

EPISODIC DISABILITY TOOLKIT OF RESOURCES

**Compiled by
The Episodic Disabilities Network**

Updated January 2015

ABOUT THE EPISODIC DISABILITIES NETWORK (EDN)

The Episodic Disabilities Network (EDN) serves as a pan-Canadian forum for episodic disability. The EDN collaborates on research, advances public policy on employment and income support and promotes broad integration to strengthen episodic disabilities activities in Canada. Episodic Disabilities Network members and their websites are listed below. The EDN website can be found at www.episodicdisabilities.ca

EPISODIC DISABILITIES NETWORK MEMBER ORGANIZATIONS

DisAbled Women's Network of Canada/ Réseau des femmes handicapées Canada

<http://www.dawncanada.net/>

DAWN-RAFH Canada's mission is to end the poverty, isolation, discrimination and violence experienced by women with disabilities and Deaf women. DAWN-RAFH is an organization that works towards the advancement and inclusion of women and girls with disabilities and Deaf women in Canada. Our overarching strategic theme is one of leadership, partnership and networking to engage all levels of government and the wider disability and women's sectors and other stakeholders in addressing our key issues.

Multiple Sclerosis Society of Canada

<https://beta.mssociety.ca/>

The MS Society provides services to people with multiple sclerosis and their families and funds research to find the cause and cure for this disease. We have a membership of 28,000 and are the only national voluntary organization in Canada that supports both MS research and services. Since our founding in 1948, the core support of the MS Society has been from tens of thousands of dedicated individuals, companies and foundations in communities across Canada. The Society receives almost no funding from government.

Canadian Council on Rehabilitation and Work

<http://www.ccrw.org/main.php>

Our mission is to promote and support meaningful and equitable employment of people with disabilities. As innovators and agents of change, we build partnerships, develop skills, share knowledge and influence attitudes. CCRW strongly believes in partnerships that bring together stakeholders from business, community agencies and job seekers with disabilities. All of CCRW's programs and services are predicated upon a partnership philosophy that promotes inclusion and ensures that our work is grounded by this balance and validated by stakeholder experience.

Canadian Working Group on HIV and Rehabilitation

www.hivandrehab.ca

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, charitable organization that responds to the rehabilitation needs of people living with HIV/AIDS. We bridge the traditionally separate worlds of HIV, disability and rehabilitation. Through research, education and cross-sector partnerships we are working to improve the lives of people with HIV. CWGHR acts as Secretariat to the Episodic Disabilities Network.

EPISODIC DISABILITY CONDITION SPECIFIC ORGANIZATIONS

There are an estimated 27 conditions that have been described as episodic in the literature (Furrie, 2010). These are noted below and links are provided to national disability groups, where they exist, in Canada.

ALS (Amyotrophic Lateral Sclerosis)

ALS Society of Canada: <https://www.als.ca/en/als-society-canada>

Arthritis

The Arthritis Society:
<http://www.arthritis.ca/page.aspx?pid=1055>

Asthma & Chronic bronchitis

Asthma Society of Canada <http://www.asthma.ca/>

Cancer

Canadian Cancer Society: <https://www.cancer.ca>

Chronic Fatigue Syndrome

Diabetes

Canadian Diabetes Association: www.diabetes.ca/

Emphysema

The Lung Association: https://www.lung.ca/home-accueil_e.php

Epilepsy

Epilepsy Canada: www.epilepsy.ca

Fibromyalgia

Guillain-Barre Syndrome

GBS/CIDP Foundation of Canada: <http://www.gbs-cidp.org/canada/>

Hepatitis B & C

Action Hepatitis Canada:
<http://www.actionhepatitiscanada.ca/>

HIV/AIDS

Canadian AIDS Society / Société canadienne du sida:
www.cdn aids.ca

Long-Term Pain

Chronic Pain Association of Canada: chronicpaincanada.com/

Lupus

Lupus Canada : www.lupuscanada.org/

Major depression

Canadian Mental Health Association <http://www.cmha.ca>

Meniere's disease

Mood Disorders

Mood Disorders Society of Canada:
www.moodd disorderscanada.ca/

Multiple Sclerosis

Multiple Sclerosis Society of Canada:
<https://beta.mssociety.ca/>

Muscular Dystrophy

Muscular Dystrophy Canada: www.muscle.ca

Parkinson's Disease

Parkinson Society Canada / Société Parkinson Canada:
www.parkinson.ca/

Personality disorders

Canadian Mental Health Association <http://www.cmha.ca>

Repetitive Strain Injury

Schizophrenia

Schizophrenia Society of Canada: www.schizophrenia.ca/

Severe migraines

Tuberculosis

The Lung Association: <http://www.lung.ca/>

ABOUT THE EPISODIC DISABILITIES TOOLKIT

Developed by the Episodic Disabilities Network, this toolkit provides links to important resources related to living with an episodic disability. Episodic disabilities are marked by fluctuating periods and degrees of wellness and disability. These periods of wellness and disability are unpredictable. Advances in medical technologies mean that many diseases and conditions are no longer imminently fatal, and disabling symptoms can often be reduced, managed or delayed. However, as a result, more and more Canadians are living longer with lifelong episodic disabilities, and overall women have a higher rate of episodic illness than men. While the specific prevalence of episodic disability is not known, millions of Canadians live with diseases/conditions linked to episodic disability. The majority of people affected by episodic disabilities are in their prime working years, may move in and out of the labour force in an unpredictable manner, and have great difficulty securing stable employment and income supports.

The hope is that through disseminating this toolkit, more people will be aware of the challenges associated with living with an episodic disability and more stakeholders will become engaged in trying to address these barriers.

