



Deciding Whether to Share Health Information at Work:

A new evidence-based tool for workers with chronic conditions

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Takeaway Messages

- Many workers do not share health or support needs at work.
- Disclosure decisions can be complex, drawing on health impacts, goals, personal preferences, support availability, and perceptions of workplace supportiveness.
- Decision information often simultaneously encourages and discourages sharing, which is stressful for many workers.
- The DCIDE Tool (*Disclosure-support for Communication of Invisible Disabilities that are Episodic*) helps workers consider whether to share some personal information at work.
- DCIDE is freely available in English and French. It links to other resources that can help with support and accommodation planning.



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Presentation Overview

Setting the stage: Disability in Canada

- Disability numbers and episodic/dynamic disabilities

Why are Disclosure Decisions so Difficult?

- What research tells us

The DCIDE Tool

- Tool Components and Output

Takeaway Messages & Next Steps



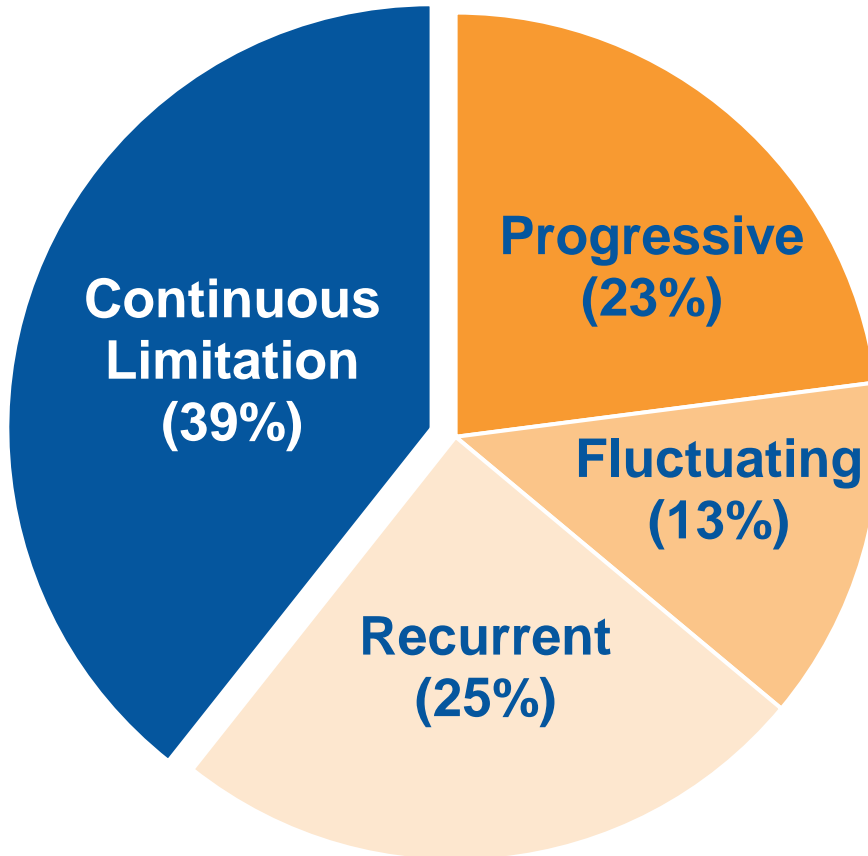
Setting the Stage: Disability in Canada

What is meant by a disability?

- Living with a chronic or episodic condition does not guarantee a disability
- A disability is a limitation in performing an activity that arises as a result of the interaction between a health condition **AND** personal and environmental factors, including negative attitudes, activity demands, public policies and practices, inaccessible physical environments, and limited social support
- Changes to work activities or work practices may help minimize or ameliorate disability

World Health Organization (WHO), <https://www.who.int/health-topics/disability>

Disability in Canada



- 8 million Canadians report living with a disability
- 61% experience **episodic or dynamic** limitations or disability:
 - Progressive: worsening over time (23%)
 - Fluctuating: changes daily or weekly (13%)
 - Recurrent: periods of a month or more with no limitations (25%)
- Many disabilities are unpredictable and invisible

Examples: depression, anxiety disorders, PTSD, arthritis, diabetes, multiple sclerosis, Crohn's, colitis, epilepsy, pain conditions, chemical sensitivities, ADHD, HIV/AIDS some cancers
(Statistics Canada, 2023; Morris et al., 2019)

Workplace Support Matters

Employment rates in Canada for people with disabilities are about 20% lower than for people without a disability (59% versus 80%) (Morris et al., 2017)

People with disabilities are more likely to be employed in precarious and lower quality jobs with less access to workplace supports (Vahid Shahidi et al., 2023)

The **episodic**, **unpredictable**, and **invisible** nature of many disabilities creates challenges in:

- Providing support and accommodations
- Workplace disability communication, disclosure, and privacy protection



Workplace Support Matters (2)

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The **episodic**, **unpredictable**, and **invisible** nature of many disabilities creates challenges in:

- Providing support and accommodations
- Workplace disability communication, disclosure, and privacy protection

Across several Canadian surveys, **25%-49%** of participants with a physical or mental health condition reported ***not sharing*** information about their limitations at work with their supervisor



Why are Disclosure Decisions so Difficult?

