

# EPISODIC DISABILITIES AND EMPLOYMENT: PROMOTING INCLUSION THROUGH POLICY AND PRACTICE

By Elisabeth Harrison, Lacey Croft, and Carla Rice

Episodic disabilities are physical, mental, or neurological conditions (e.g., multiple sclerosis, long-COVID, cancer, depression, epilepsy) characterized by unpredictability and variability in the intensity and severity of impairment. In Canada, episodic disabilities have been recognized in provincial laws and enshrined in the federal (2019). Other terms used to describe episodic disabilities include “dynamic,” “intermittent,” and “fluctuating” disabilities (Morris et al., 2019). While the specific impacts of each condition may vary, what they share is that they can all result in a fluctuating capacity to conduct daily activities, including work.

The number of Ontario workers with episodic disabilities is significant and growing. As of 2017, 945,000 Ontarians between the ages of 25 and 64 were impacted by episodic limitations. That equates to nearly one in seven of the working age adults in this province (Lero & Furrie, 2021, Statistics Canada, 2022). Despite its widespread prevalence, many people are not familiar with episodic disabilities, and current approaches to workplace accommodation often do not recognize or adapt to the needs of people in this population. In the context of an aging workforce and continuing pandemic impacts that have contributed to a labour shortage across several sectors of the economy (Morissette, 2022), doing more to include, accommodate, and retain workers with episodic disabilities is becoming a necessity for the continued viability of organizations.

## One in seven working age adults in Ontario are impacted by episodic limitations.

In this article, we draw from expert testimonials and interview data from the *From InVisibility to Inclusion* (i2i) research project to highlight the importance of recognizing and supporting episodic disabilities in the workplace.

From *InVisibility to Inclusion* (i2i) is a research project bringing together scholars, researchers, business professionals, employers, NGOs, and arts communities to build knowledge and develop practical resources that advance the inclusion of people with episodic disabilities. The project includes legal research, analysis of national data sets, and survey, interview, and digital storytelling research to better understand the laws, policies and employment experiences that impact people living with episodic disabilities.

Our research has shown that despite a growing awareness of disability access and accommodation as key elements of equity, diversity, and inclusion policies and practices in the workplace, episodic health conditions frequently go unacknowledged as disabilities. Even if they are understood as disabilities, the specific access needs of people with episodic disabilities are often not accounted for. Consequently, workers with episodic disabilities experience a number of barriers

to and within employment, and employers sometimes face difficulties with employee morale, productivity, and retention. We argue that recognizing episodic disabilities and implementing supportive workplace policies and practices will improve the work lives of people with episodic disabilities while affording significant benefits to employers.

### The Necessity of Recognizing Episodic Disabilities

Recognizing diverse health conditions under the rubric of episodic disability allows for their common features to be recognized and the needs of people living with them to be better understood and addressed, including in the workplace. When health conditions are framed as episodic disabilities, this clarifies that the people who live with them are protected by human rights and disability access laws. In an expert interview with the i2i project, Mariam Shanouda, staff lawyer at ARCH Disability Law Centre explains that in Ontario, episodic disabilities are expressly recognized in law because the Human Rights Tribunal’s interpretation of disability includes episodic disabilities, and the provincial Human Rights Code includes disability as a protected ground.

Although episodic disability is a protected ground in the Code, people with chronic or recurrent illnesses or health problems and their employers may not recognize the conditions as disabilities. This can result in the failure to uphold employees' legal right to reasonable accommodation. Lawyer and disability activist Odelia Bay shared a story with i2i about her personal experience of requesting an accommodation: Her request was initially understood as an exception, and it was denied. When she clarified that she was seeking accommodation for a disability, the request was granted.

Employers sometimes lack an understanding of the laws pertaining to accommodation, as well as accommodation options and strategies (Bay & Mykitiuk, 2020, p. 51–52). When episodic health conditions are not recognized as disabilities, this does not discharge employers from their duty to inquire as to whether an accommodation might be needed, nor employees from their duty to disclose “relevant and sufficient” (*Ibid*, p. 50) information to enable employers to meet their responsibility.

Many of our interview participants described the process of disclosing the need for accommodations as stressful, and even invasive. When employees with episodic disabilities enter the accommodation process, employers sometimes ask for specific diagnoses, believing that having more information about an employee's medical information will better enable them to understand and accommodate an unpredictable condition (Gignac et al., 2020, pp. 159–160). In her expert interview, Wendy Porch, Executive Director of the Centre for Independent Living in Toronto, points out that despite these

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## Occupational Health Nurses can take a leading role in educating employers and employees about episodic disabilities

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pressures, people with disabilities are not legally obligated to disclose their diagnosis, and should instead inform their employer that they require accommodation.

Myra Lefkowitz, Director, Workplace and Wellbeing Services at Toronto Metropolitan University, recommends that employers focus on functional limitations to identify relevant accommodations. Instead of asking for a diagnosis, employers should ask, “What's getting in the way of the individual actually being able to do their job?”