This resource toolkit was last updated in January 2015. It does not represent an exhaustive list, but does provide links to a range of articles, reports and resources that explain in more detail the unique barriers faced by the millions of Canadians living with episodic disabilities. All of the resources listed below can be found on the internet. As well as a link, a short description of the resource has been provided.

BARRIERS TO INCLUSION EXPERIENCED BY PEOPLE LIVING WITH EPISODIC DISABILITIES

People with episodic disabilities exist between the two polarities of ‘disabled’ and ‘well’. The unpredictability of episodic disabilities renders people sometimes well and sometimes disabled, often without warning and for uncertain durations. This means that supports that are typically used by people with disabilities with static, long-term disabilities may exclude them.

Barriers faced by people living with episodic disabilities can include:

1. **A lack of general awareness of episodic disabilities.** The concept of “episodic disability” is a relatively new way of thinking about chronic health concerns like HIV, MS, mental illness and arthritis, to name just a few. Although these conditions seem very different, they have in common unpredictable illness trajectories and intermittent periods of wellness and illness. Many employers, human resource professionals, policy-makers and members of government are not familiar with the concept of episodic disabilities.¹ As a

¹ Evolving the Workplace

result, workplaces, support services and government programs may not always support people with episodic disabilities in ways that are needed.

2. **Difficulties with obtaining/retaining employment.** These include specifically:
 - Lack of employer awareness of episodic disabilities and appropriate accommodation strategies
 - Employer concerns regarding productivity/profitability
 - Workplace hostility due to a perception of ‘special treatment’ related to accommodations combined with a lack of appropriate communication strategies ²
 - Employer difficulty with appropriate return-to-work strategies after an illness episode
 - Returning to work may mean losing access to needed drug treatments.

3. **Problems with qualifying for disability income supports.** People with episodic disabilities have difficulties qualifying as ‘disabled’. Episodic disabilities are often invisible, and are by nature unpredictable. This means that it can be hard to fit into programs that are designed to view disability as static. Many disability income support programs in Canada view disability as a static state:
 - Canada Pension Plan Disability: requires a disability be ‘severe and prolonged’. Also, a person with an episodic disability often has not contributed enough through workplace contributions in order to receive benefits.
 - EI Sickness Benefits: require a person to be completely unable to work and cannot be taken as a part-time benefit.
 - Provincial Disability Income programs often require that a disability be continuous for a long period of time.
 - Short-term Disability Insurance may not provide enough time off for a person with an episodic disability to recover and Long-term Disability Insurance requires “total disability” in order to qualify.

4. **People with some episodic disabilities experience stigma and discrimination related to their disabilities.** Some people with episodic disabilities, such as HIV and mental health, live with conditions that are highly stigmatized. Stigma can make it much harder to access the services and supports people need to manage their conditions as people are fearful about being mistreated or misunderstood. On a systemic level, stigma can make decision-makers reluctant to engage with the issues or dedicate necessary resources.

5. **Women with episodic disabilities experience compounded barriers related to their gender.** Many of the conditions noted as episodic disabilities affect women more frequently than men. For example, multiple sclerosis³, depression⁴ and arthritis⁵ occur more

² Ibid

³ Sex ratio of multiple sclerosis in Canada: a longitudinal study. (2006). The Lancet Neurology, Volume 5, Issue 11. Accessed at: [http://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(06\)70581-6/fulltext](http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(06)70581-6/fulltext)

⁴ Cross-National Epidemiology of Major Depression and Bipolar Disorder. (1996) Journal of the American Medical Association, Vol 276, No. 4. Accessed at: <http://jama.jamanetwork.com/article.aspx?articleid=405806>

often in women than men. Women are often the primary caregivers for children, elderly parents or other family members that may be in need of assistance. Women are also more likely than men to be living at, or near poverty and are more likely to be engaged in part-time or precarious work. Aboriginal women, in particular, face very low employment rates and low incomes. ⁶ By virtue of intersections between gender and disability, women with episodic disabilities face additional barriers to inclusion.

6. **Episodic caregivers do not receive needed supports for their role.** People living with episodic disabilities also rely on family and friend caregivers as important supports during periods of illness. Caregivers to people living with episodic disabilities frequently also have to take time out of work in order to support their loved ones through unpredictable and intermittent periods of illness.⁷ Episodic caregiving has until recently been largely absent from the caregiving literature and has not been considered in the development of caregiving policies and programs in Canada. Most caregiving programs are targeted towards either seniors or very young carers. Episodic disabilities tend to strike during mid-adulthood and affect people who have up until that point been largely healthy. This means that their caregivers are often also in their prime working years and need supports that recognize their unique needs.

HOW TO USE THE TOOLKIT OF RESOURCES

These resources are intended to support people with episodic disabilities, their caregivers, employers and other stakeholders. They are organized by the barriers discussed above, in the hope that this will assist in better understanding the experiences of people living with episodic disabilities and the numerous obstacles they face to full inclusion. The vast majority are available online, and the most up-to-date link has been given. The resources provide additional background information, strategies, discussion and research on episodic disabilities. The listings are annotated, and the authors and date published (if available) are noted. The six categories, in order, are:

1. Raising Awareness on Episodic Disabilities
2. Employment Barriers and Accommodation Strategies
3. Issues Related to Income Support Programs
4. Experiencing Stigma and Discrimination
5. Gender and Episodic Disabilities: Compounded Barriers
6. Episodic Caregiving

⁵ Arthritis in Canada. (2013). Arthritis Community Research and Evaluation Unit (ACREU). Accessed at: <http://www.arthritis.ca/document.doc?id=903>

