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**Living and Working Precariously with an Episodic Disability:
Barriers in the Canadian Context**

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Abstract

The organization of contemporary labour markets has radically altered the nature of work and its embodied or bodily performance. Changes from standard, permanent jobs to non-standard or precarious work arrangements have increasingly become the normative template for many workers, including persons with disabilities. Drawing on findings from 13 qualitative interviews associated with 'Project EDGE,' Episodic Disabilities in the Global Economy, I describe how Canadian workers with "episodic" or fluctuating disabilities experience and negotiate barriers to work within precarious work environments in Toronto, Ontario. Implications that consider the episodic dimension of disability for workforce participation and employment policy are considered.

Keywords

Episodic Disability; Precarious Employment; Barriers; Discrimination; Accommodation; Recommendations

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**Living and Working Precariously with an Episodic Disability:
Barriers in the Canadian Context**

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Recent decades have witnessed fundamental shifts in the organization of labor markets, the nature of work, and its embodied or bodily performance. Changes from standard employment relationships to non-standard or 'precarious' work arrangements including part-time, temporary, contract, home-based, seasonal, multiple job holding, on-call, and day labor have widened economic and social vulnerability among individuals. Specifically, precarious jobs are linked with lower wages, poor working conditions, insufficient protections, inadequate training opportunities, increased health problems, and more reliance on income assistance (Tompa, Scott-Marshall, Dolinschi, Trevithick, and Bhattacharyya, 2007; Vosko, 2006). This occupational milieu has significant implications for persons whose disabilities are 'episodic' or fluctuate between periods of better and worse health. Since it is difficult to anticipate when and to what extent an episodic disability will affect an individual's health and capacity to work, many people encounter significant barriers in preparing for, finding, and maintaining jobs in a labor market rife with instability (Galarneau and Radulescu, 2009).

Drawing on findings from thirteen qualitative interviews associated with 'Project EDGE,' Episodic Disabilities in the Global Economy, I describe how persons with episodic disabilities experientially encounter and navigate barriers to work within a precarious work climate in the major metropolitan centre of Toronto, Ontario. Two objectives inform this discussion. First, I open dialogue about the challenges persons with episodic disabilities experience in obtaining and negotiating the conditions of work. Second, I outline some initial directions for practice and

policy that considers the complex relationship between episodic disability and labour market participation.

Defining Episodic Disabilities

Although research exploring episodic disability is evolving in Canada, there are no statistics on the exact number of people living with episodic disabilities. The Government of Canada's 2003 report *Listening to Canadians: A first view of the future of the Canada Pension Plan Disability Program* does however suggest that the numbers are increasing over time (Government of Canada, 2003). Episodic disabilities are characterized by unpredictable, fluctuating periods of illness and wellness that wreak havoc with a person's health, employment stability, and quality of life. Episodic disabilities include, but are not limited to, multiple sclerosis, chronic fatigue syndrome, fibromyalgia, multiple chemical sensitivities, lupus, epilepsy, arthritis, diabetes, HIV/AIDS, and some mental health conditions (Canadian Working Group 2006; EDN, 2011).

Episodic Disabilities and Barriers to Work

The right to work is fundamental to the social inclusion and full participation of persons with disabilities in society (Prince, 2009). While many persons with episodic disabilities want to work and are able to work intermittently, partially, and sometimes full-time for an extended period, poor health, an uncertain illness trajectory, and fear of relapse pose major barriers to negotiating employment and often stymie work search efforts. This situation is particularly pronounced among those with psychiatric disabilities and individuals whose symptoms are not well controlled (ARCH, 2011; EDN, 2011; Shier, Graham et al., 2009; Worthington, O'Brien et

al., 2012). Equally relevant, a lack of education, ineffectual training opportunities, inadequate work experience, poor social skills, perceived and actual discrimination, and personal feelings of inadequacy, shame, incompetence, and rejection erect significant barriers to acquiring and keeping jobs (Chouinard, 2010; Vick and Lightman, 2010).

In addition to work being a right, work also conveys social meanings and is connected to social status. The social meaning of work, endemic to a precarious work culture, penalizes bodies that do not conform to normative able-bodied ideals that demand high energy, speed, stamina, flexibility, and productivity among workers (Schur, 2003; Wilton and Schuer, 2006). In attempting to craft an identity that aligns with prevailing organizational culture and work practices modeled on able-bodied norms, persons with episodic disabilities commonly self-discipline their bodies to comply with the expectations of the ideal, 'good' worker (Wilton, 2004).

