



# Does it matter what workers' reasons are for disclosing or not disclosing an episodic disability at work? Why and how?

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# Acknowledgements

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“Should I tell my employer I have a chronic health condition that sometimes makes it hard to work?”

# Some quick takeaway messages

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- Decisions whether to disclose health information at work are often stressful and complex. They occur over time.
- There is no single “right” decision whether to share or not share.
- The broad categories or types of reasons given by workers living with episodic disabilities *are* associated with reported positive or negative workplace support outcomes.
- In creating communication decision-making tools, there is value in better understanding a worker’s goals and decisions – their reasons matter.

# Chronic health conditions in Canada

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Many of the most common chronic conditions in Canada can be characterized as **episodic disabilities**

- **Intermittent**
- **Unpredictable**
- **Invisible**

Examples: depression, anxiety disorders, arthritis, multiple sclerosis, diabetes, Crohn's disease, colitis, migraine, epilepsy, some cancers, HIV

# Chronic health conditions in Canada

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Statistics Canada uses the language of **dynamic disability**:

- Recurrent limitations
- Progressive limitations
- Fluctuating limitations

Morris, S. Fawcett, G., Timoney, L.R., Hughes, J. (2019) The Dynamics of Disability: Progressive, Recurrent or Fluctuating Limitations. Statistics Canada, December 3, 2019; cat no. 89-654-x2019002.

# Chronic health conditions in Canada

A survey of 1074 individuals working with chronic physical or mental health conditions found:

Dynamic Disability	Total (n = 1074) %	Physical (n = 443) %	Mental (n = 351) %	Both Physical & Mental (n = 280) %
Recurrent	47.7			
Progressive/Fluctuating	20.0			
Continuous	32.3			

# Chronic health conditions in Canada

A survey of 1074 individuals working with chronic physical or mental health conditions found:

Dynamic Disability	Total (n = 1074) %	Physical (n = 443) %	Mental (n = 351) %	Both Physical & Mental (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



# Working with a chronic, episodic condition

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- The episodic/dynamic nature of disability often leaves workers with a choice whether or not to disclose some health information.
- Previous research highlights a range of reasons for disclosing or not disclosing

## Example reasons for *disclosing*

**I had to explain why I was absent so often**

**It's just a part of who I am, telling others is no big deal**

## Example reasons for *disclosing*

**I felt my job was secure and it was safe to discuss**

**I had a question why I was absent so often**

**It's just a part of who I am, telling others is no big deal**

**Others noticed changes in my behaviour and asked if there was a problem**

## Example reasons for *disclosing*

**I felt my job was secure and it was safe to discuss**

**My health was getting worse and I needed to say something**

**I had a question why I was absent so often**

**Others at my workplace had discussed their personal needs and the response was positive**

**Changes in my life and there was**

## Example reasons for *not disclosing*

**I can manage at work  
without others knowing**

**I was concerned  
about losing a chance  
to be promoted**

## Example reasons for *not disclosing*

**I can manage at work  
without others knowing**

**I've had problems in the  
past when I disclosed so I  
don't want to say anything**

**Nothing can be  
done so there's  
no point in  
discussing**

**I was concerned  
about losing a chance  
to be promoted**

## Example reasons for *not disclosing*

**I can manage  
without others**

**My health  
doesn't affect my  
ability to do my  
job, why say  
anything?**

**I've had problems in the  
past when I disclosed so I  
don't want to say anything**

**Nothing can be  
done so there's  
no point in  
discussing**

**I was concerned  
about losing a chance**

**It's my business – people  
don't have the right to know**

# How do we make sense of a worker's health disclosure decisions?

Research has focused on two factors behind disclosure decisions:

1. **Need** – those experiencing more activity limitations, pain, fatigue, or other symptoms are more likely to disclose health information at work.
2. **Perceived support** – Those who believe their workplace is supportive are more likely to share health needs.

(Brohan et al., 2012; Brouwers et al., 2020; Gignac & Cao, 2009; Garcia et al., 2008; Irvine, 2011; Munir et al., 2005; Oldfield et al., 2016; Robinson et al., 2015; Toth & Dewa, 2014)



# How do we make sense of a worker's health disclosure decisions?

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*What about past experiences, current and future concerns, personal preferences, the nature of the job, the role of others, the work environment....?*

# We're missing...

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- The range of reasons people give for sharing/not sharing health information
- The importance of reasons to workers
- Whether the reasons matter – are they linked to support outcomes at work?

