



A Practical Perspective on Understanding Episodic Disabilities and Employment

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Presentation Overview

- The Lived Experience
- What is an Episodic Disability?
- Current Challenges in Episodic Disabilities and Employment
- Initiatives of the Canadian Working Group on HIV and Rehabilitation
- Leading Practices in Episodic Disabilities and Employment



Goal of Presentation

Discuss a framework for understanding the impact of episodic disabilities on the work environment and highlight leading practices to support employees living with episodic disabilities.



The Lived Experience

*A Case Study of Jill and her
Journey Back to Health and
Work*





The Lived Experience A Case Study

“So, I'm forty and four years ago I hit rock bottom in the absolute worst way you can possibly do. I became so dysfunctional that I was almost catatonic, ended up in a hospital and was admitted to the psychiatric ward at Mount Sinai for three weeks. I'm a lawyer, I'm a professional, I'm a mother, I'm a wife, daughter, sister — you name it. I was at the peak of my career...”





The Lived Experience A Case Study Cont.

“To go from high-functioning to no functioning was the most dramatic thing I've ever gone through in my life. Three weeks it took me to become functional enough that I could get myself out of bed [and] I could remember to wash my face and brush my teeth, to get myself on medication, to get some kind of control over what I was doing on a day-to-day basis..”



The Lived Experience A Case Study Cont.

“So after three weeks, I was determined to be functional enough that I could be discharged and sent home. And that in many ways was like being dropped off a cliff. I went from 24-hour care with a specialist attending to the kinds of things I needed to absolutely no care at all. My husband works. I don't have family in the city and my daughter goes to school. So I was at home alone, with no care whatsoever in an extremely vulnerable state. And within about three or four weeks I was close to needing to be hospitalized again...”



The Lived Experience A Case Study Cont.

“In those three or four weeks my husband was on the phone continuously trying to find anybody who had an opening for one of the psychiatrists, any kind of interim support that we could get that didn’t cost an arm and a leg. And the only saving grace was that my mother in law picked up and came and literally stayed with me for five weeks..”



The Lived Experience A Case Study Cont.

“I had got so bad just before she came that my husband had taken me to CAMH [the Centre for Addiction and Mental Health] to visit one of the social workers because he just didn't know what to do. And this was affecting how often he was getting to work on time [and] my daughter was, she was only three at the time...”