For people with episodic disabilities who want to work and could do so with flexible supports, the difficulties with acquiring job accommodations such as frequent rest breaks, modified work tasks, flexible schedules, and physically accessible workspaces, systematically minimize their labor force participation (August, 2009; Cohen, Goldberg et al., 2008). As well, employers are often reluctant to provide support to persons with shorter job tenures such as contractual workers, and often misunderstand the nature of accommodations (Dreidger, 2003; Crooks, 2007).

In moving between periods of health and illness, persons with episodic disabilities do not fit standardized categories such as able or disabled and employable or unemployable that are used to determine income support eligibility such as that established for the Ontario Disability Support Program, a long-term form of income assistance for persons with substantially impairing

disabilities. As a result, such individuals fail to qualify for disability benefits (, 2009; Prince, 2008; Senate of Canada, 2006). Moreover, program rules create disincentives to work because of fears surrounding benefit reinstatement, claw back of earnings, and the potential for the termination of drug, dental, transportation, and other benefits (CSPC-T and Social Work Council, 2009). The Organization for Economic Co-operation and Development (2009) further suggests a 'disability benefit culture' perpetuates labor market exclusion through passive schemes that fail to support those with partial work capacity. The dilemma arising here is that because workers with episodic disabilities may be able to work sometimes but not all the time, these schemes and programs require individuals to not work at all in order to maintain eligibility. This reality provides important context for the research findings I present in this paper.

Methods

This paper reports on initial findings from thirteen qualitative interviews associated with 'Project EDGE,' Episodic Disabilities in the Global Economy. The interviews focused on participants' work experiences and the barriers they encountered in preparing for, finding, and maintaining employment. After receiving ethics approval from the University of Toronto's Office of Research Services, four non-profit, organizations, namely the Canadian Working Group on HIV/AIDS and Rehabilitation, the Ontario Episodic Disabilities Network, the Episodic Disabilities Employment Network, and the Ontario Disability Support Program Action Coalition were contacted to assist in the recruitment of participants. All of these organizations have mandates to provide employment assistance for persons with disabilities, particularly those that are episodic. Each organization was asked to electronically post through their respective membership lists, a study invitation letter detailing the nature and objectives of the project. The

letter included a telephone number and email address so that interested individuals could contact the researcher directly to indicate their interest and inquire further about the study. The letter assured potential participants that their participation was strictly voluntary, that all information collected would remain confidential, and that access to social assistance and related services would be uncompromised.

Thirty participants in total, accessed through the above four non-profit organizations, self-identified as having an episodic condition and contacted the researcher. This paper focuses on a sub-set of findings with thirteen participants. These thirteen participants were selected for inclusion in the study based on the following criteria: disabilities that fluctuated between periods of illness and wellness, receipt of income support through the Ontario Disability Support Program, and previous or current participation in the Ontario Disability Employment Supports Program. Seven men and six women self-identified as living with episodic conditions including fibromyalgia, epilepsy, traumatic brain injury, post polio syndrome, cancer, HIV, and depression. All thirteen participants were ODSP recipients and had previously or currently accessed employment preparation and training activities associated with the Ontario Disability Employment Supports Program (ODESP). The other seventeen participants were not included because their disabilities were experienced in stable rather than fluctuating ways. Since the main focus of this study examined the relationship between episodic disability and barriers to work, individuals whose disabilities did not shift between periods of better and worse health were excluded. Given the small number of participants, the experiences of these thirteen individuals are not meant to be representative of all persons living with episodic conditions but highlight the nature of employment barriers specific to their individual work experiences. While commonalities exist among the thirteen participants in relation to their work experiences, it is not

unfeasible to suggest that their reported experiences may also resonate with other episodically disabled workers in a precarious work culture.

The interviews, conducted between June 2011 and July 2012, were guided by a semi-structured format and lasted approximately two hours. All interviews took place at the Factor-Inwentash Faculty of Social Work, University of Toronto. All participants lived in Toronto and are recipients of the Ontario Disability Support Program (ODSP), a form of long-term income assistance for persons with substantial physical or mental impairments that are continuous or recurrent. In addition, all participants had previous experience with, or were currently participating in, the Ontario Disability Employment Supports Program, a program designed to provide assistance with job preparation, coaching, and placements for persons with disabilities. With the exception of one individual, all participants are college or university educated. Seven participants worked part-time and six were unemployed and actively looking for work. A range of occupations within the health care, social services, accounting, research, information technology, human resources, security, manual labour, and retail fields characterizes the participants' employment profiles. Participants received a small honorarium of \$25 for the interview in addition to transportation costs.

