



PROMOTING ACCESSIBILITY TO EMPLOYMENT FOR PEOPLE WITH
EPISODIC DISABILITIES

Project Summary Report

March 2012

Canadian Working Group on HIV and Rehabilitation
(CWGHR)

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The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national charitable organization working to improve the quality of life of people living with HIV/AIDS through rehabilitation research, education, and cross-sector partnerships. CWGHR members are individuals and organizations that have an interest in HIV, disability and rehabilitation. These include: community-based HIV/AIDS, disability and rehabilitation organizations; national professional associations; unions; government agencies; private-sector companies; people living with HIV; health care, social care and human resources professionals; and other people who are interested in HIV and rehabilitation.

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This project is funded in part by the Government of Canada's Social Development Partnerships Program – Disability component.

Summary Report

1. INTRODUCTION

Many people in Canada live with 'episodic disabilities' and the numbers are increasing (Furrie & Crawford, 2010). Episodic disabilities are lifelong conditions that are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and frequency from one person to another. Some common examples of episodic disabilities include multiple sclerosis, diabetes, HIV/AIDS, hepatitis C, chronic fatigue syndrome, migraines, chronic pain, and some forms of arthritis, cancer and mental illness.

In Canada, currently 14.3% of the population is living with some form of disability (Statistics Canada, 2008). Specifically, the proportion of women with disabilities in Canada is rising, from 15.7% in 2001 to 17.7% in 2006 (Crompton, 2010). Diagnoses of many episodic disabilities are also on the rise, including incidence rates of depression, arthritis and some forms of cancer (Stapleton & Tweddle, 2008). A recent study by (Furrie & Crawford, 2010) reported that 46.4% or 1,140,500 of the adult population with disabilities reported at least one of the 27 conditions associated with "episodic" disability. Incidence rates are also increasing for those living with co-morbid illnesses, with at least one or more disabilities (Statistics Canada, 2007).

Individuals living with any form of disability face challenges and disincentives to active employment. According to Statistics Canada (2007), 51.3% of working-age persons with disabilities were employed in 2006 compared with 75.1% of their counterparts without disabilities. The numbers of people living with disabilities in Canada who are actively employed are lower compared with the general population. Among individuals living with episodic disabilities, 49.9% indicated that they were "often" or "sometimes" limited in the workplace (Furrie & Crawford, 2010). While there may be similarities in the overall challenges among people living with disabilities to access the labour force, there are differences in the types of employment barriers faced by people living with episodic disabilities in relation to people with more 'traditional' forms of disability.

What are the challenges to living and working with an episodic disability?

Episodes of illness or disability present challenges for people with episodic disabilities who are interested and able to engage in the workforce. The employment barriers experienced by people living with episodic disabilities are unique and particularly complex, including stigma and discrimination associated with particular illnesses (Beatty & Joliffe, 2006), the unpredictable nature of these health conditions and a lack of employer understanding on accommodating the episodic nature of these disabilities in the workplace (Spataro, 2005). These barriers may become so severe that some employees living with episodic disabilities may leave the workplace unnecessarily (Varecamp, Heutink, Landman, Koning, de Vries & van Dijk, 2009) if workplace accommodations are not in place. As incidence rates continue to rise, episodic disabilities in the workplace are becoming an issue of increasing importance to employers, as episodes of illness can result in increased absences from the workplace, short and long-term disability leaves (Allaire, Niu & LaValley, 2005), increased stress levels and decreased workplace satisfaction (Roessler & Rumrill, 1998).

To date, supports for people with disabilities have often focused on the person living with the disability. These supports are certainly needed and are important in an employment context. However, the person with the disability represents only one component of the key players involved in accessing and sustaining employment. There are also challenges for co-workers, employers, income support benefit providers and health and drug benefit providers (both public and private payers).

New educational resources and supports are required for all stakeholders to fully include and engage people with episodic disabilities in the workforce. Education, information resources and other opportunities for knowledge exchange are needed for employers, human resources practitioners, senior management and other organizational decision makers. Others who provide support with return to work and work maintenance planning include primary health care personnel, vocational rehabilitation

practitioners, occupational therapists, social work practitioners and others. Among many of the above stakeholders, knowledge of the nature of episodic disabilities and their impact on employment is limited.

Promoting Access to Employment for People with Episodic Disabilities Project

This project, which ran from December 2009 through March 2012, used a cross-disability, cross-sectoral and multi-disciplinary approach to a) develop an online network for people living with episodic disabilities who are currently engaged in, or want to engage in the labour force, b) develop an online course for employers / human resources (HR) practitioners on accommodating people with episodic disabilities, c) develop information resources on episodic disabilities and employment for other key employment stakeholders outlined above, and d) develop a peer mentorship curriculum for HR practitioners to enhance their capacity to support employees with episodic disabilities to improve employment outcomes.