Why are disclosure decisions so difficult?

Mechanics of Disclosure

- People need to consider whether to share information, with whom, when, what, how much, mode of sharing
- Not a one-time decision, but involves multiple decisions

Outcome Uncertainty

- Concerns about loss of reputation, career advancement, stigma, gossip, control of information, that nothing can be done, job loss if you share, and job loss if you don't share
- Research finds positive and negative outcomes

What to Consider

- What types of information are used to make decisions?
- Is some information prioritized over other information?
- Are there decision patterns that can help us better understand disclosure?

Building a Communication Decision-Support Tool

Aimed to develop a new communication decision-support tool that focuses on what should be considered in making disclosure decisions

- How did we build the tool?
- How did a sample of workers with diverse physical and mental health conditions, and diverse jobs respond to tool questions?
- Does the tool differentiate among people with different needs, preferences, and experiences?
- Can the tool help address decision complexity?

What to Consider:

Building a Communication Decision-Support Tool

- Reviewed existing research and grey literature, held ongoing consultations with individuals with lived experience, reached out to partners and other stakeholders
- Developed tool items asking about five decision dimensions:
 - **Health impacts and needs**
 - **Goals**
 - **Communication preferences**
 - **Workplace support availability**
 - **Perceptions of workplace culture/supportiveness**
- Tested new items; reviewed tool measurement properties and initial validity
- Examined naturally occurring groups or clusters of respondents and how they differed in decisions, stress, and work context

What to Consider:

Building a Communication Decision-Support Tool (2)

1. Health Impacts and Needs

Example questions:

- Impact of health on work
- Impact of work on health
- Health changes (current/anticipated)
- Work changes (current/anticipated)
- Need for support
- Performance monitoring/disciplinary actions taken
- Health professional advised them not to perform some job activities
- Health and safety concerns



What to Consider: Building a Communication Decision-Support Tool (3)

2. Goals: Approach and Avoidance

Approach goals often encourage sharing

- Want access to accommodations
- Want information or advice
- Want to build education and awareness
- Want to build trust

Avoidance goals often discourage sharing

- Want to protect one's reputation
- Want to protect career advancement
- Want to protect one's finances
- Want to protect the status quo



What to Consider:

Building a Communication Decision-Support Tool (4)

3. Communication Preferences and Experiences

Asked about personal preferences for sharing information, maintaining privacy, and past experiences

Two dimensions:

- Positive perceptions and perceived benefits to disclosing
(e.g., “I want to be open and honest with my colleagues...”, “Sharing information about my health can help me cope better with the pressures at work”)
- Negative perceptions and perceived barriers to disclosing
(e.g., “I value my privacy and do not want to share information...” “If I share information, people will see me as someone who is a problem and not who I really am”)



What to Consider: Building a Communication Decision-Support Tool (5)

4. Workplace Support Availability

Example questions:

- Permanent/contract work
- Availability of an HR manager/department
- Benefit plan eligibility
- Paid sick days/ personal days
- Workplace support and accommodation policies
- Privacy policies
- Union/professional organization membership
- Diversity policies
- Long-term disability benefits



What to Consider:

Building a Communication Decision-Support Tool (6)

5. Perceptions of workplace culture/supportiveness

Asked about perceptions of the workplace culture related to sharing or disclosing personal information

Two dimensions:

- Positive perceptions of the workplace culture
(e.g., “I would be comfortable sharing some information about my health condition because my workplace support and accommodation policies are fair to employees”, “My colleagues are supportive and understanding of people’s differing needs”)
- Negative perceptions of the workplace culture
(e.g., “I am concerned there is too much gossip in my workplace”, “Others have not been treated well by this workplace when they have shared their personal needs”)



Study Sample Characteristics (n = 591)