Data Analysis

All interviews were audiotaped, transcribed, and coded. A "hands-on," modified, thematic analysis (van Manen, 1997) that brings the researcher into closer interpretive contact with the data was used to organize and analyze the interview data. Three analytic phases were employed. In the first phase, all interviews and notes were read to glean an overall vision of their

content. Specific paragraphs, phrases, and words that described the experience of episodic disability, employment challenges, and the management of barriers were identified. In the second phase, selected sections of interview text were organized into a separate electronic file and conceptually arranged into broad themes such as fluctuating bodily experiences, emotional struggles, programmatic barriers, and discrimination. In the third phase, interpretive categories were refined and collapsed into four broad themes including precarious bodies, emotional struggles, neglected bodies, and neglected minds. This final thematic framework forms the basis of the discussion. Given the small sample size, findings associated with this thematic framework are not intended to reflect the experiences of all persons with episodic disabilities receiving ODSP or who have participated in the ODESP. Rather, my intent was to explore how participants' episodic conditions impacted their employment experiences. All information collected from the interviews were numerically coded to protect confidentiality and stored in a secure facility on university premises. Pseudonyms are used to protect participant anonymity.

Precarious Bodies

Poor health and disability pose major barriers to seeking and negotiating employment (Lysaght, Krupa, and Gregory, 2011; Timmons, Foley, Whitney-Thomas, and Green, 2001). Living with a volatile body that unpredictably vacillates between periods of calm and unrest often implies embodying a fluctuating reality of pain, fatigue, varying energy levels, shifting functional capacities, and side effects of medications that impedes participants' ability to explore job options and work with any degree of consistency (Ferris and Lavis, 2003; Tompa, Trevithick, and Bhattacharyya, 2006). For workers with episodic disabilities, it takes a lot of work to go to work. The looming "what if" of wavering symptoms associated with a precariously disabled

body contradict the need for a foreseeable unchanging health status required for participating in employment preparation activities and remaining on the job. Living with fibromyalgia, Lorraine explained:

There are days I cannot even crawl from my bed with the pain and exhaustion. One day I can be up and then I plummet within two minutes and need to rest. It's that unpredictable. I can't guarantee I can look for work every day or stay working.

Echoing Lorraine's experience, Terri states:

I have health issues with my HIV like diarrhoea, rashes, not feeling well at times, plus fatigue. One day you're great and the next is different. There were days I wasn't feeling well but would go in because I didn't want to lose my job. A lot of times I had to be there at ten o'clock but came after eleven. I just hope for the best and get on with it.

Although Lorraine attempts to look for work when she is well enough, she also experiences having little control over a health and work trajectory that can arbitrarily change from moment to moment or day-to-day. One day may promise vigour and the body's cooperation in performing various tasks and the next day may present unrelenting fatigue, pain, and reduced energy levels. Lorraine tends to defer to the ebb and flow of her bodily rhythms that dictate whether she can muster enough strength to engage in a job search on any given day. When necessary, she rests and regains a sense of wellbeing. Terri, meanwhile, fears losing her job and this motivates her to cope with the volatility of living with HIV. The ups and downs of her illness are routinely integrated into her role as a salesperson by coming in late in the hopes of quelling symptoms and persevering with a positive attitude that "things will work out" despite disruptions due to frequent bowel movements and the discomfort of skin irritation.

Individuals with episodic disabilities typically work to meet able-bodied standards characterized by a predictable health status rather than an unsettling evolving one by hiding less than perfect, problematic bodies that fail or almost fail to live up to standards of appearance and

functioning. In doing so, their well-being can be compromised. Individuals like Terri, who identify as neither completely able nor completely disabled but residing somewhere in-between (Vick and Lightman, 2010), feel compelled to work with rather than against illness in an effort to, as she expressed it, "soldier on" or battle to meet the demands of their jobs in expected ways. This scenario, described as the self-disciplining of bodies (Wilton, 2004), is linked to the compulsory nature of able-bodiedness in our society and the conception of illness as a private matter (Campbell, 2009; Myers, 2004).

