

EPISODIC DISABILITIES NETWORK

Presentation to the Standing Committee on Human Resources,
Skills and Social Development and the Status of
Persons with Disabilities

House of Commons
Thursday, April 18th, 2013

**Canadian
Working Group on
HIV and
Rehabilitation**

Good Morning to members of the Committee. My name is Tammy Yates and I am the Coordinator, Episodic Disabilities Initiatives at the Canadian Working Group on HIV and Rehabilitation, which we refer to as CWGHR and with me is Elisse Zack, CWGHR's Executive Director. We are here this morning, on behalf of the Episodic Disabilities Network, referred to as the EDN, and on behalf of the EDN, we would like to thank members of the committee for leading this important discussion on exploring employment opportunities for persons with disabilities and for inviting the EDN to make this presentation.

**DisAbled
Women's Network
Canada**

We would also take this opportunity to applaud the Government's commitment to improving labour market opportunities for Canadians living with disabilities, which is evidenced through the strengthened federal programming for persons with disabilities in Canada's Economic Action Plan 2013, the convening of the Panel on Labour Market Opportunities for persons with disabilities and its subsequent report, 'Rethinking disAbility in the Private Sector', as well as the Private Members Motion M-430 introduced by MP Phil McColeman.

**Multiple Sclerosis
Society of Canada**

The EDN, which was formed in 2003, brings together a wide range of key stakeholders to collaborate on research, advance public policy on employment and income support and to promote the broader integration of people with episodic disabilities in Canada.

**The Arthritis
Society**

As you may recall, two organizational members of the EDN, the Canadian Coalition on Rehabilitation and Work (CCRW) and the DisAbled Women's Network Canada (DAWN) have recently made presentations to this panel. Many of the points raised in those presentations would also have shed some light on the experiences of people living with episodic disabilities.

**Canadian Council
on Rehabilitation
and Work**

Often, when people refer to disabilities, the first thoughts that come to mind are permanent disabilities. A person can live with both a permanent and an episodic disability, but there are clear distinctions between the two. An episodic disability is a long term health condition that is characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability over time and from one person to another. As Canadians are living longer, an increasing number of people are living with lifelong chronic illnesses that include episodes of disability, for example, arthritis, Crohn's disease, diabetes, hepatitis C, HIV, multiple sclerosis, and some forms of cancer and mental illness. I am sure

that most, if not all of you know someone, or several people who are living with these types of conditions. You can, therefore, appreciate how these fluctuating episodes over time can wreak havoc on their work life.

Most recent statistics show that -

- Over 4.6 million Canadians aged 15 years and older reported that they had arthritisⁱ
- 20% of Canadians will personally experience a mental illness in their lifetimeⁱⁱ
- An estimated 95,000 Canadians live with Multiple Sclerosis and Canadians have one of the highest rates of MS in the worldⁱⁱⁱ and
- There are approximately 71,300 people living with HIV in Canada, 25% of who are not aware of their positive status^{iv} but may be experiencing symptoms, or episodes of disability.

Research supported by the Government of Canada has found 27 underlying conditions identified as 'episodic' and almost half of the working-age adults identified as having a disability in the 2006 Participation and Activity Limitation Survey (PALS) reported having at least one of these conditions; this included 1,140,500 working-age adults.^v As you can see, this is a significant percentage of the population.

There are several recommendations related to the employment of people with episodic disabilities that we have for the Government of Canada. We would like to share them with you first and then provide a brief explanation:

- 1) Increase the flexibility of Employment Insurance (EI) Sickness Benefits, e.g. with units, such as, 75 individual days, or 150 half-days, making it easier for people with lifelong episodic disabilities to stay in the work force while being able to use EI sickness benefits on days or weeks when they are not able to work.
- 2) There should be more program outreach to people living with episodic illness and disability through the CPP-D Vocational Rehabilitation program.
- 3) Building on the recent work on episodic disabilities that the Government of Canada has been doing, undertake further research related to the labour market participation of Canadians living with episodic disabilities to identify the impact of these types of illness and disability and develop more responsive income and employment services to meet people's needs.

