

BEYOND BOUNDARIES



Canadian Working Group on
HIV and Rehabilitation

ANNUAL REPORT

2010-11

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

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MESSAGE FROM THE CO-CHAIRS

May 2011

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

2010-11 was a major growth year for CWGHR and it is once again our pleasure to present this year's Annual Report outlining the accomplishments of CWGHR over the past twelve months. We would like to extend our deepest gratitude to our fellow board members and community of supporters who have contributed by investing countless hours of their time and diverse expertise to our work on HIV and rehabilitation.

In 2010-11, the focus for CWGHR's Board and staff has been to increase the scope, scale and impact of CWGHR's work, to continue making new links and partnerships in Canada and globally and to increase both our understanding of the impact CWGHR is having and our accountability to our supporters and partners. CWGHR committed to evaluating how well we are doing in meeting the objectives in our strategic plan to ensure that we are fulfilling our mission. Additionally, we started a conversation with members and other colleagues to touch base on how CWGHR is doing as an organisation.

As a result of CWGHR's 2010 Partners in Aging Forum, CWGHR has been coordinating a national working group on aging issues. We have been building new partnerships with groups from the aging field who are not otherwise connected with HIV but are facing many of the same challenges. We have enhanced our internet presence with the launch of several new exciting resources including an on-line employment network web site, Episodic Disabilities Employment Network (EDEN) and CWGHR Campus, a web portal to CWGHR's educational resources. CWGHR continued to work with the Episodic Disabilities Network to promote more flexible income support and employment policies to accommodate the needs of people living with episodic disabilities.

On the international front, CWGHR continues its coordinating role with the Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC), presented at and participated in sessions on HIV, disability and rehabilitation at the XVIII International AIDS Conference in Vienna, and has built new global connections on HIV and disability through participation in the newly formed Global Contact Group on AIDS and Disability (GCGAD).

Following an evaluation of our staffing structure, new staff positions were created to complement the amazing energy and skills of the existing CWGHR staff, under the leadership of our Executive Director, Elisse Zack. This was done to maximise the impact of and continue to develop CWGHR's programs as well as to strengthen our work on changing the laws and policies that impact people living with HIV and other episodic conditions, and to continue to reach beyond CWGHR's current borders.

Moving into 2011-12, CWGHR is planning for two new education programs, focusing on HIV in the context of the recently adopted UN Convention on the Rights of Persons with Disabilities and an innovative new program for rehabilitation and HIV care providers focusing on HIV, depression, and mental health, of critical importance for people living with HIV.

This coming year will see CWGHR continue with the innovative work for which it is recognised, bridging the gaps between diverse communities facing similar challenges and being a catalyst for change in the lives of people living with HIV. Thank-you, to everyone who invested time and energy this past year to help CWGHR make this happen.

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

The **Canadian Working Group on HIV and Rehabilitation (CWGHR)** (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

Over the past 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. 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,

VISION

The daily lives of people living with HIV/AIDS 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 co-ordinating 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.

disability and rehabilitation stakeholders. Educational activities and resource development are integral components of all of CWGHR's programs.

- » Access to Rehabilitation
- » Integration between HIV and Other Episodic Disabilities
- » International Perspectives

ACCESS TO REHABILITATION

CWGHR aims to improve access to rehabilitation programs and services for people living with HIV, through a number of key strategies:

- » increasing awareness among health care providers and people living with HIV of the role of rehabilitation in maintaining and improving health and quality of life,
- » working to change policies that impede access,
- » identifying and promoting program models and policies that facilitate access to rehabilitation, and
- » identifying and undertaking research to provide evidence informed solutions

Barriers to access present challenges across Canada. Improving access to rehabilitation requires collaboration with many other groups. Over the year, CWGHR has continued our work with others in the rehabilitation field to identify and develop strategies to address these barriers.

