

GROWING IMPACT



Canadian Working Group on
HIV and Rehabilitation

ANNUAL REPORT

2014-2015



Be a part of our growing impact

As we expand our reach, we need your support more than ever. Please help CWGHR to help others—and spread the word.

- + Be a CWGHR advocate and tell someone about our work.
- + Send us a note about how involvement with CWGHR has touched your life.
- + Be a friend of CWGHR and consider becoming a monthly donor.

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CWGHR's impact is growing and we're leading the way for people living with HIV and other episodic disabilities.

If the dictionary definition of impact is “to have a strong effect on someone or something,” then *Growing Impact* is certainly an apt way to describe the year that was for the Canadian Working Group on HIV and Rehabilitation (CWGHR).

At CWGHR, we respond to—and work for—the rehabilitation needs of people living with HIV and other episodic disabilities. We bring together the traditionally separate worlds of HIV, disability and rehabilitation, and work through research, education and cross-sectoral partnership. And our approach is working, which is clear to see in the success stories featured in this summary report.

Our positive impact on the lives of people living with HIV and other episodic disabilities is certainly growing. We are spearheading critical changes to the policy and program environments that greatly affect how people are able to live their daily lives. We are working with many different stakeholders, including (most importantly) people living with HIV, to redefine what it means to live well with chronic illness in Canada and around the world. As needs change, our thinking also continues to evolve, as evidenced by our innovative programs and new directions.

We know that our continued growth is largely dependent upon our committed staff—and, of course, our capable leadership. In 2014, we lost our much-loved founding Executive Director, Elisse Zack, who fortunately left CWGHR in a strong position of possibility. Stephen Tattle, a long-time CWGHR collaborator and supporter, was able to seamlessly guide us through an extended period of searching for just the right person to further CWGHR's impact. Happily, after an extensive national search and recruitment process, Tammy Yates—CWGHR's former Programs and Communications Manager—accepted the position of Executive Director and is already making her mark.

Moving forward, we'd like to personally invite you to be a part of CWGHR's growing impact. We are proud to be leaders in the movement to improve the lives of those living with HIV and other episodic disabilities, and we need your support to go even further.

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

1 million+
Canadians live with
episodic health
conditions

Access to diverse **rehabilitation** services improves quality of life



Rehabilitation services vastly improve quality of life for people living with HIV and other episodic disabilities. Consultations with stakeholders who share an interest in increasing equitable access to rehabilitation services—including people living with episodic illnesses—have reinforced the need for a place to connect. CWGHR is playing a founding role in a new Pan-Canadian Rehabilitation Network that will enable representatives from different sectors and disciplines to collaborate, share information and build new partnerships.

A significant barrier for people living with HIV and other episodic illnesses is the cost of rehabilitation services. To access these services, a person needs money to pay out-of-pocket, an extended health

benefits plan, or the right combination of age, illness and income supports; people living with HIV often find themselves missing some of the requisite pieces to this needlessly complicated puzzle. CWGHR will continue to raise awareness amongst decision-makers about the importance of ensuring that all Canadians can access the rehabilitation services they need, starting with the distribution of our newest policy brief “Rehabilitating the Bottom Line.”



Rehabilitation in the context of HIV

Our eight-module inter-professional learning series:

- is now offered in health sciences faculties in five universities across Canada
- 500 students from eight professional health disciplines enrolled

“Learning about the role of occupational therapy for people living with HIV has given me an important new perspective for my future practice.”

—**Leah Ferreira** Graduate, McMaster University

Good mental health is key for better general health



Good mental health means better overall health outcomes for people living with HIV and other episodic disabilities. This year, we strengthened our commitment to supporting mental health and to integrating it across CWGHR’s main program areas by developing a new Mental Health Advisory Committee (MHAC). The MHAC comprises ten expert authorities in mental health and/or HIV from across the country—including researchers, clinicians, educators and legislators—who are committed to helping CWGHR re-envision how mental health permeates all our work. Despite its relative newness, this committee is off to a running start.

CWGHR looks forward to growing our impact on the mental health of people living with HIV and other episodic disabilities through our new expertise and renewed commitment.

“The CWGHR Mental Health Advisory Committee is shaping the exciting direction of this work, expanding our discussions to include trauma-informed practice and how mental health workshops can better address cultural safety.”

—**Melissa Egan** Regional Health Education Coordinator, Canadian AIDS Treatment Information Exchange (CATIE)

Success in the workforce is more than just securing a job

Working successfully isn't just about getting a job and going to work every day. It also means getting the education you need to get the job you want and, once hired, maintaining a balance between personal and professional demands. With this in mind, we expanded our focus on employment to explore two new critical areas: how young people with HIV and other episodic disabilities fare in higher education, and how caregivers manage the ups and downs of looking after someone with an episodic illness.

