



‘Uncertain Futures’: An Episodic Disabilities Discussion Paper

Episodic Disabilities Network (EDN)

Introduction

This discussion paper provides an overview of the barriers to inclusion encountered by people with episodic disabilities and, where possible, offers recommendations for addressing these barriers. It further demonstrates the complexity of barriers faced by people living with episodic disabilities through the use of a case study. Although “Vanessa” is not a real person, the struggles she faces are very real for the millions of Canadians trying to survive and cope with unpredictable episodic disabilities.

What are Episodic Disabilities?

According to the Episodic Disabilities Network (EDN), 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, especially women, are living with lifelong episodic disabilities. While the specific prevalence of episodic disability is not known, millions of Canadians live with diseases or conditions linked to episodic disability. A list of conditions considered to be ‘episodic disabilities’ is developed and maintained by the EDN. A copy of this list is included in this report’s appendix. 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.

How Many People are affected by Episodic Disabilities?

Increasing numbers of Canadians are living with lifelong episodic disabilities. It is estimated that today:

- Over 4 million Canadians are living with arthritis¹
- 20% of Canadians will experience an episode of mental illness in their lifetime²
- An estimated 100, 000 Canadians are living with Multiple Sclerosis (MS)³
- 71, 000 Canadians are living with HIV⁴
- Almost 2.8 million Canadians live with diabetes⁵

It is very likely that most people in Canada know someone living with an episodic disability, whether they are aware of it or not.

¹ Public Health Agency of Canada. (2010). Arthritis: Facts and Common Myths. Retrieved from: <http://www.phac-aspc.gc.ca/cd-mc/arthritis-arthrite/index-eng.php>

² Canadian Mental Health Association.(2014). Fast Facts about Mental Illness. Retrieved from: http://www.cmha.ca/media/fast-facts-about-mental-illness/#.VPn_JvnF98E

³MS Society of Canada. (2015). About MS. .Retrieved from: <https://beta.msociety.ca/about-ms>

⁴ Public Health Agency of Canada. (2014). HIV and AIDS in Canada: Surveillance Report to December 31st, 2013. Retrieved from: <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2013/dec/index-eng.php>

⁵ Public Health Agency of Canada. (2010). Report from the National Diabetes Surveillance System: Diabetes in Canada, 2009. Retrieved from: <http://www.phac-aspc.gc.ca/publicat/2009/ndssdic-snsddac-09/index-eng.php>

Case Study: Vanessa

Meet Vanessa. She is a 35 year old mother of two, living in St. John, New Brunswick. Vanessa works full time as a bank teller. She is currently separated from her husband. She rents the ground floor of a house near her father's house. Both Vanessa and her brother Jim look after their father, as he has mild dementia and needs help. Vanessa is living with HIV.

Throughout this paper, we will be looking at how Vanessa is specifically impacted by the barriers that are discussed. It is hoped that this will provide a more concrete sense of the complexities of living with an episodic disability and will provoke discussion relating to the kind of changes that need to be made in order to better support people like Vanessa who are living with episodic conditions and uncertain futures.

What Are the Barriers?

Episodic disability can be challenging for the person living with the disability and their family members as well. People with episodic disabilities are sometimes well and sometimes disabled and these unpredictable phases often occur without warning and last for uncertain periods of time. This means that supports that are typically used by people with static and long-term disabilities, such as vision related disabilities or physical disabilities, may not meet their needs. Barriers faced by people living with episodic disabilities can include all outlined below.

A General Lack of Awareness of Episodic Disabilities

The concept of "episodic disability" is a relatively new way of thinking about chronic health concerns. Many employers, policy-makers and the public at large are not familiar with the concept of episodic disabilities. As a result, workplaces, support services and government programs may not always support people with episodic disabilities in ways that are needed.

Case Study: How does this impact Vanessa?

Vanessa does not know anyone who is familiar with the concept of episodic disabilities. As a result, she does not know that her daily struggles with dealing with an unpredictable illness are shared by people living with other chronic conditions, like MS and arthritis. Vanessa herself has never heard the term, and therefore has never accessed any resources designed specifically to support her in navigating work and life with an episodic disability. She feels very alone and thinks no one could possibly understand what she is going through.

