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Barriers to Employment Among Women With Complex Episodic Disabilities

Andrea Vick¹ and Ernie Lightman¹

Abstract

The expansion of the global economy, characterized by shifts in the organization of labor markets, has increased demands for flexible employment. Changes from standard, permanent employment relationships to nonstandard or “precarious” work arrangements have become the normative template in many work settings. Although significant scholarship explores precarious employment among the nondisabled, little work examines precarious work among persons with disabilities, especially women. Drawing on a secondary analysis of a series of longitudinal, semistructured interviews, this article explores the personal and structural barriers to employment that five women with complex episodic disabilities identify as welfare recipients within the context of precarious employment. Implications for practice relationships and policy that consider an alternative understanding of (dis)ability and employability as a contingent, fluid embodiment are considered.

Keywords

disability, episodic, women, employment, barriers

Recent decades have witnessed fundamental shifts in the organization of labor markets, the nature of work, and its embodied or bodily performance. Trends in globalization, growing competition associated with international trade, and technological innovation have led to changes from standard employment relationships characterized by permanent, regulated jobs toward nonstandard or “precarious” work arrangements (Vosko, 2006). Precarious work includes part-time, temporary, seasonal, contract, home-based, self-employment, multiple-job holding, on-call, and day labor, all of which are synonymous with widening economic and social vulnerability, insecurity, lower wages, poor working conditions, lack of benefits and protections, and inadequate training opportunities (Tomba, Scott-Marshall, Dolinski, Trevithick, & Bhattacharyya, 2007; Vosko, 2006).

Within the Canadian context, the 1995 provincial election in Ontario witnessed the rise of a government advocating a hard-right ideological agenda of radical welfare reform based on developments in the United States. Benefits were slashed, eligibility was tightened, and a new, inaccessible delivery system was introduced. Stressing that people are better off working in even low-paying jobs, such ideological currents culminated in the transition from passive programs of entitlement based on needs to active labor market policies with an explicit work-first or workfare orientation (Lightman, Mitchell, & Herd, 2008).

Social assistance in Ontario consists of two programs that remain intact. The first, Ontario Works (OW), consisting of

financial and employment support, was established in 1997 for nondisabled individuals deemed “employable.” Championing precarious jobs as the new normative model of employment and as a desirable alternative to social assistance, OW recipients are obligated to participate in one of three program streams: community participation (up to 70 hr of unpaid work in public and nonprofit settings), employment support (job search, skills training), and employment placement (Ministry of Community and Social Services, 2008). Although there is discretion to temporarily defer participation, individuals are required to sign a Participation Agreement to maintain their benefits and can incur penalties for noncompliance with program rules (Lightman et al., 2008). The counterpart to OW, the Ontario Disability Support Program (ODSP), established in 1998, provides long-term assistance for persons with substantial physical or mental impairments that are continuous or recurrent. Although some individuals with disabilities are capable of working with appropriate accommodations, they remain categorized as “permanently unemployable” and are exempt from work expectations (Stapleton & Tweddle, 2008).

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Although significant scholarship explores precarious employment among the nondisabled, little work examines precarious work among persons with disabilities. This paucity of research is more alarming for persons with complex episodic disabilities, especially women, despite findings that they are more likely to live with episodic illness, experience higher levels of unemployment, and be more susceptible to precarious forms of employment compared to men with disabilities (Evans, 2007; Tompa, Scott, Trevithick, & Bhattacharyya, 2006).

This article describes the personal and structural barriers to employment that women with complex episodic disabilities identify as welfare recipients within the context of precarious employment. We define *complex episodic disabilities* as fluctuating mental health issues that coexist with the volatility of physical health conditions in relation to changing bodily experiences, life circumstances, and physical environments. Two objectives inform our discussion. First, our intent is to open dialogue about the challenges that women who are episodically disabled experience in obtaining and retaining employment that remain on the investigative margins. Second, we suggest initial directions for practice and policy that consider an understanding of disability and employability as a contingent, fluid embodiment. Although this article specifically refers to the employment barriers encountered by women with complex episodic disabilities in Ontario, the issues identified have wider applicability for similar welfare systems given the increasing prevalence of precarious work globally.