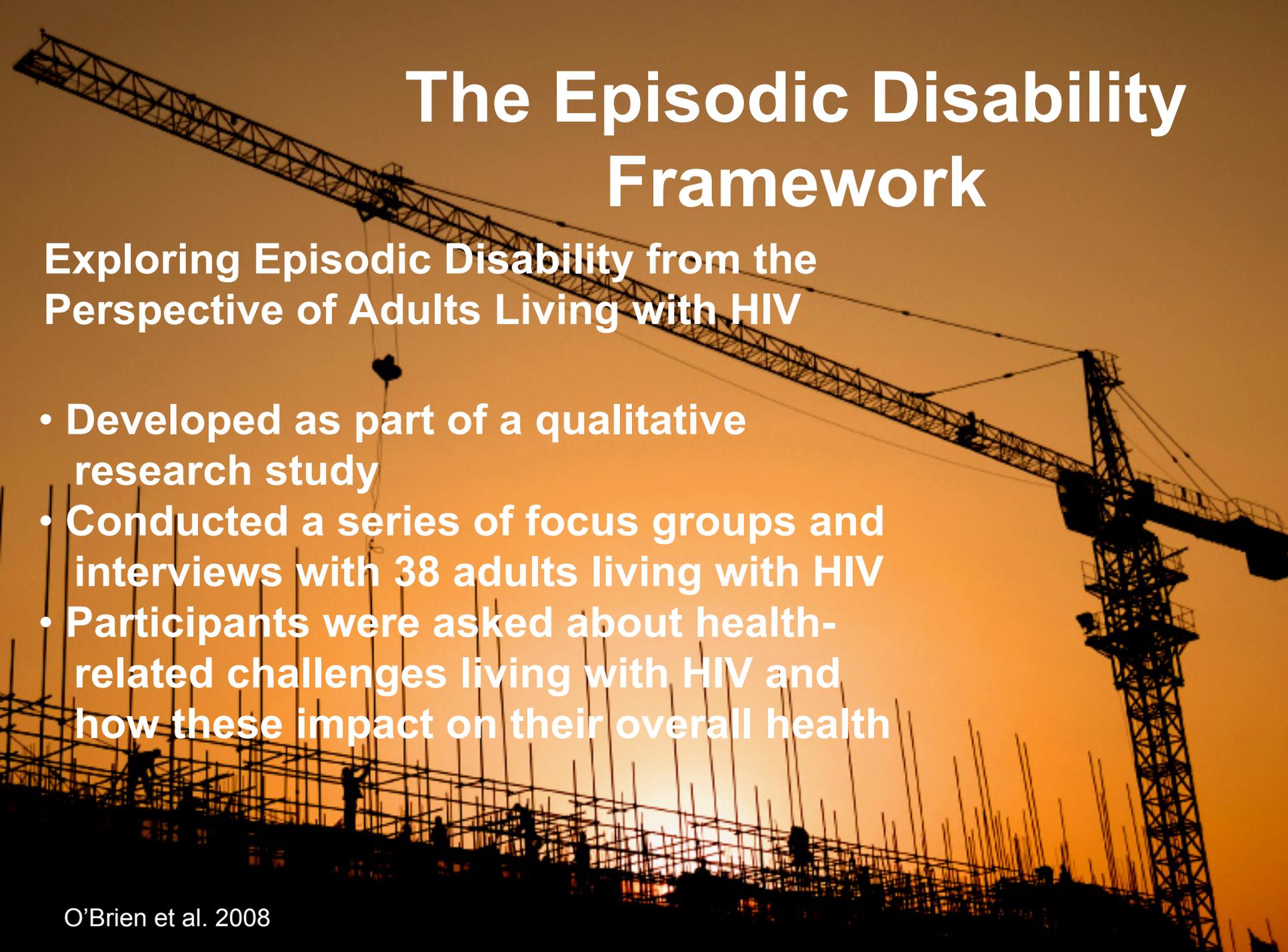
What is an Episodic Disability?

- Marked by fluctuating periods and degrees of wellness and illness
- Unpredictable
- Episodic disabilities include: some forms of mental illness, HIV/AIDS, multiple sclerosis, diabetes, and some forms of cancer and arthritis
- Presents challenges for active labour force participation, insurance benefits, income security, and social inclusion



The Numbers

- An increasing number of people are living with episodic disabilities
- It is estimated that:
 - 20% of Canadians will experience an episode of mental illness
 - Three million Canadians have diabetes
 - 63,000 Canadians are living with HIV
 - Four million Canadians are affected with arthritis and other rheumatic conditions; expected to double by 2020

