

What is episodic disability? A scoping Review

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What is Episodic Disability?



Lessons
Learned

ED is the experience of disability intertwined with experiences of fluctuating ability

Research Questions

1. What are the characteristics and ranges of definitions used to define or discuss ED by organizations (including employers, insurance companies, and practitioner groups)?
2. What issues are discussed in the literature for workers with ED?

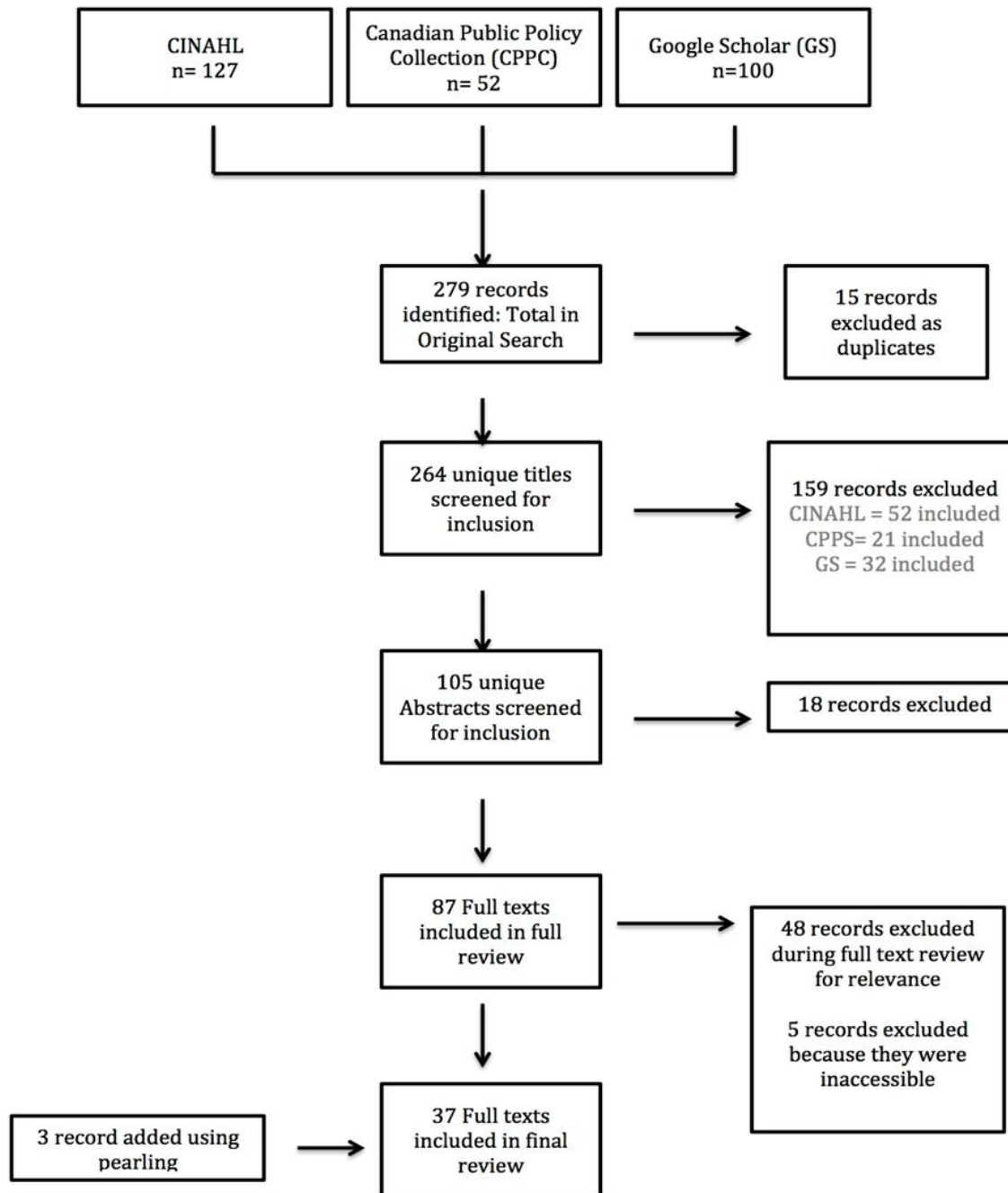
Relevance Rating Scale

as Adapted from Antao et al. (2013)

Category	Description
5 – Exceptionally relevant	Focuses primarily on ED in the workplace, including data collected from people with ED
4 – Fairly relevant	Discusses several of the issues related to ED or IWC
3 – Moderately relevant	Discusses ED but with no focus on work
2 – Somewhat relevant	Discusses ED, but ED is not the primary focus
1 – Not relevant	Not focused on ED but is indirectly linked to the issue

Methods

- Informed by Arksey and O'Malley (2005), Pham et al. (2014), and Peters et al. (2015), scoping review methods were applied:
 - Research questions created (broad)
 - Relevant data bases searched
 - Search strategy and iterative approach established
 - Qualitative thematic analysis
 - Nvivo 10 and Mendeley
 - Data was collated, summarized and synthesized



