

A blurred, vertical image on the left side of the slide showing the lower legs and feet of several people walking. The image is out of focus, with a bright light source creating a lens flare effect.

Accommodating and Communicating about Episodic Disabilities (ACED): A partnership to deliver workplace tools and resources to sustain the employment of people with chronic, episodic conditions

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



**Institute
for Work &
Health**

Research Excellence
Advancing Employee
Health

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

Project Director: Monique Gignac

Research Team:

Dorcas Beaton	William Shaw
Curtis Breslin	Peter Smith
Renée-Louise	Aaron Thompson
Franche	Emile Tompa
Emma Irvin	Dwayne Van Eerd
Arif Jetha	Julie Bowring
Joy MacDermid	Sabrina Tonima
Ron Saunders	Sara Macdonald

Partners:

Institute for Work & Health
Arthritis Society
Crohn's & Colitis Canada
Mindful Employer Canada
Ontario Ministry of Labour
Realize
University of Toronto

Canadian Mental Health
Association
Great-West Life Centre for
Mental Health in the
Workplace
Multiple Sclerosis Society of
Canada



Social Sciences and Humanities
Research Council of Canada

Conseil de recherches en
sciences humaines du Canada

Canada



CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

ACED Partnership Grant

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Chronic health conditions in Canada

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, colitis, migraine, epilepsy, some types of cancer, HIV

Chronic health conditions in Canada

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

We conducted a survey of 1087 individuals living with a chronic physical or mental health condition and found:

- Recurrent limitations: 47.7%
- Progressive limitations: 11.7%
- Fluctuating limitations: 8.3%
- Continuous limitations: 32.3%

Working with a Chronic, Episodic Condition: Workers

- Decisions whether to disclose health information at work are often stressful and complex.
- Previous research highlights need and perceived support as important to decisions
- Newer data highlight individual preferences, past experiences, appraisals and communication goals

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

Working with a Chronic, Episodic Condition: Workplaces

- Few studies have examined the perspectives of workplaces in providing support to individuals living with episodic conditions
- Our research highlights challenges related to workplace cultures, misgivings about others and their involvement in communication-support processes, and diversity in health conditions and job demands

Bottom line: A consistent and comprehensive approach to assessing job demands and support needs is needed

ACED Tools & Resources

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



“Should I tell my employer I have an episodic disability?”

Health research tends to focus 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.

“Should I tell my employer I have an episodic disability?”

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1. **Need** – those experiencing more activity limitations, pain, fatigue, or other symptoms are more likely to disclose health information at work.
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What about past experiences, current and future concerns, the nature of the job, appraisals of others, the work environment....?

“Should I tell my employer I have an episodic disability?”

We don't have research examining:

- 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 outcomes at work?

E.g., Disclosed at work because I believe it is a welcoming environment
versus disclosed because others noticed changes that I needed to explain

Did not disclose at work because I can manage my job and health demands
versus did not disclose to protect future job opportunities for a promotion

Disclosure Processes Model (DPM)

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.

Disclosure Processes Model (DPM)

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 Sample: Disclosure to supervisor (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: 18-33	29.0		37.5		0.01
36-50	34.0		33.0		
51+	37.0		29.5		
Education: High school or less	20.5		22.5		.78
Some post secondary	30.6		29.8		
Post secondary	48.9		47.7		
Job Sector: Financial, insurance, government, business	24.3		20.3		0.43
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

Study Sample: Disclosure to supervisor (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:

- I felt my job was secure and it was safe to discuss
- It's not a big deal, it's just part of who I am
- I wanted to make changes to my job and get support
- Others in my organization had discussed personal needs and the response was positive

Avoidance reasons:

- Others noticed changes in my behaviour and asked if there was a problem.
- I had to explain work absences
- My health or disability was getting worse and I needed to disclose.

Example Non-Disclosure Reasons

Approach reasons:

- I can manage at work without others knowing
- My health or disability doesn't affect my ability to do my job

Avoidance reasons:

- 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.

Most Frequently Endorsed Disclosure Reasons (n = 459)

Reasons for Disclosing	%
Approach Reasons	
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
Avoidance Reasons	
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	%
Approach Reasons	
Can manage at work without others knowing	75.6
My health/disability doesn't affect my ability to do my job	55.9
Avoidance Reasons	
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

Example Support Outcomes for Disclosure

- 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.