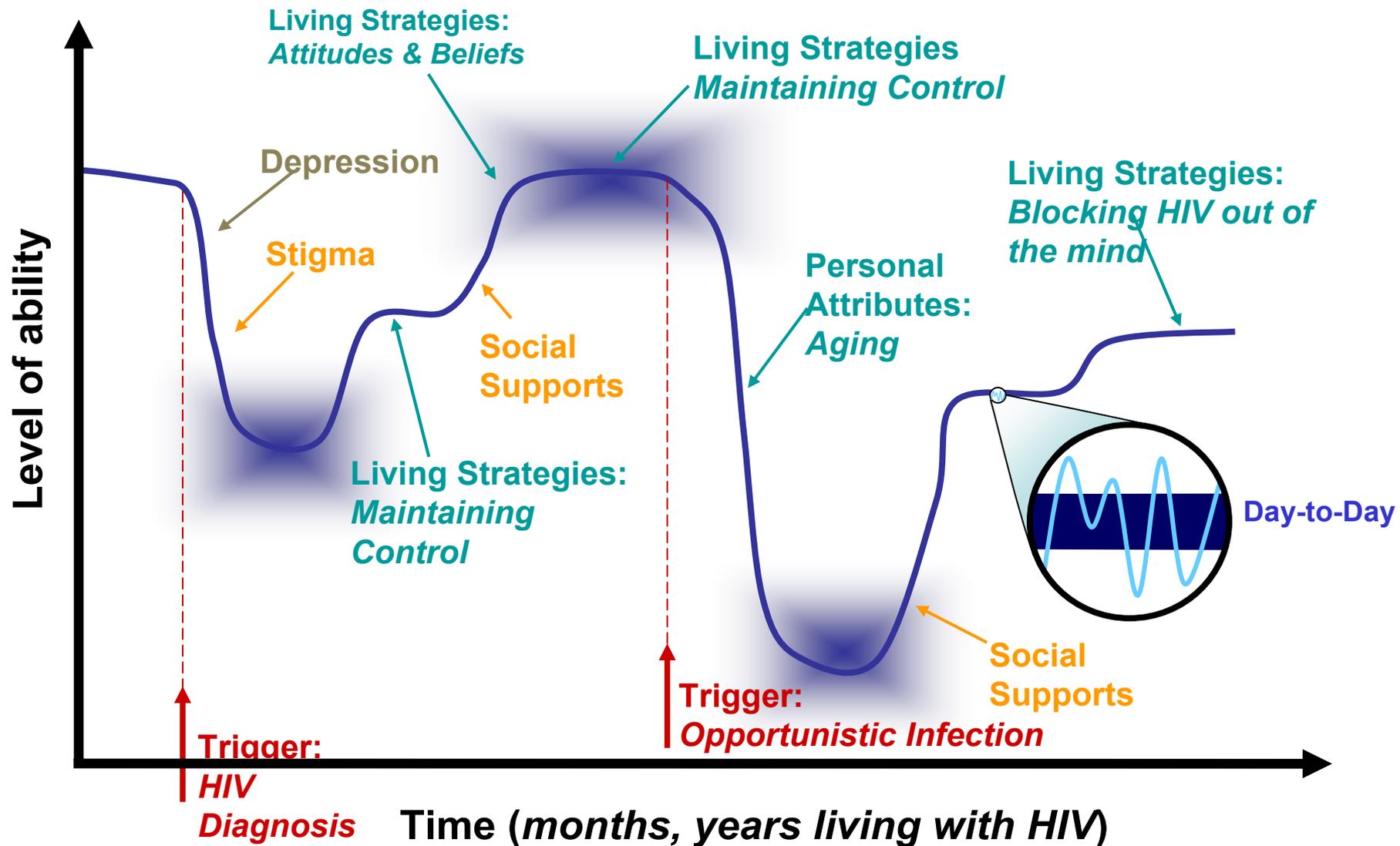


The Episodic Disability Framework

Exploring Episodic Disability from the Perspective of Adults Living with HIV

- Developed as part of a qualitative research study
- Conducted a series of focus groups and interviews with 38 adults living with HIV
- Participants were asked about health-related challenges living with HIV and how these impact on their overall health

Episodic Disability Framework



How can people use this information and apply the Episodic Disability Framework?

People Living with Episodic Disabilities
Can use it to better understand and describe their health challenges

Employers
Can use it to understand and prepare for workplace health challenges

Policy Makers
Can use it to help guide programs & policies



Summary of Some of the Challenges Facing People Living with Episodic Disabilities

Definition
of
Disability

Access to
Quality
Services

Barriers to
Employment

Income
security



Canadian Working Group on HIV and Rehabilitation (CWGHR)

Established in 1998, *CWGHR* emerged as an innovator in bridging the traditionally separate worlds of HIV, disability and rehabilitation

CWGHR is a national charitable organization *aiming to address the complex and fluctuating health and social needs* of people living with HIV and other episodic conditions by improving access to rehabilitation care, support and services.