⁶ Fact Sheet: Economic Security, Status of Women Canada. Accessed at: <http://www.swc-cfc.gc.ca/initiatives/wesp-sepf/fs-fi/es-se-eng.html>

⁷ Episodic Caregiving Support Initiative. (2014). Accessed at: http://www.hivandrehab.ca/documents/Episodic_Caregivers_Support_Initiative-ECSI-Final_Report.pdf

RAISING AWARENESS ON EPISODIC DISABILITIES

<p>Bridging Silos, Creating Connections: Addressing Episodic Disabilities in Ontario Information Sheet #1</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/OEDNInformationSheet1.pdf</p> <p>This is the first fact sheet in a series looking at recommendations for addressing the needs of people with episodic disabilities in Ontario. Recommendations include:</p> <ol style="list-style-type: none"> 1. The creation of the Ontario Episodic Disabilities Network 2. Developing an episodic disabilities resource centre with a publicly searchable online database and referral service 3. Engaging with Ontario communities to coordinate and promote educational opportunities related to episodic disabilities, including employment, income security, coordination of care and social inclusion. 	<p>Ontario Episodic Disabilities Network (OEDN)</p> <p>2010</p>
<p>Towards A Better Understanding Of The Dynamics Of Disability And Its Impact On Employment</p> <p>Accessible at: http://adelefurrie.ca/PDF/Dynamics_of_disability.pdf</p> <p>This paper examines Canadian disability data to establish a clearer picture of Canadians with episodic disabilities and outlines a range of issues they experience, including difficulties with employment and income support programs.</p>	<p>Adele Furrie Consulting Inc.</p> <p>2010</p>
<p>Bridging Silos, Creating Connections: Spotlight on the Ontario Episodic Disabilities Network (OEDN) Information Sheet #2</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/OEDNInformationSheet2.pdf</p> <p>This is the second in a series of fact sheets. This fact sheet looks at the Ontario Episodic Disabilities Network (OEDN) and states that key priorities for the network are:</p> <ul style="list-style-type: none"> • Employment and income security • Adequate and accessible housing • Reduce stigma and discrimination • Quality care, services and programs • Health promotion and wellness 	<p>Ontario Episodic Disabilities Network (OEDN)</p> <p>2010</p>

<p>Everyone Knows Someone ... Spotlight on Episodic Disabilities Information Sheet #3</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/OEDNInformationSheet3.pdf</p> <p>This is the third in a series of fact sheets. This fact sheet provides more detailed information regarding the barriers facing people with episodic disabilities. It points out that “If a person’s main source of income is a disability pension and his/her health fluctuates, disability benefits may be eliminated during periods of improved health. Complicated claim procedures may need to be repeated. Benefits may be difficult to reinstate when required again during periods of illness. This ‘all or nothing’ approach can act as a disincentive to return to work.”</p>	<p>Ontario Episodic Disabilities Network (OEDN)</p> <p>2010</p>
<p>Communicating About Episodic Disabilities in the Workplace: Information Sheet for Employers</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/CommunicatingAboutEpisodicDisabilitiesintheworkplaceFinal.doc</p> <p>This information sheet provides employers with tips and techniques on how to develop a more inclusive workplace language about episodic disabilities.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p>
<p>Leading Practices in Accommodating Employees Living With Episodic Disabilities in the Workplace An Information Sheet for Employers</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/LEADINGPRACTICESINACCOMMODATINGEMPLOYEESWITHEPISODICDISABILITIESINTHEWORKPLAC.doc</p> <p>(please note: this is an automatic download link)</p> <p>“This information sheet provides an overview of leading practices in accommodating employees living with episodic disabilities in the workplace. The information presented is relevant both for managers and human resources (HR) practitioners. Implementing leading accommodation practices will improve workplace satisfaction by helping the employee to function more effectively in their role, as well as build the trust of all employees, especially those living with episodic disabilities.”</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2011</p>

<p>The Path Forward: Addressing Episodic Disabilities in Canada: Brief to the Standing Committee on Finance</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/ThePathForward_EpisodicDisabilityNetwork.pdf</p> <p>This briefing note was presented to the Standing Committee on Finance Pre-Budget Consultations on August 12, 2011 by the Episodic Disabilities Network. Recommendations from the EDN include:</p> <ol style="list-style-type: none"> 1. Making Employment Insurance Sickness Benefits more flexible—making it easier for people with lifelong episodic disabilities to stay in the work force by allowing people to work part time and receive partial sickness benefits for 150 half-days instead of the current 15 weeks or 75 full days. This modest step would contribute to the health and well-being of people with lifelong episodic disabilities and, ultimately, to the well-being of Canada. 2. Developing a pan-Canadian body (e.g. commission, ministry, department or level of government) to oversee and report on the coordination between the eight disability support programs and five service areas and establish options for people with episodic disabilities within disability benefit programs. 3. Developing a program or combination of programs that provides partial disability income support to complement earned income from part time work for people who are living with lifelong episodic disabilities and who have a partial capacity to work. Workers with partial capacity to work should be supported to find employment and enter or remain in the workforce. 	<p>Episodic Disabilities Network (EDN)</p> <p>2011</p>
<p>Addressing Episodic Disabilities in Canada: Contribution to the Pre-Budget Consultations</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/EpisodicDisabilityNetworkFederalPre-BudgetConsultationBriefAug132010FINAL.pdf</p> <p>This briefing was submitted to the Pre-budget Consultations by the EDN on August 13, 2010.</p>	<p>Episodic Disabilities Network (EDN)</p> <p>2010</p>
<p>Action on MS Report</p> <p>Accessible at: http://mslistening.ca/pdf/Action-on-MS-English-Online.pdf</p> <p>This report outlines the results of research undertaken by the MS Society of Canada that shows that people living with MS and their caregivers have a lower quality of life than their families and friends. It issues a call to action on several issues:</p> <ul style="list-style-type: none"> • The federal government needs to take leadership with provinces and territories to improve job retention and better coordinate income and disability benefits for people impacted by MS. 	<p>MS Society</p> <p>2014</p>