# Disclosure Processes Model (DPM) (Chaudoir & Fisher, 2010)

Communication decisions are governed by two overarching goals:

**Approach goals:** individuals pursue rewarding or desired end states like improved relationships with others or support to maintain performance.

**Avoidance goals:** individuals try to avoid punishments or undesired end states like being fired for poor performance.

Goals can impact subsequent events by introducing new information, altering how others perceive us, influencing support received, or changing the dynamics of future interactions in positive or negative ways.

Chaudoir SR, Fisher JD. The disclosure processes model: understanding disclosure decision making and post disclosure outcomes among people living with a concealable stigmatized identity. *Psychol Bull.* 2010;136(2):236-56. doi: 10.1037/a0018193

# Disclosure Processes Model (DPM)

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## Research Questions

- What are the approach/avoidance reasons people living with chronic, episodic conditions give for disclosing or not disclosing?
- Are these reasons associated with positive or negative support outcomes controlling for other personal, health, and work context factors?

# Study Methods

**Design:** Online, cross-sectional survey administered in October 2018

**Eligibility:**  $\geq 18$  years of age

Employed for at least 15 hours per week

Able to complete an English-language questionnaire

**Recruitment:** National panel of > 100,000 Canadians

Recruited similar proportions of women and men and workers in three age groups (18-35 years; 36-50 years; > 50 years)

Participants living with a chronic physical or mental health condition

Gignac, M.A.M., Jetha, A., Martin Ginis, K.A., Ibrahim, S. (2020). Does it matter what your reasons are when deciding to disclose (or not disclose) a disability at work? The association of workers' approach and avoidance goals with perceived positive and negative workplace outcomes. Manuscript under review.

# Disability disclosure versus non-disclosure sample characteristics (n = 896)

Characteristics	Disclosed (n = 459)		Did not disclose (n = 437)		P value
	%	Mean (SD)	%	Mean (SD)	
Gender (women)	57.2		58.4		0.73
Age:					0.01
18-33	29.0		37.5		
36-50	34.0		33.0		
51+	37.0		29.5		
Education:					.78
High school or less	20.5		22.5		
Some post secondary	30.6		29.8		
Post secondary	48.9		47.7		
Job Sector:					0.43
Financial, insurance, government, business	24.3		20.3		
Education, health, sciences, arts	32.2		34.3		
Sales, services, retail	22.3		21.4		
Construction, utilities, agriculture, manufacturing	21.2		12.2		
Hours worked per week		37.6 (9.3)		37.5 (8.6)	0.92

# Disability disclosure versus non-disclosure sample characteristics (n = 896)

Characteristics	Disclosed (n = 459)		Did not disclose (n = 437)		P value
	%	Mean (SD)	%	Mean (SD)	
Job tenure (years)		10.0 (9.0)		8.7 (8.8)	0.04
Contract work (yes)	6.8		12.2		0.01
Perceived job stress (1-5)		3.2 (1.0)		3.0 (1.0)	0.04
Perceived workplace support (1-5)		3.2 (1.1)		2.9 (1.2)	.001
Accommodations needed (0-12)		7.0 (3.7)		5.6 (4.1)	.001
Days absent due to health (past 3 months)		5.0 (5.5)		2.6 (3.9)	.001

# Example disclosure reasons

## Approach reasons (4 items):

I felt my job was secure and it was safe to discuss.

I wanted to make changes to my job and get support.

It's not a big deal, it's just part of who I am.

## Avoidance reasons (6 items):

I had to explain work absences.

My health or disability was getting worse and I needed to disclose.

Others noticed changes in my behaviour and asked if there was a problem.

Asked whether each reason was important in deciding to share information (Yes/No)



# Example reasons for non-disclosure

## Approach reasons (2 items):

I can manage at work without others knowing.

My health or disability doesn't affect my ability to do my job.

## Avoidance reasons (8 items):

I was concerned about lost opportunities for a promotion or new job tasks.

Past experiences make me concerned about sharing.

Nothing can be done so there's no point in discussing.