Theorizing Complex Episodic Disabilities

The social model has been a revolutionary catalyst in transforming an understanding of disability from medical abnormality and personal tragedy to sociopolitical oppression. However, extricating the body from the equation of cultural oppression does not adequately address the experience of complex, fluctuating disabilities (Driedger & Owen, 2008). We propose a more porous framework that calls forth interpretive relations to both the experiential and the social. Drawing on interpretive sociological theory and queer scholarship (Vick, 2007), we develop the notion of “precarious bodies” to suggest that women with complex episodic disabilities live in between fluid realities of shifting bodily conditions, identities, circumstances, and contexts that are just as tenuous as the jobs they seek and sporadically occupy.

Precarious Bodies as Living In Between

There is limited literature theorizing the space between illness and wellness. Yet this transitional space is where many persons living with complex episodic disabilities dwell. Khayatt (2002) asserts that living in between reflects bodily

boundaries and identities that are elastic, sometimes accommodating fused alliances and sometimes embodying incongruities. This way of positioning bodies as precarious does not reify flux or the complete dissolution of any one identity but highlights the constitutive permeability of moving back and forth between embodied states and identities.

In their study of women with fluctuating illness, Moss and Dyck (2002) posit living in between health and illness as neither a merging of opposite states of being nor an oscillation between polarities, but an inhabiting of permeable borders that are fused, fleeting, and held in tension. From this vantage point, individuals with precarious bodies are both neither or provisionally well, ill, able, disabled, employable, and unemployable. Delineating this destabilization, Jackson (2005) conveys that individuals “threaten the logic of [classificatory] system[s] by straddling boundaries. [They] are neither properly well nor properly sick[, which] puts them betwixt and between the statuses of sick and well” (p. 345). Paterson (2001) characterizes this in-between ontology within a shifting perspectives model in which a person oscillates between illness in the foreground and wellness in the foreground as the illness experience and its personal and social contexts change. Following these perspectives, we suggest that living with a complex episodic disability implies embodying permutations of (dis)ability and (un)employability that arbitrarily shift depending on the body’s physicality and situatedness from moment to moment and day to day.

Precarious Bodies as Fluid Identities

The cutting-edge work of queer studies scholars complicates how we understand the embodiment of disability. The term *queer* is an umbrella expression that is not so much an embodied state or sexual orientation but a designation that twists any imagined correspondence between bodies, self-presentation, and self-identity (Scott-Dixon, 2006). Contextualizing complex episodic disability from the port-hole of queer theorizing frees us from the grasp of pre-given, fixed identities, thereby undermining notions of static, enduring embodiments. By elastically crossing shifting material (biological), experiential, and discursive boundaries, there are no cast-iron universals of bodies. Instead, there are only fluctuating, contingent, fluid bodies and identities that malleably contract and expand from one side of the binary (health/illness, ability/disability, employable/unemployable) to the other or that resist a divisive embodiment altogether (Colligan, 2004). In this way, persons with complex episodic disabilities, such as persons with mixed gender and sexual identities, are “bodies-at-odds” culturally existing in disarticulated ways because they possess the ability to live sometimes as healthy, sometimes ill, sometimes employable, and sometimes unemployable (Sandahl, 2003; Wilson, 2002).

“Queering or complicating an understanding of disability thus implies opening critical spaces of representation where multiple subjectivities or different versions of bodies and selves are the norm.” (Budgeon, 2003; McRuer, 2003; Sherry, 2004). By entertaining a shifting core of multiple selves and attenuating cherished cultural beliefs that the body is the unchanging anchor of identity, we come closer to what Siebers (2001) refers to as “a new realism of the body.” Advocating multiple subjectivities rather than absolute contrasts, Mintz (2002) avers that because disability is a universal experience, we must open ourselves to rethinking it in alternative ways that resonate with its volatility across periods of calm and unrest. This latter point is crucial given that knowledge of complex episodic disabilities as a fluid embodiment and identity remains far below our cultural and political radar.

Method

This article reports on a secondary analysis of 25 semistructured, qualitative interviews conducted annually over 5 years with five women living with complex episodic disabilities in Toronto, Ontario, Canada. The women were part of a larger longitudinal study conducted between 2002 and 2007 known as the Social Assistance in the New Economy (SANE) Project. This larger project examined everyday life experiences with social assistance, health, hunger, food security, poverty, and employment within the context of a global economy (Lightman, Herd, & Mitchell, 2006; Lightman, Mitchell, & Herd, 2005a, 2005b).