<ul style="list-style-type: none">• The federal government should initiate the development of a National Caregiver Action Plan working with provinces, territories, caregivers, employers and organizations to: reduce financial burden, improve access to resources, create flexible workplace environments, and recognize caregivers' vital roles.• The federal government must do its part and harness the forthcoming report of the National Population Health Study of Neurological Conditions to deliver an action plan for all Canadians living with diseases of the brain including MS.• Develop therapies for people living with progressive MS within the next 8 years.	
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EMPLOYMENT BARRIERS AND ACCOMMODATION STRATEGIES

<p>A Guide to Employment and Income Support</p> <p>Accessible at: http://mssociety.ca/en/pdf/EmploymentIncomeSupport_EN.pdf</p> <p>This resource is designed to help you understand the employment and income supports and strategies available to Canadians living with MS. It may also provide general strategies for those living with other episodic disabilities.</p>	<p>MS Society</p> <p>2006</p>
<p>Managing Disability in the Workplace: International Labour Organization’s Code of Practice</p> <p>Accessible at: http://www.ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_103324.pdf</p> <p>Developed by the International Labour Organization, this document provides guidance on developing an accessible and inclusive workplace. While it provides clear guidance related to general accommodations strategies, it does not focus on the specific needs of people living with episodic disabilities.</p>	<p>International Labour Organization</p> <p>2002</p>
<p>The Business Case For Hiring/Retaining People With Episodic Disabilities</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/The-Business-Case-for-Actively-Recruiting-and-Retaining-People-with-Episodic-Disabiliti.pdf</p> <p>This document examines how making a strategic decision to actively recruit and retain people with episodic disabilities addresses urgent business needs. It also provides a Cost-Benefit formula for understanding the business benefits to recruiting and retaining people living with episodic disabilities.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2014</p>
<p>MS in the Workplace: A Guide for Employers</p> <p>Accessible at: http://mssociety.ca/en/pdf/EmployersGuide.pdf</p> <p>A publication intended for employers of those diagnosed with MS. It is a stand-alone piece which is part of a resource for those affected by MS called A Guide to Employment and Income Support</p>	<p>MS Society</p> <p>2008</p>

<p>Employment Access for All: Educational Sessions to Increase Employer Awareness and Access to the Labour Force for People Living With Episodic Disabilities</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/OpportunitiesFundProjectReportJuly132010FINAL.pdf</p> <p>This document outlines educational sessions undertaken with employers to enhance their capacity to effectively accommodate people living with episodic disabilities.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2010</p>
<p>Evolving the Workplace: Identifying Opportunities to Support People With Episodic Disabilities in Employment</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/CWGHR_EvolvingtheWorkplace_Summary.pdf</p> <p>This report summarizes interviews and a survey undertaken by the Canadian Working Group on HIV and Rehabilitation to examine the complex barriers to employment faced by people with episodic disabilities. A number of barriers were identified, including:</p> <ul style="list-style-type: none"> -Differing perceptions of workplace capacity -Lack of awareness of episodic disabilities -Employer concerns re productivity -Workplace hostility experienced by people living with episodic disabilities -Need for manager training -Need for new initiatives 	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2011</p>
<p>Promoting Accessibility to Employment for People Living with Episodic Disabilities</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/Promoting_Accessibility_2009-2012_Final_Report.pdf</p> <p>This report summarizes a number of initiatives undertaken to enhance the employment options for people living with episodic disabilities. Initiatives include the enhancement of the Episodic Disabilities Employment Network, the development of a mentoring program for HR professionals and the creation of a number of resources for employers.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2012</p>

<p>Breaking Down Barriers to Employment: Developing comprehensive and practical resources to increase employer awareness and access to the labour force for people living with episodic disabilities</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Breaking_Down_Barriers_to_Employment.pdf</p> <p>This report summarizes several initiatives undertaken by the Canadian Working Group on HIV and Rehabilitation to improve employment outcomes for people with episodic disabilities, including the development of an online course and online educational resources.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2011</p>
<p>Policies and Programs to Facilitate Labour Force Participation for People Living with Episodic Disabilities: Recommendations for a Canadian Context Based on an International Analysis</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Policies_and_Programs_English.pdf</p> <p>This report reviews international practices associated with income and support that may be beneficial to people living with episodic disabilities.</p>	<p>Canadian Working Group on HIV and Rehabilitation and the Social Program Evaluation Group, Queen's University</p> <p>2006</p>
<p>Report on a Survey of Certified Human Resources Professionals Regarding Episodic Disabilities</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/HR_report_English.pdf</p> <p>The results of a survey of Human Resource Professionals regarding their knowledge of episodic disabilities are outlined in this report. Key findings include:</p> <ul style="list-style-type: none"> • Over sixty (60) percent of the respondents reported that they have little to no knowledge on approaches to managing cases of episodic disabilities. • Almost seventy (70) percent of all respondents reported that they are unable to statistically identify cases of episodic disabilities in their caseloads. 	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2006</p>

