Episodic Disabilities, COVID-19 and the Workplace

**Presented to the Workforce Planning Board of
Waterloo Wellington Dufferin
November 5, 2020**

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

ACED — Accommodating and Communicating about Episodic Disabilities

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 Franche	Aaron Thompson
Emma Irvin	Emile Tompa
Arif Jetha	Dwayne Van Eerd
Joy MacDermid	Julie Bowring
Ron Saunders	Sabrina Tonima
	Sara Macdonald

Partners:

Institute for Work & Health
Arthritis Society
Crohn's & Colitis Canada
Mindful Employer Canada
Ontario Ministry of Labour, Training and Skills Development
University of Toronto

Realize
Canadian Mental Health Association
Workplace Strategies for Mental Health
Multiple Sclerosis Society of Canada

Institute for Work & Health

Presentation Objectives

- Define episodic disabilities and share preliminary survey findings from June 2020

- Discuss organizational perspectives on the successes and challenges of disability communication-support processes

- Outline areas where new tools and resources are needed

- Present preliminary data on the Job Demands and Accommodation Planning Tool (JDAPT)

Episodic Disabilities

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

Institute for Work & Health

ACED Accommodating and Communicating about Episodic Disabilities

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.

Disability & Work in Canada, June 2020

We conducted a survey of 3068 working individuals from across Canada to examine:

- Employment experiences of individuals living with chronic conditions

- Work context factors, especially precarious work and workplace support

- Early COVID-19 experiences comparing those living with or without a chronic condition that causes episodic disability

Note: Ontario moved into Stage 2 in mid-June

Sample Characteristics

Sample Characteristics	N (%)
Gender: Women Men	1450 (47.9) 1579 (52.1)

Age (years): 18-34
            35-49
            50 and older
	1054 (34.4)
	1051 (34.2)
	963 (31.4)

Education: High school or less
            Some college/University
            College/University graduate
	256 (8.4)
	518 (16.9)
	2287 (74.7)

Job sector: Financial, insurance, government, business
            Education, health, sciences, arts
            Sales, services, retail
            Construction, utilities, agriculture, manufacturing
	1102 (36.2)
	1007 (33.1)
	347 (11.4)
	589 (19.3)

Institute for Work & Health

ACED Accommodating and Communicating about Episodic Disabilities

Sample Characteristics

Sample Characteristics	N (%)
Organization size: Under 20 people 20 – 99 people 100 - 299 people 300 – 500 people More than 500 people	721 (24.3) 790 (26.6) 471 (15.9) 258 (8.7) 729 (24.5)
Work location during COVID-19: Mostly from home A combination of workplace and at home Mostly at the workplace	1461 (59.4) 283 (11.5) 716 (29.1)
Disability type: No chronic condition causing disability Physical disability Mental health disability Both physical and mental health disability	1822 (62.9) 443 (15.3) 351 (12.1) 280 (9.7)

Sample Characteristics

Characteristic	No disability %	Physical %	Mental Health %	Both Physical & Mental Health %
Disability Dynamic Group: *				
Recurrent	-	46.5	53.0	43.6
Continuous	-	36.1	31.9	25.7
Progressive/Fluctuating	-	17.4	15.1	30.7
Employed Full-time *	78.7	74.7	74.7	66.7
Years at current job *	9.2	11.3	6.5	8.7
Contract job *	10.7	12.6	11.9	16.3
Job stress (mean 1-5) *	3.0	3.1	3.4	3.6

Institute for Work & Health

ACED Accommodating and Communicating about Episodic Disabilities

Sample Characteristics

Characteristic	No disability %	Physical %	Mental Health %	Both Physical & Mental Health %
Willing to disclose personal needs (mean 1-5) *	3.2	3.2	2.9	2.7
Feel "locked in" job *	27.2	33.9	36.1	48.5
Unmet accommodation needs (mean # 1-6)*	0.8	1.1	1.1	1.7
Laid off due to COVID-19 *	16.4	17.8	18.7	28.5

Institute for Work & Health

ACED
Accommodating and Communicating about Episodic Disabilities

COVID-19 Perceptions

How concerned are you about the impact of COVID-19 on your health?