The larger study began after receiving ethics approval from the University of Toronto’s Office of Research Services. Following this, 1,500 male and female social assistance recipients randomly drawn from the Toronto Social Services master database of 80,000 claimants received a study invitation letter detailing the nature and objectives of the study. Participants were provided with a telephone number to contact the research team directly to indicate their interest. The letter assured potential participants that their participation was voluntary, that all information collected would remain confidential, and that access to welfare benefits and services would be uncompromised. In total, 123 participants contacted the research team. Over the course of the five interview rounds, there was substantial attrition due to lack of participant availability, changes in address and telephone number (or loss of phone service), lack of sustained interest, and other reasons unknown to the research team. This was expected given the unstable lives of many welfare recipients. In total, 203 interviews were conducted, guided by a partially open-ended schedule focusing on participants’ experiences from year to year with the welfare system and issues of hunger, food security, poverty, and labor market participation. Participants received a small honorarium of \$25 for each interview and, where applicable, transport and child care costs were paid.

Although respondents are not statistically representative of the larger population of social assistance recipients in Toronto, the available literature implies that the experiences described are indicative of the challenges faced by many individuals receiving welfare or who are members of the working poor (Lightman et al., 2005a).

All interviews were audiotaped, transcribed, and coded. Field notes were written following the interviews. The majority of the interviews, which lasted approximately 1 hr, took place at the Faculty of Social Work, University of Toronto, as this proved a readily accessible setting for participants. All information collected from interviews, including tapes, transcriptions, and field notes, were numerically coded and stored in a secure facility.

Data Analysis

In revisiting the SANE Project’s longitudinal data, the authors of this article identified a subset of 25 interviews in which issues related to the experience of disability and employment warranted further investigation. This secondary analysis informs our present discussion. Our intent with this secondary examination of 25 qualitative interviews conducted with a subset of five women living with complex episodic disabilities is not to provide exhaustive explanation but to profile the relationship between complex episodic disability and precarious work, an issue that remains largely unexplored in the literature on disability policy.

With this second tier of analysis, we approached the data anew to tease out, in a more nuanced way, interpretive connections between complex episodic disability and barriers to employment. Given the small number of participants, a hands-on, modified, constructivist thematic analysis (Charmaz, 2000; 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 characterize the secondary analysis. In the first phase, to obtain the present working sample, 203 interview transcripts derived from the original project were electronically reviewed by entering key search terms such as “disability,” “health,” “illness,” “work,” “jobs,” and “barriers” to narrow the scope of the data. Twenty-five interviews and their corresponding field notes were identified and then read to glean an overall vision of their content. Specific paragraphs of text, phrases, and words that described the experience of episodic disability and employment challenges were identified. In the second phase, selected sections of interview text were cut and pasted onto large index cards. These “data cards” were conceptually organized into broad themes such as bodily experiences, emotional struggles, lack of understanding, job challenges, and institutional barriers. In the third phase, we refined the descriptive and substantive connections between themes and collapsed them into two major analytic frames (personal and structural barriers) and

various subthemes (precarious bodies, emotional struggles, institutional misunderstanding, employer misunderstanding, and the embodiment of work). This interpretive scheme forms the basis of our discussion. A colleague familiar with the research findings engaged in an independent review of the codes and provided feedback for purposes of internal consistency. Although we distinguish between personal and systemic employment barriers for analytic purposes, we recognize that they are not mutually exclusive but interconnected in the women's lives.

Participant Overview

The five women living with complex episodic disabilities whose experiences form the basis of our discussion are between 30 and 49 years of age. Although all five participants experience depression, the contexts of their experiences vary in relation to conditions including Bipolar Disorder, Posttraumatic Stress, Seasonal Affective Disorder, and Dissociative Disorder. Complicating their mental health histories, four women live with fluctuating physical conditions that magnify their mental health problems, including bulimia, diabetes, arthritis, panic attacks, anxiety, and learning difficulties. At the time of the interviews, all the women lived in Toronto, Ontario. Four women are single, and one is a single parent. Of the five women, three reported cycling on and off OW as they moved into and out of the labor force. Two women experienced longer periods of unemployment and did not transition between assistance and paid work. Although respondents are not statistically representative of the larger population of social assistance recipients in Toronto, the available literature implies that the experiences described are indicative of the challenges faced by many individuals on welfare and who are members of the working poor (Lightman et al., 2005a). Pseudonyms are used throughout.

