Summary Report of Research Activities and Findings INDEED: INvestigating the DEvelopment of Accessibility Standards in Canada and the Inclusion/Exclusion of Episodic Disabilities

# 1. Executive Summary

The INDEED (INvestigating the DEvelopment of Accessibility Standards in Canada and the Inclusion/Exclusion of Episodic Disabilities) research project looks at how people with episodic disabilities are often left out of workplace accessibility rules. It’s an important time to do this, because Canada is reviewing its employment accessibility standards.

Episodic disabilities are long-term health conditions that come and go. People may feel well for a while, then have times when they are unwell or unable to work.

To better understand how these conditions are included in workplace rules, we looked at employment accessibility standards across Canada. We also talked to 25 people with lived experience in five focus groups, and interviewed four experts from the disability community.

This study will help create better, fairer rules. By listening to people with these health conditions, we hope to make workplace standards more supportive and inclusive.

**Key Findings**

**1. Understanding Episodic Disability**: People shared that these conditions are often invisible and change from day to day. They said symptoms, how they feel about themselves, and their ability to work often vary. This made it hard to ask for help or feel supported at work.

**2. Awareness and Misconceptions:** Many participants said their bosses and coworkers don’t understand episodic disabilities. Because the disabilities can’t always be seen, people often don’t believe them. Those who also faced racism, poverty, or sexism had an even harder time.

**3. Employment Accessibility Experiences:** Some people said it was hard to get support or accommodations at work. A few had good experiences, usually in government or union jobs. Others said that telling their employer about their disability sometimes led to losing their job or being passed over for promotions.

**4. Policy and System Gaps:** The research and experiences of people in this project described that laws and rules about accessibility don’t often include episodic disabilities. Most focus on visible or permanent disabilities. This leaves out people with changing health needs.

**5. What Works: Accommodations and Advocacy:** People we talked to in this project said they had better results when jobs were flexible — offering part-time work, remote options, or understanding HR teams. Some started their own businesses. Peer support from others with lived experience also helped.

**Recommendations**

1. **Add Episodic Disability to the Law:** Clearly define episodic disability in both federal and **provincial accessibility rules.**

**2. Include** **People with Lived Experience**: Work with people who have episodic disabilities when making policies. Set up advisory groups led by them.

**3. Support Inclusive Workplaces:** Train managers and HR teams to understand episodic disabilities. Make sure workplace accommodations are followed through.

**4. Teach the Public:** Run campaigns to help everyone learn about episodic disabilities.

**5. Help Small Businesses:** Give tools and examples to small businesses so they can support workers with episodic disabilities.

6. **Reduce Barriers and Support People:** Make it easier to get help without proving a disability over and over — especially for people without steady jobs or healthcare.

**Next Steps and Future Directions**

In the future, we want to include more people and organizations from French-speaking communities. We also want to hear from workers in jobs that weren’t part of our earlier discussions.

**Acknowledgement**

We acknowledge the financial support of Accessibility Standards Canada.

# 2. Project Overview and Objectives

BACKGROUND: Existing literature on episodic disability in Canada is growing, and highlights the unique challenges faced by individuals living with episodic disabilities, particularly in the context of employment (Department of Canadian Heritage, 2020). Episodic disabilities can significantly impact an individual's ability to work consistently, leading to disruptions in employment and financial insecurity (Furrie et al., 2016).

Despite this, many current workplace accommodations and disability support programs are designed with more static forms of disability in mind and may not adequately meet the needs of those with episodic disabilities. Accessibility standards, including those for employment, vary from province to province, with standards for access to the built environment (such as ramps for wheelchairs) being most common, as they are required by law.

A scan of provincial accessibility standards for employment has provided valuable insights into the current landscape of accessibility standards in Canada. Currently, six provinces (ON, BC, MB, SK, NL, NS) have any type of employment accessibility standard, though no reference to episodic disability is made in any of the reviewed documents. The absence of episodic disability in accessibility policies across Canada underscores the importance of this project in informing the development of more inclusive and effective standards.

By examining the incorporation of episodic disabilities into employment accessibility standards and exploring the meanings of accessibility for individuals living with episodic disabilities, this project aims to inform the development of more inclusive and effective employment accessibility standards in Canada. Through collaboration with key stakeholders and the active involvement of individuals with episodic disabilities, the project seeks to promote greater awareness and understanding of episodic disabilities and advocate for their sustained inclusion in future employment accessibility standards development.