HIGHLIGHTS

- » Hosted CWGHR's 2010 National Forum, "Breaking Barriers, Advancing Access", focussed on access to rehabilitation and included discussion on the policies and priorities that impede access to rehabilitation and strategies to address these challenges
- » Participated in a national priority setting initiative to determine key research questions related to access to rehabilitation. One of the primary research questions is to determine and articulate the health and economic benefits of increased access to rehabilitation
- » Convened a national Think Tank session on equitable access to rehabilitation. This session produced a discussion paper describing the issues, challenges and opportunities for achieving greater access to rehabilitation
- » Undertook education initiatives among rehabilitation professionals and people living with HIV to increase awareness:
 - » an HIV mentorship program among rehabilitation professionals and including people with HIV as co-mentors,
 - » on-line interactive interprofessional course on HIV and rehabilitation for currently practicing and pre-entry-to-practice rehabilitation professionals, in partnership with Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA), Canadian Association of Occupational Therapists (CAOT) and Canadian Physiotherapy Association (CPA)
 - » new on-line reference document on HIV and rehabilitation (E-Module for Evidence-Informed HIV Rehabilitation) for rehabilitation and other professionals
- » Developed alliances with experts in aging, including the Canadian Association on Gerontology. Coordinating national HIV and Aging working group, including three sub-committees:
 - » Research
 - » Clinical practice
 - » Programs and Services.
- » Launched CWGHR Campus, a portal on CWGHR's website providing access to rehabilitation and other on-line resources including courses, research reports, and other important resources

"I think I said this to you before, but I joined as mentor but I totally feel like I was a mentee in terms of what I gained from it. Which is amazing. It completely reframed the work that I am doing to look at things in the context of rehab. Actually it gave me the framework for the work that I am doing. It's definitely given me direction in my role, but needed some firm structure and I feel that this gave me that."

— Participant in HIV and rehabilitation mentorship program

Mental Health is a key component of effective rehabilitation. CWGHR has begun an important new project to build capacity for front line HIV, rehabilitation, and other health care workers to identify and appropriately address depression among people living with or vulnerable to HIV and other episodic disabilities. The project includes:

- » new curriculum
- » workshops to be held across Canada in 2011
- » new network to support front line workers
- » focus on Mental Health at CWGHR's 2011 Forum on HIV and Rehabilitation



Over the past year, CWGHR has been coordinating collaborative research on HIV and rehabilitation through our expanded and strengthened Canada – UK research collaborative (CUHRRC). CUHRRC provides a mechanism for teams of researchers to work together on priority areas of research in HIV and rehabilitation in Canada and the UK. New research initiatives undertaken in 2010 include participating in projects such as:

- » a survey on the types of rehabilitation services that people with HIV use
- » analysis of policies related to rehabilitation services that impede or facilitate access

This E-Module for Evidence-Informed HIV Rehabilitation is absolutely great work and will be of so much use to us. Can I list this in our Good Practice Collection?

— Colleague in South Africa

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 mental illness. These conditions can often include an episodic component where people experience fluctuating states of health and 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.

In the past year CWGHR continued to play a leading role in addressing the challenges facing people living with episodic disabilities, including employment participation, income security, social inclusion and access to quality care and services, in a comprehensive and integrated fashion at both the national and provincial levels.

In 2010, CWGHR continued to coordinate the national and Ontario Episodic Disabilities Networks (EDN, OEDN), working together to address the challenges facing people living with episodic disabilities. The networks collaborate on cross-disability research and 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 Disability Strategy to promote overall coordination and governance among disability support programs that impact the lives of Canadians living with episodic disabilities.