<ul style="list-style-type: none"> • The use of part-time work arrangements and continuing salary are the most common forms of income support programs utilized by respondents. • Seventy (70) percent of HR professionals reported that the workplace accommodation policies at their organizations need review. 	
<p>Report on the National Summit on the Episodic Disability Project</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/National_Summit_Report_English.pdf</p> <p>This report discusses the two-day National Summit on Episodic Disability held in Ottawa in 2006. Items discussed included:</p> <ul style="list-style-type: none"> • An international disability policy review • Recommendations for comprehensive disability supports in Canada • A costing analysis of key recommendations and • An analysis on a national survey of Human Resources professionals. 	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2006</p>
<p>Final Report for the Labour Force Participation and Social Inclusion of People Living With HIV and Other Episodic Disabilities Project</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/23-08-07FinalWebsitereport.pdf</p> <p>This a final project report.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2007</p>
<p>Working With Employees with an Episodic Disability: Information Sheet for Managers</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/EpisodicDisabilitiesFactSheetFinalLeon.pdf</p> <p>This fact sheet is specifically for managers working with employees with episodic disabilities. It provides an overview of helpful workplace initiatives including:</p> <ul style="list-style-type: none"> - Flexible work arrangements - Anti-discrimination policies - Management leading by example 	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2010</p>

<p>Employment and Episodic Disabilities Information Sheet for Vocational Rehabilitation Specialists and Employment Counsellors</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/EpisodicDisabilitiesandEmploymentforEmploymentCounsellors.pdf</p> <p>This fact sheet is for Vocational Rehabilitation Specialists and Employment Counsellors. Recommendations include:</p> <ul style="list-style-type: none"> • Thoroughly understand functional and activity limitations • Review activities and task analysis within the client’s current job description that may be adapted • Recognize that concerns of workplace discrimination may be a barrier for clients to workplace participation and accessing workplace accommodations 	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2010</p>
<p>An Analysis of Responses of Human Resources Professionals on Supporting Persons With Episodic Disabilities</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/HR_Survey_Fact_Sheet.doc</p> <p>This is the fourth in a series of fact sheets resulting from CWGHR’s Labour Force Participation for Persons Living with Episodic Disabilities project. This fact sheet outlines recommendations for Human Resource (HR) professionals on working with people living with episodic disabilities. Recommendations include:</p> <ul style="list-style-type: none"> • Expand the existing income support mechanisms available to HR professionals, such as partial Canada Pension Plan Disability benefits. • Demonstrate leadership through the Canadian Council of Human Resources Associations and their affiliated associations to foster collaboration amongst episodic disability interest groups to create solutions to systemic and legislative barriers, such as the development of a national network of Disability Management Centres. • Develop resources for HR professional members so that they can provide appropriate support for employees with episodic disabilities. 	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2007</p>
<p>A Practical Perspective on Understanding Episodic Disabilities and Employment Presented by Melissa Popiel</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/Episodicdisabilityemploymentrehabwebinar.pdf</p> <p>An overview of what episodic disabilities are and what barriers might be encountered in employment by those living with an episodic disability. As well, a case study is provided that further illuminates the complexity involved in trying to navigate work when living with an unpredictable disability.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p>

<p>Understanding Episodic Disabilities and Employment Presented by Martine Mangion, Melissa Popiel and Deanna Matzanke</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/EDUPresentationEN.pdf</p> <p>This presentation offers an overview of employment barriers experienced by people living with episodic disabilities and useful supports. The presentation also includes the Episodic Disability Framework; a graphic depicting the unpredictable illness course of an episodic disability and the kinds of supports that are often helpful.</p>	<p>Canadian Working Group on HIV and Rehabilitation and Scotiabank</p>
<p>Understanding Episodic Disabilities and Employment This presentation was provided to staff at the Ontario Ministry of Education. It includes discussion from a lived experience and an overview of international best practices.</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/Video%20Vault/UnderstandingEpisodicDisabilitiesandEmploymentApril2010.htm</p>	<p>Canadian Working Group on HIV and Rehabilitation and Scotiabank 2010</p>
<p>Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario?</p> <p>Accessible at: http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf</p> <p>This report examines the experiences of people with intermittent work capacity in Ontario. It examines the factors that must be present in order to support those who can, and want, to work to be successful in their workplace engagement.</p>	<p>Human Resource and Skills Development, Canada</p>
<p>Managing Episodic Disabilities: An Introduction</p> <p>Accessible at: http://www.hivandrehab.ca/EN/information/employers/ManagingEpisodicDisabilitiesOnlineCourse.php</p> <p>This is the first in a series of online courses developed by CWGHR intended for Human Resources (HR) professionals to deepen their understanding of the impact of episodic disabilities on the workplace. This course is worth 15 Continuing Professional Development (CPD) Hours through the Human Resources Professionals Association of Ontario (HRPA), 15 Recertification Points through the BC Human Resources Management Association (BCHRMA), the Human Resources Institute of Alberta (HRIA) and the Human Resources Association of New Brunswick (HRANB).</p>	<p>Canadian Working Group on HIV and Rehabilitation</p>