Variable	N (%) / Mean (SD)	Variable	N (%) / Mean (SD)
Gender		Job Sector	
Women	283 (48)	Financial, business, gov't, tech	225 (38)
Men	299 (51)	Education, health, professional	203 (34)
Non-binary	8 (1)	Sales, services, retail	66 (11)
Age (range 21-75 yrs)	47.6 (11.6)	Construction, utilities, manufacturing	95 (16)
Condition Type		Full-time	507 (86)
Physical only	241 (41)	Organization size	
Mental health only	141 (24)	< 100 employees	155 (27)
Both	209 (35)	100-500 employees	101 (18)
Episodic/Dynamic Disability		> 500 employees	320 (56)
Continuous	143 (24)	Years with Employer	10.7 (9.2)
Recurrent	260 (44)	Union/Professional Association	254 (43)
Progressive/Fluctuating	186 (32)		

Disclosure (n = 591)



Disclosed to a supervisor: 58%



Disclosed to some colleagues: 55%

Disclosed to most/all colleagues: 15%



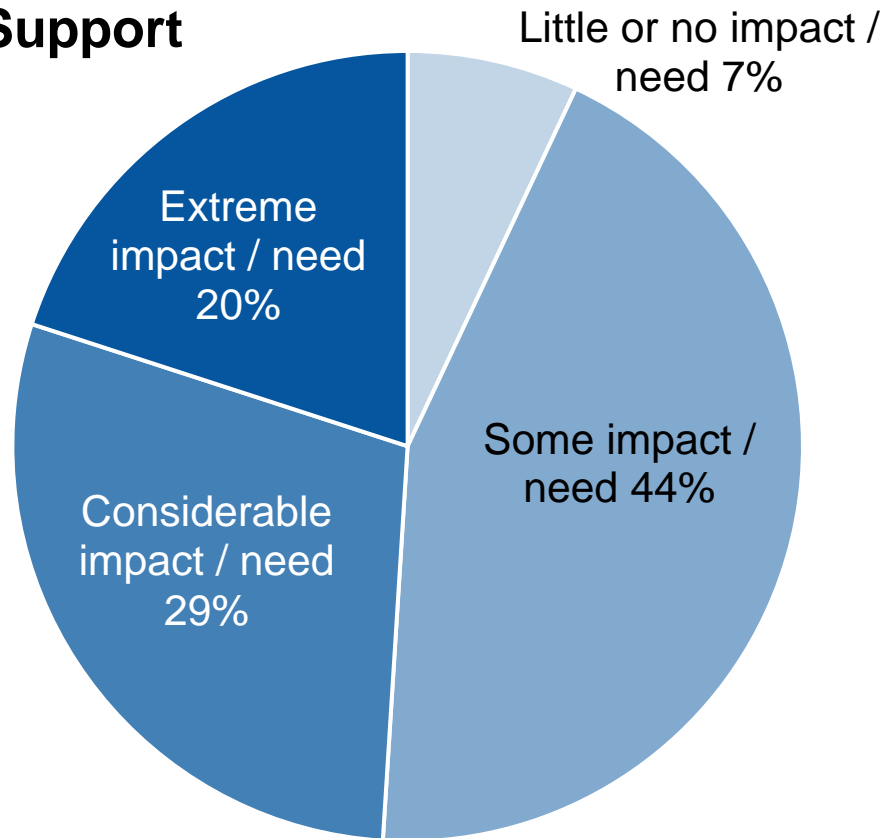
Disclosed to others at work (e.g. HR, union rep, disability manager, OHS): 27%



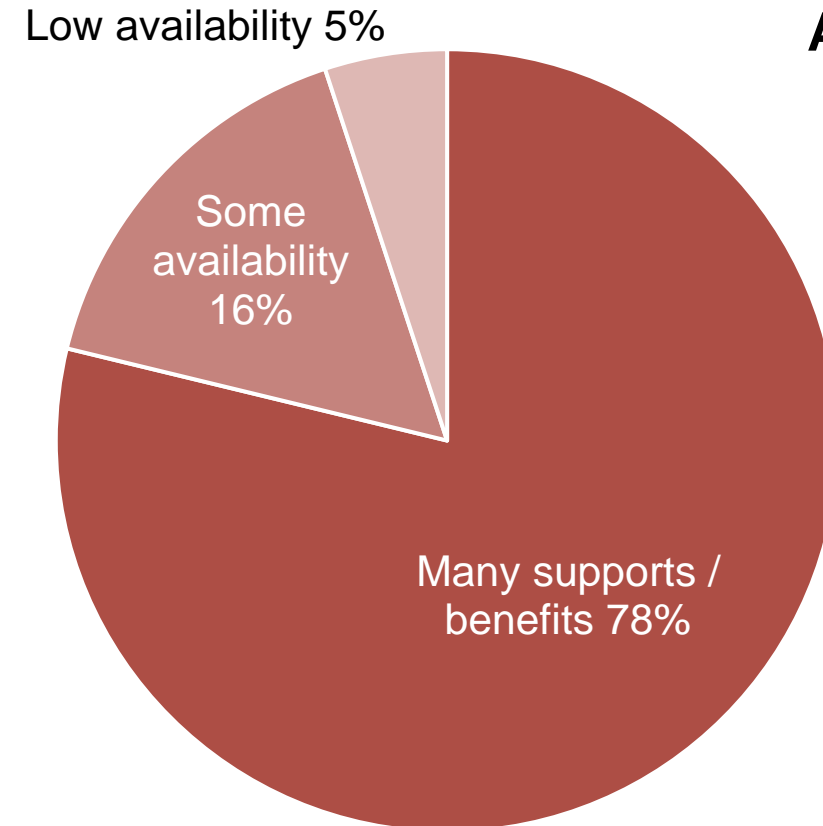
Experienced pressure in making disclosure decisions: 65%