2. PROJECT OBJECTIVES

To promote employment access for people with episodic disabilities through:

- Building the capacity of and enhancing employment information resource supports for people with episodic disabilities to engage in the labour force
- Increasing awareness among people living with episodic disabilities and other key stakeholders involved in the employment of people with episodic disabilities

3. KEY PROJECT ACTIVITIES

The project involved four key areas of activity.

Activity 1: Episodic Disabilities Employment Network (EDEN)

This activity involved developing the EDEN. EDEN is a national information and knowledge exchange electronic network and website on employment. The EDEN website is a place where people living with episodic disabilities, including HIV, can connect with each other to find and generate answers to tough employment questions.

Website features include:

- A cross-disability employment forum
- Information on employment programs and services
- An 'Ask Human Resources (HR)' message centre to pose employment-related questions to certified human resources professionals
- Personal accounts of how people living with episodic disabilities, including HIV, have successfully handled challenging work situations
- Videos on:
 - Personal stories, such as returning to work
 - Employment law and
 - Workplace accommodations, such as flexible work hours

Activity 2: Managing Episodic Disabilities: Accommodation Best Practices online course

This activity involved the development of an interactive online course for human resources practitioners called *Managing Episodic Disabilities: Accommodation Best Practices (the course)*. The *course* is a follow-up to the successful online course *Managing Episodic Disabilities: An Introduction* which was launched in 2008. This interactive self-directed online course includes 11 multimedia modules made up of: case studies; reading materials; videos; and interactive learning techniques.

Activity 3: Developing knowledge based resources on episodic disabilities and employment

Knowledge based resources on episodic disabilities and employment were developed on workplace legislation and accommodation practices for employment stakeholders who work with people with episodic disabilities. The formats of the resources included information sheets, presentations and webinar resources. Target audiences for the information resources included: physicians, occupational therapists, vocational rehabilitation specialists, and social workers.

Activity 4: Developing a mentorship program for human resources professionals on episodic disabilities in the workplace

Content for the mentorship program was developed to provide instruction on foundational principles in accommodating clients living with episodic disabilities, working collaboratively through a series of case scenarios, and mentorship. The 6 month program includes case studies and collaborative problem solving amongst participants with one meeting per month. Between sessions, participants are encouraged to work through a series of relevant readings and participate in forum discussions.

As part of this project, the content and structure of the mentorship program were developed.

4. PROJECT OUTCOMES

Project outcomes included:

- Enhanced communications between and among people with episodic disabilities and other key stakeholders involved with people with episodic disabilities
- Improved access to and integration in the labour force for people with episodic disabilities
- Enhanced capacity of people living with episodic disabilities to engage in the labour force to their capacity
- Improved awareness of key stakeholders on health and systemic barriers to employment for people living with episodic disabilities
- Enhanced capacity of HR professionals, physicians, occupational therapists, vocational rehabilitation specialists and social workers to respond to the employment needs of people living with episodic disabilities

5. PROJECT HIGHLIGHTS

Activity 1: Episodic Disabilities Employment Network (EDEN)

To determine the content and structure for the EDEN website, four focus groups were held with people living with episodic disabilities and organizations representing people living with episodic disabilities. The focus groups were held with member organizations of the episodic disabilities network¹, members of the National Network for Mental Health, women living with disabilities and members of the Multiple Sclerosis Society of Canada. An initial version of the EDEN website was developed and piloted in 2010. The target audience for the pilot was people living with HIV and other episodic disabilities across Canada.

The website was built by people living with episodic disabilities for people living with episodic disabilities. The EDEN website is accessible to audiences with a variety of types of disabilities and is compliant with WCAG 2.0 web standards at a AA level.

The pilot version of the website included features such as: blogs, forum, videos, and information

¹ The Episodic Disabilities Network brings together organizations working on issues affecting people with episodic disabilities and serves as a pan-Canadian forum for issues relating to episodic disabilities.

resources on topics related to episodic disabilities and employment. Based on the feedback received from the pilot, the website was revised to include:

- A forum fully integrated within the website
- Additional information resources on topics including: disclosure in the workplace, extended drug and health benefits, employment counseling, employment rights, income security, returning to work, stigma and discrimination, work/life balance and workplace accommodation
- Enhanced online accessibility features, including video accessibility
- Additional images and videos
- Enhanced description of the purpose of EDEN, the target audience and who was involved in the development of EDEN

After significant revisions to ensure that the EDEN website responded to the needs of EDEN users, the website was officially launched in January 2012. The launch consisted of a series of email blasts to various target user groups. The website was immediately well received with over 1,400 visits to the site in the first two months of activity.