OBJECTIVES:

**Short-term objectives:**

To understand the incorporation of episodic disabilities into employment accessibility standards in Canada.

To explore the meanings of accessibility for people living with episodic disabilities.

**Medium-term objectives:**

To raise public awareness of the incorporation of episodic disabilities into employment accessibility standards.

To inform the next generation of employment accessibility standards development in Canada.

**Long-term objectives:**

To promote sustained utilization of episodic disabilities principles in the development of future employment accessibility standards.

# 3. Research Activities and Methods

**Demographic Survey:** An online demographic survey (Appendix A) was completed by 25 participants before attending the focus group. It was designed to identify some general characteristics of people living with episodic disabilities in Canada and asked about age, gender, location in Canada, employment status, and nature/duration of episodic disability, and other information using a unique link generated and sent by Qualtrics software. The survey was available in English and French to all participants. These data are described in Table 1.

**Focus Groups:** Five virtual focus groups using Zoom, were conducted with 25 individuals living with episodic disabilities to explore their perspectives on employment, accessibility, and the incorporation of episodic disabilities into current employment standards. Participants were recruited through existing partnerships with stakeholders in the disability sector and members of the project advisory committee. Discussions were guided by a semi-structured interview guide (Appendix B), developed based on the project objectives and relevant literature. Participants received an honorarium of $100 to compensate them for their time. Groups were led by trained co-facilitators.

**Key Informant Interviews**: Four key informant interviews were conducted (using Zoom), with stakeholders in the disability sector, including representatives from disability organizations, advocacy groups, and policymakers. These interviews explored the stakeholders' understanding of episodic disabilities, their views on current employment accessibility standards, and any existing promising or best practices in accommodating episodic disabilities. The interviews were guided by a semi-structured interview guide (Appendix C), developed based on project objectives and relevant literature.

Despite efforts to recruit participants for a French language focus group and key informant interviews, all data collection activities were conducted in English.

Research ethics approval was obtained from the University of Toronto Research Ethics Board before study activities commenced.

The focus group and interview guides were developed with input from the project advisory committee, made up of stakeholders within the accessibility community. Outreach and engagement for focus group and interview participant recruitment were supported by members of the project advisory committee. Data collection took place from October 2024-March 2025. Qualitative analysis of the focus group and interview data was carried out using Nvivo software. Descriptive statistics will be used to summarize participant demographic information.

**Focus Group Participants -** **Demographic Characteristics**

The majority of participants lived with chronic, fluctuating conditions such as depression, anxiety, and rheumatoid arthritis, each affecting 15-16% of participants. Multiple sclerosis and fibromyalgia were each reported by 12% of respondents. Other conditions, including ADHD, bipolar disorder, and substance use disorder, were also reported.

Symptoms varied widely, with chronic pain (12%) and fatigue/exhaustion (10%) being most prevalent. Fluctuating symptoms (13%) and joint/muscle pain (8%) were also frequently mentioned, reflecting the episodic nature of these disabilities.

Notably, over half of participants (52%) reported living with episodic disabilities for more than 10 years, while 36% have lived with their conditions for 5-10 years.

* Age: The largest age group was 35-44 years (36%), followed by 45-54 years (24%). Younger participants, aged 18-24, made up a small percentage (4%).
* Gender: A large majority of respondents identified as female (84%), with 16% identifying as male and 4% as nonbinary.
* Sexual Orientation: Most respondents (60%) identified as heterosexual, with smaller numbers identifying as bisexual (8%) or queer (12%).
* Race/Ethnicity: White respondents represented 52% of the sample. Other groups included Black (12%) and smaller representations of East Asian, South Asian, Middle Eastern/North African, and Mixed Heritage respondents.
* Participants were predominantly from Ontario (60%) and Nova Scotia (20%), with smaller numbers from Quebec, Alberta, and other provinces.
* 76% of respondents were born in Canada, while 20% were immigrants, having arrived across multiple decades

Employment Status

* 32% of participants were employed full-time, while 36% worked part-time

# 4. Key Findings

The project’s key findings are drawn from the knowledge and experiences shared by the focus group and key informant interview participants. Quotes from focus group participants are included throughout the key findings section.