Impact / Need for Support & Workplace Support Availability

Impact/Need for Support



Workplace Support Availability



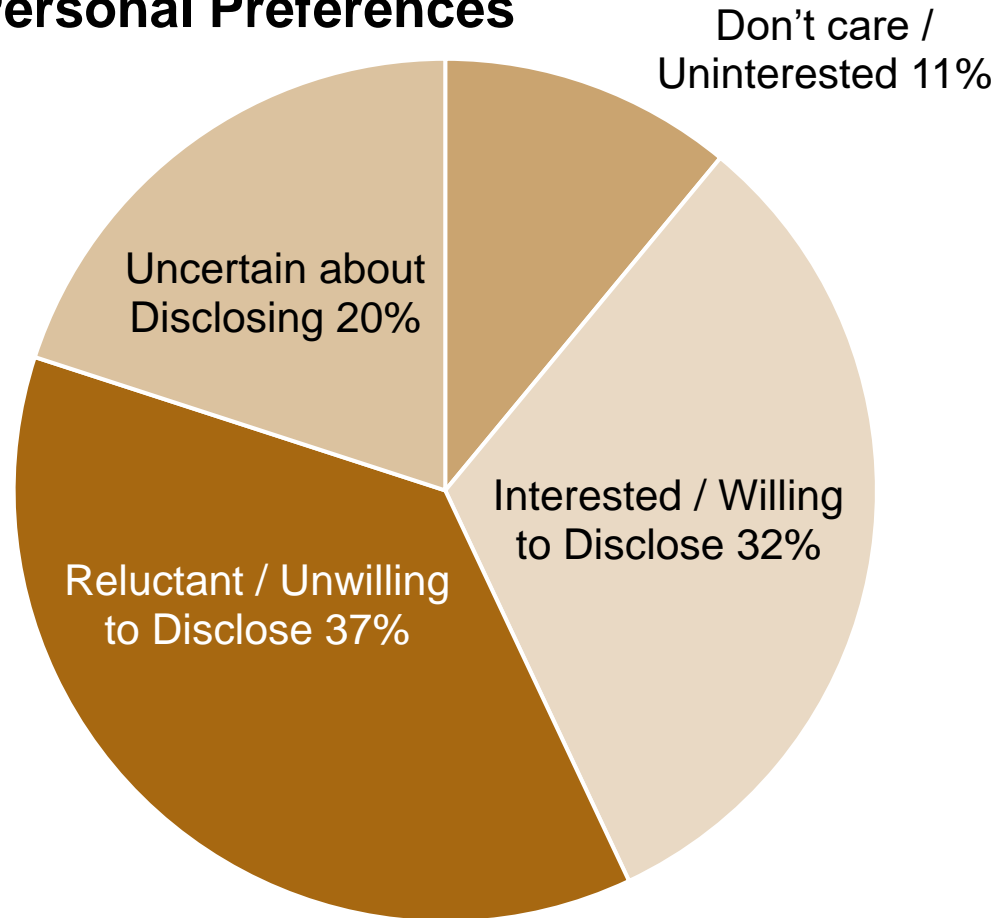
Goals



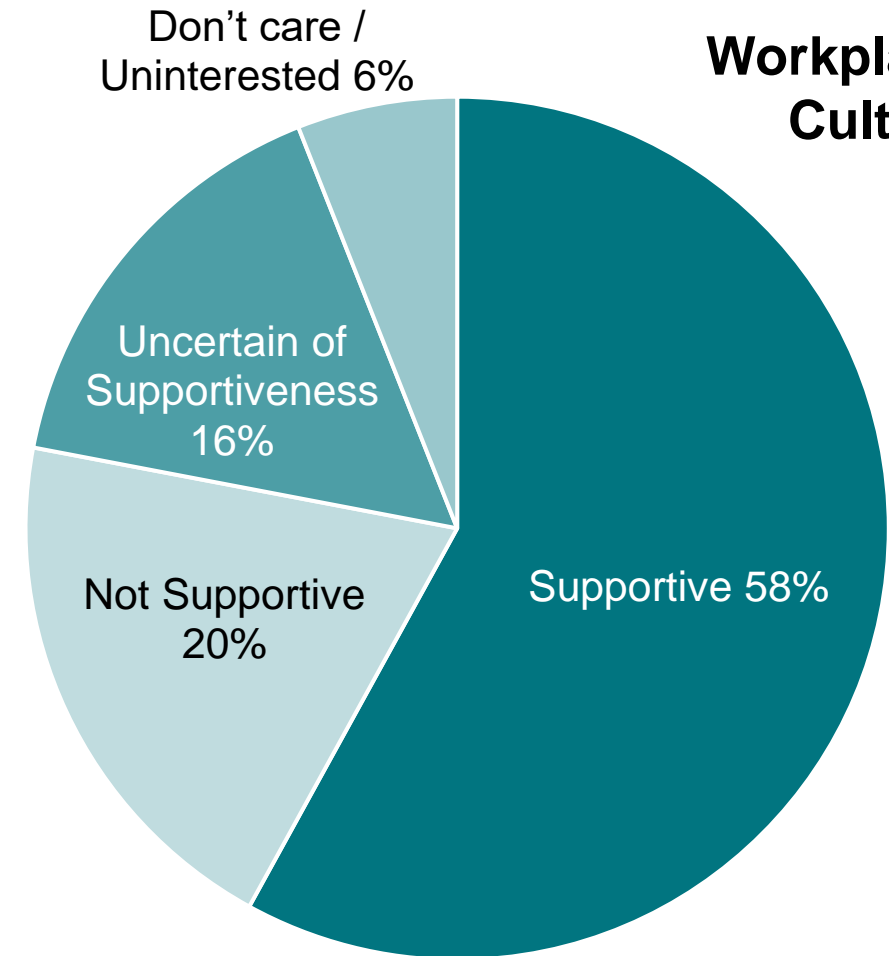
- 13% of participants reported *mostly* approach goals that would encourage sharing
 - e.g., getting information, building awareness, seeking accommodations
- 29% of participants reported *mostly* avoidance goals
 - e.g., protecting their reputation, protecting their finances
- 35% of participants reported many goals that simultaneously encouraged and discouraged them from disclosing, that is, both approach and avoidance goals
- Nearly one quarter of participants had no goals in mind when making disclosure decisions (23%)

Personal Preferences & Perceived Workplace Culture

Personal Preferences



Workplace Culture



What Does it All Mean?

- How do we make sense of all this information?
- Are there naturally occurring clusters or groups of people who use or prioritize information differently?
- The answers can give us insights into how people are likely to respond using the DCIDE tool
- It can also inform the feedback we give to DCIDE tool users



Cluster Analysis and Findings

- Statistical technique that helps identify distinct groupings (clusters) of people in terms of their similar responses to a set of variables
- Variables: the five decision dimensions – impact/needs, goals, personal preferences, workplace support availability, workplace culture
