

Disclosure and Accommodation Planning – What do we need to improve job retention for people who are living with a disability?

Presented at the 2022 Rethinking Disability Conference (RDC): The Future of Work

Monique A. M. Gignac, PhD.
Scientific Director & Senior Scientist, Institute for Work & Health
Professor, Dalla Lana School of Public Health, University of
Toronto







A research partnership to support the sustained employment of people with intermittent, chronic health conditions

Project Director: Monique Gignac

Research Team:

Dorcas Beaton Curtis Breslin Renée-Louise Franche Emma Irvin Arif Jetha Joy MacDermid Ron Saunders William Shaw

Peter Smith Aaron Thompson Emile Tompa Dwayne Van Eerd Julie Bowring Sabrina Tonima Sara Macdonald Lahmea Navaratnerajah

Partners:

Institute for Work & Health **Arthritis Society Canada** Canada Life Workplace Strategies for Mental Health Canadian Mental Health Association Crohn's & Colitis Canada

Mindful Employer Canada Multiple Sclerosis Society of Canada Ontario Ministry of Labour Realize **University of Toronto**









Social Sciences and Humanities Research Council of Canada

Conseil de recherches en sciences humaines du Canada



Overview

How do we improve the communication-support process for people living with episodic disabilities to enhance their ability to gain and sustain employment?

- What are episodic disabilities? Why do they matter?
- What unique challenges do episodic conditions create for workers and workplaces that service providers should be aware of?

What does research tell us about next steps and solutions?







What is meant by Episodic Disabilities?

- 6.2 million Canadians live with a disability
- A disability is not a character trait or state of being of a person
- A disability arises as a result of the interaction between a health condition AND personal and environmental factors, including negative attitudes, activity limitations, public policies and practices, inaccessible physical environments, and limited social support

Morris et al., 2019, The dynamics of disability. Statistics Canada World Health Organization (WHO), https://www.who.int/health-topics/disability





What is meant by Episodic Disabilities?

Many of the most common chronic conditions in Canada are:

- Episodic or intermittent
- Unpredictable
- Invisible

An episodic disability can be dynamic: recurrent, progressive, fluctuating

Examples include: depression, anxiety disorders, arthritis, multiple sclerosis, diabetes, irritable bowel syndrome, migraines, some types of cancer, epilepsy, HIV, Long COVID

Morris et al., 2019, The dynamics of disability. Statistics Canada





Episodic Disability

A survey of 1074 respondents working with chronic physical or mental health conditions found (Gignac et al., 2020):

Episodic/Dynamic Disability	Total (n = 1074) %	Physical (n = 443) %	Mental/Cognitive (n = 351) %	Both Physical & Mental/Cognitive (n = 280) %
Recurrent	47.7	46.5	53.0	43.6
Progressive/Fluctuating	20.0	17.4	15.1	30.7
Continuous	32.3	36.1	31.9	25.7





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Episodic Disability

The **episodic/dynamic**, **unpredictable**, and **invisible** nature of many chronic conditions creates challenges in balancing:

- Workplace disability communication, disclosure, and the protection of privacy
- Needs for support or accommodations and the maintenance of workplace productivity







Disclosure of a Disability – Survey Studies



- In 5 Canadian surveys (n = 3387), 25%-49% of participants *had not shared* any information about their mental or physical health limitations at work with their supervisor
- Decisions whether to share are ongoing and complex even when deciding not to say anything
- People often have a range of both approach and avoidance reasons for sharing and not sharing personal health information

Gignac & Cao, 2009; Gignac, Cao & McAlpine, 2015; Gignac, Kristman, Smith et al., 2018; Gignac, Bowring, Jetha et al., 2020; Gignac, Jetha, Ginis & Ibrahim, 2021; Gignac et al., 2022 (ongoing)

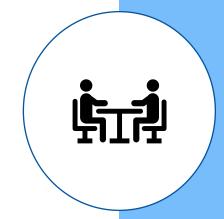




Disclosure of a Disability (n = 896)

Examples of Approach reasons:

I felt my job was secure and it was safe to discuss (71.4%) I wanted to make changes to my job and get support (36.6%) I can manage at work without others knowing (75.6%) It's not a big deal; it's just part of who I am (63.4%)



Examples of Avoidance reasons:

My health was getting worse and I had to let others know (41.9%)
Others noticed and asked if there was a problem (47.1%)
I said nothing because I was concerned about losing my job (36.9%)
I'm concerned about lost opportunities for a promotion or new job tasks (40.6%)





Qualitative Study: Workers aged 50+ years (n = 68)

Trust in others Perceptions of job Perceived need to Maintaining one's and perceived insecurity reputation communicate support



Qualitative Study: Older Workers (n = 68)

Perceived need to communicate

"It's a personal issue until it affects what you're doing." (Male, 66 years, security guard)

Maintaining one's reputation

"It can be
dangerous, it can
be – you make
yourself
vulnerable if you
give away too
much...There's
certain information
you don't share."
(Male, 61 years,
gardener)

Trust in others and perceived support

"I would always say, err on the side of privacy and discretion...
You don't know if you can trust everybody you speak to, to not spread things around that are private." (Female, 63 years, teacher)

Perceptions of job insecurity

"You have to ask yourself, is it really worth antagonizing the person who controls your career? And the answer is, 'No'."