**Understanding of Episodic Disability**

*“We’ve been talking a lot about how things are invisible, and where I've struggled with people not understanding is how much things can change to day-to-day...”* (FG Participant)

*“…a lot of employers still don’t really have awareness of many conditions that are episodic or that are more invisible.”* (FG Participant)

Participants across the focus groups and key informant interviews emphasized a personal and professional understanding of episodic disability from a lived experience perspective. These understandings emphasized variability, invisibility, and fluctuation of symptoms. Many described discomfort and tension between not feeling a sense of belonging with persons who are without disabilities nor with the disability community. The life course impact on disability - how symptoms, life experiences, and self-image evolved over time - was a common theme.

**Public Perceptions of Episodic Disability and Misconceptions**

*“I think your need for accommodation fluctuates, and it’s hard for people to understand that … It would be better if you just had a broken leg with a cast that people could physically look at and be like, okay, for the next six months, she’s going to need support.”* (FG Participant)

Widespread lack of awareness about episodic disabilities was noted by participants, with visible/permanent/physical disabilities being better understood and accommodated than invisible or fluctuating conditions. Participants critiqued reliance on a medical model that required validation of an episodic disability by a health care professional prior to workplace accommodations, and called for a broader uptake of the social model of disability, which recognizes how physical and social environments, policies, and practices can contribute to disability.

**Experience with Accessibility in Employment**

*“From my experience, I tried to apply for a job and I actually disclosed my condition. I think I did well in the interview, but they never really called me back. And I realized I made a mistake. I shouldn’t say anything.”* (FG Participant)

*“They just sent me a form and asked me to fill and asked me maybe you need to get medical proof. And then all the questions were just ridiculous because I was talking about invisible disability. They were talking about a physical disability.”* (FG Participant)

Many faced inconsistent access to accommodations, employer ignorance, and stigma at all stages of employment, including interviewing, onboarding, and in the workplace. The need to provide continual medical proof was cited as demoralizing. Disclosure was often perceived to result in negative employment outcomes, including being fired or not hired.

**Knowledge and Awareness of Accessibility**

*“I don’t think that episodic disability is well understood or considered in terms of the accessibility standards in Canada. Because I don’t think people grasp the idea of episodic very well…”* (FG Participant)

*“The short answer is that we do not have any good concepts of needs to help people in accessibility standards for employment in Canada.”* (FG Participant)

Knowledge of accessibility standards was patchy and inconsistent, with participants often only aware of what applied to them directly. Key Informants noted that episodic disabilities were underrepresented in policy documents. Ambiguous terms like “reasonable accommodation” and “undue hardship” were perceived as hindering effective implementation.

**Sources and Barriers to Information**

*“Nobody actually talks about the dollar figure it costs to actually maintain accessibility in your disability. Whether it’s paying for second opinion, or different prescriptions, or travel for a specialist...”* (FG Participant)

*“lts well and good to have the policy, but when people don’t follow through the burden is always on the person with the disability to be able to prove that something has happened that contravenes whatever policy or legislation is in place.”* (FG Participant)

Participants noted barriers to working with an episodic disability that included the cost of diagnoses, lack of access to HR, and inapplicability of workplace standards in entrepreneurship or informal work. The burden on the individual to research accessibility accommodations and the barriers to seeking external information and support regarding employment rights, such as legal assistance or the Human Rights Tribunal were also raised.

**Inclusive and Participatory Policy Development**

*“Fostering disabled leadership would be a good idea, it doesn’t seem to occur.”* (FG Participant)

*“In my experience, in order to understand an invisible disability, you actually have to have one.”* (FG Participant)

There was a strong demand for the inclusion of people with lived experiences of disabilities in leadership roles in policymaking, particularly those with episodic conditions. The power imbalance between decision-makers and individuals living with disabilities, and the lack of understanding of their experiences, were viewed as a key barrier to developing effective accessibility measures. The complexity of, and time required to collect and complete relevant disability documentation, was just one example provided by participants illustrating this point.