Average score = 2.7; 27% concerned quite a bit/a great deal

How concerned are you about the impact of COVID-19 on your finances?

Average score = 2.8; 32.3% concerned quite a bit/a great deal

Would you say your organization has been supportive of your personal needs during the COVID-19 pandemic?

Average score = 3.5; 52.9% reported quite a bit/a great deal of support

Responses: 1 = not at all; 2 = a little; 3 = somewhat; 4 = quite a bit; 5 = a great deal

COVID-19 Perceptions

- Is living with a ***chronic condition causing episodic disability*** at work significantly related to COVID concerns about health and finances or perceptions of workplace support?

- What other ***personal*** and ***work context*** factors are important in understanding COVID concerns and perceptions of workplace support?

Variables	Concerns: Health	Concerns: Finances	COVID support
Disability Type	✓ (Physical, Both)	✓ (Mental, Both)	✓ (Both) (-)
Age (older)			
Gender (women)			
Education (college/university)			
Job sector (compared to business, finance, government, insurance, professions)			
Contract work			
Job tenure (fewer years)			
Job control			
Job stress			
Have unmet accommodation needs			
Willing to disclose personal needs			
Feel "locked in" to job			

Variables	Concerns: Health	Concerns: Finances	COVID support
Disability Type	✓ (Physical, Both)		
Age (older)	✓ (+)	✓ (-)	✓ (+)
Gender (women)	✓ (+)		
Education (college/university)		✓ (-)	
Job sector (business, finance, government, insurance, professions)		✓ (-)	✓ (+)
Contract work		✓ (+)	
Job tenure (fewer years)		✓ (+)	
Job control			✓ (+)
Job stress	✓ (+)	✓ (+)	✓ (-)
Have unmet accommodation needs	✓ (+)	✓ (+)	✓ (-)
Willing to disclose personal needs		✓ (-)	✓ (+)
Feel "locked in" to job		✓ (+)	✓ (-)

COVID-19 Impact

- Not all workers are equal - some are more vulnerable.

- People with disabilities, especially both physical and mental health limitations were:

  - More likely to be laid off during COVID-19

  - Less likely to work full-time and more likely to work in contract jobs

  - Reported more job stress, less job control, more unmet accommodation needs and were less willing to disclose personal needs

- Episodic disabilities can have direct and indirect effects on COVID-19 concerns and support perceptions that arise through job greater job precarity.

Working with an Episodic Condition: Workplace Perspectives

- Decisions whether to disclose health information at work are often stressful and complex.

- Few studies have examined the perspectives of workplaces in providing support to individuals living with episodic conditions