<p>Managing Episodic Disabilities: Accommodation Best Practices</p> <p>Accessible at: http://www.hivandrehab.ca/EN/information/employers/MEDAccommodationsCourse.php</p> <p>This is the second in a series of courses on managing episodic disabilities in the workplace. It is designed to prepare HR professionals to deal more effectively with employees with episodic disabilities, who compose an ever-increasing segment of Canada's workforce. This course is worth 15 Continuing Professional Development (CPD) Hours through the Human Resources Professionals Association of Ontario (HRPA), 15 Recertification Points through the BC Human Resources Management Association (BCHRMA), the Human Resources Institute of Alberta (HRIA), the Human Resource Management Association of Manitoba (HRMAM) and the Human Resources Association of New Brunswick (HRANB)</p>	<p>Canadian Working Group on HIV and Rehabilitation</p>
<p>Employers' Perspectives on Intermittent Work Capacity - What can qualitative research tell us?</p> <p>This paper provides the perspective of employers on working with employees with intermittent work capacity.</p> <p>The online link to this paper is currently not working.</p>	<p>Lysaght, R. , Krupa, T. & Gregory, A 2011</p>
<p>Examination of Arthritis-Related Work Place Activity Limitations and Intermittent Disability Over Four-And-A-Half Years and its Relationship to Job Modifications and Outcomes</p> <p>Accessible at: http://onlinelibrary.wiley.com/doi/10.1002/acr.20456/full</p> <p>Looked at the experiences of people living with arthritis over 4.5 years and found that although people with arthritis required job accommodations, it was only when disability was consistently severe that any impact on productivity was noted.</p>	<p>Monique A. M. Gignac, Xingshan Cao, Kenneth Tang and Dorcas E. Beaton 2011</p>
<p>Mythbuster: Myths About Hiring Persons With Disabilities</p> <p>Accessible at: http://www.ccrw.org/wp/wp-content/uploads/2013/05/Myths-and-FAQs-Employer-Resource.pdf</p> <p>This report debunks the myths associated with hiring people with disabilities.</p>	<p>Canadian Council on Rehabilitation and Work</p>
<p>Working Bodies: Chronic Illness in the Canadian Workplace</p> <p>Accessible at: http://www.mqup.ca/working-bodies-products-9780773543782.php</p> <p>This book examines the experience of navigating the Canadian workplace while living with a chronic health condition.</p>	<p>Edited by Sharon-Dale Stone, Valorie A. Crooks and Michelle Owen 2014</p>

<p>Episodic Disabilities Network Feedback on the Disability Tax Credit</p> <p>Accessible at: http://episodicdisabilities.ca/docs/EDN_Feedback_Disability_Tax_Credit.pdf</p> <p>This paper presents several recommendations for addressing barriers to the Disability Tax Credit faced by people living with episodic disabilities. In particular, it recommends ensuring that the definition of disability, used to access the Disability Tax Credit and other federal disability programs, be adjusted to include people whose disabilities are episodic in nature.</p>	<p>Episodic Disabilities Network</p> <p>2014</p>
<p>'Not Disabled Enough': Episodic Disabilities and the Ontario Disability Support Program Ernie Lightman, et al.</p> <p>Accessible at: http://dsq-sds.org/article/view/932/1108/</p> <p>This article examines how people who have fluctuating or episodic disabilities confound the qualification requirements of the Ontario Disability Support Plan. It also discusses how episodic disability, by sitting between the two poles of 'sick' and 'well' represents a transgressive state.</p>	<p>Disability Studies Quarterly</p> <p>2009</p>
<p>What Stops Us From Working? New Ways To Make Work Pay, By Fixing The Treatment Of Earnings Under The Ontario Disability Support Program</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/ODSPReportfinal.pdf</p> <p>This paper presents a number of recommendations aimed at improving the Ontario Disability Support Plan in order to facilitate a return-to-work for people living with mental health issues. Amongst the recommendations is a suggestion to "Expand OSAP's definition of permanent disability to acknowledge the episodic nature of much mental illness."</p>	<p>The Dream Team, Houselink, Community Homes and Centre for Addiction and Mental Health</p> <p>2011</p>
<p>Episodic Disabilities Employment Network (EDEN)</p> <p>Accessible at: http://edencanada.ca/</p> <p>The EDEN website provides a place where people in Canada living with episodic disabilities, including HIV, can connect with each other to find and generate answers to tough employment questions.</p>	<p>Episodic Disabilities Employment Network</p>

ISSUES RELATED TO INCOME SUPPORT PROGRAMS

<p>Statement of Common Agenda on Episodic Disability, Full Participation & Employment</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/StatementofCommonAgenda10January2011FINAL.pdf</p> <p>This Episodic Disabilities Network Statement, from 2011, calls for a number of changes including convening a national policy dialogue to explore:</p> <ul style="list-style-type: none"> - Developing a body (e.g. commission, ministry, department or level of government) to oversee and report on the coordination between eight disability support programs and five service areas and establish options for people with episodic disabilities within disability benefit programs. - Developing a program or combination of programs that provides partial disability income support to complement earned income from part time work - Making Employment Insurance (EI) sickness benefits more flexible 	<p>Episodic Disabilities Network</p> <p>2011</p>
<p>Insuring Your Future: Your guide to life insurance and multiple sclerosis</p> <p>Accessible at: http://mssociety.ca/en/pdf/InsuringYourFuture2001.pdf</p> <p>This guide offers immediate assistance to people with MS who need to make decisions that will affect them and their families right now on matters relating to insurance and future financial planning.</p>	<p>MS Society</p> <p>2001</p>
<p>Caregiver & Poverty Stakeholder Forum Summary Report</p> <p>Accessible at: http://mssociety.ca/en/pdf/pub_C&PFinalReport.pdf</p> <p>On November 24th and 25th 2009, the Multiple Sclerosis Society of Canada (MS Society) hosted a two day forum in order to share knowledge and develop recommendations that would contribute to lessening the financial burden borne by many who undertake to provide care for a loved one. This report outlines the findings of the stakeholder Forum.</p>	<p>MS Society</p> <p>2009</p>