**Structural and Policy Gaps**

*“I tried to talk with HR. I tried to see whether I can get accommodation. I’m still taking with them because it seems like they don’t have a lot of experience helping people with invisible disability.”* (FG Participant)

*“I do not think that the concept of an episodic or changing disability is very well incorporated into employment accessibility standards in Canada...”* (FG Participant)

Participants stressed that current workplace accessibility policies and the Canada Accessibility Act often failed to recognize episodic disabilities as legitimate. There is an overemphasis on static or visible disabilities, and a lack of knowledge about invisible and episodic conditions. As such, workplaces were described as often too rigid to accommodate the fluctuating health and accommodations employees may need.

**Inconsistent Implementation and Workplace Culture**

*“I feel that static side of it [standards] needs to be addressed a bit, the duty to accommodate, and maybe a little more onus on employers to understand that part of it.”* (FG Participant)

*“…that whole rigid definition of disability and the fact that in the standards it feels like it’s seen as more permanent or static. It needs to have more fluidity, for lack of a better word.”* (FG Participant)

Implementation of standards was described by focus group participants as inconsistent, with many workplaces doing the bare minimum or approaching accessibility as a rigid checklist item. Workplace culture was described as lacking flexibility, especially in corporate or work environments outside of the disability sector.

**Stigma, Disclosure, and Employment Precarity**

*“Because there’s so much stigma and judgment, we’re not talking about what’s wrong with us because we’re so worried about the paycheque paying for our living expenses…”* (FG Participant)

*“Accessibility is good for everyone…just removing that stigma and understanding of not having to prove your disability is a huge thing. That emotional labour can be really, really a struggle for a lot of us.”* (FG Participant)

Participants expressed distress over the stigma they experienced in hiring, onboarding, and throughout job retention; needing to prove one’s disability status on an ongoing basis was also noted as a manifestation of institutional bias.

**Intersectional Barriers**

*“What does accessing well-being look like for a person of color or a person who has certain identities of race and ethnicity and gender and class and language and religion and so on? I think these considerations are imperative to understand episodic disabilities.”* (FG Participant)

*“There is this misogyny that comes with, oh, you’re just being emotional, or you’re just not taking on the tasks that you should be able to. Other people can, why can’t you right now?”* (FG Participant)

Participants faced layered challenges due to race, gender, queerness, and work in sex industries. Access to medical diagnosis and ongoing care, a key step in ensuring support for work accommodations, was cited as a barrier by women in general and racialized people across focus groups.

**Effective Accommodations and Practices**

*“I’ve worked at home and found a way to get my own job, but no, not because of these rules. Not because of employment standards.”* (FG Participant)

Success stories included the adoption of flexible, individualized accommodation, supportive HR, and mental health aware workspaces. Examples cited of accommodating work environments included working from home as needed, more flexible sick day policies, and physical workspace design and equipment considerations, among others. Entrepreneurship emerged as a self-advocacy tool for those unable to secure accommodation in traditional workplaces.

**Self-advocacy and Community**

*“…when I’m in the peer group, my blood pressure goes down, my heartrate is nice and steady and slow. I’m so happy to be there because there is a camaraderie, there is an understanding, there is an unconditional welcoming… if we had that at our workplace … it would make my work life so much easier and therefore my work performance so much better.”* (FG Participant)

*“…I think it’s also beneficial for employers to really lean on…their front-line staff in the peer groups to help give some education on what episodic disabilities can look like.”* (FG Participant)

Participants noted the importance of peer networks at work and in the community, recognizing the emotional labor often required for self-advocacy. Artistic and project-based careers provided more control, though these were not without challenges for success.

**Leadership and Representation**

*“…unfortunately, most of the policymakers are not disabled, the people. So, we’re already coming from a place that is against the independent living philosophy and the idea of nothing for us without us.”* (FG Participant)

Success in accessibility was often linked to disabled leadership in policy **and** workplace settings. The involvement of people with lived experience was seen as essential for meaningful progress (“nothing for us without us”).

# 5. Action oriented solutions from participants

**Supportive Accommodations for Workers with Episodic Disabilities:**

**Remote or hybrid options**: Working from home may reduce fatigue, pain, or immune risk during low-health periods.

**Extended deadlines or alternate formats**: Recognizing that some days are better than others, and productivity may not be linear may help in setting realistic deadlines and in getting work completed.