- Expect groupings to differ in the decision dimensions that characterize them
- Also expect the groups to differ in their disclosure decisions, perceived stress, and work characteristics
- We found six different clusters/groupings
- Despite impact/need and support availability, most groups were characterized by their emphasis on subjective perceptions

Six Clusters of Decision Dimensions Emerged

All is generally well	Need help but reluctant to disclose	Need help but uncertain about disclosing	Feel supported but few options	Not a concern; No need to act (2 groups)
Sample: 48%	Sample: 24%	Sample: 12%	Sample: 8%	Sample: 6% & 2%
66% low or some impact/need	69% considerable or extreme impact/need	86% considerable or extreme impact/need	Mix of impact/needs	No or little impact / needs
Mixed goals	51% avoidance goals	69% both approach and avoidance goals	Mix of goals	Few goals; avoidance goals
Mixed disclosure preferences	100% reluctant to disclose	85% uncertain about disclosing	50% willing to disclose	Uninterested in sharing
96% positive culture perceptions	58% negative workplace culture	63% uncertain about culture at work	100% positive workplace culture	Uninterested in workplace culture
100% many supports available	78% many supports available	75% many supports available	100% few supports available	Mix of support availability

Clusters Differ in Disclosure, Stress, Perceived Decision Pressure, Productivity, and Employment Worries