(Male, 56 years, accountant)





What do we know about communication decisions?

There is no single correct communication decision. There are examples of positive and negative experiences with both decisions.

	Positive outcomes include:	Negative outcomes include:
Disclose	supportgreater understanding	having to prove oneselfstigma
Do not disclose	less stressless concern about how others view you	 absence of support misperceptions about reasons for any job difficulties

(Gignac & Cao, 2009; Gignac, Bowring, Jetha, et al., 2020; Gignac, Jetha, Ginis, Ibrahim, 2021; Hayward et al., 2016; Stergiou-Kita et al., 2016; Stutterheim et al., 2017)





Summary: Research on communication of a disability

- Communication and whether to disclose is a complex decision
- Similarities and few differences were found between workers living with physical versus mental health disabilities in disclosure decisions, reasons, and outcomes
- People often delay sharing disability support needs until there is a performance problem





Summary: Research on communication of a disability

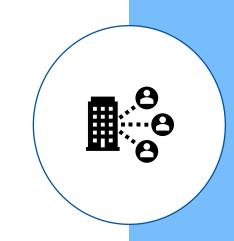
- There is no single "right" decision whether to share or not to share. However:
 - Approach reasons were significantly associated with positive support outcomes like greater understanding, less stress, and more acceptance compared to avoidance reasons
 - Workers with mental health conditions reported more negative outcomes like stigma and negative performance evaluations when they chose NOT to disclose
 - This may be because of "leaked" signs of a disability and misperceptions about the workers as lacking motivation, being unreliable, or having poor interpersonal skills





Workplace Perspectives

What do those whose job it is to support workers with episodic disabilities believe are the key issues and challenges to disability support?





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Disclosure, Privacy and Workplace Accommodation of Episodic Disabilities: Organizational Perspectives on Disability Communication-Support Processes to Sustain Employment

Monique A. M. Gignac ☑, Julie Bowring, Arif Jetha, Dorcas E. Beaton, F. Curtis Breslin, Renee-Louise Franche, Emma Irvin, Joy C. Macdermid, William S. Shaw, Peter M. Smith, Aaron Thompson, Emile Tompa, Dwayne Van Eerd & Ron Saunders

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Abstract

Purpose Employers increasingly are asked to accommodate workers living with physical and mental health conditions that cause episodic disability, where periods of wellness are punctuated by intermittent and often unpredictable activity limitations (e.g., depression, anxiety, arthritis, colitis). Episodic disabilities may be challenging for workplaces which must comply with legislation protecting the privacy of health information while believing they





Challenge 1: Workplace Cultures

Medical versus biopsychosocial models of support

- Workplaces had different implicit models to frame disability and support
- Medical models were common (i.e., health information needs to be validated and closely monitored)
- Biopsychosocial models were in place in some organizations (i.e., disability goes beyond a medical diagnosis to include the workplace environment). Participants noted:
 - a) Health professionals were not able to provide relevant information
 - b) Workers could not get timely or appropriate access to specialist care
 - c) A worker's condition didn't remain private depending on the specialization of the health professional providing a medical note





Challenge 1: Workplace Cultures

Medical versus biopsychosocial models of support

"... because our third-party providers have that [diagnosis], in most cases, it's a much smoother transition.... return to work recommendations are more meaningful... the most important thing is that people are properly diagnosed." (Disability manager, Utilities)

"Seventy five percent of cases do not involve a medical practitioner at all for six months — up till they go to long-term disability.... We're trying to accommodate people as opposed to manage their diagnosis, which is a complete and utter waste of time. You can't explain everything by medicine...by diagnosis, and you need to find some way to be fleet of foot and manage these because, if you don't, they go sour very quickly." (Medical director, Business/finance)





Challenge 2: Misgivings about others in workplace support

- Participants acknowledged the important roles others play in supporting individuals with health and disability needs
- Yet, comments frequently included concerns about others' skills, training, motivation and involvement in support efforts





Challenge 2: Misgivings about others in workplace support

Comments about supervisors/managers

"They just don't have any sort of broad basis of knowledge upon which to base things. So they are often coloured by stereotypes or predispositions and unknown discriminatory attitudes." (Labour lawyer representing workers)

Comments about physicians

"The physician role is really to diagnose and treat and we need to stop asking them if the person can do their job...They are very intelligent people... but they do not have the time to understand the workplace." (Disability manager, consulting firm)