Personal Barriers

Precarious Bodies

Poor health and disability are major barriers to negotiating employment (Statistics Canada, 2008). Yet little is known about how bodies that shift between quiescence and chaos affect, and are affected by, the experience of precarious work. The interminable fear of capricious shifts in physical and cognitive functioning, pain, fatigue, varying energy levels, side effects of medication, and the uncertainty of one's health trajectory stymies participants' ability to explore employment options and work with any degree of consistency (Ferrier & Lavis, 2003; Tompa et al., 2006). Introducing how fluxing bouts of depression complicated by multiple health problems circumscribes her capacity to work for any length of time, Candace exclaims:

I have depression, arthritis, high blood pressure, diabetes, trouble with my back and neck, and my memory is bad. I haven't always been on welfare. I haven't completely got off because I don't know if I'm going to be capable of working. That's my worry.

Sharing Candace's concerns, Deena explains:

My biggest barrier getting a job is my seasonal affective disorder. Last year I stayed home and in summer months, I get better. Another barrier is my bulimia. I gained a lot of weight and it has affected my health. I also have arthritis. There have been times that I got a job but wasn't able to keep it cause I would get sick in different ways.

For Lewchuck, Clarke, and de Wolff (2008), Candace's and Deena's trepidation mirrors "employment strain." The constant search for work and efforts to keep working are common stressors confronting contingent workers. Sverke, Hellgren, and Naswall (2002) add that job insecurity is equally burdensome precisely because of its prolonged ambiguity. When applied to persons with complex episodic disabilities whose lack of control over job opportunities and experiences of the threat of work continuity and economic marginality are already magnified by the instability of their erratic bodies, such insight directs attention to how the strains associated with precarious employment further "disable" individuals and exacerbate their vulnerability as periodic workers.

Inherent to their bodily discord, participants perceive themselves as unreliable or "risky" workers because the constant threat of getting sick implies that they cannot predict when intervals of health and illness will appear and how long they will last (Honey, 2003; Tompa et al., 2006). Unable to anticipate when, where, or how relapses and remissions will occur, women fear exploring work options and leaving the stable refuge of income security programs to commit to jobs requiring a habitual physical and performative compliancy they cannot always meet (Tompa et al., 2007). This revolving unease associated with deficits in human or bodily capital, coupled with reservations about job retention, specifically becoming acclimatized to the routine and discipline of work, ultimately perpetuates women's self-identification as "labour market liabilities" (Barron & Salzer, 2002). Cathy, who experiences panic attacks, memory problems, and depression, attests to how the ebb and flow of her disabilities intermittently force her out of the labor force without warning and back into an unsettling cycle of welfare exits and (re)entries:

I have anxiety and panic attacks and depression. After being on welfare, I got better, went back to work, then didn't work for a while, then went back on. I got three different jobs and the last job I lost

because of my memory problems. There wasn't any sense of security.

Sharing her trials in sustaining a job as a massage therapist with a body that capriciously moves between moments of (in)coherence due to disabling blackouts, Abbey relays:

The main barrier for me finding work is my dissociative disorder. I black out. Sometimes it's only ten or twenty minutes. Sometimes I don't even know they've happened. So there's no consistency for me to go out and work on a full- or part-time basis. I'm not reliable. If my boss calls me to do a massage, I sometimes can't because I'm not well enough to leave the house. If I was an employer, I wouldn't hire me.

Abbey observes that living with an episodic mental health disability that shuttles her between moments of (un)consciousness parallels an erratic dependability that is antithetical to full-time employment arrangements and the temporary, part-time, and often standby nature of precarious jobs. Driedger (2003) comments that because women who are chronically ill cannot guarantee they will feel well enough to come to work with any consistency, their situation directs attention to the nature of work in our society and the rigid ideals of flexibility exemplifying 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 bodies, Lewis, Lee, and Altenbernd (2006) argue that pressures including a stable attendance record and a culturally ingrained work ethic supporting performative ideals may intensify bodily symptoms. Speaking to this scenario, Abbey intimates that routine absences from the workplace due to her fluctuating illness course are fatal obstacles to entering the job market and remaining stably on the job (Schur, 2003):

I have so many doctors' appointments. I see my psychiatrist every week. Who is going to hire me when I say, "Oh I can't work on Thursdays. I need to see my psych."

Mirroring Abbey, Deena contends that the "ups and downs" of her health problems restrict her participation in the labor force with any constancy:

It's been up and down trying to work with my health issues. I keep wondering if I get a job, can I keep going regularly. Am I going to be calling in sick before the three-month probation? That's my big concern.