"Over a million Canadians live with episodic health conditions ... and we know very little about their caregivers or the impact that episodic caregiving has on their life. CWGHR is with us at the forefront of this important research."

—**Dr. Donna Lero**

Jarislowsky Chair in Families and Work, Centre for Families, Work and Well-Being, University of Guelph

More than **25%** of **Unemployed persons** were **denied a job** because of their **disability status**



CWGHR is now at the centre of two landmark research initiatives that will provide important snapshots of these two stakeholder groups. We will continue to integrate findings from these studies into our ongoing work with employers, decision- and policy-makers and other leaders to better support the active workforce participation of people living with episodic disabilities and their caregivers.

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First-ever think tank on **Episodic Disabilities and Post-Secondary Education in Canada**

brought together many professions, 56 participants, and 32 institutions

Aging with HIV is the new reality for many

Aging with HIV presents new and important challenges for many Canadians. This year, we worked with a range of community partners to provide cross-sectoral training on HIV and aging for front-line service providers. Using video case studies, we brought to life common issues experienced by older adults living with or vulnerable to HIV when they access community services. We continued to use conferences and forums to bring HIV and aging to the fore, for many different audiences.

In 2014, the National Coordinating Committee on HIV and Aging, for which CWGHR serves as secretariat, introduced a Programs and Services Working Group. This enthusiastic team includes representatives from the HIV, chronic disease, LGBTI and palliative care sectors, as well as older adults living with HIV.

Over **20,000** people living with HIV in Canada are age **50** or older

The group will coordinate the sharing of findings from a ground-breaking environmental scan of HIV and aging services led by Charles Furlotte (McMaster University, University Without Walls).

The lived experience of people who are aging with HIV across Canada informs all of this work. In 2015, poignant discussions with key partners have inspired CWGHR to undertake new work related to advance care planning for people living with HIV.

"I don't live with HIV; HIV lives with me. Twenty-five years after my diagnosis, I find myself living a very real human experience—I am aging."

—**Jeff Potts** CWGHR colleague



Remembering **Elisse Zack**

We simply cannot speak about growing impact without reflecting upon the inspired life of Elisse Zack, CWGHR's founding Executive Director and great friend to many in our community. Elisse passed away peacefully in late July 2014, and leaves behind a great legacy.

Elisse dedicated fifteen years to building CWGHR and to advocating on behalf of those living with HIV and other episodic disabilities. As a result of her tireless efforts, CWGHR—like Elisse herself—became a pioneer in many of the areas she championed, including HIV and aging, and access to rehabilitation.

Elisse engendered enormous respect as one of our sector's strongest leaders, and was known and loved for her expert knowledge, as well as her candour, integrity, kindness and great sense of humour. Her presence is sorely missed, and her impact is very often seen and felt. In 2015, Elisse was posthumously awarded the Canadian Association for HIV Research (CAHR) Red Ribbon for her "outstanding service to the cause of research in a way that has increased our understanding of the treatment and prevention of HIV/AIDS, while enhancing the quality of life of those living with this disease."

At CWGHR, we honour Elisse's exceptional life by continuing to grow the organization she founded and loved. In 2014, the CWGHR Award of Excellence in HIV and Rehabilitation was fittingly renamed the Elisse Zack Award for Excellence in HIV and Rehabilitation.

Dr. Kelly O'Brien, 2015 award recipient and longstanding friend and colleague of Elisse, has said that she "works in Elisse's wonderful legacy each and every day."

With sincere thanks

Many people, including our deeply committed Board of Directors, staff, members, volunteers, donors and partners have contributed to our success.

Funders, including the M·A·C AIDS Fund, Ontario Trillium Foundation, Scotiabank and the Public Health Agency of Canada, make our work possible.

ACRIA (AIDS Community Research Initiative of America), the Canadian Home Care Association, Closing the Gap Healthcare Group, Epilepsy Toronto, members of the Episodic Disabilities Network (EDN), the Ontario HIV Treatment Network, Revera Home Health, University of Guelph, the Wellesley Institute and WoodGreen Community Services all provided in-kind support.



In 2014-2015 ...

- 83 volunteers contributed over 700 hours
- CWGHR reached more than 8,700 people and shared more than 4,000 resources

Demand grows for our E-Module for Evidence-Informed HIV Rehabilitation

This on-line resource, updated annually by a panel of clinical experts, continues to be our most accessed resource.

In 2014-2015 it was:

- downloaded over 10,000 times
- given to over 5,000 people at events and meetings



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