**Paid leave/sick days**: Ensuring health-related absences don’t risk job loss or academic failure is important to workers.

**Ergonomic and environmental adjustments**: Options like seating, lighting, noise control, or temperature regulation may reduce a variety of symptoms related to episodic disabilities.

**Non-punitive attendance and performance management policies**: Ensuring that disability support is not recast as a productivity problem and avoiding disciplinary action when illness-related absences occur is important to improving workplace support.

**Disability Inclusion Access Passports (a.k.a. "Disability Passport")**: A document or digital tool that records a person’s accommodation needs, so they don’t have to re-explain themselves across departments or during transitions.

# 6. Discussion

The findings of the INDEED project highlight critical insights into the lived experiences of individuals with episodic disabilities and key stakeholders in the sector, revealing systemic gaps in policy, workplace culture, and public awareness experienced by participants. Participants—both in focus groups and key informant interviews—shared a nuanced understanding of episodic disability, emphasizing the fluctuation, invisibility, and unpredictability of symptoms.

An early and consistent theme was the persistent misunderstanding and under-recognition of episodic disabilities. Participants noted that public and institutional frameworks often prioritize visible disabilities, leading to a lack of adequate accommodations for episodic conditions. This is further exacerbated by a dominant medical model of disability, which reinforces the need for continual medical proof—an exhausting, costly, and often demoralizing process.

Workplace accessibility emerged as a significant concern. Participants frequently reported stigma, inconsistent or absent accommodations, and discriminatory hiring and onboarding practices. The terminology used in policies—such as “reasonable accommodation” and “undue hardship”—was described as vague and unhelpful, often leaving too much discretion to employers, and overburdening employees living with episodic disabilities. Structural barriers were compounded by intersectional challenges. Participants described how race, gender, queerness, and socioeconomic status further limited access to diagnosis, support, and stable employment.

Despite these challenges, there were also encouraging examples of success. Flexible, individualized approaches to accommodation, mental health-informed environments, and supportive HR practices were cited as enabling factors. The message from participants was clear, they were willing and eager to work and be productive members of teams. Inclusive practices are central to engaging the workforce of people living with episodic disabilities. Finally, leadership by individuals with lived experience was identified as essential for progress.

Inclusive policy development and meaningful co-creation—"nothing for us without us"—must underpin any future initiatives. The recommendations outlined point to clear next steps: clearer legal definitions, more inclusive workplace cultures, and a reorientation of public understanding toward a strengths-based view of episodic disability. Together, these actions can build a more equitable and responsive system for individuals living with episodic disabilities.

# 7. Recommendations and Next Steps

**Policy Reform and Standards Improvement**

* Clearly define “episodic disability” in law and practice.
* Replace vague terms like “reasonable accommodation” and “undue hardship” with actionable definitions.
* Consider universal basic income as a stabilizing measure for people living with episodic disabilities.

**Workplace Culture and Flexibility**

* Promote anti-ableist inclusion training for HR and managers.
* Develop flexible workplace cultures, allowing remote work and self-paced schedules.
* Build accountability mechanisms to ensure accommodations are followed through.

**Inclusive Policy Development**

* Hire more disabled policymakers and include disabled advisory councils in drafting and reviewing accessibility laws.
* Prioritize co-creation of policy with the disability community.

**Training and Capacity Building**

* Increase awareness of episodic disability through public education campaigns.
* Provide sector-specific guidance to mid-size and small businesses.
* Promote strengths-based approaches over deficit-based narratives.

**Enforcement and Monitoring**

* Improve compliance auditing and feedback loops for organizations.
* Require follow-up to ensure accommodations are maintained

# 8. Future Considerations

As Canada moves toward more inclusive employment practices, future considerations must expand across policy, organizational, and individual levels to ensure the full integration of people living with episodic disabilities into the workforce. **At the policy level**, a foundational step is to formally recognize episodic disability within accessibility legislation, using a clear, inclusive definition that reflects the fluctuating nature of these conditions. Future revisions of the Accessible Canada Act and provincial standards should explicitly include episodic disabilities as a category requiring targeted accommodations. Beyond definitions, policies must be designed to reduce administrative burdens by eliminating repeated proof-of-disability requirements, especially for those whose conditions are well-documented but fluctuate over time.