<p>A Population-Based Economic Analysis of Episodic Work Benefits</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Population-Based Economic Analysis English.pdf</p> <p>This report summarizes findings related to a more flexible Canada Pension Plan Disability (CPP-D) benefit program. The new policy would allow persons with disabilities who resume work to retain a portion of their previous CPP-D benefits.</p>	<p>Canadian Working Group on HIV and Rehabilitation with RiskAnalytica</p> <p>2006</p>
<p>Episodic Disabilities and Insurance: An Information Sheet for Employers</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/documents/EPISODICDISABILITYANDPRIVATEINSURANCEFinal.doc (please note: this is an automatic download link)</p> <p>“This information sheet provides an overview of episodic disabilities and how to best support the employees living with episodic disabilities who may access insurance programs for short term disability or long term disability. It also identifies ways in which employers can be more aware of and sensitive to the challenges to stable income access, and how they can help minimize them — all in an effort to collectively build a healthier, more diverse and more productive workplace.”</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2011</p>
<p>An International Policy Review and Analysis Fact Sheet</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Policy_Review_Analysis_Fact_Sheet.doc</p> <p>This is the first in a series of fact sheets resulting from CWGHR’s Labour Force Participation for Persons Living with Episodic Disabilities project. To determine what policy changes are needed in order to better meet the needs of people living with episodic disabilities in Canada, an international review of effective labour policies and programs affecting people with episodic disability was completed by the Social Program Evaluation Group (SPEG) at Queen's University. This fact sheet outlines those findings.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2007</p>

<p>Program and Policy Recommendations for Episodic Disability Support Fact Sheet</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Canadian Model%20 Fact Sheet.doc (please note: this is an automatic download link)</p> <p>This is the second in a series of fact sheets resulting from CWGHR’s Labour Force Participation for Persons Living with Episodic Disabilities project. This fact sheet provides recommendations on legislative and structural changes to be made to improve income support stability for Canadian with episodic disabilities. Recommendations include:</p> <ul style="list-style-type: none"> • Increased flexibility in the degree of workplace participation for CPP(D) recipients to include part-time work with partial CPP(D) benefits. • A Canada Pension Plan Disability Drop-Out Provision for those persons whose illness causes them to move in and out of the workforce. • A working income tax benefit (WITB) for low-income working persons with disabilities. • To encourage disabled employee hiring practices, a progressive tax refund or benefit subsidy to employers to address the costs of accommodations and of ‘sick days’ of employees with episodic disabilities. • Federal incentives provided to private health insurers to underwrite the premiums for employers to facilitate the employment of persons with pre-existing episodic disability conditions. • A federal plan to subsidize private insurers for the equivalent of the increased premiums paid by employers for employees with episodic disabilities. • A federal plan to continue the payment of premiums to the insurer for persons with episodic disabilities with comprehensive plans considering self-employment or employment without access to a benefits plan. 	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2007</p>
<p>A Population-Based Economic Analysis of Episodic Work Benefits Fact Sheet</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Costing Fact Sheet.doc</p> <p>This is the third in a series of fact sheets resulting from CWGHR’s Labour Force Participation for Persons Living with Episodic Disabilities project. This fact sheet discusses the work undertaken by RiskAnalytica to assess the economic impact from the present through 2033 of a more flexible Canada Pension Plan Disability (CPP-D) benefit program. The theoretical change would allow persons with episodic disabilities who resume work to retain a portion of their previous CPP-D benefits. Results of this theoretical change to CCP-D include a significant number of people with episodic disabilities being supported back to work.</p>	<p>Canadian Working Group on HIV and Rehabilitation</p> <p>2007</p>

<p>Workplace Health Video Series</p> <p>Accessible at: http://www.hivandrehab.ca/EN/resources/Video%20Vault/WorkplaceHealth-IncomeSupports.php</p> <p>This series features Renée Lang and Jill McNall of the HIV and AIDS Legal Clinic Ontario (HALCO) discussing the following topics:</p> <ul style="list-style-type: none"> • Income Supports • Job Development • Managing Your Health in the Workplace 	<p>Canadian Working Group on HIV and Rehabilitation and HALCO</p>
<p>Possible improvements to the Ontario Disability Support Program: A Scoping Exercise. April, 2005</p> <p>http://www.stchrishouse.org/get-involved/community-dev/Special%20Projects/ModernizingIncomeSec/MiswaaCommisionedPap.php</p> <p>This paper outlines some suggested improvements to ODSP as it was in 2005.</p>	<p>by Harry Beatty</p>

EXPERIENCING STIGMA AND DISCRIMINATION

<p>The Episodic Challenges of Living with a Mental Illness Presented by Dave Gallson and Richard Chenier</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Episodic_Challenges_NNMH_White.ppt</p> <p>This presentation provides an in-depth look at mental illness as an episodic disability. It provides a number of statistics regarding people with mental illness in the workforce and also identifies a number of gaps in supports. Employer support recommendations include:</p> <ul style="list-style-type: none"> - Employers, Unions, Rehabilitation Specialists, Peer Support, and Private and Public insurance are major stakeholders and must be included at all phases of the program including consultations, program development and employment support - Employers need the tools to support people who suffer from episodic illnesses - Conversely, employees need the tools and requisite support to re-integrate successfully back into the workplace - Early intervention programs must be designed to assist employees navigate the Disability Insurance Claim and Accommodation Processes - Obtain the support of workers and their representatives - Obtain the commitment, support and participation of management 	<p>The National Network for Mental Health and Chenier Consulting Canada.</p>
<p>The Episodic Challenges of Living with Lupus Presented by Louise B.</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/louise_b.ppt</p> <p>This presentation provides a first-person perspective on what it is like to live with Lupus – an unpredictable autoimmune condition that can result in episodes of illness interspersed with episodes of wellness. Louise B offers her perspective on what is needed in order to make conventional employment work for her and for her employer. Her recommendations for employers include:</p> <ul style="list-style-type: none"> • Employers need to be compensated to hire my replacement, pay the higher insurance premium that would occur. • Work colleagues need training on my illness so that they know what to expect and can support instead of become frustrated with the scenario of an episodic disability 	<p>Louise B – a woman living with Lupus</p>