Recommendations: Raising the awareness of employers, decision makers and policy developers as well as the public in general would work towards improving the lives of people with episodic disabilities. The Canadian Working Group on HIV and Rehabilitation (CWGHR) offers two online courses on episodic disability that can be completed on an individual basis. Many other disability-specific organizations also offer training or fact sheets that can be used to raise awareness of the unique needs of people living with episodic disabilities. See:

- CWGHR website www.hivandrehab.ca
- Episodic Disabilities Network: <http://episodicdisabilities.ca/>
- MS Society: <https://beta.msociety.ca/>

- Arthritis Society: <http://www.arthritis.ca/>
- Lupus Canada: <http://www.lupuscanada.org/>
- Epilepsy Canada: <http://www.epilepsy.ca/en-CA/Home.html>

Difficulties with Obtaining/Retaining Employment

Difficulties with employment are encountered by many people living with episodic disabilities. Unpredictable fluctuations in health can mean that someone who is able to work today may not be able to work tomorrow. These difficulties also impact others as well, as they necessitate that managers and co-workers will have to identify ways of working that can accommodate unpredictable health needs. Support systems that are typically in place to assist people with disabilities do not necessarily meet the needs of people with episodic disabilities, whose accommodation needs can fluctuate regularly and without warning.

Specific employment challenges include:

- Lack of employer awareness of episodic disabilities and appropriate accommodation strategies
- Employer concerns regarding productivity/profitability
- Workplace hostility due to a perception of accommodations as ‘special treatment’ and a lack of appropriate communication strategies
- Employer difficulty with appropriate return-to-work strategies after an illness episode
- Returning to work, if already in receipt of social assistance, may mean losing access to health insurance that covers the cost of needed drug treatments.

Case Study: How does this impact Vanessa?

Vanessa has worked as a bank teller for several years. She has experienced a number of occasions when she has had to take time off work in order to see her doctor and cope with issues related to depression, fatigue and insomnia. Her HIV medication, called Atripla, contains three different types of HIV medication combined into one pill. One of the medications causes difficulties getting to sleep and disturbed sleep. This has resulted in Vanessa also having periods of time where her functioning in the morning has been impaired. Vanessa has explained her absences and late-starts by saying she has “health problems” but she has not specifically disclosed her HIV diagnosis to anyone at work. She did, however, request an accommodation on the grounds of disability and asked to start a little later in the morning. Her manager seemed suspicious at the time, but after referring her to the Human Resources (HR) department, who asked for a letter from her doctors stating that she does indeed have a medical condition that could be accommodated by having a later start in the morning, HR told her manager to let her start a bit later. Vanessa gets the feeling however, that her manager is not happy about this arrangement. As well, Vanessa has already used up her 7 days of sick leave and most of her two weeks of vacation time on medical appointments and caring for her father and her two kids when they are ill. She is worried that she might become very ill again, and may need more time off than she has left in holiday time.

Recommendations: Raising awareness of appropriate accommodation strategies for people with episodic disabilities can prepare managers, staff and co-workers to be more supportive when working with people with episodic disabilities. See:

- Episodic Disabilities Employment Network <http://www.edencanada.ca/>
- Mental Health Works <http://www.mentalhealthworks.ca/>
- MS Society's Guide to Employment and Income Support http://mssociety.ca/en/pdf/EmploymentIncomeSupport_EN.pdf
- Arthritis Society's Joint Matters at Work <http://www.arthritis.ca/jointmatters>
- Canadian Council on Rehabilitation and Work <http://www.ccrw.org/>

Problems Qualifying for Disability Income Supports

People with episodic disabilities have difficulties qualifying as 'disabled' when it comes to income support programs. Episodic disabilities are often invisible and are, by nature, unpredictable. This means that it can be hard to qualify for programs that view disability as a static state and therefore require that the person claiming the benefit be totally and permanently disabled. For example:

- Canada Pension Plan Disability: requires a disability be 'severe and prolonged'. Also, a person with an episodic disability may not have contributed enough through workplace contributions to receive benefits as a result of periods of absence from the workforce related to their episodic disability.
- 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.
- Long-term Disability Insurance: requires "total disability" in order to qualify.