HIGHLIGHTS

- » Presented at the federal and provincial pre-budget consultations on changes to disability income support policies and programs in Ontario and Canada to better support people living with episodic disabilities
- » Worked to develop a federal private member's bill on changes to Employment Insurance Sickness Benefits
- » Began work with the Technical Advisory Group for Canada's new data collection strategy for people with disabilities to ensure that the perspective of people with episodic disabilities is adequately reflected

Until recently, the concept of episodic disabilities was little known or understood. By working together in the Episodic Disabilities Network, organizations such as the Multiple Sclerosis Society of Canada have been able to take the needs of people with episodic disabilities directly to politicians and policy makers as well as to private employers. We are beginning to see real recognition of what it means to have an episodic disability and, most importantly, the start of real policy and program change. Together, we are making a difference.

— Multiple Sclerosis Society of Canada

I have lived with an episodic disability for more than a quarter century and have battled to ensure my basic rights with educators, employers, government agencies and insurance companies on my own, and mostly unsuccessfully, for most of that time. Now that the OEDN exists there is a way for all Ontarians like me to join forces and have a real voice. Persons with episodic disabilities fall between the cracks as the disability is often not visible and not continuous. As an individual already living with limited physical and mental energy, I have little to no hope of gaining access to decision, policy and law makers but the OEDN pools resources to give me a voice. The OEDN gains access to politicians and other policy makers and works with all stakeholders to offer reasonable and realistic solutions. Staying involved but not having to fight every single battle on my own is in itself a huge benefit to my health and well-being.

— Member of the Ontario Episodic Disabilities Network (OEDN)

Momentum continued to build in CWGHR's episodic disability and employment initiatives.

HIGHLIGHTS

- » Developed new interactive, accredited online course for human resources practitioners Managing Episodic Disabilities: Accommodation Best Practices, to be launched in spring/summer 2011
- » Developed and launched an employment social network website for people with episodic disabilities called the Episodic Disabilities Employment Network (EDEN)
- » Continued to conduct training sessions and workshops with employers across Canada
- » Participated as a community partner in several episodic disabilities research initiatives, including a qualitative research on the perspectives of Ontario employees with intermittent work capacity

CWGHR and Bridgepoint Health (a rehabilitation and complex care hospital in Toronto) are collaborating to develop 'Health Compass', a web-based information/referral resource centre, to meet cross-disease and cross-disability challenges and information needs of people living with episodic disabilities, their caregivers and employers. Whether newly diagnosed and/or living in the community, Health Compass is a resource 'gateway' to guide people living with episodic disabilities, their caregivers and employers through the maze. Health Compass will be launched in summer 2011.

As a national HIV 'partner' organization, CWGHR collaborates with other national HIV organizations in Canada on issues of common concern. CWGHR continued to work with the other national HIV partners on shared planning, input into federal policy issues and programs related to HIV and promoting integration of rehabilitation within national HIV programs.

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

- » At the XVIII International AIDS Conference, collaborated with Health Canada, UNAIDS and several disability groups to host a satellite session on HIV and disability
- » Coordinated a session with HIV and disability groups to plan for continued work on HIV and disability internationally. This led to the formation of the Global Contact Group on AIDS and Disability
- » Attended Conference of States Parties to the Convention on the Rights of Persons with Disabilities (CRPD) at the United Nations in September 2010

These initiatives have led to CWGHR's development of an important education and policy project on HIV in the context of the CRPD. This initiative will begin in the spring of 2011.

AWARD OF EXCELLENCE IN HIV AND REHABILITATION

In 2008, CWGHR launched its 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 2010, the 3rd Annual Award recipient was Dr. Francisco Ibáñez-Carrasco. Francisco is an exceptional leader and has contributed significantly to the field of HIV and rehabilitation. This award was presented at a reception and dinner held in conjunction with CWGHR's national Forum and Annual General Meeting in June 2010.



DR. FRANCISCO IBÁÑEZ-CARRASCO,
recipient of 3rd Annual Award of Excellence

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 new 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

We are now working on an evaluation framework for the strategic plan.

» **Development Strategy**

CWGHR's Development Committee has finalized a strategy to guide CWGHR's work in the area of promoting 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.

