Overview: From Invisibility to Inclusion (i2i)

*From Invisibility to Inclusion: Developing and Evaluating Policies and Practices to Facilitate the Inclusion of Workers with Episodic Disabilities in Ontario Workplaces* is a 4-year SSHRC-funded Insight Grant that brings together researchers, business professionals, NGOs, and arts communities. This intersectoral and interdisciplinary research aims to improve social, economic and employment opportunities for people with episodic disabilities (EDs). The project examines and assesses existing information about demographic characteristics (prevalence, employment patterns) of persons with EDs, and the laws, policies, and programs that currently address responses to persons with EDs in Ontario workplaces. It also generates knowledge based on insights gained from online surveys, interviews, and arts-based digital stories, knowledge that can be used as resources to enhance employers’ and co-workers’ attitudes and perceptions and to facilitate organizational change.

While technology continues to flourish, and more discussions centre around technology within the workplace, individuals with disabilities continue to be largely excluded from the conversation. Discussions like the one taking place at the *Roundtable on The Socio-Economic Impacts of Disruptive Technology: Opportunities and Challenges* are critical to ensure that employees with disabilities are able to have their voices heard regarding which technology would be helpful, and which would be harmful in terms of their employment prospects. In this brief, we explore disability, the social model of disability, episodic disability, and the role of technology in the workplace as it pertains to episodic disability.

What is Disability?

A dominant way of understanding disability hinges on the medical model, which asserts that a person’s impairments or physical differences are the root cause of disability and disadvantages. The medical model looks at what is ‘wrong’ with a person and holds that differences should be ‘fixed’ or changed by medical intervention and other treatments. This approach to understanding disability is firmly rooted in individualism indicates that if you have an impairment, the problem is your body. The medical model of disability
takes little or no account of environmental impacts on how disability is understood, represented, experienced or generated. It may contribute to people losing independence, choice and control in their lives.

An alternative way to understand disability is through the social model. The social model of disability, which highlights that disability is caused by social organization and physical infrastructure rather than by a person’s impairment or difference. It reflects that social and structural barriers restrict access to life choices for people with disabilities. This definition acknowledges the complex interplay between self and other, individual and environment, and the ways in which our social and physical climate can exacerbate or create disability. Using this model allows educators, policy makers, advocates, and individuals to thoughtfully consider how to create living, working, and playing spaces that are increasingly barrier-free not only for disabled individuals, but for all Canadians. Moving toward a social model of disability involves profound shifts toward seeing the world as comprised of difference, and seeing this difference as vital to the dynamism of social life.

What is Episodic Disability?

From Invisibility to Inclusion draws, on the path-breaking work of REALIZE (formerly the Canadian Working Group on AIDS and Rehabilitation) to define episodic disability (ED) as a physical or mental condition characterized by unpredictability and variability in the intensity and severity of impairments that results in a fluctuating capacity to conduct daily activities, including work¹. This definition, like the social model understanding of disability, recognizes that EDs result from complex interaction between people’s physical and mental condition and the broader environment, which can ignore and exacerbate or accommodate and ameliorate that condition.

EDs may be either visible or invisible; either way, they can significantly impact people’s daily lives. EDs may impact people’s capacities to carry out their work, causing an “intermittent work capacity,”—unexpected and/or periodically diminished capacity relative to their usual or expected workload, or absence from the workplace frequently or for extended periods of time². Examples of episodic disabilities include but are not limited to: arthritis, migraine, fibromyalgia, chronic depression, HIV, cancer, diabetes, and epilepsy.

The social model of understanding disability offers valuable tools for cultivating workplace inclusivity, productivity and job security for people living with episodic disabilities. For example, a person living with HIV may have to wait for the side effects from medications to wear off before being able to work, making regular office hours challenging. Under the social model, the person would be supported so that they are

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enabled to take time off from work. They may have flexibility around when their work will be completed and/or their work may be supported and completed by their coworkers.

**Challenges to Labour Force Participation**

At last count, more than two million Canadians aged 15 to 64 self-identified as living with a disability, with 80% of Canadians with disabilities aged 18 to 64 years reporting living with an episodic health condition as either a primary or secondary condition. Further, studies show that nearly 80% of active labour force participants with episodic disabilities report that their disability impacts their ability to participate in paid work. With disabled individuals experiencing only a 49% employment rate, the implications of having a disability—and specifically an episodic disability—on workforce participation is staggering.

Importantly, statistics regarding exactly how many Canadians live with episodic disabilities are both difficult to find, and, ultimately, most likely an underestimation of the true rates and impact of episodic disability. For example, according to the 2006 PALS survey, nearly 1.2 million Canadians reported living with at least one of the 27 commonly cited episodic conditions. However, an additional 704,000 adults reported that they were “often” or “sometimes” limited at school or work due to their disabilities, despite reporting health conditions that are not traditionally thought of as episodic or as disability.

