



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

Parliamentary Brief

Episodic Disabilities

A Brief Prepared for the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA)

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December 7, 2018

Leadership, Partnership & Networking

ABOUT THE DISABLED WOMEN'S NETWORK OF CANADA (DAWN CANADA)

DisAbled Women's Network (DAWN) Canada is a national, feminist, cross-disability organization whose mission is to end the poverty, isolation, discrimination and violence experienced by Canadian women with disabilities and Deaf women. DAWN 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.

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Episodic Disabilities

Introduction

On behalf of the Board, Staff and Membership of the DisAbled Women's Network (DAWN) Canada we are pleased to submit a brief to this Committee for consideration regarding your current Study linked to Episodic Disabilities and Chronic Illness in Canada. We were disappointed not to have been called to present to the Committee as we have been working on this issue and advocating for greater attention to this issue for more than a decade, including with many partners that you have heard from in person.

Intersectional Gender Analysis must always be applied to any questions that come before the HUMA Committee, and for that matter all the Committees of the House and Senate.

Indeed, the research we present below, the result of a recent body of work led by DAWN Canada with partners, including REALIZE, begins a long overdue area of enquiry to better understand not only the gender aspects of disability in Canada but the many women and girls who face the same barriers because of an episodic or chronic illness.

With the newest Statistics Canada data now confirming that the rate of disability among women in Canada is 24% (one quarter of all women in Canada) and the important research findings below from Wendy Porch and REALIZE, we posit to this committee the urgent need for more data, including longitudinal data so that we can begin to stem the tide of episodic and chronic illness that so many Canadians are facing, a majority of whom are women.

Why are we seeing this emergence and the dramatic differences by gender in Multiple Sclerosis, Arthritis, Irritable Bowel Syndrome, Chronic Fatigue and yes, mental health? We must begin with an understanding that women began entering the workforce in large numbers in Canada post World War II. Yet we still do not have universal childcare in Canada, we still do not recognize unpaid caregiving and the enormous burden it is placing on generations of women in Canada.

We urge the committee to take great care to go deeper with your enquiry into this issue and to ensure that adequate resources are provided to deepen our understanding of this harbinger among women in Canada.

Episodic Disability Defined

According to the Episodic Disabilities Employment Network: “Episodic disabilities are long-term conditions that are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability from one person to another. Some common examples of episodic disabilities include multiple sclerosis, arthritis, diabetes, HIV/AIDS, hepatitis C, chronic fatigue syndrome, migraines, chronic pain, some forms of cancer and mental illness. Unlike permanent disabilities, episodic disabilities are periodic — the episodes of illness come and go — but because they are also unpredictable, they can often be more difficult to manage with regard to employment.”¹.

Unique Needs

Women were more likely than men to report episodic health conditions: “Consistent with the literature, both EPI populations include more females than males: 54.3% (EPI/WD) and 62.3% (EPI/No WD) versus 42.4% (No EPI/WD).”

Social Exclusion

The health conditions that can, in combination with the environment, result in episodic disabilities include some conditions that are highly stigmatized. For people living with mental health related disabilities and/or HIV the experience of stigma can be a very regular occurrence. Stigma is known to have an impact on the well-being of people living with HIV².

As well, women living with HIV face additional intersections of stigma, particularly if they are also members of an ethno-racial minority, are LGBTQI2S and/or are sex workers³. For women living with stigmatized episodic health conditions, social exclusion can be directly linked to social exclusion as individuals seek to avoid stigmatizing interactions through avoiding social situations.

¹ EDEN - What are “Episodic Disabilities”? <http://www.edencanada.ca/en/faqsepisodicdisabilities>

² Meta-analysis of health and demographic correlates of stigma towards people living with HIV.

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3222645/#pmed.1001124-Logie1>

Disclosure

Given the stigma often associated with episodic disabilities, issues around disclosure can become particularly important. Most episodic disabilities are invisible.

As a result, for women living with episodic disabilities, decisions about disclosure must be made on a day to day and person to person basis. In research related to women living with fibromyalgia, disclosure decisions are likened to “impromptu disclosure dances” where women must decide if and how much information to share depending on assessments made regarding the risks involved.⁴

Chronic pain is often associated with episodic disabilities and has been considered an episodic disability in its own right⁵. In one study looking at perceived pain behaviours and readiness to work, women “were perceived as being less ready to work than men, but not necessarily because they were perceived as having more intense pain than men (ie, even when accounting for observers’ judgments of pain).”⁶

Employment

Employment is an important issue where episodic disabilities are concerned. Episodic disabilities are different from stable non-recurring disabilities in that they are characterised by uncertainty. Uncertainty impacts employment significantly. Women with episodic disabilities face specific employment related barriers that are related to an unpredictable and fluctuating capacity to work arising out of their episodic health conditions. Unpredictability of the condition makes it hard for women with episodic disabilities to get a job because of gaps in one’s resume, it makes it hard to stay at work as flares can occur at any time, resulting in intermittent work capacity. Women with episodic disabilities may gain employment but live in fear of a relapse. Intermittent work capacity is also difficult for employers and co-workers too and can be particularly hard in certain kinds of jobs – especially those with hard scheduling requirements or those that are customer-facing.