LOOKING AHEAD 2011-12 AND BEYOND

CWGHR has a very busy agenda in 2011-12 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:

- » Continuing to expand the HIV and rehabilitation mentorship program to promote the interprofessional model in regions across Canada
- » Launching the new on-line E-module on Evidence-Informed HIV Rehabilitation
- » Expanding the on-line version of CWGHR's interprofessional curriculum on HIV, disability and rehabilitation
- » Launching a second on-line course for human resource managers and employers on employment related accommodations related to people living with episodic disabilities
- » Developing curriculum and leading educational sessions on HIV and mental health with people working in HIV and/or rehabilitation across Canada
- » Developing curriculum on HIV in the context of the UN Convention on the Rights of Persons with Disabilities
- » Continuing the development and coordination of the Canada-UK research collaborative (CUHRRC) on HIV and rehabilitation, including specific current and upcoming research initiatives
- » 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
- » Launching Health Compass: Establishing the Episodic Disabilities Resource Centre and continuing to coordinate national and provincial episodic disabilities networks for research, education and policy advancement
- » Coordinate research and educational initiatives on HIV and aging, including new collaborations between fields of HIV and aging
- » Participating in global networking development among HIV, disability and human rights groups via the newly formed Global Contact Group on AIDS and Disability. This includes the development of a clearinghouse on HIV and disability and integrating HIV and disability in the context of country strategic plans, the High Level Meetings on HIV/AIDS at the United Nations (June 2011) and the Conference of States Parties to the UN Convention on the Rights of Persons with Disabilities (New York, September 2011)
- » Preparing for XIX International AIDS Conference in Washington D.C. 2012, including sessions on HIV, disability and rehabilitation

CWGHR BOARD OF DIRECTORS 2010-11

- » **Deborah Randall-Wood**, Co-chair (to June 2010)
- » **David Salter**, Co-chair (as of June 2010)
- » **Glyn Townson**, Co-chair
- » **Larry Baxter**
- » **Jeremy Buchner** (to June 2010)
- » **Tara Carnochan** (as of June 2010)
- » **Alan Casey** (as of June 2010)
- » **Paul Curwin**
- » **Richard MacLachlan**
- » **Kelly O'Brien**
- » **Marina Sampson**

CWGHR STAFF, STUDENTS AND CONSULTANTS

STAFF

- Sarah Burdeniuk**, Communications Coordinator
(to June 2010)
- Le-Ann Dolan**, Program Director
(as of June 2010)
- Jordan Lewis**, Senior Mental Health Specialist
(as of January 2011)
- Janet London**, Administrative Coordinator
- Martine Mangion**, Manager, Episodic Disabilities Initiatives
- Catherine Nasije**, Project Assistant
- Tim O'Fallon**, Project Coordinator
(January – March 2011)
- Melissa Popiel**, Project Coordinator, HIV and other
Episodic Disabilities
- Wendy Porch**, Disability Specialist and Education
Coordinator (as of January 2011)
- Manna Tang**, Finance Manager (as of March 2011)
- Gillieen Witkowski**, Workshop Coordinator
(as of January 2011)
- Elisse Zack**, Executive Director

STUDENTS

- Roustam Souleymanov**, Master of Social Work practicum
(from January 2011)
- Rahim Thawer**, Master of Social Work practicum
(to May 2010)

CONSULTANTS ON PROJECTS

- Georgina Blanchard**, Development of e-module
- Blue Lemon**, Social networking website development
- Cathy Cameron**, Evaluation
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www.go-coco.com
- Maria Kubyshkina**, Video production
- San Patten**, Evaluation
- Lynne Sinclair**, Interprofessional Learning Curriculum
and Mentorship outreach coordination
- Marilyn Swinton**, CUHRRC coordination
- Sheila Thomas**, Mentorship program coordination
- Pat Vandesompele**, Web design
- Annette Wilkins**, Development of e-module

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