Case Study: How does this impact Vanessa?

Vanessa found coping with an increase in her sleep difficulties and a down-swing in her father's health to be overwhelming and she became depressed. Her doctor recommended that she see a psychiatrist and the psychiatrist recommended that she take time off work. Vanessa was unable to get out of bed for several months and only when the 3rd round of anti-depressants she was given by her psychiatrist started working was she well enough to leave the house to attend therapy sessions. Vanessa used up the last of her allocated holiday and sick leave during this time and was advised by her work to apply for EI Sickness Benefits. There is a 2 week waiting period for EI Sickness Benefits and the claim can take up to 28 days to process so Vanessa had to borrow from her brother enough money to pay the rent in the interim. While she was receiving EI Sickness Benefits, Vanessa received approximately 55% of her salary, which was not enough to pay her regular monthly bills so Vanessa borrowed more money from her brother. After 15 weeks, Vanessa exhausted her EI Sickness Benefits and was told to apply for Long Term Disability Insurance (LTD) through her work. Her application for LTD was turned down as she was not viewed by the insurance company as meeting the criteria for "total disability". Her next option is to try

to apply for Canada Pension Plan Disability, but she has been advised that it is unlikely that she will meet their criteria, as neither her depression nor her episodic impairments that result from living with HIV are consistently severe or prolonged. Vanessa employment is in jeopardy and she will soon be without a source of income. She is very worried about how she will support herself and her children.

Recommendations: Encouraging employers to offer flexible work hours and extended health benefits (including part-time work with benefits) helps to ensure that employees with episodic disabilities can stay engaged in the workforce while they are dealing with an episode of illness. It is also important for management to understand the complexities of accessing income support, should their employees be unable to work. This will help motivate managers and supervisors to support employees in staying connected to the workforce. As well HR should be able to assist employees with navigating complex income support systems, to the best of their ability.

Leaders and policy-makers must consider the unique needs of people with episodic disabilities when designing income support programs. These programs need to be flexible enough to support people when they are not able to work and also assist people in getting back to work when they are well and want to work. Complicated income reporting requirements and unclear rules related to what benefits people may be entitled to can act as disincentives to work. There is also a need for a part-time employment support benefit, in which a person with an episodic disability can receive some income support while still working part-time. Such a program would enable individuals to retain a connection to the workforce while still taking time to manage their health condition. It is recommended that these initiatives be better explored in order to ensure that people with episodic disabilities receive the supports they need.

People with Episodic Disabilities Can Experience Stigma and Discrimination

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

Stigmatization is a dynamic process that arises from the perception that there has been a violation of shared community attitudes, beliefs, and values⁶. In the case of stigma against people living with conditions like HIV or mental illness, this stigma may relate to fear of contagion (i.e. that someone with HIV could pass on the illness) or to worries related to mistaken perceptions (i.e. that people with mental illness are more dangerous than others). These mistaken perceptions can lead to managers, co-workers, supervisors and others developing and acting on prejudicial thoughts.

⁶ Zierler, S. et al. (2000). "Violence victimization after HIV infection in a US probability sample of Adult patients in primary care," *American Journal of Public Health* 90(2): 208-215. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446146/pdf/10667181.pdf>

Case Study: How does this impact Vanessa?

Vanessa only ever disclosed her HIV diagnosis to her insurance company when she applied for Long-Term Disability Insurance (LTD). She had heard the negative way that some of her colleagues had talked about people with HIV and had decided that she was not going to tell anyone about her status. Had she felt that she might be better supported by her manager after disclosing her HIV status, Vanessa might have been able to build a better relationship with her manager that took into account her need for extra breaks and time away for medical appointments. These additional accommodations could have saved Vanessa's health and potentially her job. Unfortunately, stigma in part prevented Vanessa from being able to fully access the kinds of workplace supports that could have helped her stay connected to employment.