Working with an Episodic Condition: Workplace Perspectives
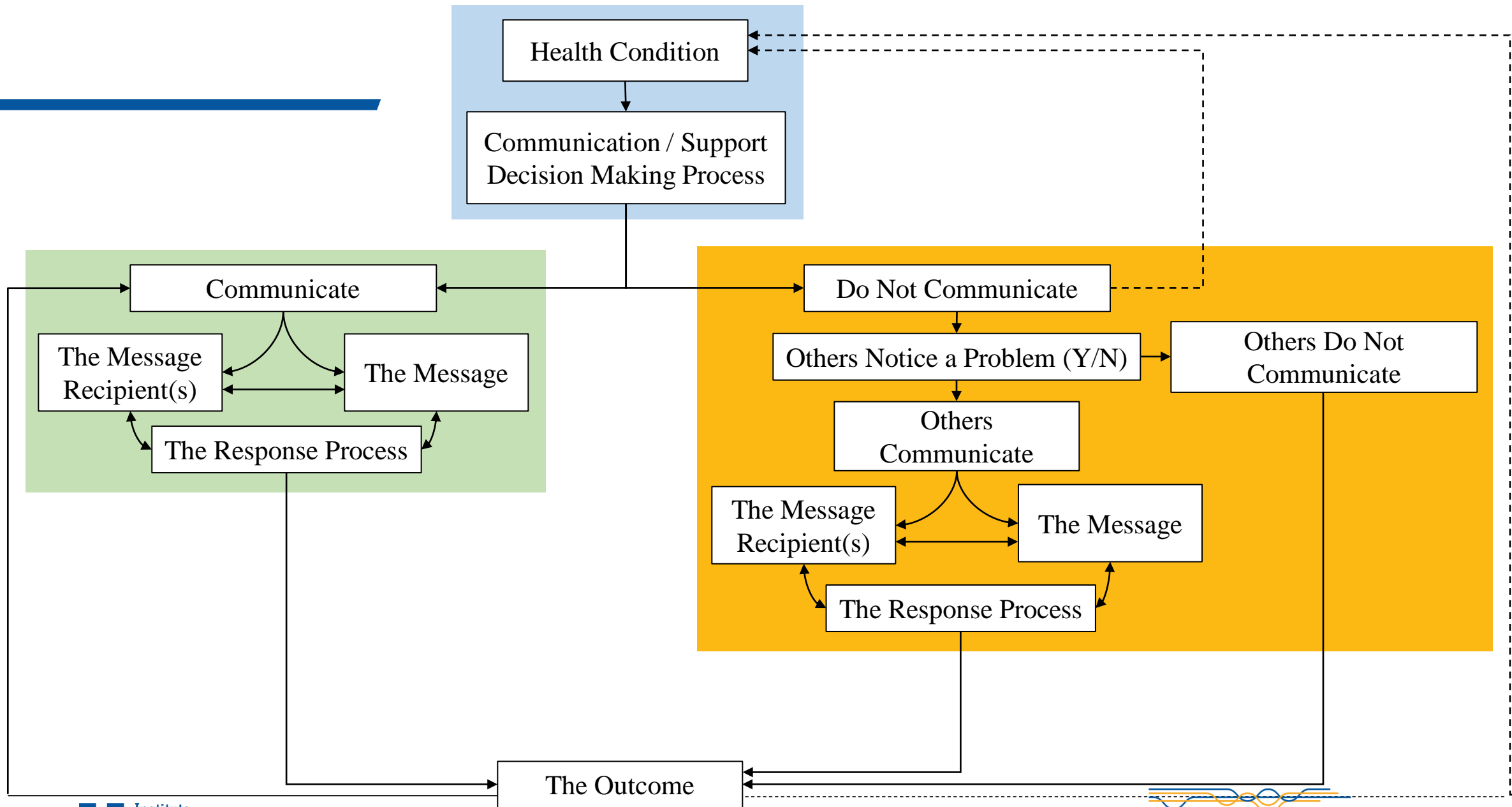
Research Questions