In hoping for the best as Terri describes, and remarking on the absence of any guarantee of health as Lorraine states, these participants perceive themselves as physically "risky" workers in a precarious labour market because the constant threat of getting sick implies they cannot predict when intervals of health and illness will appear and how long they will last (Tompa et al., 2006). This corporeal ambiguity and the "employment strain" (Lewchuck, Clarke, and de Wolff, 2008) it implies, acts as a unique stressor around a lack of control over job opportunities, many of which are equally insecure, as well as the vulnerability of persons with episodic disabilities as reliable, periodic workers. Given this scenario, individuals living with episodic disabilities may prefer to depend on the stability of social assistance benefits rather than risk taking unstable, poorly paid jobs that may jeopardize their health and fail to improve the quality of their lives (Vick and Lightman, 2010; Fawcett, 2000).

Driedger (2003) comments that because chronically ill workers cannot guarantee they will feel well enough to come to work with any consistency, there is also a need to direct attention to the nature of work in our society, especially the rigid ideals of flexibility that characterize many low-waged, insecure jobs. Notwithstanding Schur's (2003) claim that contingent work assignments enable some individuals to work who would otherwise not have the

opportunity because of their shifting bodily conditions, Lewis et al. (2006) argue that able-bodied performative ideals exemplified by stable attendance records and a culturally ingrained work ethic pressure individuals to meet unreasonable expectations that in the case of persons with episodic disabilities, intensify bodily symptoms that become increasingly difficult to manage. Discussing his trials in maintaining a job as a facilitator in a harm reduction program for recovering drug addicts, Paul relayed:

Sometimes my health impacts my job. I can be bedridden for a day and a half. It impacts your ability to work, to concentrate the way you need to. Then you end up worse off.

Describing an erratic dependability that is antithetical to full-time employment arrangements and the temporary, part-time, and often stand-by nature of precarious jobs, Jordanna commented:

I've been fired from a low-wage, temporary job as a cleaner because of my fibromyalgia flares. Sometimes I get very stressed out and sick on meds so how am I supposed to hold a job?

Chandra similarly noted that cycles of depression disrupt her work life:

No matter what kind of job I have, I get depressed and just don't want to do it anymore. For me to hold a job permanently, it doesn't work. I might slack off or ignore people. It's my strategy.

Questioning their body's trustworthiness as it shifts from health to illness and back again and apprehensive about tumultuous work patterns stemming from this friction, Chandra's comments highlight the tension between the demands for reliable, productive bodies and the ongoing challenge of coping with the fluid corporeality of their episodically disabled bodies. Since waves of bodily impairment will always pose difficulties for their labour force participation, the job tenure of episodically disabled workers can be short-lived at best, or exclusionary at worst.

Unable to anticipate when, where, or how relapses and remissions will occur, searching for work

and committing to jobs requiring a habitual physical and performative compliancy they cannot always meet engenders a life of insecurity and anxiety about the future.

The institutional structuring of the welfare system situates the body as a commodity through paid work to liberate disabled people from state dependency. This scenario requires episodically disabled workers like Calvin to take short-term jobs that can be antithetical to their physical welfare and safety. Caught between a welfare system that bureaucratically rejects the fluidity of their disabilities and work potential and an occupational culture in which a stable able body/mind remains the unquestioned norm (Wilton, 2004; Wilton & Schuer, 2006), individuals like Calvin, whose periodic seizures present a safety concern on the job, reluctantly accept any job, even when it threatens an illness episode because of the limited job options available to those with intermittent work capacity.

I didn't want kitchen work but it was pushed on me anyways. There might be a fire or danger working with knives. I need to be safe. But there was nothing else and because I have seizures, I can't do a lot of jobs.

Ultimately, episodically disabled workers often find themselves in a no-win situation in which the expectation and fear of preparing for, finding, and maintaining work when their health allows is complicated by unforeseen illness spells. The unpredictability of illness disrupts the hope of finding work and the ability to show up and do the job once employed. Consequently, Calvin expressed that managing one's health often takes precedence over working and the possibility of becoming increasingly ill (Ferris and Lavis, 2003). Differing from persons whose disabilities are embodied in a more permanent, experientially stable way that enables them to work with greater consistency, persons with episodic disabilities who are neither fully able or disabled struggle to attain economic and societal inclusion because of the fluctuations in their health and work capacity. Managing an episodic disability often becomes a full-time "job" in

itself that precariously situates individuals as able and ready to work sometimes, in the right conditions, and at other times, forces individuals to live with a shifting uncertainty that promotes an unstable, poor quality of life and ongoing economic and societal disadvantage in a precarious labour culture that remains closed to the diversity of disability.