	All is generally well	Reluctant to disclose	Uncertain about disclosing	Feel supported, few options	Not a concern, etc. (2 groups)
Disclosed to supervisor	69%	33%	68%	81%	32%; 50%
Decision stress (range 6-30)	13.7 (4.6)	18.3 (5.3)	19.4 (4.4)	13.9 (5.7)	14.3 (5.1); 14.5 (2.9)
Felt Pressured (range 1-5)	2.0 (0.9)	2.8 (1.3)	3.1 (1.3)	2.0 (1.1)	2.3 (1.1); 2.1 (0.8)
Productivity Problems (0-10)	3.3 (2.3)	4.6 (2.4)	5.2 (2.4)	3.7 (2.6)	3.1 (2.2); 4.0 (2.3)
Job Worries (1-5)	1.8 (1.0)	2.8 (1.4)	3.4 (1.4)	1.9 (0.8)	2.3 (1.3); 2.2 (1.3)

Means and SDs for stress, felt pressured, productivity, job worries

Clusters Differ in Age, Education, Condition Type, Full-Time Work, Job Sector, Size of Organization

All is generally well	Need help but reluctant to disclose	Need help but uncertain about disclosing	Feel supported but few options	Not a concern; No need to act (2 groups)
Older			Younger	Older
Greater education	Greater education	Greater education		Less education
More physical conditions	Mix of conditions	More mental health or both physical and mental health		
			More part-time workers	
			More sales / service jobs	More construction, manufacturing, utilities jobs
Larger organizations	Larger organizations		Smaller organizations	

No significant differences in gender or absenteeism

Where do you fall?

- A lot of variability among respondents
- Many people were positive about some sharing, but others were not willing or uncertain about disclosing despite needs
- Subjective perceptions often guided decisions
- A decision-support tool can help:
 - a) identify important decision elements
 - b) Help users consider a full range of dimensions to better balance decision making
 - c) organize and summarize information
 - d) point to additional resources

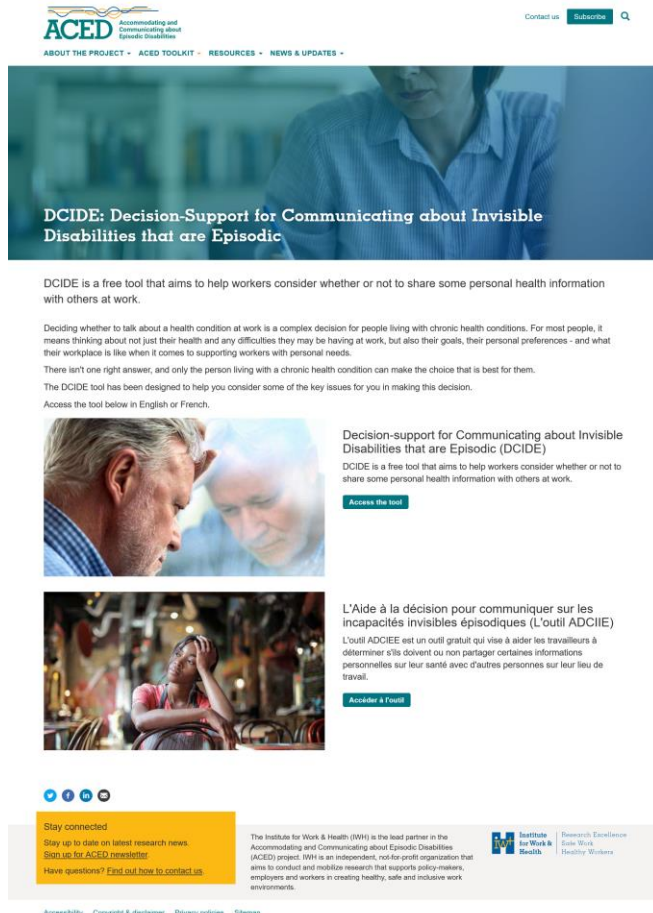




DCIDE

Decision-Support for Communicating about Disabilities that are Episodic

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



Goals:

- Adopt a prevention & support framework – help users be more proactive, less crisis-focused
- Provide a tool that is personalized, interactive, accessible and evidence-based
- Be relevant to diverse health conditions and disabilities, different jobs, and personal preferences
- Provide feedback and links to other resources
- Improve the disclosure decision process
- Protect privacy

Using the DCIDE Tool (1) <https://aced.iwh.on.ca/dcide>

- Select English or French DCIDE
- Read through the introduction
- Answer questions for the five decision dimensions

Introduction

Welcome to the DCIDE tool (Decision-Support for Communicating about Invisible Disabilities that are Episodic).

DCIDE (pronounced “decide”) aims to help workers consider whether or not to share some personal health information with others at work. It was developed by research experts, people living with episodic conditions, and community groups.

DCIDE is an easy-to-use online tool that:

- helps you to consider key issues that can be important in determining whether to disclose information about a health condition at work;
- helps you to assess your personal situation and preferences;
- links to other materials and resources that you might be able to use – regardless of whether you decide to share anything about your health at work at this time or not.