Individuals with episodic disabilities report a number of concerns regarding access to and success within the workforce. Commonly cited barriers to workforce participation include:

- A lack of accommodations: accommodations might include flexible work schedules, telecommuting, and sick days
- Skepticism on the part of employers, which can result in termination if employees need “too much” time off work due to their symptoms; and
- Stigma, particularly among individuals with mental health concerns and HIV/AIDS
- Financial barriers complicate this landscape of barriers: both government- and insurance-based disability supports are predicated on an all-or-nothing view of disability—that is, an individual requiring these supports would either need to be

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employed on a regular basis or not at all. This leaves individuals who are sometimes able to work and sometimes not, stuck between choosing abject poverty and precarious work, and meagre benefits but no work.

Unfortunately, the “malleable embodiment [of episodic disability] is considered experientially impossible within the realm of public policy”\(^8\), leading to significant gaps in access to support. Future iterations of financial support policies must attend to how binary (either/or) thinking about disability ignores the lived experiences of many disabled Canadians. To ensure that policies meet the needs and desires of Canadians with disabilities, such policies must take into account the fluctuating, fluid, and unpredictable character of many disabilities.

**Facilitating Employment**

Many individuals with episodic disabilities who are able to maintain employment report receiving “soft” accommodations at work which allow them to retain their employment status\(^9\). These accommodations include modified, flexible, or reduced job hours, and telework – all of which have been shown to improve employment outcomes among disabled workers\(^10\). Some employers have been able to successfully implement these accommodations for some of their employees. Unfortunately, these accommodations are often implemented on an ad hoc basis and lack a clear and directive government-driven employment policy, despite attempts like Ontario’s Accessibility for Ontarians with Disabilities Act and the Access Talent Initiative\(^11\). This illustrates the limits of existing policy and legislation around disability to attend to the needs of people with episodic disability.

**Why Consider Episodic Disability**

Individuals with episodic disabilities have historically been—and continue to be—overlooked by employers and by policy makers who are able to significantly influence employment opportunities and outcomes for disabled individuals. However, the case for considering the ways in which employers can and should attract and retain disabled employees is clear: individuals with episodic disabilities want to work\(^12\). Further, people with disabilities contribute to the richness of social and professional productivity of

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workplaces. Disability-positive workplaces promote psychological safety\textsuperscript{13}, are work/life balance friendly, and family caregiver friendly. By being flexible and accommodating, these workplaces promote employee engagement and attachment\textsuperscript{14}, reduce absenteeism/presenteeism, and may reduce costs associated with long-term disability claims\textsuperscript{15}.

As the workforce ages, there is a growing number of employees living with episodic disabilities\textsuperscript{16}. Many employers are already informally accommodating employees in order to facilitate their continued workforce participation. Formalizing these practices via comprehensive and compassionate legislation will serve to ensure that individuals with EDs are able to access and maintain suitable employment, and will guide employers who seek to provide the best supports for their workers.

**Technology and Disability in the Workplace**

We already know that increased access to technology, and development of new workplace technologies, can have a significant impact on the ability for individuals with episodic disabilities to enter and remain in the workforce, while often costing very little to employers\textsuperscript{17}. Technology can improve workplace flexibility, allowing disabled individuals to work from home either on a permanent basis, or as needed in order to facilitate their employment. Technology can allow an individual who experiences rheumatoid arthritis flares to work from home when she cannot walk, but come into the office when she is feeling well. Or, it can allow an individual with multiple sclerosis to move from a frigid climate that exacerbates his symptoms to one that is warmer, and telecommute permanently. By improving access to employment, technology can, in turn, allow for access to financial stability that otherwise would be out of reach for many individuals with episodic disabilities.

And yet, workplace technologies can also have their downfalls. With the ability to work from home, the lines between wellness and illness become increasingly blurred, and studies show that disabled individuals who are able to telecommute consequently work


further into periods of illness, and resume work sooner into recovery, than employees who travel into a physical workspace\textsuperscript{18}.

With all of the conjecture regarding the future of disruptive technologies within the workplace, and the ways in which AI and other high-concept tech will alter the workforce, disabled workers remain vulnerable. As various jobs, both blue-collar and white-collar, are increasingly replaced by machines, who will be forced out of, or shuffled around within, the workforce? Who risks getting left behind? Undoubtedly, disabled workers who are unable to safely and effectively participate in more demanding labour risk being shut out of the workforce even more extensively than they are today. As such, it is imperative that tech creators, policy makers, and employers keep disabled workers top-of-mind as they determine which technology to develop, and how to implement that technology in such a way that it enhances rather than diminishes disabled workers’ experiences and opportunities. The precarity of episodic disability within disability legislation and policy, coupled with the limits and possibilities of technology in the workplace, creates a moment in which we might explore how to ensure that technology enables more than it constrains. At this crossroads, the policies we make must be collaboratively generated and attend to the diverse needs and desires of people with disabilities.