Recommendations: The Mental Health Commission of Canada (MHCC) identifies three different types of stigma⁷ associated with mental illness:

1. **Self-stigma:** This is the result when people living with mental illness believe the negative perceptions of themselves offered by others. People living with self-stigma will avoid disclosing their illness or taking actions, like seeking treatment, which may result in others knowing about their condition. They may also avoid any action that could result in people acting in a stigmatizing fashion towards them, such as disclosing the need for accommodations at work.
2. **Public stigma:** According to the MHCC, public stigma "encompasses the prejudicial attitudes and discriminatory behaviours expressed toward people with a mental illness by members of the public."
3. **Structural stigma:** "occurs at the level of institutions, policies, and laws." This type of stigma is enacted when laws and policies lead to people with mental illness being denied human rights or being treated unfairly.

Although the stigma categories above were developed in the context of mental illness, they can easily be considered to extend to other kinds of stigmatized episodic disabilities such as HIV and Hepatitis C, amongst others. Many people living with HIV and/or mental illness say that dealing with stigma is worse than dealing with the illness itself. As a result, employers must undertake concerted efforts to combat stigma within the workplace.

Recommendations for anti-stigma actions include:

- The development of clear anti-discrimination and workplace harassment policies and a transparent and fair complaints system for addressing stigma-related matters when they occur.

⁷ Michael Pietrus.(2013). Opening Minds Interim Report, Calgary: Mental Health Commission of Canada. Retrieved from: http://www.mentalhealthcommission.ca/English/system/files/private/document/opening_minds_interim_report.pdf

- The implementation of contact-based education initiatives. These programs involve inviting people living with stigmatized conditions into the workplace to speak to employees about their illness and their lives.

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 of people living with episodic disabilities frequently also have to take time away from work in order to support their loved ones through unpredictable and intermittent periods of illness⁸. 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 caregivers. 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.

Case Study: How does this impact Vanessa?

Women more often act as caregivers when other family members are ill than do men. Much of the stress that led to Vanessa's depression and eventual exit from the workforce was related to her role as a caregiver to both her aging father and her two children, in addition to her own health worries. Vanessa's workplace did not have any particular supports for family caregivers and so any leave she took to tend to the wellbeing of her father or children came out of her holiday allowance. Had Vanessa been able to access either in-work supports for caregivers or caregiving support services in the community, she may have been better able to manage her own health and would have been able to stay connected to the workforce.

Recommendations: The issue of better supporting family/friend caregivers at work is one that has recently attracted the attention of researchers, disability organizations and government alike:

- In 2014, the Canadian Federal Government enacted the Canadian Employers for Caregivers Plan (CECP) to explore ways in which Canadian Employers can better support caregivers: <http://www.esdc.gc.ca/eng/seniors/reports/cec.shtml#h2.10>
- In 2014, CWGHR undertook the Episodic Caregiver Support Initiative with the goal of uncovering the needs of family/friend caregivers who are supporting people living with episodic disabilities: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/ECSI_Executive_Summary.pdf
- As well, the Canadian Caregiver Coalition continues to advocate on behalf of family caregivers everywhere: <http://www.ccc-ccan.ca/>

⁸ Episodic Caregiving Support Initiative. (2014). Retrieved from: http://www.hivandrehab.ca/documents/Episodic_Caregivers_Support_Initiative-ECSI-Final_Report.pdf

Through these initiatives, we are learning that programs that support flexible employment are beneficial to both people living with episodic disabilities and their caregivers. Recommendations include offering opportunities for:

- flexible stop/start times;
- banking of hours;
- compressed work weeks;
- part-time work;
- job sharing;
- access to health benefits, even for part-time employees;
- adequate paid and unpaid leave;
- emergency caregiving leave as part of paid leave provided to employees; and/or
- using sick leave to care for ill family members

In general, workplaces should be encouraged to develop initiatives that offer support to family/friend caregivers including those that are caring for people with episodic conditions and those that are both living with an episodic disability and providing care to others. Government should also remember the needs of caregivers to people living with episodic disabilities when designing new caregiving support programs and initiatives. Remember, people with episodic disabilities may be both care recipients and care providers too.

Women with Episodic Disabilities Experience Compounded Barriers Related To Gender

Many of the conditions noted as episodic disabilities affect women more frequently than men. For example, multiple sclerosis⁹, depression¹⁰ and arthritis¹¹ occur more often among women. Life with an episodic disability can be complicated for women by the fact that they are often the primary caregivers for children, elderly parents or other family members who may also be in need of assistance. Women are also more likely than men to be living in, 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 incomes¹². By virtue of intersections between gender and disability, women with episodic disabilities face additional barriers to inclusion.