DCIDE was designed for workers with an episodic disability—that is, a chronic health condition, often invisible, that reoccurs, fluctuates or gets worse over time. It can also be useful to anyone who needs to make a decision about sharing personal health information.

How does DCIDE work?

DCIDE asks you to respond to questions in five different areas that are often important when deciding whether to share some personal health information with others at work.

1. **Your Needs:** Why are you thinking about whether to share some personal health information at work? What is happening now that

How does DCIDE help?

Sometimes people feel like little, or nothing, can be done about their limitations at work, or they aren't sure whether they are ready to share information with others. Sometimes a crisis in health can force changes or lead to others finding out about your health condition, even if you would rather keep that information private.

The image displays a collage of screenshots from the DCIDE tool, illustrating its five decision dimensions. The sections shown are:

- Your Work Culture:** Questions about workplace supportiveness.
- Your Work Supports:** Questions about available workplace resources.
- Your Communication Preferences:** Questions about sharing health information.
- Your Goals:** Questions about the importance of goals and actions.
- Your Needs:** Questions about the reasons for considering disclosure.

Each section includes a set of questions with response options: 'No', 'Not sure', 'Yes', and a 4-5 scale (Strongly agree, Strongly disagree, etc.).

Using the DCIDE Tool (2)

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

For each of the five decision dimensions, the tool programming will place you in a category that reflects your responses.

e.g., for “Your Work Culture, categories include supportive workplace culture, not supportive, uncertain about the culture of support at your workplace, etc.



Your Work Culture

How supportive are others in your workplace?

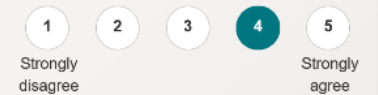
Are there benefits or downsides to sharing personal information with others at work?

The last part of the DCIDE tool asks you about your experiences with others, and the attitudes and practices at your organization related to supporting workers.

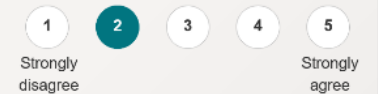
Please read each of the statements below and indicate whether you agree or disagree with that statement. Answers are on a scale from 1 to 5 with 1 meaning that you strongly disagree, 3 meaning that you neither agree nor disagree, and 5 meaning that you strongly agree.

Please answer all the questions to get your personalized review and summary of your perceptions of your workplace, its culture, and those you work with.

I would be comfortable sharing some information about my health condition because my workplace's support and accommodation policies are fair to employees.



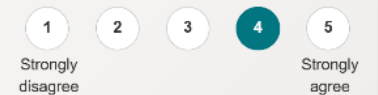
I am concerned about sharing information because I don't think my workplace applies its support and accommodation policies in the same way for everyone.



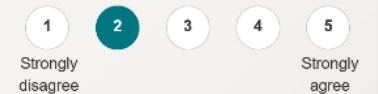
I think my supervisor will keep my personal information confidential when thinking about my support needs.



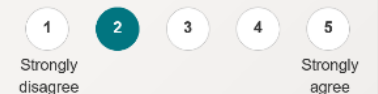
I've shared information about my health with other work colleagues in the past and most people have been supportive.



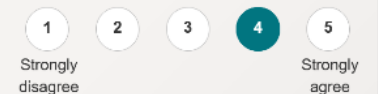
I have not worked at my workplace for a long time and would be concerned about sharing information about my health condition.



Others have not been treated well by this workplace when they have shared their personal needs.



I am concerned that there is too much gossip in my workplace.



Using the DCIDE Tool (3) <https://aced.iwh.on.ca/dcide>

After each section, you receive a short summary of “*Your Situation*” and guidance on “*Things to Think About*”

Your Work Culture

How supportive are others in your workplace?

Are there benefits or downsides to sharing personal information with others at work?

Below is a summary of your perceptions of your workplace and how supportive the culture is. The green border indicates that you have reported a positive workplace environment and culture where sharing may be helpful, and support may be available if you need it.

Your situation

You currently believe that your workplace has a culture that is likely to be supportive if you share some information with others about health and work issues.

You noted several positive aspects of your workplace. This includes the supportiveness of your colleagues and/or your supervisor, and the availability of accommodation policies that treat people fairly.

You also reported few concerns about potential negative outcomes of

Things to think about

Your insights into your workplace are important to make decisions that are right for you. You believe that your organization has a culture of supporting the needs of their workers and has experience helping workers with health needs.

At the same time, knowing that you have a positive workplace culture does not mean that you are necessarily ready or comfortable with sharing information at this moment.

Goal:

- Distil information into manageable chunks;
- Have users think about next steps and potential benefits/drawbacks to their choices

Using the DCIDE Tool (4) <https://aced.iwh.on.ca/dcide>

Thank you for completing the DCIDE tool

Please save your DCIDE tool results as a PDF now.