Similarly commenting on how her mental health problems from alcoholism and an eating disorder jeopardized her job at a doughnut store and seriously affected her health by exposing her to dangerous food choices, Amy conveys:

A real barrier to getting back into the workforce is my alcoholism and my eating disorder. I have bingeing and purging episodes. Right now, I can't work. I need to get well to work. My last job was at a doughnut shop and it wasn't the best place to be because I was dealing with [an] eating disorder and trying to get myself together.

Questioning their bodies' trustworthiness as they shift from health to illness and back again and apprehensive about tumultuous work patterns from this friction, participants highlight the tension between the demands for reliable, productive bodies and the fluid corporeality of their episodically disabled bodies. Complicating this scenario, while welfare restructuring situates the body as a commodity through paid work in order to "liberate" people with disabilities from state dependency, women like Amy commonly take jobs they are not well suited to because the turbulence of their disabilities, as embodied in the turmoil of their labor power, circumscribes other job choices. Furthermore, as a gender, women with disabilities are highly concentrated in semiskilled and unskilled jobs and are forced into segregated jobs to maintain their income benefits (Fawcett, 2000).

Beyond the assuredness and what-ifs of wavering symptoms, job interruptions, and prospective job loss, women with episodic illnesses struggle as social assistance recipients with the expectation of preparing for work precisely because of their volatile subjectivities. Because they are not always ill and have the capacity to work when their health permits, these women are institutionally socialized in accord with able-bodied norms that denote an unchanging, foreseeable health status rather than an unsettling, evolving one. Articulating how bureaucratic demands for job readiness counteract what it means to live with shifting disabilities, Candace explains:

They push you to work, volunteer, get out there for a job. I can't always hold a job. I gotta see about my health because there's no point going out and all of a sudden, you're worse.

Eventually, women with episodic disabilities find themselves in a catch-22 position in which the expectation and fear of preparing for and finding work when their health allows are complicated by unforeseen illness spells. Consequently, as Candace implies, managing one's health takes precedence over the short-term benefits of working and the possibility of becoming increasingly ill (Ferrier & Lavis, 2003). Bolstering this view, Fawcett (2000) claims that even though employment is the best defence against poverty, many women prefer to rely on the stability of meager social assistance payments rather than risk taking a low-paying job they may not be able to keep because of fluctuations in disability.

Emotional Struggles

Transitions between health, illness, employment, and unemployment exact a profound emotional toll on women. Feelings of inadequacy, shame, incompetence, poor self-worth, and rejection erect barriers to acquiring and keeping jobs in a competitive economy in which there is no room for personal shortcomings. Because productive work is fundamental in promoting positive mental health and access to meaningful paid work is a basic right of every citizen, cycles of unemployment influence how women feel about themselves privately and publicly as workers.

Women with complex episodic disabilities are subject to perceived and actual employment discrimination on several levels (Fawcett, 2000). An invisible and unspoken feature of this disadvantage is the self-injurious feelings Amy and Deena allude to that locate the "problem of disability" (Titchkosky, 2007) within their turbulent bodies rather than in the ways society excludes disabled bodies from the culture of work (Barnes, 2000). Commonly deemed the "hard-to-employ" (Lewis et al., 2006), these women express how awkward, humiliating, and uncomfortable it is to explain lengthy gaps in work histories to employers because of their troubling shifting subjectivities and the psychological impact this vulnerability engenders (Ferrier & Lavis, 2003). Amy and Deena respectively concur:

It's a big issue, the disability, the self-confidence, the shame of being out of the labour market for so long and having to explain to employers why. It's frustrating to be turned down for jobs.

With the gaps in my work history because of my illness and them asking where you've been working for the last couple of years, like what do you say? It's an awful feeling.

Similarly, feelings of ineptitude and disenchantment inhibit women from reentering the workforce after prolonged absences. Although part-time and temporary jobs offer individuals with complex illness the opportunity to test their abilities as they transition from phases of unemployment into more stable work periods (Schur, 2002), difficulties performing work tasks and meeting employer expectations are often insurmountable challenges to remaining on the job (Human Resources Development Canada, 1999). Candace portrays how the transiency of her disability betrays her self-confidence as a retail merchandiser and incites feelings of inferiority:

You go out and work and you really believe you're doing something right until they tell you it's wrong. They tell me to set up a display but when I do it, they

say that's not what I told you. I have problems retaining stuff and concentrating. My mind mixes things up sometimes. It affects you personally and you start believing you're stupid.

