in the XIX International AIDS Conference (Washington DC, July 2012), including sessions on HIV, disability and rehabilitation

# CWGHR BOARD OF DIRECTORS 2011–12

- » **David Salter**, Co-Chair
- » **Glyn Townson**, Co-Chair
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## CWGHR STAFF, STUDENTS AND CONSULTANTS

### STAFF

- » **Le-Ann Dolan**, Program Director
- » **Jordan Lewis**, Senior Mental Health Specialist
- » **Janet London**, Administrative Coordinator
- » **Martine Mangion**, Director, Episodic Disabilities Initiatives
- » **Catherine Nasije**, Project Assistant
- » **Melissa Popiel**, Project Coordinator, HIV and other Episodic Disabilities
- » **Wendy Porch**, Disability Specialist and Education Coordinator
- » **Manna Tang**, Finance Manager
- » **Gilleen Witkowski**, Workshop Coordinator (to August 2011)
- » **Elisse Zack**, Executive Director

### STUDENTS

- » **MacKenzie Graham**, Summer Student (2011)
- » **Roustam Souleymanov**, Master of Social Work practicum (to May 2011)

### IT SUPPORT

- » **Joe Batista**, Business Computer Solutions

### TRANSLATION

- » **Christiane Devaud**, C.D. Translation

### CONSULTANTS ON PROJECTS

- » **Blue Lemon**, Social networking website development
- » **Glen Brown**, Facilitation and planning
- » **Cathy Cameron**, Evaluation
- » **Coco\* Creative**, Publication design and layout – [www.go-coco.com](http://www.go-coco.com)
- » **John Hajdu**, Video editing
- » **Chia-Yu Lin**, CUHRRC Coordinator
- » **Leon Mar**, Communications
- » **Sandra Moll & Erika Pond Clements**, HR mentorship program content
- » **Jessica Cattaneo**, Evaluation
- » **Desire2Learn**, Online course technical development
- » **Lynne Sinclair**, Interprofessional Learning Curriculum and Mentorship Coordinator
- » **Marilyn Swinton**, CUHRRC Coordinator
- » **Pat Vandesompele**, Web design
- » **Richard Weston**, HR course content development

### FINANCIAL ADMINISTRATIVE SUPPORT

- » **Brendan Pennylegion**, Auditor
- » **Marc Weisz**, Arthur Gelgoot and Associate