Example Support Outcomes for Not Disclosing

- 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

Exploratory Factor Analyses: Cronbach's alphas

Disclosure Outcomes (n = 13)

Positive Outcomes, $\alpha = .86$

Negative Outcomes, $\alpha = .90$

Non-Disclosure Outcomes (n = 13)

Positive Outcomes, $\alpha = .66$

Negative Outcomes, $\alpha = .88$

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

	Perceived Positive Outcomes	Perceived Negative Outcomes
Gender (Men)	*	
Age		
Education		
Disability Type		
Work Stress	* (-)	**
Workplace Support	**	** (-)
Accommodations Needed		**
Days Absent		*
Approach reasons for disclosure	**	** (-)
Avoidance reasons for disclosure		**
* p < .05; ** p < .01		

Multivariable analyses for positive and negative outcomes of not disclosing (n = 437)

	Perceived Positive Outcomes	Perceived Negative Outcomes
Gender (Men)		
Age		
Education		
Disability Type (mental; both physical & mental)		*
Work Stress		*
Workplace Support		** (-)
Accommodations Needed		**
Days Absent		
Approach reasons for non-disclosure	**	** (-)
Avoidance reasons for non-disclosure	**	**
* p < .05; ** p < .01		

Worker Study Summary

- 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.
- No single “right” decision whether to share or not share.
- The study does not suggest that one's reasons CAUSE an outcome.

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

Worker Study Summary

- Mental health research often focuses on negative outcomes of disclosure (e.g., stigma).
- In this study, type of condition did not predict positive or negative outcomes of disclosing.
- Having a mental health condition (or both physical & mental health condition) was associated with negative outcomes for NOT disclosing.
- Qualitative data provides some support for this finding: supervisors and HR note 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).

Questions?

We're missing the perspectives of workplace parties...

Research Questions

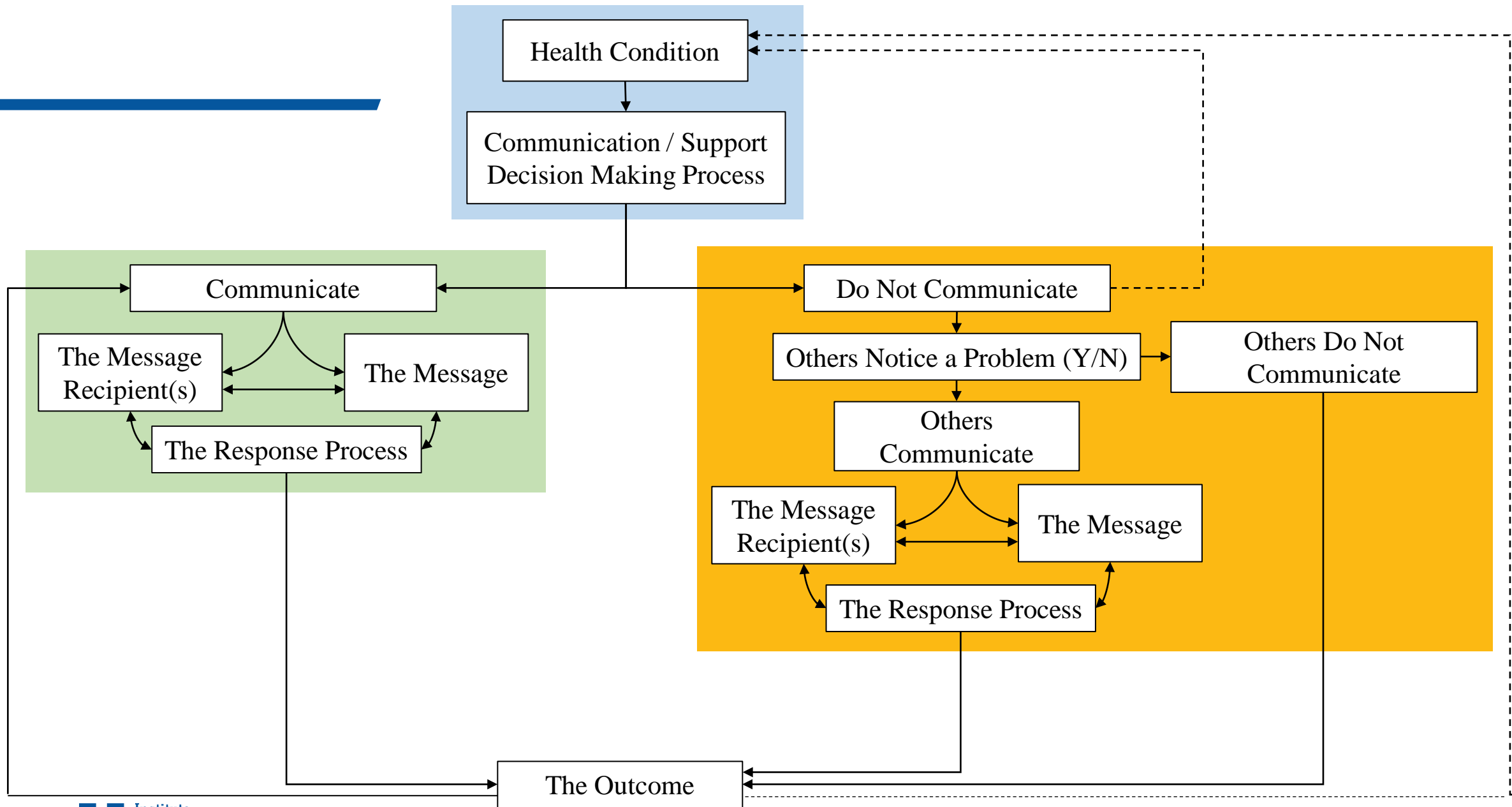
- What do those whose job it is to support workers with episodic disabilities believe are the key issues and challenges to disability support?
- How do communication processes within a workplace facilitate or act as a barrier to disability prevention and support efforts?