Struggling to demonstrate that she has the proficiency to arrange a store display, Candace conveys the frustration and degradation she experiences in relying on her ability to cognitively process information correctly but being informed that her efforts are unsuccessful. Although many people with cognitive disabilities require additional time to familiarize themselves with work tasks, Candace interprets her ineffectual performance as an attack on her personhood based in a problematic mind/body rather than in an insensitive, disabling workplace that excludes the requisite interpersonal and practical support to accommodate the needs of different bodies at different times (Crooks, 2007; Wilton & Schuer, 2006).

Given that workforce participation (and exclusion) influences the self-esteem of persons with disabilities (Shier, Graham, & Jones, 2009), a culture that supports the changeable employment needs and challenges encountered by persons with complex episodic disabilities is critical to developing better opportunities for income security and social well-being. Although they are structural barriers, limited education, fewer marketable skills, and inadequate training opportunities are also emotionally embodied, contouring a woman's self-worth and impeding employment potential. Amy's circumstances parallel findings suggesting that despite governmental intent to shift people from social assistance to work, most employment programs are available more in theory than in practice and fail to provide appropriate assessment, job search, and training for those who can work periodically (Timmons, Foley, Whitney-Thomas, & Green, 2001). For persons with complex episodic disabilities who require long-term or ongoing job support, such strategies contradict legislation mandating the shortest route to employment and neglect the mutable character of many disabilities within the context of current labor markets (Income Security Advocacy Centre, 2004). Given the lack of investment in education and skills training and postemployment resources, women with complex episodic disabilities continue to enter unstable, low-paid jobs that do not improve their quality of life. Referring to the futility of a government work contract, the absence of conversation regarding training options, and the despondency this entails, Amy discloses:

The Participation Agreement was something shoved in front of me and I signed. There was no discussion of a plan towards employment. Ontario Works won't help me get a job. They don't really work with people to get them back on their feet. If you're not being given opportunities to go forward with training, it affects your self-esteem. You end up going nowhere.

Differing from Amy, Cathy articulates a favorable outcome from job preparation courses that resulted in three interim placements. Tempering her optimism, however, is the marked insecurity of workfare jobs characterized by company layoffs and organizational restructuring that prompt Cathy's premature dismissal and return to welfare during periods of relatively good health (Lightman et al., 2005b):

Ontario Works set me up with training courses. I went to a course at Job Start and I got three jobs through them. . . . But they send you to places that are in receivership or downsizing. That's what happened to me and I was well then. So there's no security.

The precariousness of complex episodic disabilities as physically and emotionally "lived in" raises unique obstacles to securing and retaining employment in a global economy in which the organization and conditions of labor markets aggravate rather than support the variability of women's needs. In tandem with personal barriers that catapult women across intervals of health, illness, employment, and unemployment, women experience systemic barriers that circumvent their labor force participation, a topic explored next.

Structural Barriers

Institutional Misunderstanding

The experience of disability is as much about what happens inside bodies as it is about how society constructs the experience of bodies. Bureaucratic dictates mandating work preparedness expose women with complex episodic disabilities to systemic barriers that construct the experience of disability and employability in intransigent, oppressive ways. Programmatically, within welfare systems that condition persons for a volatile labor market, job preparation rests on individuals to "rehabilitate" themselves toward rapid (re) entry into the workforce rather than addressing how welfare policies, guided by the culture of precarious work, impair those with cyclic disabilities (Broad & Saunders, 2008). This prescriptive, individualizing treatment ethos neglects the experiential complexities of episodic disabilities and the need for accommodating practices and policies. The reality that disability affects people in different ways and that individuals with the same disability may have different needs across different times remains unacknowledged in the actual translation of workfare programs and policies. Amy reasons that caseworkers lack elemental knowledge of and sensitivity to the diversity of disability in relation to the uniqueness of each person's changing (in)capacities, variable work potential, and life circumstances. Instead, government officials, guided by a one-size-fits-all model of employment reattachment, homogenize all workers' bodies

as always ready, willing, and able to work. As a result, women like Amy are compelled to be immediately job ready and can become ill:

I'd like to see people who have physical and mental health issues and cannot work at times have different workers . . . people with more tolerance. The caseworkers don't understand disability. I wasn't ready to be working one time and I got sick from it. So that's a real barrier.