Comments about human resources professionals

"I did find that the turnover in that group was quite high...Even mid-process...I was dealing with one person and then all of a sudden they had moved on...That continuity, just organizationally, was a challenge." (Manager, public sector)





Challenge 3: Casting disability as a performance problem

- In larger organizations, formal communication was triggered by a threshold of work absences (e.g., attendance management/ attendance support programs)
- Workers AND workplace parties acknowledge they can:
 - 1. Pressure workers into disclosing something
 - 2. Re-cast disability as a performance problem (i.e., progressive disciplinary actions needed)
 - 3. Focus future discussion on performance deficits and not skills and abilities
 - 4. Erode trust and confidence in the disability support process
- Workers with mental health issues sometimes admit to performance problems rather than risk disclosing a mental health issue





Challenge 3: Casting disability as a performance problem

"It sets up an urgency at the beginning because usually by the time they might involve [a disability manager] ... they're quite high in the [attendance management] program....The employee, in a lot of situations, [is] not getting along all that well with management because they're being attendance managed." (Disability manager)

"Too often where we find out as the representative of the worker, it's...because they're in a position of discipline...and they have not indicated that they have an issue and have tried to sort of hide it. Then suddenly it reaches a point where it's now become discipline." (Union representative, multiple sectors)





Challenge 4: Difficulties Arising When a Worker Denies a Problem

- In rare instances, workers with mental health conditions deny a problem when confronted by a supervisor or HR professional
- These were among the most challenging, prolonged, and stressful situations for all parties
- Success in managing was variable and often resulted in heightened interpersonal tensions





Challenge 4: Difficulties Arising When a Worker Denies a Problem

"People themselves, they may not see it. It may be a slow progression...they start missing deadlines, showing up late for work, looking dishevelled.... If a person doesn't realize, they're just thinking, 'I'm having a bad day." (Disability manager, Consulting firm)

"This one individual was saying that people were talking about her...Staff would come in and do some work, and she would think that they were spying on her... We talked to the physician, the psychologist about it, trying to get some information about accommodation. Is she getting the right kind of treatment or does she need any treatment? She thought she was fine. We don't know if she was or not... But, really, she came very close to being fired." (HR representative, Service sector)





Bottom Lines:

Workers often want guidance on their options, whether to communicate, and what, when and how to share information.

Workplaces want a transparent, consistent and comprehensive approach to assessing worker job demands and support strategies and options is needed.





Accommodating and Communicating about Episodic Disabilities (ACED)

New Workplace Tools: https://aced.iwh.on.ca/jdapt/worker-en

- Job Demands and Accommodation Planning Tool (JDAPT)
- Communication Decision-Support Tool







ACED Partnership Aims:

Enhance work sustainability for people with episodic disabilities

Workplace tools, resources & interactive evidence-based

ACED Materials will:

- Not give advice
- Be responsive to needs and preferences
- Promote discussion and brainstorming
- Adopt a disability prevention and support framework
- Emphasize skills and abilities
- Improve process outcomes





- Focuses on work demands that may be challenging at times or on a regular basis
- Guides the user through a series of simple questions about their job tasks and working conditions
- Provides a personalized list of suggested ideas relevant to an individual's job demands. The ideas can help generate solutions that work for a person's needs
- Can be used to discuss support needs with others and focus on work solutions, not a health or disability diagnosis or symptoms







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24 types of job demands and working conditions organized in four domains:

Physical tasks (5 items)

Cognitive or "thinking" tasks (6 items)

Working with others (5 items)

Working conditions (8 items)

- Worker version: self-assessment of job demands & challenges
- Organizational version: can be completed by workplace staff & employee for planning





24 types of job demands and working condition organized in four domains:

Physical tasks (5 items)

e.g., working with your hands

Cognitive or "thinking" tasks

(6 items)

e.g., concentrating for long periods

Working with others

(5 items)

e.g., communicating, negotiating or motivating others

Working conditions

(8 items)

e.g., working with hazardous equipment or situations

For each demand, user rates

- a) Importance to the job
- b) Difficulty due to health
- c) Change in ability over time



Personalized Report



Linked Support Strategies & Accommodation List





Report links to suggested support strategies & accommodations

Support Strategies & Accommodations

 changes to help someone with an episodic disability manage their job demands

Strategy Types

- Things to consider outside of the job
- Things a worker might try on their own at work
- Adjustments to try at work (may need to discuss with others)
- Formal accommodations to consider requesting

Personalized list

- linked to challenging demands (some or a lot of difficulty)
- option to print all or edit to pick out which strategies user thinks might be helpful





Things you might try on your own

- o Try to maintain a good posture to reduce pain and/or fatigue when working
- o Wear comfortable shoes with a good grip and support