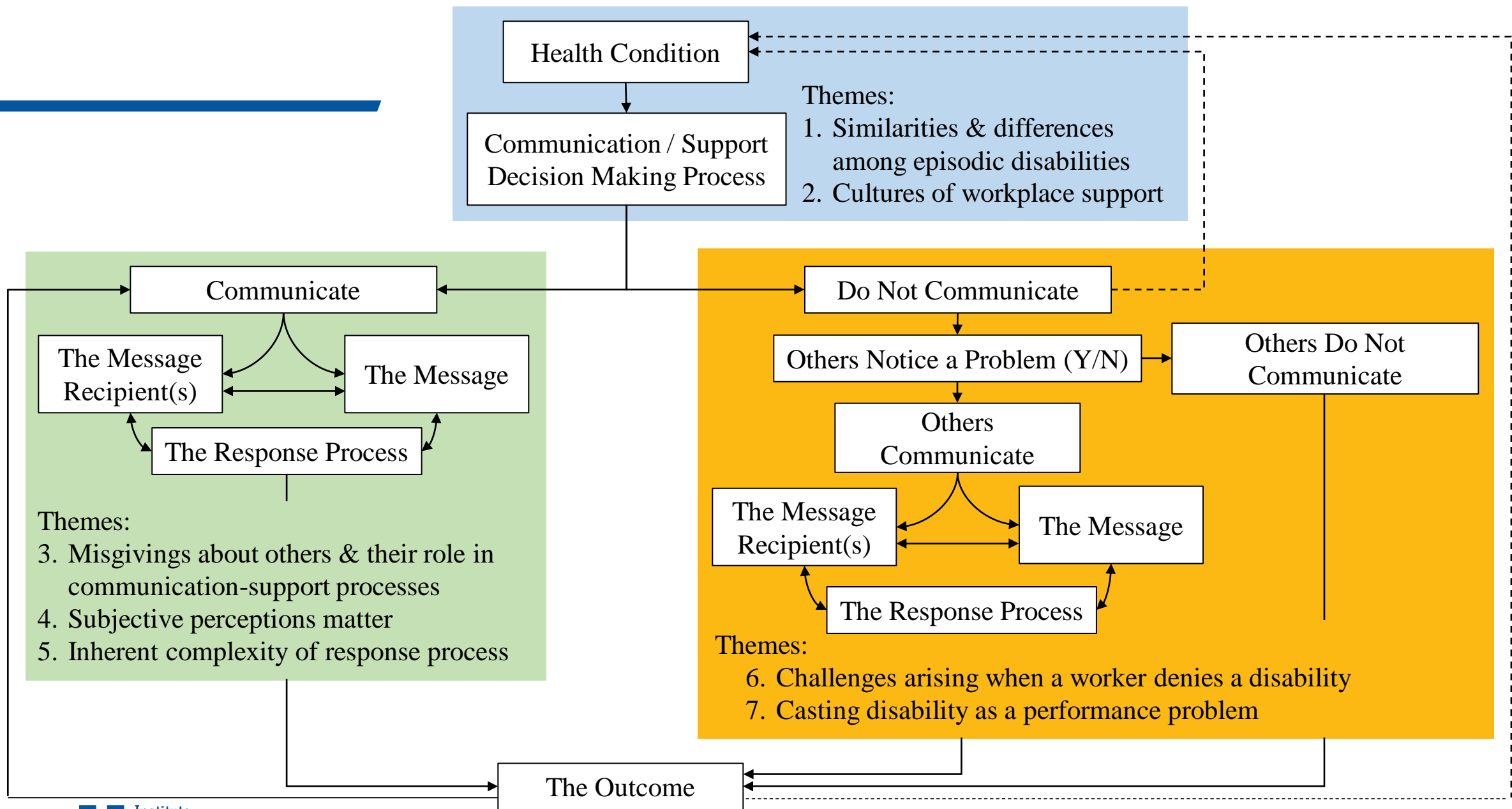
Study Methods

- Sample of organizational “key informants” involved in disability support (e.g., supervisors, HR, disability managers, union/labour advocates, occupational health professionals, labour lawyers)
- Qualitative methods; in person & telephone interviews
- General topics probed:
 - i. Communication and accommodation processes;
 - ii. Successes and challenges
 - iii. Who is/should be involved;
 - iv. Contextual factors;
 - v. Gaps in support and resources
- Qualitative content analysis

Gignac, M.A.M., Bowring, J., Jetha, A., Beaton, D.E., Breslin, F.C., Franche, R.-L., 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>.

Results: Key Informant Demographics		N (%)	Mean (Range)
Gender	Female	20 (74%)	
	Male	7 (26%)	
Years in profession (mean, range)			19.5 (8-30)
Roles*	Disability manager	7	
	Human resources personnel	5	
	Managers/supervisors	5	
	Worker advocate/union representative	5	
	Labour lawyers	3	
	Small business owner	2	
	Medical director	1	
	Occupational health nurse	1	
	Key informants with an episodic condition	5	
Sector Served	Business/Finance/Professional Services	4	
	Education/Government	6	
	Healthcare	6	
	Manufacturing/Construction/Utilities	4	
	Service/Retail	1	
	Non-profit	1	
	Multiple Sectors	5	
* A participant could have more than one role (e.g., manager and person with a disability)			





Health condition and communication-support decision-making process

Workplace Cultures: Medical versus Biopsychosocial Models of Support

- Workplaces differed in the implicit models they adopted to frame disability and support