Moss and Dyck (2002) indicate that fluctuating illness discursively destabilizes immutable bureaucratic scripts of health, illness, ability, disability, employability, and unemployment that are tightly woven into the ableist fabric of society. Translated into the practicalities of the welfare system, employability, as exemplified by ideals of bodily performance, is not a matter of degree but an unchanging state. Consequently, institutions pressure persons to identify with an either/or status as able or disabled, employable or unemployable, rather legitimating in-between, fluid identifications (Moss, 2000). As Amy's observations evince, this divisive packaging and the inequity it engenders preclude developing insight and support that are responsive to the nuances of disability.

Employer Misunderstanding

Women with complex episodic disabilities are caught between a welfare system that 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). The latter, as Candace concedes, is on par with existing institutional ignorance of what it means to live with fluxing capacities and the discrimination they breed on the job. Recollecting the tension between job performance expectations intrinsic to a precarious work culture—such as quick familiarity with tasks, adaptability, competency, and productivity—and her difficulty following instructions because of changes in memory, Candace remarks:

I worked at Buck or Two for seven months but they laid me off. When I've had jobs, they would eventually lay me off and I always wondered why. I could tell something was up because they used to repeat things to me. A friend would tell me, "something is wrong. Why aren't you getting it?" I really believe it has to do with my problems but they're not going to tell you that.

Corroborating Candace's suspicions, Magee (2004) affirms that performance deficits associated with disabling illness increase the likelihood of discharge. Wendell (1996) cautions that it is problematic to present as a competent

worker with fluctuating bodily symptoms in precarious work environments where the practices of physical normality are antithetical to shifting bodies and less than exemplary bodily performances. Hence, Candace's trouble processing information and her dismissal not only are discernible indicators of a body failing to conform to expected intellectual norms but also accentuate how the embodiment of work experientially and ideologically disables workers.

The Embodiment of Work

The precarious position of complex episodic disability within the global economy is endemic to the social organization of work. Epitomized by ablecentric discourse depicting the normative worker who embodies unwavering stamina, speed, and agility and who embraces a 40-hr, 5-day workweek, the nature and embodied performance of contemporary work sanction a disabling work culture that oppresses bodies defying conformity. Individuals unable to function with a sound body and mind, as Candace evinces, are "problem workers" and unjustly penalized. Although part-time and temporary jobs are advantageous for persons with health problems because of the discretion they provide over scheduling and the management of physical energy (Schur, 2002), rigidly imposed conditions of versatility and the insecurity of jobs can agitate fluctuating limitations. Demands related to the scheduling, pace, specificity of tasks, and changing physical environments can be adversative to the altering bodily rhythms of episodic disabilities. Jobs that demand flexibility from workers offer little flexibility in return and exclude bodies with differing work capacities. As the participants' accounts indicate, flexibility means something different for persons with complex episodic disabilities. To expect persons with disabilities to work in a conventional sense and be as productive as the nondisabled is one of the most repressive aspects of modern society (Barnes, 2000). Not everyone with a disability can or should be expected to work in the same way, at the same pace, and under the same conditions as the nondisabled. Bodies that work fast, work hard, and easily conform to changing employer needs disadvantage and devalue persons whose shifting biographies transgress contemporary notions of work and worker flexibility (Driedger, 2003). Consequently, measures purported to increase worker flexibility, in actuality, discriminate against bodies requiring greater leniency.

The organization and meaning of work are social constructions and, like all social constructions, are subject to change (Barnes, 2000, p. 445). Although a full exploration of the concept and practice of work is beyond the scope of this article, we suggest that any transformation in thinking must include the standpoints of persons with disabilities and advocate pliant protocols that account for volatility as expected, routine, and "normal" (Moss, 2000). Echoing this

amenability, Abby claims, "I can't function on a full-time basis so my boss says I can come in when I can. My goal is to work two hours a day." Such modifications and others, including job sharing, task adaptation, job redesign, partial work hours, rotating schedules, and working from home, better reflect the shifting capacities and equitable integration of workers (Cohen et al., 2008).

Rethinking Barriers: Implications for an Embodied Politics

The personal and systemic barriers that participants struggle with hold implications for practice relationships and policy. 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 preparing for, securing, and retaining work within an occupational milieu, echoing its own risks and instabilities. As the participants' observations illustrate, episodic disabilities vary across physical, personal, and contextual dimensions. Fluctuations in disability can have vastly different impacts on different people that change with time and across circumstances. Given this, disability and employability are not constant, foreseeable, permanent events but rather libratory subjectivities that conflict with welfare tenets espousing the permanency of job readiness, compliance, and malleability. Because women's waves of bodily impairment and the nature of precarious jobs will always pose difficulties for their labor force participation, premising income security on the unassailable value of work, its stability, and the physical and performative disciplining of bodies is unconscionable and unjust.