**At** the **organizational level**, employers must be encouraged—and in some cases, mandated—to adopt flexible accommodation practices. These could include job-sharing, hybrid or remote options, self-paced deadlines, and the ability to temporarily modify roles during episodes of illness. Public funding or tax incentives could be introduced to support small and medium-sized enterprises (SMEs) in implementing such strategies. Creating centralized training hubs for HR professionals and managers on episodic disability would support sustained change in workplace culture. Importantly, disability inclusion strategies should include monitoring and accountability tools, such as tracking the outcome of accommodation requests and ensuring policies are equitably applied.

At the **community and individual level**, people with episodic disabilities should be positioned as leaders and co-creators in the process of change. Their voices must be embedded in every stage of policy and workplace development—from design to implementation to evaluation. **Peer support programs**, mentorship initiatives, and employee-led disability networks can offer crucial social support and promote shared advocacy within workplaces. To reduce isolation and stigma, future efforts should also focus on **public education campaigns** that challenge misconceptions about disability, especially those shaped by ableism, racism, or gender-based discrimination.

Finally, as non-standard work arrangements increase, Canada must also examine how **gig workers, freelancers, and entrepreneurs** living with episodic disabilities can be supported. Future accessibility standards must consider protections for workers outside traditional employment models, ensuring equity in all forms of labor. Creating a truly inclusive labor market means embracing flexibility, dismantling systemic barriers, and centering lived experience at every level of decision-making.

**Acknowledgements**

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# References

Department of Canadian Heritage. (2020, December). Systemic barriers to the full socio-economic participation of persons with disabilities and the benefits realized when such persons are included in the workplace. https://www.canada.ca/en/canadian-heritage/corporate/transparency/open-government/literature-review.html

Furrie, A., Gewurtz, R., Porch, W., Crawford, C., Haan, M., Stapleton, J. (2016). People with episodic disabilities in Canada: Who are they and what supports do they need to obtain and retain employment? <https://www.crwdp.ca/sites/default/files/Research%20and%20Publications/episodic_disabilities_in_canada_-_october_4_-_final.pdf>

Morris, S., Fawcett, G., Hughes, J., & Timoney, L. R. (2019, December 3). The Dynamics of Disability: Progressive, Recurrent or Fluctuating Limitations. <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2019002-eng.htm>

Realize. (2022, February 3). What is episodic disability? Realize. <https://www.realizecanada.org/our-work/episodic-disabilities/what-is-episodic-disability/>

# Table 1. INDEED Focus Group Demographic Summary Data, n=25

|  |  |  |
| --- | --- | --- |
| Question | Response | Proportion |
| Length of time with episodic disability | 1 to 5 years  5 to 10 years  More than 10 years  Prefer not to answer | 2(8%)  9(36%)  13(52%)  1(4%) |
| Age | 18-24  25-34  35-44  45-54  55-64 | 1 (4%)  6 (24%)  9 (36%)  6 (24%)  3 (12%) |
| Sex | Female  Male  Prefer not to answer | 21 (84%)  3 (12%)  1 (4%) |
| Gender | Man  Women  Non-binary | 4 (16%)  20 (80%)  1 (4%) |
| Sexual Orientation | Heterosexual  Demisexual  Queer  Questioning  Lesbian  Gay  Bisexual  Prefer not to answer | 15 (60%)  1 (4%)  3 (12%)  1 (4%)  1 (4%)  1 (4%)  2 (8%)  1 (4%) |
| Race | Black  East Asian  Middle Eastern/North African  Mixed Heritage  South Asian  Southeast Asian  West Indian  White | 3 (12%)  1 (4%)  2 (8%)  2 (8%)  2 (8%)  1 (4%)  1 (4%)  13 (52%) |
| Province | Alberta  New Brunswick  Nova Scotia  Ontario  Quebec  Saskatchewan | 1 (4%)  1 (4%)  5 (20%)  15 (60%)  2(8%)  1 (4%) |
| Born in Canada | Yes  No  Prefer not to answer | 19 (76%)  5 (20%  1 (4%) |
| Employment Status | On long-term or permanent disability leave  Employed full time  Employed part time  Unemployed, but looking for work  Not working due to my health  Not working at all for other reason(s): Retired, full-time student, staying at home to care for my family | 4 (16%)  8 (32%)  9 (36%)  2 (8%)  1 (4%)  1 (4%) |