How CWGHR works

CWGHR's programs are based on 4 key pillars that are essential to developing and implementing comprehensive, effective and relevant rehabilitation policies and programs:

- **Education/knowledge exchange**
- **Policy**
- **Practice**
- **Research**



How CWGHR works

CWGHR focuses on 4 principal areas within each of its 4 pillars of work:

- 1. Access to Rehabilitation**
- 2. Income Security and Employment**
- 3. Integrated Approaches to Episodic Disabilities**
- 4. International Linkages**



Integrated Approaches to Episodic Disabilities

To promote cross-disability linkages and action on issues of mutual concern

Policy: National Episodic Disability Network (EDN) and Ontario Episodic Disability Network (OEDN)

Practice: Episodic Disability Employment Network (EDEN)

Education: Managing Episodic Disabilities Course Series

Research: Barriers and Facilitators to Labour Force Participation for People Living with HIV



Leading Practices in Episodic Disabilities and Employment



Current Challenges in the Workplace

- Consultations/research identified concerns about return to work and sustaining work
 - Stigma and discrimination
 - Length of time out of workforce
 - Disclosure
- Uncertainty/fear can take many forms
- Many unknowns with employment



Accommodating Employees with Episodic Disabilities

- Episodic disabilities vary over time
- Possible concurrent conditions
- Require long term perspective
- Regular check-ins with employee
- Need access to supports outside of the workplace: emotional & community supports
- Develop accommodation plans including processes to complete work during illness absences



When is an Accommodation Needed?

- Examples of times when a workplace accommodation may be needed:
 - Doctor's appointments
 - Periods of personal illness
 - Periods of illness with a family member
 - Taking medications at work
 - Dealing with the side effects of medications at work



Examples of Accommodation Best Practices

- Flex time
- A private space to take medications
- More frequent breaks
- A private space to rest
- Adaptive technologies
- Peer supports
- Part-time with full benefits
- Part-time with pro-rated benefits
- Consult an OT or visit the Job Accommodation Network website



Helpful Hints for Employers

General Counsel:

- Maintain regular contact with the employee
- Ask the employee if there is anything you can do to help
- Ensure that the employee knows the process of requesting an accommodation
- Help the employee develop a plan for illness periods
- Recommend that employees keep files meticulously up to date



Helpful Hints for Employers

General Counsel cont.:

- Help the employee make an informed decision about illness disclosure
- Develop an elevator story with the employee



Helpful Hints for Employers

Medical & Community Resources:

- Understand that on-going management of the episodic disability is dependent upon access to care
- Ensure that the employee has clear guidelines from their medical team
- Be aware of resources that may help the employee i.e. Health Gateway



Building an Inclusive Workplace Culture

- Educate all staff on episodic disabilities & employment
- Inform all employees on organizational policies on sick days & disability
- Inform all employees on how to request workplace accommodations
- Develop a process for workplace absences that does not create hardship for other employees
- Use language that is inclusive & sensitive
- Be proactive in communicating



Additional Workplace Supports

- Family/Employee Assistance Programs (FEAP)
- Peer Associations
- Variety of disability associations (e.g. National Network on Mental Health (NNMH), Arthritis Society, Canadian AIDS Society (CAS))
- Episodic Disabilities Employment Network (EDEN) website



Summary

- Develop a long-term perspective
- Educate all employees on workplace accommodation policies and processes
- Examine a variety of creative accommodation solutions with employees living with episodic disabilities
- Create an accommodation plan with employees for illness absences
- Maintain good contact with the employee



Additional Information

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Thank You

For more information see
www.hivandrehab.ca