- Medical models were common, especially in large organizations familiar with compensation systems related to workplace injuries
- Some organizations recognized:
 - a) Health professionals were not able to provide the information needed
 - b) Workers can't always get timely or appropriate access to specialist health care
 - c) A worker's condition didn't always remain private depending on the specialization of the health professional providing a medical note

Medical versus biopsychosocial cultures

“ ... because our third-party providers have that [diagnosis], in most cases, it’s a much smoother transition.... I find even return to work recommendations are more meaningful because they have the diagnosis. As you know, 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)

Workers communicate information about their episodic disability at work

Misgivings about others and their role in communication-support processes

- Participants acknowledged the important roles others play in supporting individuals with mental health and other episodic disabilities
- Yet, comments frequently included concerns about others' skills, training, motivation and involvement in supporting individuals with episodic disabilities

Workers communicate information about their episodic disability at work

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 that they might have, and not even be aware of it.”

(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, they certainly have the ability, but they do not have the time to understand the workplace.”

(Disability manager, consulting firm)

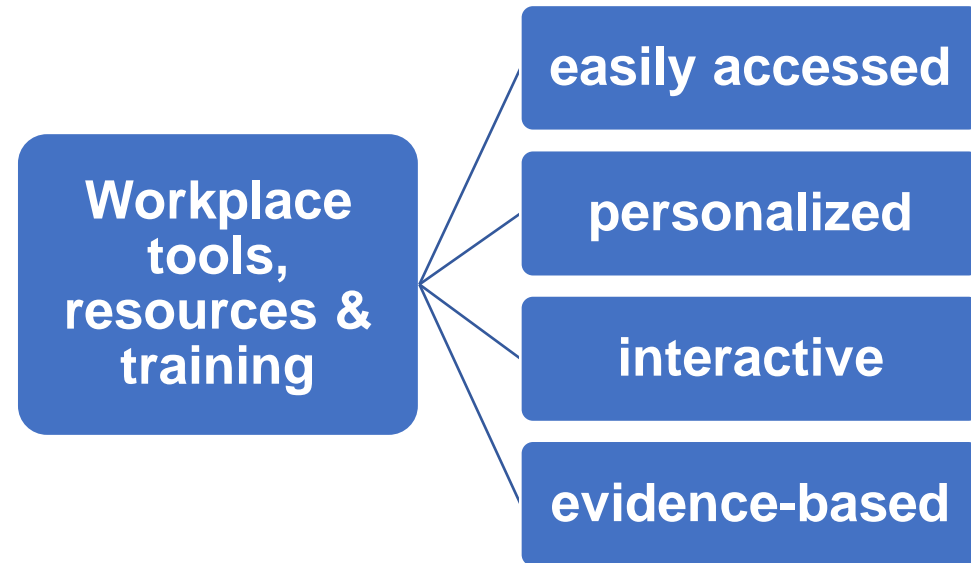
Comments about human resources professionals

