



Understanding Episodic Disabilities and Employment

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Presentation Overview

- Who are we?
- What is an Episodic Disability?
- The Challenges Facing People Living with Episodic Disabilities
- The Lived Experience: The Reality of Working with an Episodic Disability
- Episodic Disabilities in the Workplace
 - How to Support the Employee
 - Building Strong Coworker Relationships
 - Additional Workplace Supports



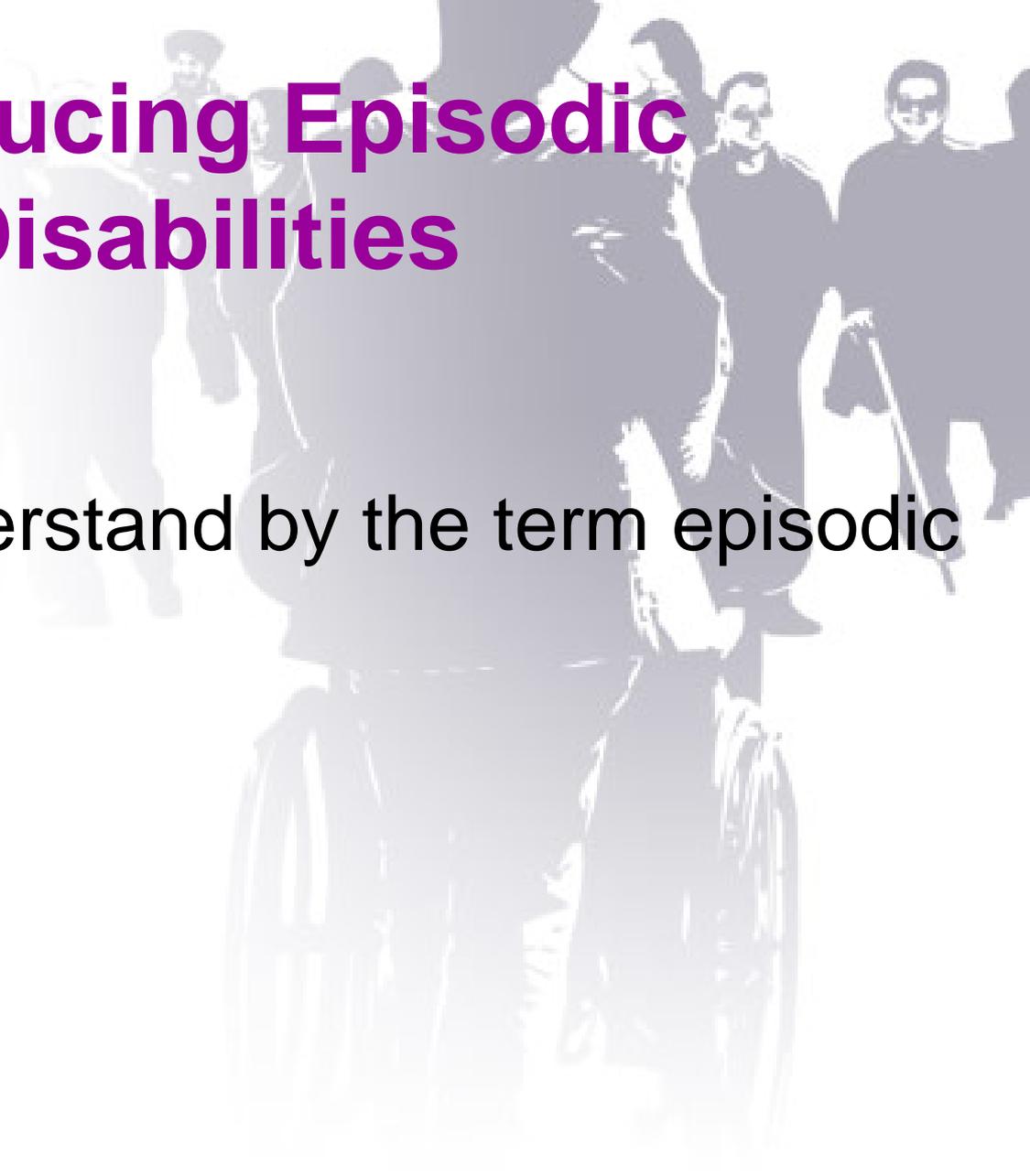
Canadian Working Group on HIV and Rehabilitation

- National, multi-sector, NGO established in 1998
- Centred on the needs of people living with HIV
 - Promoting quality of life through rehabilitation research, education & cross-sector partnerships
 - Bridging HIV/AIDS, disability & rehabilitation
- Addresses rehabilitation issues in the context of HIV/AIDS
- Collaborative work on cross-disability issues since 2003 through the Episodic Disability Network and Ontario Episodic Disability Network