We do not save your information so you will not be able to return to your results in the future



[DCIDE results summary.pdf](#)

Next steps

You may decide to share some personal information with others at work or not to share information at this time. No matter what you decide, there are some things that you will wish to think about to support yourself and plan for the future. These include:

- What are your options if you choose not to share any information at this time?
- If you do choose to share, what do you want to share and what do you not want to share?
- When should you talk to someone?
- Who might be able to help?

We have included some guidance about next steps at the end of your results summary pdf. Please take some time to read this material when it is convenient for you.

Job Demands and Accommodation Planning Tool (JDAPT)

To help you think more about your work and health, and to provide you with ideas for support strategies, we have created the Job Demands and Accommodation Planning Tool (JDAPT).

JDAPT

The JDAPT is an award-winning tool that provides workers with practical support and accommodation ideas that are relevant to their job demands. It can be used even when you do not want to share any information with others at this time.

Using the DCIDE Tool (5) <https://aced.iwh.on.ca/dcide>

Next Steps

What you can do if you choose not to share any information at this time

You might choose not to share information about difficulties that your health and job demands can create. For example:

- You might feel there is no need to say anything because your health is not currently affecting your job
- You might not believe that sharing information about your health will help you achieve your goals
- You might have a strong personal preference for keeping your health private
- You might not feel comfortable sharing information because you believe your workplace would not be supportive or you have had bad experiences in the past

If you have decided not to share any information about your difficulties at work related to your health, there are ways that you can help yourself continue to work well.

Identify what you can do on your own to help manage your health and work

The ACED Job Demands and Accommodation Planning Tool (JDAPT) provides strategies that you can use on your own – whether at work or at home – to help you better manage your workplace demands. Use the JDAPT to figure out which job demands you are having difficulty with due to your health. Then look through the list of suggested strategies and supports to see which ones you might be able to use at work.

How to approach communicating about your health in the workplace

Think about where and how you would like to talk to someone in your workplace about your health. There are different ways you can share information.

	Advantages of this approach	Disadvantages of this approach
You can share information in person (for example, in a face-to-face meeting, a videoconference, by telephone)	<ul style="list-style-type: none">• You can respond to questions or concerns as they arise• You may be better able to build a relationship and establish trust• You can gauge the other person's reactions and add information or correct misunderstandings• It may be easier to have a discussion and be less time-consuming	<ul style="list-style-type: none">• You may have difficulty arranging a meeting when you need it• You may feel pressured to say more than you wish to• You may be concerned about keeping your emotions in check when sharing sensitive information• You may have less control over

Using the DCIDE Tool (6) <https://aced.iwh.on.ca/jdapt>

Job Demands and Accommodation Planning Tool (JDAPT)

The Job Demands and Accommodation Planning Tool (JDAPT) helps workers with chronic and episodic conditions—and the workplace parties who support them—identify accommodations tailored to job demands that allow workers to successfully stay in their jobs.



JDAPT for workers

This version is for workers with chronic conditions who are most comfortable working with an English-language tool and are looking for practical supports and accommodation ideas tailored to their specific job demands.

[Go to the tool](#)



L'OPA-ET destiné aux travailleurs et travailleuses

Notre outil en français s'appelle "L'Outil de planification d'accommodements pour répondre aux exigences liées au travail" - ou OPA-ET en abrégé. L'OPA-ET s'adresse aux travailleurs atteints de maladies chroniques qui se sentent plus à l'aise avec un outil en français et qui recherchent des soutiens

Takeaway Messages & Next Steps (1)

- Many workers do not share health or support needs at work.

Additional efforts are needed to improve workplace support provision. Availability of supports is not sufficient for many workers to seek support.

- Disclosure decisions can be complex, drawing on health impacts, goals, personal preferences, support availability, and perceptions of workplace supportiveness.
- Decision information often simultaneously encourages and discourages sharing, which is stressful for many workers.

Our findings showed how different workers prioritize decision information and that this was related to work context. More research is needed to identify modifiable factors related to support provision.



Takeaway Messages & Next Steps (2)

- The DCIDE Tool helps workers consider whether to share personal information at work.

*Initial assessment of construct, face, and criterion validity are promising.
More research is needed, including evaluating DCIDE tool outcomes*

The ACED website (<https://aced.iwh.on.ca>) provides:

- a) DCIDE: a decision-support tool, including what to consider after you have made a disclosure decision (to share or not share)
- b) JDAPT: job demands and accommodation planning tool, and
- c) definitions of key concepts and further information on employment and accommodation rights in Canada.

ACED tools are free, confidential, and available in English and French.



Thank you!

Questions? Comments?

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

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