As employees, women with episodic disabilities experience a number of significant challenges:

“Experientially, women with complex episodic disabilities live in two seemingly contradictory worlds: the world of the healthy (and sometimes employable) and the world of the ill (and sometimes unemployable). This fluid, in-between embodiment is a pivotal obstacle to

⁴ Old eld, M., MacEachen, E., Kirsh, B., & MacNeill, M. (2016). Impromptu everyday disclosure dances: how women with fibromyalgia respond to disclosure at work. *Disability and Rehabilitation*, 38(15), 1442 – 1453. 60 Episodic Disabilities in Canada https://www.crwdp.ca/sites/default/files/Research%20and%20Publications/episodic_disabilities_in_canada_-_october_4_-_nal.pdf

⁵ Episodic Disabilities in Canada https://www.crwdp.ca/sites/default/files/Research%20and%20Publications/episodic_disabilities_in_canada_-_october_4_-_nal.pdf

⁶ Martel, M., Wideman, T., & Sullivan, M. (2012). Patients who display protective pain behaviours are viewed as less likable, less dependable, and less likely to return to work. *PAIN*, 153, 843 – 849

preparing for, securing, and retaining work within an occupational milieu, echoing its own risks and instabilities.” P. 77⁷

Women living with episodic disabilities are required to prove their disabilities in order to be eligible for employment supports and/or income security programs. In Vick 2013⁸ women with MS discuss adding additional layers of substantiating evidence to their requests for accommodation that women with visible physical disabilities are not required to do.

For many women, the changing dynamic of their episodic health conditioned combined with insufficient support systems and hostility from managers and co- workers proves to be overwhelming at times, making maintaining employment extremely difficult. However, people with episodic disabilities can work, as long as the employer is able to see flexibility as an accommodation.

Education

There is not a great deal known about the specific educational experiences of young women living with episodic disabilities, however what is known is concerning. *Realize* has undertaken initial research examining the educational experiences of students living with episodic disabilities through conducting a literature review and through working in partnership with Dalhousie University to survey and conduct key informant interviews with students and staff at 5 post- secondary institutions in Canada.

The research reveals a bias against students living with episodic disabilities, from other students who may exclude them due to negative perceptions of their ability and/or hostility related to accommodations they may have received. It also reports bias from staff and faculty who may or may not believe that the student has a need for accommodations and who suspect the student is trying to access an unfair advantage.

Through the survey students with episodic disabilities reported concerns with accessing accommodations related to the need for medical documentation and access to specialists to substantiate their requests for accommodations. Long waiting times to access specialists meant that the needed information was not provided in time for accommodations to be in place in a timely manner. Students also reported difficulties accruing financial debt while simultaneously finding it very challenging to complete their course work while managing a chronic and unpredictable episodic health condition.

⁷ Vick, A. & Lightman, E. (2010). Barriers to employment among women with complex episodic disabilities. *Journal of Disability Policy Studies*, 21(2), 70 -80.

⁸ Vick, A. (2013). The embodied experience of episodic disability among women with multiple sclerosis. *Disability & Society*, 28, 176-189

Unpaid Labour

There is no research identified that examines the experiences of people living with episodic disabilities as caregivers, although, as many conditions that can result in episodic disabilities impact women more frequently than men, there is little doubt that women with episodic disabilities are assuming caregiving roles in their families.

As well, in those circumstances where women with episodic disabilities become ill and must seek assistance with maintaining caregiving duties at home, there must be significant barriers encountered as in neither the childcare or eldercare sector is it possible to arrange for care services with little notice and for an unpredictable period of time.

Research Gaps

More research needs to be conducted regarding the specific experiences of women living with episodic disabilities. Many conditions associated with episodic disability occur more often in women than men. For example, the sex ratio of multiple sclerosis for women in Canada has been gradually increasing over the last 50.⁹

Arthritis, and mental illness are also conditions that more commonly occur in women. Still there is very little research that looks at the experiences of women living with episodic disabilities specifically. One possible issue for this is that episodic disability is a relatively new way of thinking about disability and does not have a mature and widely accepted terminology associated with it. There is a great deal of overlap with chronic illness literature. There are also numerous different terms used to denote episodic disability including “episodic health condition” and “episodic illness”. Although Statistics Canada does currently undertake the Canada Survey on Disability, it is not a longitudinal survey and there has only very recently been a marker introduced for ‘episodic disability’. Consequently, it has been very hard to understand the overall numbers of people living with episodic disabilities.

⁹ Sex ratio of multiple sclerosis in Canada: a longitudinal study Orton S Herrera B Yee I Valdar W Ramagopalan S et. al. The Lancet Neurology 2006 vol: 5 (11) pp: 932-936