Adjustments you could try at work (you may or may not need to request permission to do these)

- Use a stool or footrest to help you change positions while working
- o Pace your work to avoid becoming tired
- Take the time you need to follow workplace safety guidelines and keep your attention up to avoid injuries
- o Plan your more difficult tasks for when you are feeling better
- Switch between tasks to vary your position and reduce strain
- When doing the same task, take the time to change your position to reduce strain
- Adjust your breaks to help maintain your energy this could mean either taking regular or more frequent breaks, or fewer but longer breaks, depending on your needs
- o Ask others for assistance
- Ask your supervisor for adjustments for work meetings or events

Formal accommodations to consider requesting

- Furniture or equipment that can help reduce strain
- Request a flexible or alternative work schedule which allows you to work when feeling better and have more energy
- Permission to work at home on some days if this is possible in your job
- Temporary or permanent job modification, which means re-assigning or reducing time spent on less important or less essential tasks





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Use a stool or footrest to help you change positions while working

- high stool for alternative sitting and standing at a counter
- low stool or rail to rest feet on one at a time when standing
- footrest to raise feet while sitting





Things you might try on your own

 Do calming or refreshing activities during breaks to bring back focus or to "reset"

Adjustments you could try at work (you may or may not need to request permission to do these)

- o Turn off phone and/or computer notifications while working on a specific task
- Use a timer to set working times and mini breaks which can help with concentration
- Use applications to reduce distractions
- If there are no safety or interpersonal concerns, wear headphones or ear plugs to exclude other sounds
- o Introduce background noise if that helps you focus
- Adjust light and/or heat to enhance concentration
- o Plan your more difficult tasks for when you are feeling better
- Schedule blocks of time to concentrate on one task without distractions or interruptions
- Adjust your breaks to help maintain your energy, either regular or more frequent breaks, or fewer but longer breaks
- Move your work temporarily to a less distracting location and/or new surroundings which may help with focus

Formal accommodations to consider requesting

- Changes to your workstation to reduce distractions
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Use a timer to set working times and mini breaks which can help with concentration

 work at one task for 30 minutes, then take a mini break to stretch or walk around before working for another 30-minute session





Things you might try on your own

- o Do calming or refreshing activities during breaks to bring back focus or to "reset"
- o Understand your limits and potential challenges and triggers

Adjustments you could try at work (you may or may not need to request permission to do these)

- Discuss with others that you are interested in working as a team and value the input from others
- Be open with your recognition and praise of your co-workers' skills and work and give positive feedback
- Try to build connections rapport with others by talking what you can do for each other
- If possible, increase the time you have available to meet with others to promote open communication
- o Clarify job tasks and responsibilities as a team and with supervisor(s)
- Check in with others to assess work outcomes
- Check that you have the same information and understanding of discussions that others do
- Ask a co-worker or friend for advice or strategies for handling interpersonal situations
- Identify an informal or formal mentor(s) who can provide support and problemsolving ideas

Formal accommodations to consider requesting

- Request a flexible or alternative work schedule which allows you to work when feeling better and have more energy
- Permission to work at home on some days, if this is possible in your job
- Professional advice or training to build skills to improve communication and interpersonal skills
- o Request mediation to resolve interpersonal conflict





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Check that you have the same information and understanding of discussions that others do

- repeat back instructions in your own words
- send a summary after a meeting to confirm decisions





JDAPT Testing



In-depth pilot testing and cognitive debriefing of the JDAPT conducted with:

- ~ 20 research experts
- ~ 12 partner representatives from different health charities
- 46 workers living with diverse types of episodic health conditions
- 23 organizational representatives (e.g., supervisors, HR personnel, disability managers)
- Diverse organizations and job types (e.g., sales/service, education, manufacturing, health, government, transportation, financial, hospitality)





JDAPT Testing



- Participants liked the JDAPT overall and reported high need for it
- Participants living with episodic conditions reported somewhat more usefulness than organizational representatives
- The JDAPT was relatively easy to understand and relevant to a range of different episodic disabilities, occupations, and personal characteristics (e.g., gender, age)
- An evaluation testing the JDAPT is underway (n = 289). Participants complete:
 - An initial assessment and the JDAPT
 - A 3-month follow-up
 - A 9-month follow-up





Five Take-Home Messages

Many of the most common chronic physical and mental health conditions contribute to experiences of episodic disability at work.

A condition alone does not create disability at work. Disability arises when health and work demands, situations, and environments interact.

The impact of a disability can often be minimized or ameliorated with support and accommodations.

The decision whether or not to disclose personal information about one's needs is complex, ongoing, and often stressful.

New tools can facilitate support provision in the workplace.





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Thank you!

Questions? Comments?

Monique Gignac: mgignac@iwh.on.ca

ACED website with JDAPT:

https://aced.iwh.on.ca/jdapt/worker-en



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