- 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?
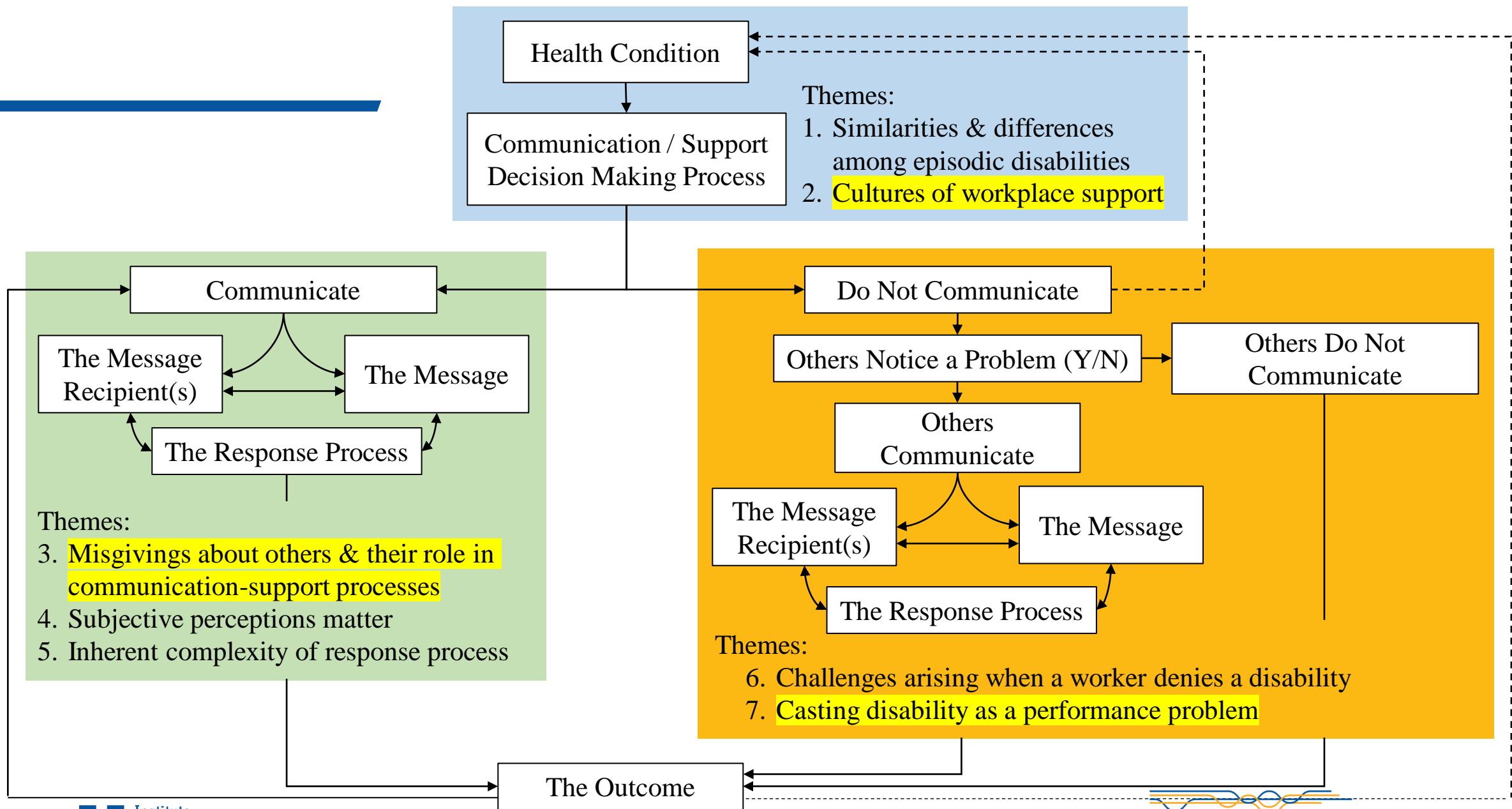
Study Methods

- 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)			

Institute for Work & Health

ACED
Accommodating and Communicating about Episodic Disabilities

Health Condition

Communication / Support Decision Making Process

Themes:
1. Similarities & differences among episodic disabilities
2. Cultures of workplace support

Communicate

The Message Recipient(s) — The Message

The Response Process

Themes:
3. Misgivings about others & their role in communication-support processes
4. Subjective perceptions matter
5. Inherent complexity of response process

Do Not Communicate

Others Notice a Problem (Y/N)

Others Do Not Communicate

Others Communicate

The Message Recipient(s) — The Message

The Response Process

Themes:
6. Challenges arising when a worker denies a disability
7. Casting disability as a performance problem

The Outcome

Institute for Work & Health

ACED
Accommodating and Communicating about Episodic Disabilities

21

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 (i.e., health information needs to be validated and closely monitored over time)

- Some organizations adopted biopsychosocial approaches (i.e., disability goes beyond a medical diagnosis):

    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

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…. 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)

Misgivings about others and their role in communication-support processes

- Participants acknowledged the important roles others play in supporting individuals with episodic disabilities

- Yet, comments frequently included concerns about others' skills, training, motivation and involvement in support efforts

Institute
for Work &
Health

Misgivings about others and their role in communication-support processes

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)

Casting Disability as a Performance Problem

- In larger organizations, formal communication is often triggered by reaching 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

- Some workers (especially with mental health issues) will admit to performance problems rather than risk disclosing a mental health issue