<p>What is required from an Employer:</p> <ul style="list-style-type: none"> • Understanding of the episodic nature of my illness. • Flexibility • Work from home • Assurance of a disability pension, for financial security when not able to work due to periods of sickness. 	
<p>The Episodic Challenges of Living with HIV and Depression Presented by Raymond B.</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/Raymond_B_final.ppt</p> <p>This presentation provides a first-person perspective on what it is like to live with HIV and the difficulties associated with securing stable income and affordable housing while living with an unpredictable life-long episodic disability. This presentation highlights a difficult situation faced by people living with episodic disabilities; attempting to regain paid employment can bring with it a fear of losing housing, drug benefits and income stability.</p>	<p>Raymond B – a man living with HIV</p>
<p>The United Nation’s Convention on the Rights of Persons With Disabilities (CRPD)</p> <p>Accessible at: http://www.un.org/disabilities/default.asp?id=259</p> <p>The purpose of the CRPD is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” Canada ratified the CRPD in 2010.</p>	<p>United Nations 2008 (came into force)</p>
<p>International Labour Organization ‘s Vocational Rehabilitation and Employment Disabled Persons Convention</p> <p>Accessible at: http://www.ilo.org/dyn/normlex/en/f?p=1000:12100:0::NO::P12100_ILO_CODE:C159</p> <p>Canada has not to date ratified this convention.</p>	<p>International Labour Organization 1983 (came into force)</p>

<p>International Labour Organization 's Discrimination (Employment and Occupation) Convention</p> <p>Accessible at: http://www.ilo.org/dyn/normlex/en/f?p=NORMLEXPUB:12100:0::NO:12100:P12100_ILO_CODE:C111</p> <p>Canada ratified this convention as a member organization of the ILO in 1964.</p>	<p>International Labour Organization</p> <p>1960 (came into force)</p>
<p>HIV/AIDS & Episodic Disability: Keys to HEALing</p> <p>Accessible at: http://www.disabilityalliancebc.org/docs/healgd-episodicweb.pdf?LanguageID=EN-US</p> <p>This guide is intended to help better understand the links between HIV and disability, and utilizes the HEAL Framework (Health Education, Advocacy and Leadership).</p>	<p>BC Coalition of People with Disabilities</p>
<p>National Standard of Canada for Psychological Health and Safety in the Workplace (the Standard)</p> <p>Accessible at: http://www.mentalhealthcommission.ca/English/node/5346</p> <p>In order to support the mental health of Canadians, the Mental Health Commission of Canada along with Canadian Standards Association (CSA Group) and the Bureau de normalisation du Québec (BNQ), developed this standard. The standard is a voluntary set of guidelines and tools designed to promote psychological health and prevent psychological harm due to workplace factors.</p>	<p>Mental Health Commission of Canada</p> <p>2013</p>

GENDER AND EPISODIC DISABILITIES: COMPOUNDED BARRIERS

<p>Gender Differences in Determinants and Consequences of Health and Illness</p> <p>Accessible at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3013263/</p> <p>This paper examines a number of studies on gender differences as they impact health and illness.</p>	
<p>Fact Sheet: Women with Disabilities and Poverty</p> <p>Accessible at: http://www.dawncanada.net/?attachment_id=994</p> <p>This fact sheet presents an overview of the linkages between women, living with a disability and poverty in Canada.</p>	DAWN/RAFH Canada
<p>Policy Brief Re: Study on Economic Security on Women with Disabilities</p> <p>Accessible at: http://www.dawncanada.net/?attachment_id=669</p> <p>This policy brief discusses how disabled women contribute to the Canadian economy and clarifies their financial responsibilities and economic hardships. This policy brief is organized into five themes: economic contribution, workplace and volunteer participation, income protection, access to affordable housing and food resources and attitudinal barriers.</p>	DAWN/RAFH Canada
<p>Presentation to the Standing Committee on the Status of Women</p> <p>Accessible at: http://www.dawncanada.net/?attachment_id=672</p> <p>This presentation outlines a number of recommendations for improving the lives of women with disabilities in Canada.</p>	DAWN/RAFH Canada 2007

EPISODIC CAREGIVING

<p>Episodic Caregiver Support Initiative Project Report Executive Summary</p> <p>Accessible at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/ECSI_Executive_Summary.pdf</p> <p>The Episodic Caregiver Support Initiative (ECSI) was launched in the fall of 2013 as a yearlong developmental grant funded by the Ontario Trillium Foundation to explore the needs of family / friend caregivers of individuals with episodic disability in Ontario. An important aspect of this work was also to increase awareness of episodic disability throughout the province. This report provides an overview of the work and the lessons learned by the project partners.</p>	<p>Episodic Caregiver Support Initiative</p> <p>2014</p>
<p>MS Society: A Guide for Caregivers</p> <p>Accessible at: http://mssociety.ca/en/pdf/pub_caregiverguide.pdf</p> <p>This guide provides information on practical issues faced by caregivers. A resource list is included.</p>	<p>MS Society</p> <p>2007</p>
<p>The Care-Ring Voice Network</p> <p>Accessible at: http://www.careringvoice.com/about.php</p> <p>Care-ring Voice is a free, bilingual and confidential program that connects caregivers and families to information and support through the use of tele-learning.</p>	<p>Care-ring Voice</p>
<p>Health Gateway</p> <p>Accessible at: http://www.healthgateway.ca/</p> <p>Health Gateway is a website intended to meet the health information and support needs of people living with complex chronic illnesses and episodic disabilities and their loved ones in Canada.</p>	<p>Health Gateway</p>