The EDN would also be happy to work with the newly formed Employers Disability Forum to better understand and address the needs of people living with episodic disabilities.

Many people with chronic illnesses leading to an episodic disability have no alternative but to rely on disability benefits such as:

- Employment Insurance (EI) sickness benefits
- Long term disability (LTD) provided by employee group insurance plans
- Canadian Pension Plan Disability Program (CPP-D), and
- Provincial Disability and Social Assistance programs.^{vi}

However, most existing disability policies and programs do not accommodate the realities of a person living with an episodic disability. Rigid definitions and policies govern these benefit programs as people must be either 'fully-disabled', or 'fully able to work', when many people with episodic disabilities fall somewhere along the continuum. Eligibility criteria in some programs include that the disability must be severe and prolonged which often excludes people with episodic disabilities. As result, people may have difficulty accessing or maintaining benefits even when their disability prevents them from being able to work.

It is critical to have disability programs that are flexible enough for people with episodic disabilities to enter, leave and re-enter the paid work force easily when their episodes of disability fluctuate, without putting their income security at risk.^{vii} Existing policies also make it difficult for people who are receiving benefits to work part-time or when their health allows. Some people could contribute greatly if they had the opportunity to work part-time over a longer term if they could earn a part-time income when their health allows and also be able to receive part-time disability benefits for the portion of time that they are not able to work. This would enable them to maintain some level of income security. Flexible units of EI sickness benefits could be one mechanism to address this issue.

Some key issues that act as barriers to labour force participation for people living with episodic disabilities include:

- **Lack of partial disability benefits:** In practice, most policies define people as either "fully disabled" or "able to work". If someone returns to work part-time during periods of good health, they lose their disability income support, even though they are only working part-time.
- **Loss of extended health benefits** (vision, dental, prescription drugs, physiotherapy, etc.): People fear loss of extended health benefits if they return to work, stop receiving benefits and then become ill again. If they return to work with a new employer, they also may not be eligible for benefits because they have a pre-existing condition.
- **Limits on income:** Although CPP-D allows people to earn some income while on disability; the fear of losing CPP-D benefits discourages many people from working during periods of good health.

- **Claim procedures:** Complicated claim procedures are often required every time someone is absent from the workforce for an extended period of time.^{viii}

It is clear that we need to find ways to provide employment supports to help people manage the impact of illness and disability on their work.

People with illness and disabilities often experience stigma and discrimination due to the fear of illnesses, disabilities and difference inherent in our society. It is critical that our systems promote inclusion and respect. It is also critical for our systems to recognize the disproportionate impact that living with a disability has on women. For example, the unemployment rate for women with disabilities is 74% and while there is currently no specific data on women living with episodic disabilities, we deduce that their situation is not much better.

Most employers, whether in the public or private sector, are hesitant to hire people with disabilities, including persons with episodic disabilities, for a number of reasons, such as:

- Fear of the costs associated with hiring: Employers fear the costs associated with accommodations that might be required for a person with a disability.
- Fear of additional supervision and loss of productivity: Employers fear supervisors having to spend additional time and also fear having to make productivity concessions.
- The fear of being stuck forever: Employers fear that once they have hired someone with a disability, they end up with an employee with low or substandard productivity indefinitely.
- Fear of 'damaged goods': Employers fear that the person they are hiring will not be up to the demands of the job.
- Concerns regarding higher premiums and insurance payments
- Difficulty planning for unpredictable absences
- Concerns regarding other employees seeing accommodations as 'special treatment' which in turn can create disruptive work environments or difficult team relationships.^{ix}

Recent research, however, highlights a number of reasons why in today's economy people living with episodic disabilities should be hired and where already in the workforce, retained.

Some of these reasons are that:

- People with disabilities represent an underutilized labour pool
- Workers with disabilities tend to be loyal to their employers and experience long retention rates
- Curb-cut Advantages: When supports are developed for people with disabilities, including people with episodic disabilities, companies create supports that positively impact everyone within a company.
- Capital Investment: Most episodic disabilities affect people who are in their prime working age. Companies have already invested years of training and development and should seek to retain their investment. Efforts made to retain employees result in considerable cost-savings associated with having to train new staff.
- Positive Return on Investment: A positive return on investment in accommodating workers with episodic disabilities has been demonstrated.^x

The EDN has worked collaboratively with Human Resources and Skills Development Canada to research the impact that episodic disabilities have on workforce participation and to identify and promote opportunities to address the needs of Canadians with episodic disabilities. The EDN has also worked to raise awareness of the need for reforms to EI and federally provided income support programs to better support Canadians with episodic disabilities.

