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

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ACED — Accommodating and Communicating about Episodic Disabilities

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Overview

- The ACED Partnership Grant

- Resource Scan related to disclosure and workplace accommodations

- Employer perspectives on accommodating people living with episodic disabilities

- Job Demands and Accommodation Planning Tool (JDAPT)

- ACED Communication Decision-Making Tool

ACED — Accommodating and Communicating about Episodic Disabilities

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

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Partners:

Institute for Work & Health	Canadian Mental Health Association
Arthritis Society	Great-West Life Centre for Mental Health in the Workplace
Crohn's & Colitis Canada	
Mindful Employer Canada	
Ontario Ministry of Labour	Multiple Sclerosis Society of Canada
Realize	
University of Toronto	

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

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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: epilepsy, depression, anxiety disorders, arthritis, multiple sclerosis, diabetes, irritable bowel syndrome, migraine, some types of cancer, HIV

In the workplace

Privacy legislation protects workers from having to disclose disease diagnoses and symptoms – in the workplace there should be a focus on job-related activity limitations
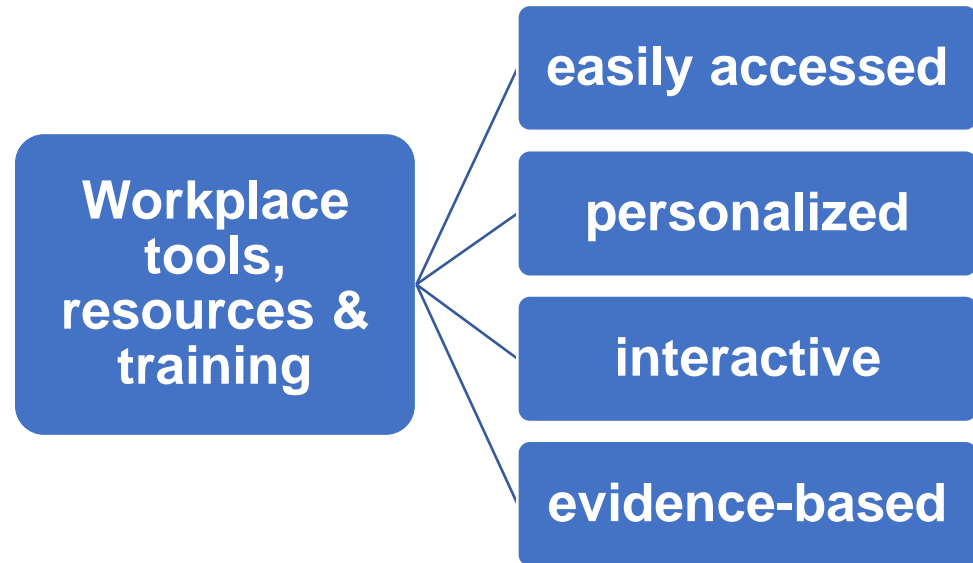
In the workplace

But…

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

- Workplace health communication and the protection of privacy

- Needs for support or accommodations and the maintenance of workplace productivity

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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

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ACED Research Activities: Resource Scan

Identify and describe existing publicly available resources related to working with an episodic disability

- Characteristics of available resources (e.g., audiences, health conditions)

- Content of resources (e.g., disclosure information, accommodation strategies)

- Availability of interactive content

Van Eerd, D., Bowring, J., Jetha, A., Breslin, F. C., Gignac, M. A. M. (2020). Online resources supporting workers with chronic episodic disabilities: An environmental scan.

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ACED Research Activities: Resource Scan

Identify and describe existing publicly available resources related to working with an episodic disability

- English-language resources

- Structured key-word searches using Google between Nov 2016 – Jan 2017

- Over 5400 links to websites identified

- Final review of 210 resources from 149 organizations

- Resources from Canada, United States, United Kingdom, Ireland, Australia, New Zealand

ACED Research Activities: Resource Scan

Most resources provided some information about:

- Symptoms and care related to a particular episodic condition

- Employment rights and responsibilities

- Lifestyle strategies to sustain good health and employment

- Accommodation examples

- Challenges inherent in disclosing information to others at work

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ACED Research Activities: Resource Scan

Resource gaps:

- Most resources were not personalized or interactive

- Helpful information can go unnoticed across different episodic conditions

- Lots of duplication of material

- Protection of privacy an issue with some materials

ACED Research Activities: Resource Scan

Resource gaps:

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- Lots of duplication

- Protection of privacy an issue with some materials

There is a need to enhance existing resources to make them more personalized, interactive and relevant across health conditions

ACED Research Activities: New studies

We have undertaken new research:

- Focus groups with workers (10 focus groups; n = 67)

- One-to-one interviews with workplace representatives ("Key Informants") providing support to people with episodic disabilities (e.g., supervisors, HR, disability managers, union representatives, labour lawyers) (n = 27)

- Two large surveys (n = 1600; n = 3000)

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Key Informant Interviews: 7 Themes

1. Similarities across different types of episodic disabilities

2. Different cultures of workplace support

3. Misgivings about the role of others

4. Subjective perceptions matter

5. Inherent complexity in the response process

6. Challenges when workers deny a disability

7. Challenges when disability is cast as a performance problem

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

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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 would benefit from personal health details to meet a worker's accommodation needs. This research aimed to understand organizational perspectives on disability communication-support processes. *Methods* Twenty-seven participants from diverse employment sectors and who had responsibilities for supporting workers living with episodic disabilities (e.g., supervisors, disability managers, union representatives, occupational health representatives, labour lawyers) were interviewed. Five participants also had lived experience of a physical or mental health episodic disability. Participants were recruited through organizational associations, community networks and advertising. Semi-structured interviews and qualitative content analysis framed data collection and analyses, and mapped communication-support processes. *Results* Seven themes underpinned communication-support process: (1) similarities and differences among physical and mental health episodic disabilities; (2) cultures of workplace support, including contrasting medical and biopsychosocial perspectives; (3) misgivings about others and their role in communication-support processes; (4) that subjective perceptions matter; (5) the inherent complexity of the response process; (6) challenges arising when a worker denies a disability; and (7) casting disability as a performance problem. *Conclusions* This study identifies a conceptual framework and areas where workplace disability support processes could be enhanced to improve inclusion and the sustainability of employment among workers living with episodic disabilities.

Keywords Chronic disease · Episodic disability · Employment · Disclosure · Accommodation · Support · Communication · Mental health

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.

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

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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?

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ACED Communication Decision-Making Tool

Five Broad Topic Areas in Development:

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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