### Accommodating Episodic Disabilities

The accommodation needs of people with episodic disabilities vary, but the most requested accommodations for workers with episodic disabilities are flexible hours and the option to work from home (Vick, 2014; Duval et al., 2020). Several interview participants shared that prior to the COVID-19 pandemic, their health and careers were damaged because employers persistently denied their requests to work from home. Yet, the emergency response to the pandemic has proven that flexible practices can be implemented across many workplaces and industries, and research has shown that employees can retain their effectiveness and productivity while benefiting from the flexibility of remote work (Berinato, 2014).

The kinds of flexibility that many employees with episodic disabilities need are also desirable to

other employees and can become a competitive advantage for employers. Lefkowitz warns that employers seeking a mandatory return to the office as COVID-19 protections are dropped should be aware that employees are often willing to change jobs to maintain the flexibility and improved quality of life that working from home has afforded during the pandemic.

### Barriers to Accommodation

Porch notes that when an employee with episodic disabilities who is in need of accommodations does not receive them, their work may suffer, and it can appear that they are having a performance issue. Consequently, they may be channeled into performance management or disciplinary action. An i2i interview participant shared what happened after they disclosed their anxiety disorder to their employer and were denied accommodations:

It was just something [my manager] would not accept. They felt it was more my performance than anything else. It's almost like not admitting to it. It's like, “Well it's not my fault, it's your fault.”

When the participant's employment contract came to an end, it was not renewed.

Some episodic disability-associated conditions (including those associated with mental health) are stigmatized and misunder-

stood, which is another reason why people with episodic disabilities may encounter hostility from supervisors and colleagues. An interview participant who disclosed her PTSD diagnosis to her employer while requesting accommodations reported that her manager's biased and hostile response caused her to leave her job:

[My manager] basically was just like, "You're not up to this job. Like you're too emotional... You're soft and you're not gonna make it in this line of work." Which, like, is bullshit. I was really good at my job. I was able to cope really well and never had a problem when I was at work... It was super frustrating. And he phased me out. He didn't fire me because of it, but he just made it such a hostile work environment that I quit.

When episodic disabilities are not accommodated and supported in the workplace, unpredictability can lead to frustrations for managers and co-workers. Managing the unpredictable impacts of episodic disabilities is often seen as a particularly difficult challenge for employers. However, in her expert commentary, Lefkowitz reminds us that most employers are already accustomed to planning for unforeseen events, ranging from developing strategies to maintaining organizational continuity in the event of a crisis, to dealing with routine staff absences due to illness or family responsibilities. Employers can use similar strategies to accommodate employees with episodic disabilities.

### **Inclusion is an Opportunity for Employees and Employers**

Employers who work to enact equity, diversity, inclusion, accommodation and belonging policies in their

organizations can benefit in many ways. Hiring and retaining employees with episodic disabilities help create a more representative, diverse workforce. Research shows that diverse teams are more creative, innovative, and effective at problem solving than homogenous ones (Galinsky et al., 2015).

Accommodating employees can help reduce staff turnover, which results in reduced hiring and training costs as well as the maintenance of institutional knowledge (Akinyomi, 2016). Employee interview participants whose accommodation needs were met at work reported feeling valued and supported by their co-workers and employers. In her expert commentary to the i2i team, Drew Sousa, executive director of the Ontario Occupational Health Nurses Association (OOHNA), points out that a successful accommodation plan includes support for co-workers, promoting positive team relationships.

As with flexible work location and scheduling policies, implementing other episodic disability-friendly policies is beneficial to all workers, and can help foster inclusion and trust across the workplace. These changes can include promoting a workplace culture that respects and values diversity; creating realistic attendance and leave policies that prioritize health and work-life balance; and considering offering benefits to part-time and temporary workers.

By meeting legal accommodation obligations (Bay & Mykituk, 2020) and implementing inclusive workplace policies, employers can avoid the potential costs associated with legal actions. Some interview participants told us that they had considered pursuing a lawsuit or a human rights complaint when they perceived that they had encountered discrimination or that their right to reasonable

accommodation was violated.

Elaine Newman, CEO of Global Learning, suggests that making a genuine commitment to diversity, equity, and inclusion "not only resonates with employees, but also with the marketplace." Although many employers recognize that there can be costs associated with accessibility and accommodations, they should also consider the pitfalls of inaction: "What is it going to cost you if you don't do it? What is going to be the cost to your organization, to your employees, to that feeling of inclusion for people referencing you?"

### **The Role of Occupational Health Nurses**

Sousa advises that due to the unique nature of their job, Occupational Health Nurses (OHNs) are well positioned to navigate the complexities of accommodating and retaining employees with episodic disabilities:

We are representatives of both the organization and the employees, and we come at it thinking that it's in everyone's best interest—not just the employees, but also the organization's—not to lose this valuable resource; so how do we work together to make sure that that's understood?

Our research shows that accommodation policies and workplace leave programs often fail to recognize the particular needs of employees with episodic disabilities. For example, a recurrent and unpredictable need for time away from work may not fit the parameters of either a short-term illness or a long-term disability leave program.

Occupational health nurses can promote program and policy change to better plan for the needs of the many workers in this

previously overlooked category, and in doing so can advocate for genuine inclusion. They can also take a leading role in educating employers and employees about episodic disabilities.

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