Asked whether each reason was important in deciding not to share information (Yes/No)

# Support outcomes for disclosure

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13 Items generated based on previous research. Examples include:

- There was greater understanding of my personal needs.
- I don't need to hide who I really am from others at work.
- There was less stress at work.
- I have to spend more effort to prove I'm as good as others.
- Others focus on my difficulties and not my skills and abilities.
- I have experienced rejection or stigma from others.

Responses on a 5-point Likert-type scale with 1 = strongly disagree to 5 = strongly agree

# Support Outcomes for non-disclosure

13 Items generated based on previous research. Examples include:

- People see me more positively
- People focus on my skills and abilities
- Others don't gossip about my personal situation
- I am more stressed
- I have to hide who I really am from others
- I have experienced rejection or stigma from others

Responses on a 5-point Likert-type scale with 1 = strongly disagree to 5 = strongly agree

# Exploratory factor analyses: Cronbach's alphas

## Disclosure Outcomes

Positive support outcomes,  $\alpha = .86$ , average score = 3.4

Negative support outcomes,  $\alpha = .90$ , average score = 2.7

## Non-Disclosure Outcomes

Positive support outcomes,  $\alpha = .66$ , average score = 3.6

Negative support outcomes,  $\alpha = .88$ , average score = 3.0

# Most frequently endorsed disclosure reasons (n = 459)

Reasons for Disclosing	%
<b>Approach Reasons</b>	
Felt job was secure and it was safe to discuss	71.4
Not a big deal; just a part of who I am	63.4
Wanted to make changes to my job and get support	36.6
<b>Avoidance Reasons</b>	
My health/disability could affect my job so I let others know	61.0
Others noticed and asked if there was a problem	47.1
My health/disability was getting worse and I needed to disclose	41.9

# Most frequently endorsed non-disclosure reasons (n = 437)

Reasons for Not Disclosing	%
<b>Approach Reasons</b>	
Can manage at work without others knowing	75.6
My health/disability doesn't affect my ability to do my job	55.9
<b>Avoidance Reasons</b>	
People don't have the right to know	63.3
Nothing can be done so there's no point in discussing	51.9
Concerned about lost opportunities for a promotion or new job tasks	40.6
Didn't feel secure in my job	37.0

# Multivariable analyses for positive and negative outcomes of disclosure (n = 459)

	Perceived Positive Outcomes beta (95% CI)	Perceived Negative Outcomes beta (95% CI)
Gender (Women)	-0.69 (-1.37, -0.02)*	
Age		
Education		
Disability Type		
Work Stress	-0.47 (-0.85, -0.10)*	1.16 (0.53, 1.79)**
Workplace Support	1.36 (1.05, 1.67)**	-1.38 (-1.91, -0.85)**
Accommodations Needed		0.37 (0.21, 0.53)**
Days Absent		0.14 (0.03, 0.25)*
<b>Approach reasons for disclosure</b>	1.03 (0.71, 1.34)**	-0.99 (-1.52, -0.47)**
<b>Avoidance reasons for disclosure</b>		0.74 (0.30, 1.18)**
* p < .05; ** p < .01		

# Multivariable analyses for positive and negative outcomes of non-disclosure (n = 437)

	Perceived Positive Outcomes beta (95% CI)	Perceived Negative Outcomes beta (95% CI)
Gender (Men)		
Age		
Education		
Disability Type: Mental		1.67 (0.15, 3.19)*
Both physical & mental		1.45 (0.14, 2.75)*
Work Stress		0.58 (0.00, 1.17)*
Workplace Support		-1.46 (-1.93, -0.98)**
Accommodations Needed		0.19 (0.06, 0.32)**
Days Absent		
<b>Approach reasons for non-disclosure</b>	0.78 (0.36, 1.21)**	-1.23 (-1.95, -0.51)**
<b>Avoidance reasons for non-disclosure</b>	0.18 (0.04, 0.32)**	1.09 (0.85, 1.32)**
* p < .05; ** p < .01		



# Summary

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- One of the first studies to examine the relationship between a worker's reasons for disclosure/non-disclosure and perceived support outcomes.
- Most respondents had multiple approach/avoidance reasons for decisions that went beyond perceived need and support.
- Decisions included issues of personal identity, control of information, past experiences, perceived helplessness, personal preferences, the role of others, job demands, etc.
- There was no single “right” decision whether to share or not share – many participants reported positive outcomes regardless of the decision to share or not share information.
- The study does not suggest that one's reasons CAUSE an outcome.