Self Reported Episodic Disability and Symptoms

|  |  |  |
| --- | --- | --- |
| Episodic Disability | Responses | Proportion |
|  | Multiple Sclerosis  Fibromyalgia  Depression  Anxiety  Diverticulitis  Rheumatoid Arthritis  Spondylitis  Osteoarthritis  Bipolar 2  HIV  ADHD  Substance Use Disorder  PTSD  Unnamed episodic disability | 3 (11.5%)  3 (11.5%)  4 (15.4%)  4 (15.4%)  1 (3.9%)  4 (15.4%)  1 (3.9%)  1 (3.9%)  1 (3.9%)  1 (3.9%)  3 (11.59%)  1 (3.9%)  1 (3.9%)  1 (3.9%) |
| Symptoms (open text list) | Allergy, Brain fog  Chronic pain, Circulation issues  Dietary issues, Digestive issues  Dysphagia, Headaches, Executive function issues,  Fatigue/Exhaustion, Joint/Muscle pain  Light headedness, Migraines  Mobility issues, Sensory sensitivities, Social isolation, Stress | n/a |

Note: Participants were able to list multiple symptoms and disabilities, therefore totals in this table to not add to 100%

# Appendix A Demographic Survey

1. **In your own words, how would you describe your episodic disability.**
2. **How long have you been living with an episodic disability? (Choose one)**

* Less than 1 year
* 1-5 years
* 5-10 years
* More than 10 years
* Prefer not to answer

1. **Please indicate which age group you fall into:**

* 18-24
* 25-34
* 35-44
* 45-54
* 55-64
* 65 or older
* Prefer not to answer

1. **What was your sex at birth:**

* Male
* Female
* Intersex
* Prefer not to answer

1. **What is your gender identity?**

Gender identity refers to a person’s internal sense or feeling of being a woman, a man, both, neither or anywhere on the gender spectrum, which may or may not be the same as the person’s sex assigned at birth.

* Woman
* Man
* I do not identify within the gender binary. I am: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* I prefer not to disclose information concerning my gender

1. **Which best describes your sexual orientation? (Your sexual identity based on who you are romantically or sexually attracted to)**

* Asexual
* Bisexual
* Demisexual
* Gay
* Heterosexual (straight)
* Lesbian
* Pansexual
* Queer
* Questioning/Not sure
* Two-spirit
* Not listed, (please describe) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don’t know
* Prefer not to answer

1. **We know that people of different races receive different treatment by individuals and institutions. Which race category best describes you?”**

* Black (e.g., African, Afro-Caribbean, African Canadian descent)
* East Asian (e.g., Chinese, Korean, Japanese, Taiwanese descent)
* Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent)
* Indigenous (e.g., First Nations, Métis, Inuk/Inuit descent)
* Latino (e.g., Latin American, Hispanic descent)
* Middle Eastern/North African (e.g. Arab, Egyptian, Algerian)
* West Asian (e.g. Afghan, Iranian, Turkish, Kurdish)
* South Asian (e.g., East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean)
* White (e.g., European descent)
* Not listed, (please describe) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to answer

1. **What province or territory do you live in? (Select one)**

* Alberta
* British Columbia
* Manitoba
* New Brunswick
* Newfoundland and Labrador
* Northwest Territories
* Nova Scotia
* Nunavut
* Ontario
* Prince Edward Island
* Quebec
* Saskatchewan
* Yukon
* Prefer not to answer

1. **Were you born in Canada?**

* Yes
* No
* Prefer not to answer

If no, what year did you arrive in Canada? \_\_\_\_\_\_\_\_\_\_

1. **Which category best fits your current job status:**

* Employed full time (35 or more hours per week)
* Employed part time (less than 35 hours per week)
* On short term leave from work (leave of absence for one month or more, extended sick leave)
* On long-term or permanent disability leave
* Temporarily laid off from my job (i.e., furloughed)
* Unemployed, but looking for work
* Not working due to my health
* Unemployed and not looking for work
* Retired, full-time student, staying at home to care for my family, or not working at all for other reason(s)
* Prefer not to answer

# Appendix B Facilitated Semi Structured Focus Group Guide

**Theme: Meanings of Accessibility**

Questions:

1. What does “accessibility” mean to you as a person living with an episodic disability?

* Do you think that others understand what accessibility is about for someone with an episodic condition or is the focus more on permanent disabilities?
  + Prompt: Can you explain what you mean and how episodic conditions create different challenges for accessibility?