Emotional Struggles

The process of acquiring a job and staying employed exacts a profound emotional toll on persons with episodic disabilities that remains an invisible, unspoken feature of their work lives. Chronic, self-injurious feelings of shame, incompetence, poor self-worth, hopelessness, and rejection pose serious obstacles in an unstable labour market where there is no room for personal shortcomings. Since work is important for promoting positive self-esteem (Shier et al., 2009) and access to meaningful, paid work is a basic right of every citizen (Prince, 2009), cycles of unemployment can influence how the participants feel about themselves privately and publicly as workers (Vick and Lightman, 2010).

To illustrate, episodically disabled workers internalize negative feelings that problematize the experience of disability within their turbulent bodies rather than how society excludes disabled bodies from the culture of work (Barnes, 2000). Commonly deemed the "hard-to-employ," (Lewis et al., 2006) because of the episodic character of their disabilities, three participants, in different ways, expressed concern about their potential for work. Feeling powerless over his inability to change his life circumstances, Jim relayed how humiliating and uncomfortable it is to explain lengthy gaps in work histories to prospective employers because of his shifting subjectivity and the negative psychological impact this vulnerability engenders (Ferris and Lavis, 2003). Prolonged absences from the workforce typically result in exclusion

from job interviews and preclude making relevant contacts. Jim discussed the dilemma in presenting as a competent, dependable worker in the face of illness fluctuations and a scant work history. Disclosing his despondency over being unable to find work and the isolation he experienced Jim stated:

I've been in the hospital a year and a half for the depression. That's a huge strike against me. I never got a lot of calls from prospective employers and I assume it's partly from that gap. It's finding work that's extremely difficult so I avoid it. I don't have a lot of hope that anything will work out.

Poor employer awareness and misperceptions of episodic disability as evidenced in a recent poll of Canadian workplaces (McKee, 2007), equally foster negative self-judgments and damaging impressions that exclude persons with episodic disabilities from labour force participation. Shier et al. (2009) highlight that because of this lack of awareness, negative labelling by employers remains a primary factor that psychologically impedes the search for and maintenance of work among persons with disabilities. Such stigma is a particular obstacle affecting persons with episodic disabilities. Terri, for example, mirroring Fowler's (2011) observations, suggested that employer misperceptions about persons with episodic disabilities as weak, sickly, indolent, sympathy seekers who exploit their illness for their own benefit are harmfully internalized and daunting to overcome in remaining employed.

People think people with episodic disabilities are lazy or that you're using your symptoms as an excuse. They don't understand you need to have the right job to maintain employment that considers your needs. It affects your self-esteem.

Living with the mutability of a traumatic brain injury, Mandy similarly contended that employer ignorance about episodic disability and partial work capacity breeds discrimination for those seeking jobs. Negative assumptions about ineffectual work performance among the episodically disabled ultimately lodged itself in an attack on Mandy's personhood based on a problematic mind-body rather than in an insensitive, disabling work culture that excludes the requisite

interpersonal and practical support to reasonably accommodate the needs of different bodies at different times (Crooks, 2007; WHO, 2011; Wilton and Schuer, 2006). Mandy recounted how individuals unable to function with a sound body and mind are considered "problem workers" and are unjustly penalized because they cannot meet the normative expectations associated with a forty-hour, five-day work week such as regular attendance, unwavering stamina, speed, and task flexibility. Describing herself as "File 13" material, the refuse of humanity that no one wants to employ, Mandy's feelings of powerlessness and frustration over future job prospects reflect her loss of hope of being a valued and productive member of society that being a worker entails.

People like me, we're File 13 material. You feel like garbage because there's no use for you. Who's going to train a 55 year old with a head injury? I don't know what to do to get a job.

As Jim, Terri, and Mandy's remarks imply, the precariousness of episodic disabilities as emotionally "lived-in" creates obstacles to finding and retaining employment. Self-injurious feelings including negative self-worth, failure, anxiety, and rejection are a largely hidden and painful reality that poses formidable barriers. While the privacy of emotional struggles necessitates validation and support, it is the systemic structuring of this emotional vulnerability and the distancing of participants from the paid labour market that equally demands our attention. An ablecentric discourse that constructs normative employment standards around "regular" work attendance, a steadfast work ethic, and employee reliability in repressive ways is adversative to the altering bodily rhythms of episodic illness (Vick and Lightman, 2010). An allegiance to ideals that promote a statically able embodiment rather than fluid ability is emotionally impairing and further substantiates employment inequities and deprivation among persons with episodic disabilities.