To promote the website, three webinars were held in February 2012 with service providers working with clients living with various episodic disabilities and facing employment barriers. The webinars were attended by service providers from across Canada and one participant internationally. The webinars included information on the EDEN website and its features, background information on CWGHR and a tour of the website. Two webinars were held in English and one webinar was held in French. A total of 17 individuals attended the three webinars.

As part of the marketing of EDEN, CWGHR listserv members, EDEN listserv members and other CWGHR contacts in the area of episodic disability and employment were encouraged to post the information on the EDEN website on their organizational websites. For example: the Coalition des organismes communautaires québécois de lutte contre le sida in Quebec, the Canadian AIDS Treatment Information Exchange (CATIE) and the Ontario Disability Employment Network (ODEN) have all added a link² to the EDEN website from their organizational websites. The EDEN website is also being promoted through the widespread distribution of information resource cards and through ongoing electronic marketing of the website. To date requests have been made to distribute more than 1200 EDEN resource cards.

Here are comments made by EDEN website users:

"Congratulations. The website looks great and I've become a member. I think it's a wonderful resource for people like me."

"It's great. I just found it – its 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. Lovely. Thanks."

"I just love the site!! I read through many of the resources and FAQs and found them to be very easy to follow and clearly helpful!"

Next steps for the EDEN website include ongoing marketing to disability organizations across Canada, employers and people living with episodic disabilities and the development of new website content including additional blogs, forum posts and resource information.

² Organizational website links:

-Coalition des organismes communautaires québécois de lutte contre le sida - www.cocqsida.com/

-Canadian AIDS Treatment Information Exchange - www.catie.ca/

-Ontario Disability Employment Network - <http://www.odennetwork.com/>

Activity 2: Managing Episodic Disabilities: Accommodation Best Practices online course

The development of the second course in the Managing Episodic Disabilities course series was much anticipated. The content was developed in conjunction with a curriculum expert in the area of workplace accommodations for people living with episodic disabilities. The course builds upon the foundational principles in episodic disability accommodation discussed in the first course in the series entitled Managing Episodic Disabilities: An Introduction.

The course includes a series of 11 online modules on topics including:

- What an episodic disability is
- Legislation and workplace standards
- Best practices in accommodating people with episodic disabilities in the workplace
- Communicating about episodic disabilities in the workplace
- Creating an inclusive workplace culture
- Attendance management
- Working with insurers
- Evaluating your organization
- Case studies

Case studies are included throughout the course for participants to be able to apply and learn from the content presented.

To enhance the learning uptake and online accessibility of the course, accessibility consultants and e-learning consultants were involved in a review of the course. The course is accessible for people living with a variety of disabilities and also includes captioned videos.

Upon completion of the draft version of the content and the development of the online version of the course, a piloting of the course was done with 33 HR professionals in partnership with the Human Resources Professionals Association. More than 120 requests were received to participate in the pilot. Each participant attended an in-person workshop introducing the topic of the course and the process for participating in the pilot. Each participant then had 4 weeks to review the course and provide feedback online. At the end of the pilot, each participant attended an in-person focus group to share ideas and thoughts on the course and how it could be improved.

Based on the feedback received from the pilot, additional content was added on attendance management and difficult to manage employees and a participant workbook was created to allow participants to better retain the course information. In addition, it was recommended that a training program be developed for front-line managers on episodic disabilities in the workplace.

The course content was subsequently translated into French and a French version of the course was developed online. The course is accessible to audiences with a variety of disabilities and is compliant with WCAG 2.0 AA accessibility standards.

The course has been accredited for continuing education credits through HR associations in Ontario and British Columbia. The course was launched in Ontario in June 2011 and in British Columbia in March 2012. In addition, a partnership agreement is being developed with Humber College and the online learning web consortium of Ontario colleges, Ontario Learn, to distribute the course.

Participants have reported making the following changes to their practice based on the learnings from the course:

- Being much better prepared to manage employees living with episodic disabilities
- More discussion with employees
- Greater confidence in speaking with the employer on behalf of the employee
- Greater confidence in dealing directly with the employee and asking what accommodations might work

- Educated colleagues and encouraged them to become more knowledgeable on episodic disabilities

Next steps for the Managing Episodic Disabilities: Accommodation Best Practices course include ongoing reviews of the course and the workbook content and marketing to human resources associations and academic institutions across Canada.