Just yesterday, the EDN convened a *'Forum and Policy Dialogue on Workforce Participation by People Living with Episodic Disabilities in Canada'*. The goal of the policy dialogue was to develop a multi-stakeholder-informed strategy and action plan to promote workforce participation for people living with episodic disabilities. The session brought together government representatives and policy-makers, employers and unions, as well as people living with episodic disabilities and their representatives. Two of the major highlights of the policy dialogue were the opening remarks delivered by MP Phil McColeman and the keynote lunchtime speech by MP Bernard Trottier.

In conclusion, I would like to say that life is unpredictable. While you or I may not be living with an episodic disability today, it does not mean that tomorrow our life circumstances may not change and we may then be diagnosed with an illness that is episodic in nature. To this extent, therefore, the policies and programs, or revisions to policies and programs, that we have suggested

don't only work for people living with episodic disabilities; flexibility works for every Canadian.

The Government of Canada's *Economic Action Plan 2013* shows a commitment to improve the labour force participation of Canadians living with disabilities, many of whom are people living with episodic disabilities. If more people with episodic disabilities are able to participate in the workforce when their health allows, without putting their income security at risk, many people who are currently excluded will have an opportunity to both contribute to the labour force and become more economically independent which in turn will be a win-win for all Canadians.

Authors:

Episodic Disability Network (EDN), including:

Canadian Council on Rehabilitation and Work: 416 260 3060 ext 222 or mhaan@ccrw.org

Canadian Working Group on HIV and Rehabilitation: 416 513 0440 ext 240 or TYates@HIVandRehab.ca

DAWN-RAFH Canada: 514 396 0009 or admin@dawnCanada.net

Multiple Sclerosis Society of Canada: 780 440 8752 or neil.pierce@mssociety.ca

The Arthritis Society: 416 979 3353 ext 3347 or lmoore@arthritis.ca

ⁱ The Arthritis Society, 2012. *Arthritis in Canada Update*. [Fact Sheet]. September, 2012. The Arthritis Society.

ⁱⁱ Canadian Mental Health Association, 2013. *Fast Facts About Mental Illness*. [online]. Available at: <http://www.cmha.ca/media/fast-facts-about-mental-illness/#.UW2R1a13sRE> [Accessed April 16th, 2013]

ⁱⁱⁱ The Multiple Sclerosis Society, 2013. *About Us*. [online]. Available at: <http://mssociety.ca/en/information/default.htm> [Accessed April 16th, 2013]

^{iv} Public Health Agency of Canada, 2011. *At A Glance-HIV and AIDS in Canada: Surveillance Report*. [online]. Available at: <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2011/dec/index-eng.php> [Accessed April 16th, 2013]

^v Adele Furrie, 2010. *Towards a better understanding of the dynamics of disability and its impact on employment*. [online] Available at: http://www.adelefurrie.ca/PDF/Dynamics_of_disability.pdf [Accessed April 17th, 2013]

^{vi} The Episodic Disabilities Network, 2011. *The Path Forward, Addressing Episodic Disabilities in Canada: EDN Brief to the Standing Committee on Finance*. [online] Available at: http://www.hivandrehab.ca/EN/episodic_disabilities/documents/ThePathForward_EpisodicDisabilityNetwork.pdf [Accessed April 16th, 2013]

^{vii} Ibid.

^{viii} Ibid.

^{ix} Chronicle Analytics and Canadian Working Group on HIV and Rehabilitation, 2012. *The Business Case for Hiring/Retaining People with Episodic Disabilities*. Available at:

http://www.hivandrehab.ca/EN/episodic_disabilities/EmploymentandEpisodicDisabilitiesResearchProject.php [Accessed April 16th, 2013]

^x Ibid.