Neglected Bodies

Despite governmental intent to shift people from social assistance to paid work, many individuals are not "job ready" (Fowler, 2011). This lack of preparedness is evident within the problematic structure and practices of programs like the Ontario Disability Employment Support Program (ODESP) that assists persons with disabilities to obtain jobs by eradicating barriers to work. Forms of employment assistance available to those receiving ODSP include employment preparation and planning, job coaching, on the job training, help with workplace accommodation, job placement, and other forms of support (Fowler, 2011).

Negotiating successful employment within the ODESP has never been a reality for study participants, a finding echoed in related studies (Chouinard, 2010; Timmons et al., 2001). A performance-based funding model informs the ODESP. Employment service providers, contracted out by the Ministry of Community and Social Services who are responsible for the provision of welfare and the Ontario Disability Support Program among other community services in Ontario, receive payments for placing disabled clients in stable employment defined as 13 weeks duration (Fowler, 2011). This focus on the fastest route to employment through low-wage, unskilled, often physically demanding jobs homogenizes all workers as always ready, willing, and able to work at any job in any setting. Compounded with the competition for jobs in an already inadequate labour market, the fixity of this kind of employment model can result in poor outcomes rather than equitable job integration. Two participants commented on having to constantly explain to ODESP officials how physically demanding and hazardous work environments can exacerbate their disability and impact their safety. Jim and Calvin respectively

complained that the voices of persons with episodic disabilities and their rights as workers are rarely legitimately acknowledged in job placements. Jim said:

Service providers want you to get a job as fast as you can regardless of whether the job suits you. I have back pain and physical labour is not what I want but they come back with a job at Home Depot putting lamps together. They're only interested in placing workers in menial labour.

Calvin remarked:

I wanted to work three days a week but the employment worker said five. I told them I couldn't do that. They finally cut it down to three days, three hours a day. They sent me to a factory to work on a saw band. I told my worker I have seizures and she said "you're totally fine to work on this big machine by yourself. It's simple and easy." I had a seizure three different times.

For Jim, there is no recourse but to refuse jobs that are too laborious and that can endanger his health. There is no discussion with his worker about the ways in which an alternate, less physically strenuous job could work with appropriate accommodations. This situation contrasts with the stark risk that Calvin experienced in accepting a job he knew was both unreasonable and life threatening given his seizure disorder. The experiences of Jim and Calvin illustrate how barriers to work are often impossible to negotiate for ODSP recipients with episodic disabilities like themselves. The experiential complexity and employment rights of persons with episodic conditions are delegitimized by ODESP caseworkers because they lack elemental knowledge of and sensitivity to, the diversity of disability, the right to accommodation, and its relationship to a precarious work climate.

Program barriers also raised specific concerns for three older, episodically disabled workers with professional backgrounds. These participants stressed they were seasoned workers at the peak of their work lives who needed assistance with advanced job search strategies such as networking at higher levels of management and locating jobs beyond entry-level, unskilled labour that respects their unique backgrounds and skill sets, as well as follow-up support to

ensure necessary accommodations are implemented. Equally challenging, false assumptions made by service providers and employers that all persons with disabilities are poorly educated and only suited to trivial jobs (Chouinard, 2010) compound the labour market exclusion and underemployment of older, educated workers. Padma, a nurse with post polio syndrome from India in her late 40's, described her chronic unemployment and workforce exclusion this way:

I connected with disability job supports through the Canadian Paraplegic Association and the Ontario March of Dimes. I was a nurse in India for many years but they find me jobs like labourer, customer service. I am still looking for a medical job and it's been six years.

Mandy, a woman in her late 50's, remarked on the irony that employment programs are mandated to successfully position disabled workers in appropriate jobs but fail to implement creative solutions for integrating older people back into the workforce.

I went to an agency called WISE- Women in Successful Employment. Their mandate is to hire persons with a disability. I have yet to see any job openings. These agencies have the rap down pat but don't back it up with the actions. I mean there's flex time, job sharing. I've mentioned that and they look at me like I'm from the moon.

Charlie, a cost-analyst from East Asia in his early 60's, articulated his disappointment with employment support programs like "Ability Works" that is designed to provide assistance with job search, job coaching, and unpaid work trials in the community for persons with disabilities. Charlie stated that his frustration with this program is that it restricts clients from initiating contacting with employers directly in their work search efforts. This paternalistic concealment of and exclusion from the job search process curtails the autonomy of experienced, older workers who want to play an active role in their job search and the negotiation of job conditions. Questioning whether the practices of this program act as a barrier to finding work Charlie stated:

I am under the Ability Works Program. They forward your resume to companies and don't tell you what companies. They discourage persons with disabilities to write directly to employers. Is this a barrier? Yes. It's almost been more than a year and no job is available.