⁹ Orton, S.M. et al.(2006). Sex ratio of multiple sclerosis in Canada: a longitudinal study. *The Lancet Neurology*, Volume 5, Issue 11. Retrieved from: [http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(06\)70581-6/fulltext](http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(06)70581-6/fulltext)

¹⁰ Weisman, M.M. et al.(1996) Cross-National Epidemiology of Major Depression and Bipolar Disorder. *Journal of the American Medical Association*, Vol 276, No. 4. Retrieved from: <http://jama.jamanetwork.com/article.aspx?articleid=405806>

¹¹ Arthritis Community Research and Evaluation Unit (ACREU). (2013). *Arthritis in Canada*. Retrieved from: <http://www.arthritis.ca/document.doc?id=903>

¹² Status of Women Canada.(2015).Fact Sheet: Economic Security. Retrieved from: <http://www.swc-cfc.gc.ca/initiatives/wesp-sepf/fs-fi/es-se-eng.html>

Case Study: How does this impact Vanessa?

Women with disabilities are poorer, less educated, more likely to be precariously housed and more likely to be victims of abuse than non-disabled women¹³. Vanessa exemplifies many of these unfortunate realities. Vanessa's marriage ended when her partner started to become abusive towards her. Vanessa could not afford to purchase a house of her own and therefore she and her two children moved into a small rented apartment in a house. Vanessa tries very hard to provide for her family, but living with an unpredictable episodic condition combined with work, home, and caregiving duties provides her with little energy or opportunity to do much else.

Recommendations: To date, the intersection of gender and episodic disability has not been extensively studied, so specific recommendations based on proven good practices for addressing this consideration are limited. Implementation of the recommendations made in other sections of this document would improve the circumstances of women living with episodic disabilities. In particular, implementation of the recommendations to support caregivers would greatly benefit women with episodic disabilities, as we know women are also more likely to be primary caregivers for both elderly parents and children. As well, the provision of flexible work options, such as working from home and flexible start and end times while keeping the number of work hours the same, would also benefit women with episodic disabilities especially, as women tend to have more responsibilities tied to the home than men. The intersection of gender and episodic disability is an area that requires further study.

Conclusion

While we have come some way in terms of recognizing that people living with episodic health conditions face barriers to inclusion from the unpredictable nature of their conditions, we are still a long way from integrating this knowledge into how we structure disability support mechanisms. Many supports and services that are intended to help people stay employed and/or out of poverty do not yet formally recognize the significant differences in support needs that people with episodic disabilities have. It is hoped that this discussion paper has illuminated some of the specific barriers encountered by people with episodic disabilities and has offered some food for thought on how support systems may be improved to better address their needs and provide people like Vanessa with a more certain future.

For more information about episodic disabilities, please see the Episodic Disabilities Network website at www.episodicdisabilities.ca or contact Wendy Porch, Manager Episodic Disabilities Initiatives at the Canadian Working Group on HIV and Rehabilitation at wporch@hivandrehab.ca. For specific information regarding employment issues, please see the Episodic Disabilities Employment Network (EDEN) at www.edencanada.ca

¹³ DAWN/RAHF Canada Fact Sheets. Retrieved from:
<http://www.dawncanada.net/resources/resources/factsheets/>

Appendix

Episodic Disabilities Network (EDN) Episodic Conditions List

(Updated March 2015)

- Arthritis
- Asthma
- Some forms of Cancer
- Chronic Obstructive Pulmonary Disease including:
 - Chronic Bronchitis
 - Emphysema
- Chronic Fatigue Syndrome
- Chronic Pain
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
- Crohns & Colitis
- Diabetes
- Epilepsy
- Fibromyalgia
- Hepatitis C
- HIV/AIDS
- Lupus
- Mental Health Conditions including:
 - Depression
 - Anxiety
 - Bi-Polar Disorder
 - Schizophrenia
- Meniere's Disease
- Multiple Sclerosis
- Migraines
- Parkinson's Disease
- Systemic Exertion Intolerance Disease (SEID)