Casting Disability as a Performance Problem

"What happens with episodic conditions is that they have incidental absences and… if they pass that ten-day threshold, then a progressive discipline approach is taken with them and that's not always the right approach to take for someone who just needs time off periodically to attend to their health" (Disability manager, healthcare)

"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 when they've come forward…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)

Working with a chronic, episodic condition

Bottom lines:

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

2. A consistent and comprehensive approach to assessing job demands and support needs is needed
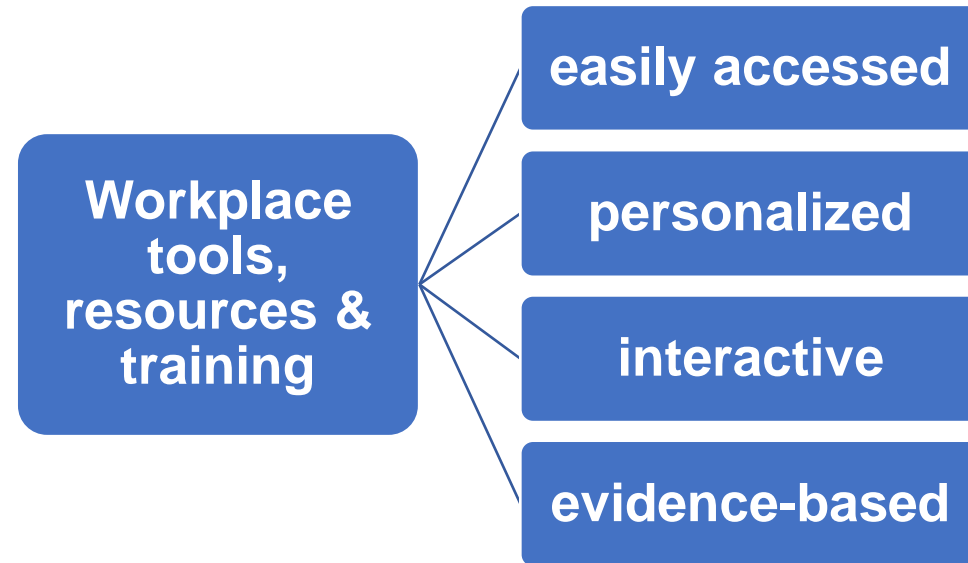
ACED Tools & Resources

- Job Demands and Accommodation Planning Tool (JDAPT)

- Communication Decision-Making Tool

ACED Partnership Aims:

Enhance work sustainability for people with episodic disabilities

Workplace tools, resources & training

- easily accessed
- personalized
- interactive
- evidence-based

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

Institute for Work & Health

ACED
Accommodating and Communicating about Episodic Disabilities

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

Institute for Work & Health

ACED
Accommodating and Communicating about Episodic Disabilities

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

Institute for Work & Health

ACED Accommodating and Communicating about Episodic Disabilities

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

Physical 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

Cognitive 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

Institute for Work & Health

ACED
Accommodating and Communicating about Episodic Disabilities

Pilot Testing the JDAPT

Testing focused on:

- Ease of understanding

- Interpretation of items

- Item relevance for different episodic conditions, occupations and personal characteristics (e.g., gender, age)

Pilot Testing the JDAPT

Input from:

- ~ 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)

Pilot Testing the JDAPT

Sample Characteristics (n = 69)	N (%)
Gender: Women Men	54 (78.3) 15 (21.7)

Age (years): 18 – 34
           35 – 49
           50 or more
	24 (34.8)
	29 (42.0)
	16 (23.2)

Job Sector:
  Financial, insurance, government, business
  Education, health, sciences, arts
  Sales, services, retail
  Construction, utilities, agriculture, manufacturing
	23 (33.3)
	31 (44.9)
	8 (11.6)
	7 (10.2)

Institute for Work & Health

ACED
Accommodating and Communicating about Episodic Disabilities

Pilot Testing the JDAPT- Early Findings

• Takes about 14 minutes to complete (range = 4 - 38 minutes)

• 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 adding new examples

•**Next steps:** The JDAPT is being put online and more testing will occur in early 2021

Questions? Comments? Interested in getting involved?

Visit our website: https://aced.iwh.on.ca/