The competition for jobs in an insecure economy allows employers to exercise greater selectivity in choosing employees. Three participants noted forms of discrimination ranging from being refused an interview to being refused a job recommended by ODESP service providers. Charlie found that potential employers claimed they were committed to diversity in their hiring practices but in practice, privately discriminated against persons with disabilities as job candidates:

I have tried and tried in the banks. I told them I belong to a disability group and I never get an interview. Once I met a vice-president and said, "I have a disability, will it be an advantage or disadvantage?" She said, "We are committed to diversity."

More flagrant instances of discrimination characterized the work histories of two participants. Although George and Jeremy attempted to educate their employers about the episodic nature of their seizures, they found it challenging to convincingly present as a competent employee in work environments that demand physical normality rather than shifting bodies and less than exemplary bodily performances. As George described, this scenario can result in wrongful dismissal rather than supported job retention.

I was working at a cookie factory and I had a seizure on the production line. When I regained consciousness I tried to talk to them about the epilepsy and that I needed a break a few times a day. Then I had a holiday. When I came back, they told me we don't need you anymore.

Jeremy, who also experienced episodic seizures, affirmed:

I worked in the portrait studio at Walmart. The manager started raising an eyebrow when I had a seizure at work. I heard her say "I don't think he should be working here anymore because of his health." Then it was evaluation time. They let me go. Officially it was failure to meet company standards but I know it was my health. They covered it up.

Despite constitutional and advanced antidiscrimination legislation in Canada that promotes the equitable inclusion and treatment of all persons with disabilities in all areas of life, workplace discrimination including claims of wrongful dismissal remains a formidable barrier. Ultimately, for persons with episodic disabilities like George and Jeremy, unpredictable illness flare-ups can signal their liability as workers to employers rather than their right to be accommodated on the job. This kind of discrimination engenders violations of human rights instead of the implementation of legal protections that safeguard human dignity, worth, and security as equal employees.

Neglected Minds

Four participants observed that an immutable barrier to work was a palpable governmental disinterest in investing in the diversity of human capital among persons with episodic conditions. These participants specifically indicated that education and training geared to today's job market was crucial for developing updated knowledge and practical skill sets for effective work (re)entry and remaining competitive in the job market. Mike commented on the disparity of seeing public transit campaigns advertising the need for continuing adult education and his unsuccessful requests for funding to pursue certification as an English as a Second Language Instructor.

Everywhere I look on a subway it says George Brown College this, University of Toronto that, Seneca College this, "Be All You Want To Be." I get angry because I have the brains but there is no provision for that through ODSP. I've asked for funding several times but they always say no. I want a sustainable career.

Paul similarly remarked on the injustice in wanting educational upgrading but being stuck between the bureaucratic status of student and welfare recipient. Commenting on the

government's apathy towards the future of ODSP recipients beyond "survivor jobs" he remarked:

I wanted further training and my worker advised a student loan but who wants that? What about people stuck in-between? They want training but they're not students, they are within social services. They are writing disabled people off.

A disregard for participants' futures is also evident among creative and artistic people like Chandra. Chandra observed that there are no employment opportunities in the arts for social assistance recipients because of the questionable stability such jobs imply. Chandra's employment provider consistently failed to connect her with jobs where she could apply her skills in photography and graphic design implying that such jobs were neither available nor suitable for persons on social assistance. Rather than encouraging individuals to draw on their unique talents and interests, employment service providers offered only access to immediate, unskilled, insecure jobs. Consequently, Chandra terminated her relationship with her employment worker and independently secured a volunteer job that lead to stable part-time work.

I went to university for photography and graphic design but ODSP said we don't have jobs in those areas. There is no support for artists or creative people. I was sent to jobs that weren't suitable like switchboard operator, piecing clothing, or assembly line work. So I left and found a volunteer job that made use of my skills. That job is my current part-time job.

Similarly, Lorraine's interest in pursuing photography was not supported because it was perceived as an impractical option for ODSP recipients who are unpredictably ill and deemed incapable of meeting the demands of alternate, artistic careers. She stated:

They want people to go into positions that suit the government, not that suit the person and give them a quality of life. They don't support the arts because there is no guarantee of employment. I am interested in photography but they say, "How can you do that? Or what are you going to do with that?"