Now we are going to talk a bit about Canada’s current Employment Accessibility Standards

**Theme: Understanding of Accessibility Standards**

1. Before this focus group, were you familiar with the accessibility standards in Canada (or your province), specifically regarding employment?

* Prompt: If yes, why how did you hear about it and what was your experience?
* Prompt: If no, did you have other information that you were relying on to learn about working with an episodic disability? Is this information new for you?

1. Thinking about the Employment Accessibility Standards, will they /do they meet your needs living with an episodic disability?

* Are there experiences where you have encountered barriers or challenges related to accessibility standards in your work (or you think you might in the future)?

**Theme: Incorporation of Episodic Disabilities**

1. How well do you think the concept of an episodic or changing disability is incorporated into employment accessibility standards in Canada (your province)? Can you explain?

* Prompt: If not well / at all, what could be immediately improved?
* If something is well done, please describe

1. Can you provide examples of how these standards have been applied or used in your experience (both as facilitators or barrier in employment)?

**Theme: Awareness and Utilization of Episodic Disabilities Principles**

1. Are you aware of any specific principles or guidelines related to episodic disabilities?

* If yes, how do you think these principles should be integrated into the development of future accessibility standards?
* Prompt: if no one has head of guidelines or principles, what would you suggest should be integrated into future accessibility standards?

**Theme: Impact and Achievements**

1. When you think about your own life and the lives of people living with episodic disabilities, what impact do you think employment accessibility standards have?
2. Can you share any success stories or examples of positive outcomes related to employment accessibility standards?

**Theme: Future Development of Accessibility Standards**

1. What improvements or changes would you like to see in future employment accessibility standards to address the needs of people with episodic disabilities?
2. How can the development of future standards better involve and reflect the experiences of people living with episodic disabilities?

# Appendix C Facilitated Semi Structured Key Informant Interview Guide

**Theme: Understanding of Episodic Disability**

Questions:

1. How would you define or describe episodic disabilities?

* Prompt: provide definition of episodic disabilities: a disability or chronic condition that results in periods of time when you have relatively good health with fewer, if any, limitations to your activities, and periods of poorer health with more limitations to your activities.
* Prompt: If you are unfamiliar with the term, please describe your understanding about disabilities or the scope of you work with disability

1. In your experience, what are some common misconceptions about episodic disabilities?

* Prompt: what the term means, how they are identified, how do people get support? How does it align with what is the current definition of disability

**Theme: Awareness of Accessibility Standards**

1. Please describe your experience with employment accessibility standards in Canada (your province)?

* Have you encountered any challenges or limitations in implementing these standards in your work?
* Prompt: if no experience of employment standards, as more generally about accessibility standards in the built environment (accessible entries, etc.)

**Theme: Incorporation of Episodic Disabilities**

1. Do you believe that employment accessibility standards in Canada adequately address the needs of people with episodic disabilities? Why or why not?
2. Can you provide examples of how these standards have been applied or implemented in your organization or sector?

**Theme: Meanings of Accessibility**

1. From your perspective, what does employment accessibility mean for people living with episodic disabilities?
   * Prompt: examples might include workplace accommodation ( on site) or hybrid and remote work options
2. How can the concept of accessibility be further refined or expanded to better accommodate episodic disabilities?

**Theme: Existing Practices and Challenges**

1. What promising or best practices have you observed in the inclusion of episodic disabilities in employment accessibility standards or initiatives?

* Prompt: any policies or practices in own workplace or seen in other organizations?

1. What are some key challenges or barriers that hinder the effective inclusion of episodic disabilities in accessibility standards?

**Theme: Future Development of Accessibility Standards**

1. What recommendations would you make for improving the integration of episodic disabilities into future accessibility standards?
2. How can stakeholders like yourself contribute to the sustained utilization of episodic disabilities principles in the development of future standards?