Search Strategy

- CINAHL Complete as hosted by EBSCO, and the Canadian Public Policy Collection were initially searched
- A supplemental Google Scholar search was done to locate grey literature and documents on ED
- Experts and practitioners in the field were asked for any input

Coding

- Nvivo was used for thematic coding
- Initially 20 codes were identified
- 3 rounds of coding, resulted in 5 primary codes

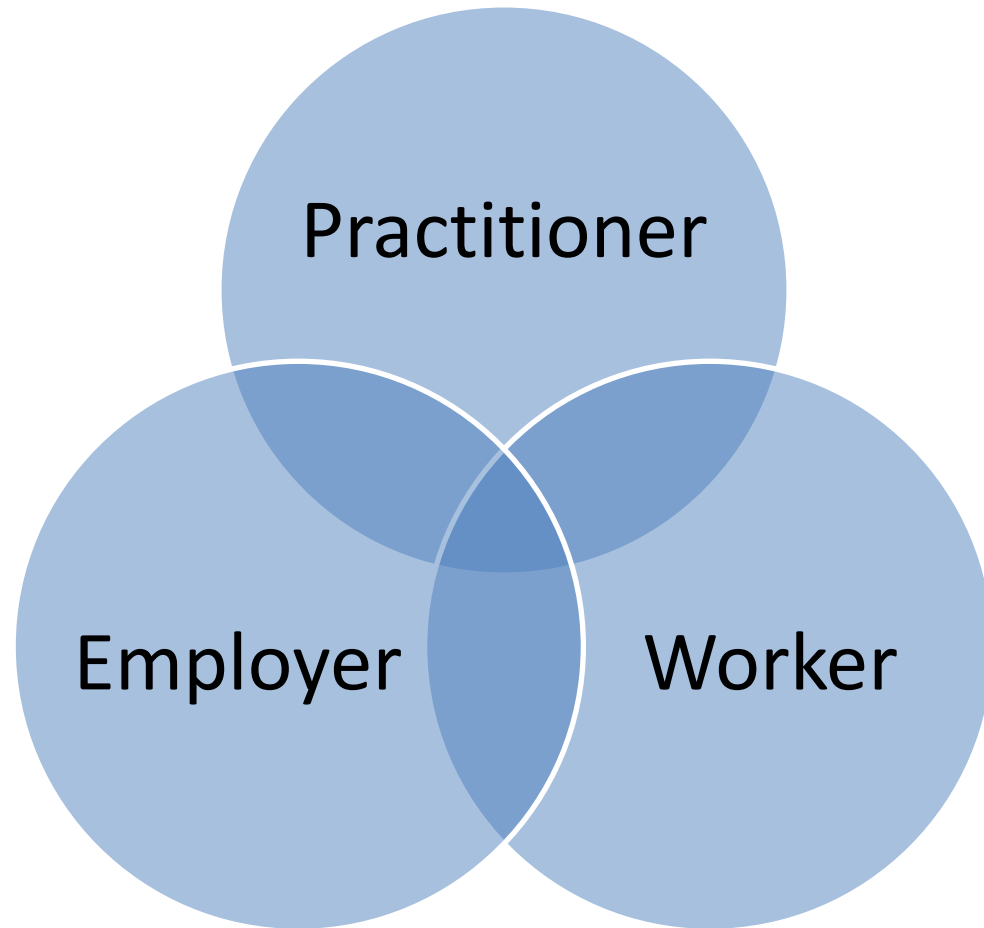
Barriers and Facilitators

- professional *education* (b)
- *financial* hardship (b)
- systemic issues, policy issues, and stigma (b)
- **Personal resiliency (f)**
- **Unique employer relationships (f)**

Illness or Disability

- What is an episodic disability?
 - multiple sclerosis,
 - chronic fatigue syndrome,
 - fibromyalgia,
 - multiple chemical sensitivities,
 - lupus,
 - epilepsy,
 - arthritis,
 - diabetes,
 - HIV/AIDS,
 - Chronic headaches or migraines

Practitioner, Employer, Worker



Psychological and Social Influences

- Self-advocacy
- Social status
- Financial support



Variations in Disability

- Each experience is unique
- The individuals' ability to understand and manage their symptoms in the workplace
- Personal skills and the employer flexibility

What's next?

- Can we agree on a practical definition?
- What does this mean in practice?
- Variation in personal experience is at the root of the problem
- Flexibility in ability and disability
- Access to supports when needed
- Empowering workers to advocate for their own needs without fear of repercussion from employers or insurance providers

My definition

Episodic disabilities are characterized by unpredictable, fluctuating periods of ability that wreak havoc with a person's health, work, and quality of life.

Take away message

Take Out



"It's Not Chicken"

- ED is a problem in the workplace
- Workers with ED experience issues accessing and participating in work