Government officials need to understand the problems individuals face before offering viable solutions (Matthews, 2004). As a first step, frontline workers require specialized training that distinguishes the features of complex episodic disabilities from disabilities whose bodily materiality does not dramatically alter. For those who navigate the peaks and valleys of episodic disability, the transition from welfare to work is not a linear route but an evolving process without finite resolution. Interventions geared to rapid, sustained (re)employment contravene a vacillating embodiment in which health improves and then worsens and, in turn, in which employment is attainable and, at times, unfeasible. Tailoring assessments and employment plans to recognize how disability fluctuations, employment status, work objectives, and client strengths vary across time and are shaped by changing labor markets is imperative. Providing this assistance in a supportive, nonjudgmental manner lays the foundation for establishing positive, client-centered relationships that legitimate employment success in alternative, less resolute ways.

Raising consciousness of disability trajectories and applying an ethics of care in practice extend to employers, community organizations, and service providers that partner with the government in the training and job placement of individuals. Given the prevalence of nonstandard jobs among persons with disabilities and the barriers they create, interest groups need to be educated about how dimensions of work insecurity intersect with the fluxing of bodies. Because disability is part of the human condition, understanding the ways it permeates all aspects of life, particularly working life, is crucial. Many people with episodic disabilities want to work and could do so within a welcoming and accommodating environment in which work potential and productive capacity are more flexibly and inclusively considered (August, 2009). Although finding supportive employers and coworkers may prove problematic with the growth of precarious jobs and erratic work patterns, this instability holds promise for rethinking the nature of employment flexibility that is responsive to the shifting patterns of precarious bodies and precarious work.

The new paradigm of disability underscores an inclusive social citizenry through the advancement and protection of human rights. This objective remains largely absent in policy at the governmental level. Employment inequalities remain institutionally perceived and managed as individual rather than systemic failures (Barnes & Mercer, 2005). Legislation designed to liberate marginalized populations from economic dependency through paid work remains unsympathetic to persons with complex episodic disabilities. The material and discursive onus on “fixing” individuals through “learn-fare” programs (Torjman, 1996) informed by unattainable and discriminatory able-bodied values neglects the wider sociopolitical landscape framing worker identities and jobs as precarious.

The borders between the lived experience of disability and its legislative construal are wide (Lightman, Vick, Herd, & Mitchell, 2009). Language, as part of policy design, shapes how we think about and identify disability. Yet “The problem of disability is explained as if it resides in embodiment alone, and the social processes of interpretation that help to constitute disability as such are typically excluded from collective consideration” (Titchkosky, 2007, p. 134). The rhetoric of welfare regards disability myopically rather than pluralistically. One must be entirely well or sick, able or disabled, and employable or unemployable rather occupying an in-between embodiment. These classificatory schemes should be reexamined to include alternative, more malleable descriptors that subjectively resonate with the cyclic character of episodic disabilities such as “employable if and when able,” “periodically employable,” or “partially employable” (Canadian Working Group, 2006). Prince (2008) argues that these kinds of intermediate categories could combine flexible, person-centered income protections with rehabilitation and employment services for those who move on and off jobs. Although these designs have not yet entered into political consciousness and disability policy, it is not beyond feasibility that positive change might occur.

More concretely, welfare rules place individuals with complex illness biographies at risk by exacerbating poverty and human indignity through the promotion of insecure jobs, poor wages, and normative ideals that many cannot achieve. Attempts to integrate vulnerable bodies into the workforce remain unaccompanied by proactive strategies that promote access, inclusion, and equity. Given that disability exists across a wide spectrum, approaches focused “beyond work-first” (Herd, 2006) toward a continuum of options that invest in the health, income security, and actualization of human potential across the life course demand greater legitimacy. Mindful of this reasoning, the challenge for policy makers becomes one of aligning stable social protections with strong incentives that promote the participation of all bodies in society.

Ultimately, in suffering the brunt of a social assistance system and volatile economy in which working for welfare precedes the welfare of human beings, women with complex episodic disabilities encounter multiple barriers that preclude the economic independence demanded of them. By rethinking the chasm between barriers and opportunities, and between conditional protections and enduring supports, we come closer to an embodied politics that recognizes the precariousness of all lives and acknowledges the risks we must take for the well-being of all society’s members.

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