Activity 3: Knowledge based resources on episodic disabilities and employment

As part of the project activities, a series of four information sheets were developed to educate professional groups working with people living with episodic disabilities. The target audiences for the information sheets included: physicians, vocational rehabilitation/employment counselors, occupational therapists and social workers. All of the information sheets developed were reviewed by professionals practicing within their respective communities. Credentialing bodies including the Canadian Medical Association (CMA), the Ontario Association of Social Workers and Social Service Workers and the Canadian Association of Occupational Therapists also reviewed the information sheets. The information sheets were translated into French and are available on the CWGHR website³.

The information sheets were distributed through several professional associations including the Canadian Association of Occupational Therapists and the Ontario Association of Social Workers and Social Service Workers.

The information sheet for physicians is undergoing a subsequent review by the CMA and will be translated and distributed when the final review is completed.

In addition, a list of information resources on episodic disabilities and employment was developed and enhanced over the course of the project. This list of resources is available by contacting CWGHR.

In February 2012, rehabilitation professionals from various disciplines were invited to participate in a webinar on episodic disabilities and employment. A total of 18 rehabilitation professionals attended the webinar from across Canada. Subsequent to the webinar, five participants requested copies of the slides used during the webinar.

Next steps include ongoing access to the information sheets and resources on the CWGHR website and continuing to promote these materials through speaking engagements and meetings with contacts, businesses and other groups.

Activity 4: A mentorship program for human resources professionals on episodic disabilities in the workplace

Building on the momentum from the Managing Episodic Disabilities: Accommodation Best Practices course, an interactive, discussion based mentorship curriculum was developed for HR practitioners. A structure for the program content was also proposed.

The content of the curriculum is based on the content from the accommodations course with a focus on collaborative discussion between and amongst participants. The discussions during the six sessions will focus on several case studies demonstrating different factors related to episodic disabilities and employment including: gender, age, stigma/discrimination, care giving, social determinants of health, such as housing, access to care, etc. Participants will also connect with one another between sessions via an online discussion forum.

Next steps include preparing to pilot the mentorship program with HR professionals across Canada.

³ The information sheets on episodic disability and employment for various rehabilitation professionals can be found at: http://hivandrehab.ca/EN/resources/episodic_disabilities.php

6. LESSONS LEARNED

Over the course of the project, there were a number of lessons learned about the administration of the project activities and about how to more effectively work in the area of episodic disability and employment. The following are the highlights of the lessons learned:

Project Administration

- Communication using social media technology, such as forums, is more effective and more broadly used when the technology is easy to use for the average user
- Be transparent with the identities of organizations and individuals involved with a social media website. Transparency enhances the trust of the user and users are more likely to engage in dialogue on the website when the website is a trusted resource
- Plan for accessibility of any online resources during the initial planning stages. Accessibility features for people living with a variety of visual, auditory and cognitive disabilities are critical to ensure that all audience members are effectively included

Improving initiatives in the area of episodic disability and employment

- Collaborative work amongst all key stakeholders including employers, human resources practitioners, managers, unions, insurers, disability organizations, rehabilitation providers, and medical teams is vital to the successful labour force engagement of people living with episodic disabilities
- Small/medium sized employers have unique challenges in accommodating employees living with episodic disabilities. These challenges are at least in part related to access to financial and human resources
- Information resources developed in the area of episodic disabilities and employment should target both professionals and students in their respective disciplines
- When accommodating employees living with episodic disabilities in the workplace the following are important:
 - A tolerance for uncertainty in: the illness course, working through the process of accommodations and the reactions of staff and management to the illness
 - A willingness to engage in a trial and error process of determining which accommodations will be most appropriate at a given time
 - A collaborative attitude that an appropriate outcome will be found in the end if everyone is actively involved that is impacted by the accommodation
 - Clear communication amongst all individuals involved

7. NEXT STEPS

The next steps for the project include the following activities:

- Continue to host and maintain and further develop the EDEN website. EDEN website promotions will continue to target audiences and service providers across Canada. Additional content will be added to the “What’s New” and to the “Issues” sections regular basis
- Adding additional bloggers to the EDEN website
- Launching the Managing Episodic Disabilities: Accommodation Best Practices course through the online website consortium for colleges in Ontario, Ontario Learn
- Continuing to market the Managing Episodic Disabilities: Accommodation Best Practices course to HR associations across Canada
- Piloting the mentorship program for HR professionals in 2013
- Marketing the mentorship program to HR professionals across Canada

- Continuing to disseminate the information resources to target audiences across Canada

For additional information on any of the project activities or reports mentioned in this report, please contact info@hivandrehab.ca.

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