“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)

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

Job Demands and Accommodation Planning Tool (JDAPT)

- **Worker version:** self-assessment of job demands & challenges; identifies potential self-management, support, and accommodation strategies
- **Organizational version:** can be completed by workplace staff & employee for planning

Physical tasks
(5 areas)

Mental or “thinking”
tasks (cognitive
demands)
(6 areas)

Working with others
(interpersonal work
demands)
(5 areas)

Working conditions
(environmental work
demands)
(8 areas)

- Not a formal functional assessment, job analysis or cognitive demands analysis tool; not intended as a performance review

JDAPT Example Questions

Is **moving around, or working in awkward positions or postures** an important part of your job?

☐ Yes ☐ No

Examples include:

- moving around the workplace
- moving around obstacles or equipment
- crouching or crawling
- bending, kneeling, squatting or twisting
- climbing or balancing
- working in small or confined spaces

Is **responding to changing work demands** an important part of your job?

☐ Yes ☐ No

Examples include:

- adapting quickly to new job demands or changes at work
- learning new information or skills (e.g. new technology)
- shifting focus when needed
- being able to meet changing deadlines
- dealing with sudden emergencies
- dealing with increased workload at certain times

JDAPT Example Questions

Is **communicating, negotiating or motivating others** an important part of your job?

☐ Yes ☐ No

Examples include:

- Instructing, teaching or mentoring
- negotiating with or persuading others
- providing information to the public and others in person, on the telephone, in writing, online or through other means
- presenting or performing to groups or audiences

Does your job require **working around distractions**?

☐ Yes ☐ No

Examples include:

- working around a lot of interruptions from others
- unpleasant or distracting noises or odors (smells)
- low lighting or flashing lights
- working in an open-concept or shared space
- busy traffic conditions

Example Supports and Accommodations

Job demand

Moving around, or working in awkward positions or postures

Suggested supports and accommodations

- | | |
|---|---|
| • Seek professional advice and care for injuries | • Move or adjust your workstation |
| • Engage in regular physical activity | • Switch tasks to vary your posture |
| • Plan your movements to avoid injury | • Ask others for assistance |
| • Use kneeling protection | • Practice proper ergonomic techniques, e.g. lift by bending your legs, not your back |
| • Request an ergonomic assessment of your workspace | • Use employer benefits for physical therapy, massage therapy, etc. |

Example Supports and Accommodations

Job demand Responding to changing work demands

Suggested supports and accommodations

- | | |
|--|---|
| • Get plenty of rest outside of work | • Get additional training |
| • Practice mindfulness and positive self-care | • Ask others for assistance |
| • Seek professional advice about managing your cognitive demands at work | • Move to a new environment to help with brainstorming of solutions |
| • Use checklists to remember new procedures or techniques | • Arrange tasks to work on more challenging tasks when feeling better |
| • Prioritize work tasks according to deadlines | • Do calming or refreshing activities during breaks |

Pilot Testing the JDAPT- Cognitive Debriefing

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)

We included individuals from different sized organizations, job types and job sectors (e.g., sales/service, education, manufacturing, health, government, financial, transportation, hospitality)

Pilot Testing the JDAPT- Early Findings

- Testing focused on:
 - Ease of understanding
 - Interpretation of items
 - Item relevance for different episodic conditions, occupations, and personal characteristics (e.g., gender, age)
- Participants liked the JDAPT overall and reported high need for it
- Participants living with episodic conditions reported somewhat more usefulness than organizational representatives
- Feedback was mostly around clarifying instructions and new examples

ACED Communication Decision-Making Tool

Five Broad Topic Areas in Development:

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?

Questions? Comments? Interested in getting involved?

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