# Summary

- Mental health research highlights concerns about negative outcomes if personal health information is disclosed (e.g., stigma).
- In our study, type of condition *did not* predict positive or negative outcomes of disclosing.
- Note: we don't know how much personal health information was shared.
- Having a mental health condition (or both physical & mental health condition) was associated with negative outcomes for NOT disclosing.
- Qualitative data provides support and additional insights: workplaces report considerable challenges when individuals with mental health conditions experience symptoms but are not aware of them or choose to deny a problem.
- “Leaking” symptoms was interpreted negatively by others (e.g., motivation problems, negative interpersonal style).

Gignac, M.A.M. et al., (2020). Disclosure, privacy and workplace accommodation of episodic disabilities: Organizational perspectives on disability communication-support processes to sustain employment. *Journal of Occupational Rehabilitation*. <https://doi.org/10.1007/s10926-020-09901-2>

# Going forward...

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We need to tap a range of factors to help workers negotiate the communication decision that is right for them.

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

**Project Director:** Monique Gignac

**Research Team:**

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**Partners:**

Institute for Work & Health	Canadian Mental Health Association
Arthritis Society	Workplace Strategies for Mental Health
Crohn's & Colitis Canada	Multiple Sclerosis Society of Canada
Mindful Employer Canada	
Ontario Ministry of Labour	
Realize	
University of Toronto	

# ACED Tools & Resources

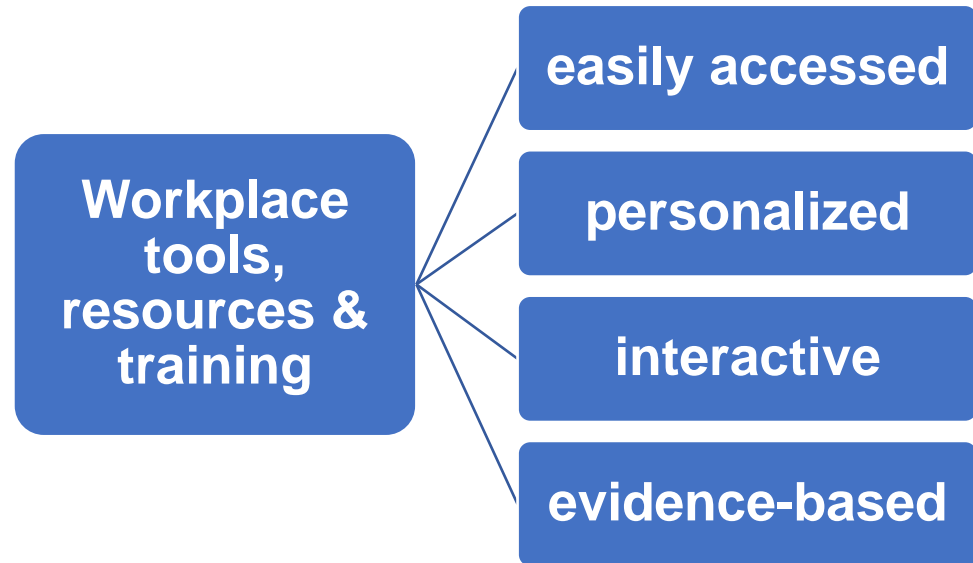
- Job Demands and Accommodation Planning Tool (JDAPT)
- Communication Decision-Making Tool



<https://aced.iwh.on.ca/>

# ACED Partnership Aims:

Enhance work sustainability for people with episodic disabilities



## ACED Materials will

- Be responsive to needs and preferences
- Promote discussion
- Facilitate brainstorming
- Be feasible and broadly applicable
- Adopt a disability prevention and support framework
- Emphasize skills and abilities
- Improve short and long-term workplace outcomes

**We will NOT give advice**

# ACED Communication Decision-Making Tool

## Five broad communication areas will be covered:

1. What is your current work situation? Why are you thinking about sharing personal health information at work (asking yourself some hard questions)?
2. What are your goals in sharing or not sharing information?
3. What matters to you? What do you need to understand about yourself in making a decision?
4. What do you need to consider about your job and your organization?
5. When should you say something? What do you need to think about now and in the future?

# Thank you

**Monique Gignac**  
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