A culture that supports the aspirations, learning potential, and work needs of persons with episodic disabilities is vital to inspiring real hope and promising opportunities that lead to

economic security and social well-being. This scenario however, is far removed from the experiences of persons with episodic disabilities whose inability to participate continuously in the workforce places them on the social and economic margins (Furrie, 2010). Although mandated to erode barriers among the disabled for their equal participation in the workforce, the ODESP inspires little confidence and hope for individuals intent on securing meaningful employment when their health permits (ISAC, 2011). Despite their ardent requests for assistance with employer contacts, accessing jobs that respect their backgrounds, and funding for sustainable careers, the work lives of participants, akin to many episodically disabled people remain neglected.

Conclusion: Rethinking Barriers

People with episodic disabilities confront barriers that hinder their labour force attachment and aggravate their already precarious lives. In the end, the question is not whether persons with episodic disabilities can work but to what extent physical, emotional, organizational, attitudinal, institutional, programmatic, and environmental factors impede their ability to seek, maintain, and negotiate the conditions of work. While there are several implications surrounding the findings presented here, I limit my comments to a few key concerns.

As the participants' observations reveal, individuals have diverse experiences negotiating episodic disability within a precarious work milieu. Often, the instability of an episodically disabled body is managed in ways that respects both the fluidity of physical symptoms and the pressures of a precarious job culture at the expense of forfeiting one's health and safety to retain work. Psychologically, trying to attain a job within a work culture that perceives persons with

episodic illness as unreliable, unproductive workers erodes confidence and over time, diminishes the motivation to look for work. In addition, employer misconceptions about persons with episodic disabilities and instances of discrimination are vexing to battle. These barriers identified by participants are not fully recognized within contemporary labour markets and require intervention on several levels.

Many episodically disabled people want to work and could do so within a welcoming and accommodating environment in which shifting physical capacities and variable work potential are more flexibly and inclusively considered (August, 2009). Those involved with the training and job placement of individuals with episodic disabilities including government officials, employment service providers, employers, and community agencies need to be educated about how the inimitable features of episodic disabilities differ from more stable disabilities that do not alter over time and unpredictably affect work potential. Rather than subscribing to stereotypical assumptions such as that all persons with disabilities are disabled in the same ways across all circumstances and contexts, various officials, particularly those on the front-lines, need to cultivate a professional sensitivity to the diverse expression and value of disability and advocate for supports and job placements that recognize shifting disability subjectivities. This kind of awareness is essential to defending basic human rights and promoting the economic inclusion of disadvantaged populations.

Programmatically, employment and workplace policies affect how persons with disabilities get employed, stay employed, or become re-employed. Current performance-based models geared to placing people in unstable jobs fail to consider the personal interests, needs, and work rights of episodically disabled workers, especially for older workers with professional backgrounds. Many positions are too physically demanding and perilous given the nature of

some episodic conditions. Rather than mainstreaming persons with episodic disabilities into existing government employment programs, programs that address the unique complexities and work issues associated with episodic disabilities and intermittent work capacity should be considered. Efforts to involve persons with episodic disabilities in the development of such programs are essential. Innovative programs need to uniquely tailor client assessments and work plans to individuals in ways that recognize how disability fluctuations and personal work objectives vary across time and are shaped by changing labour markets. Ongoing evaluation and follow-up for individuals seeking work or already positioned in jobs is crucial to ensure a 'goodness of fit' between a person's skills, education, experience, and ongoing employment needs. An emphasis on antidiscrimination practices for continuing education and training, hiring, work retention, and worker accommodations such as rotating schedules, reduced hours, job reassignment, and alternate forms of work that are less physically onerous are vital for increasing the marketability of episodically disabled workers and promoting their labour market integration.

Despite the evolution of disability rights legislation such as the Accessibility for Ontarians with Disabilities Act (AODA), the Convention on the Rights of Persons with Disabilities (CRPD), and public policies that stress inclusion of disabled people in the labour market, people with episodic disabilities struggle in securing and managing work. Persons with episodic disabilities do not have equal rights with others, especially when it comes to the right to participate in the labour market. As a nation, Canada must continue its efforts to promote and ensure that human rights including the right to work are afforded to all citizens, particularly its most vulnerable members. The creation and promotion of laws and policies that recognize and legitimate the episodic nature of many disabling conditions and that support a more fluid

conceptualization of disability and work in the implementation of labour and antidiscrimination practices offers a sound beginning.

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