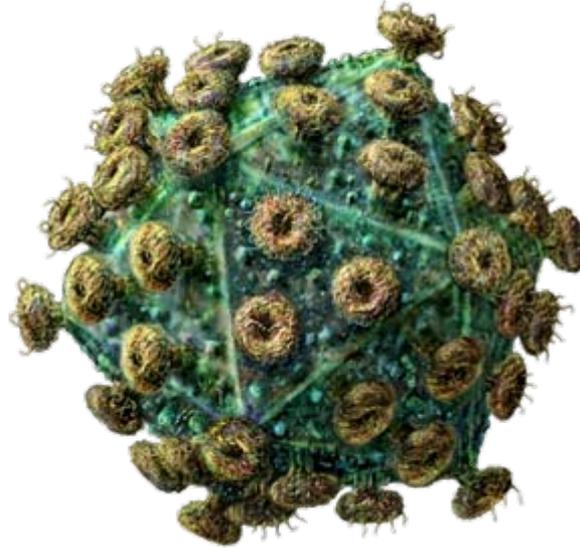
Introducing Episodic Disabilities

- What do you understand by the term episodic disability?





Introducing Episodic Disabilities Cont.



Disability



What is an Episodic Disability?

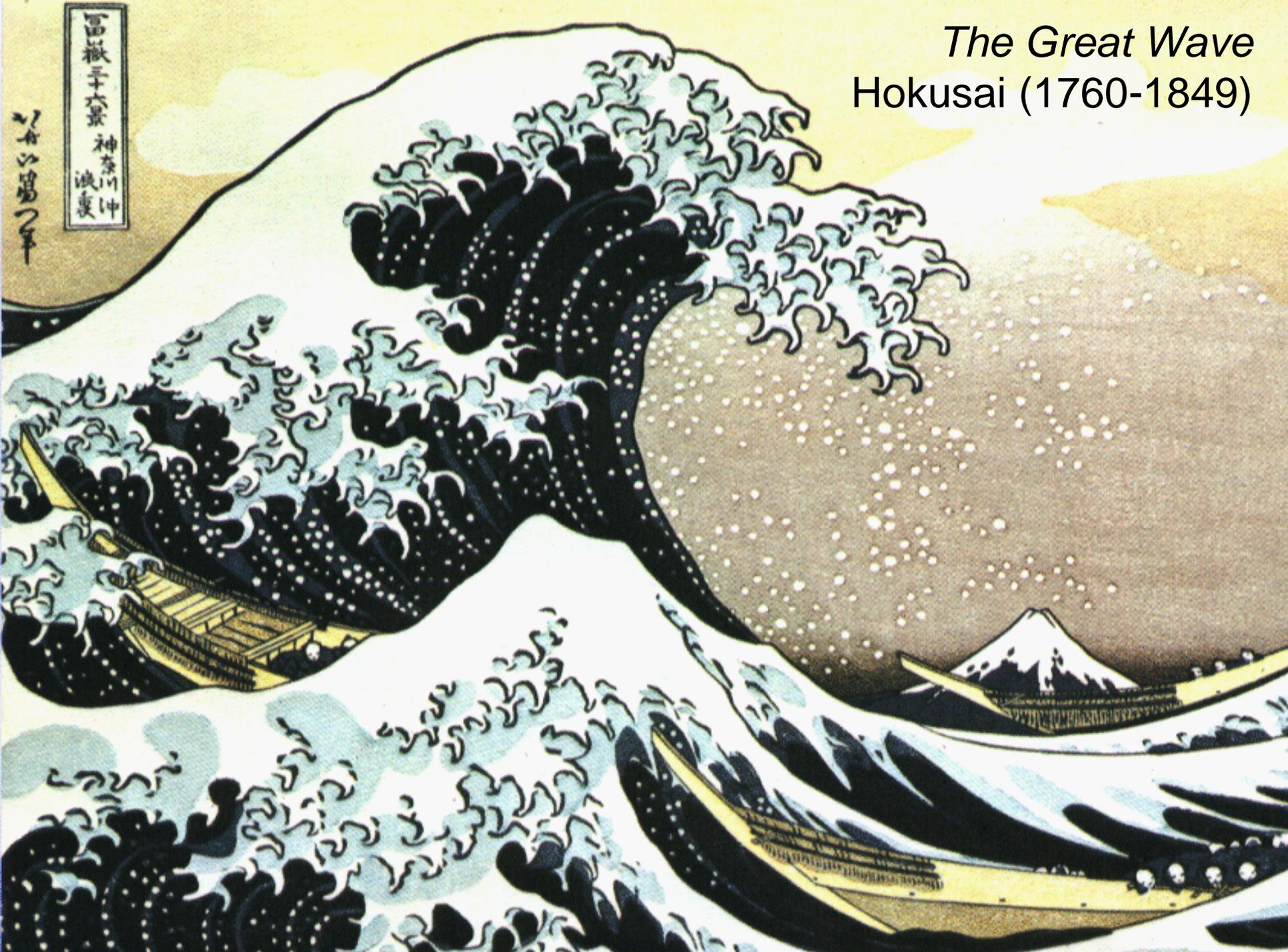
- Marked by fluctuating periods and degrees of wellness and illness
- Unpredictable
- Episodic disabilities include: some forms of mental illness, HIV/AIDS, multiple sclerosis, diabetes, arthritis, lupus and some forms of cancer



Episodic vs. Traditional Understanding of Disability

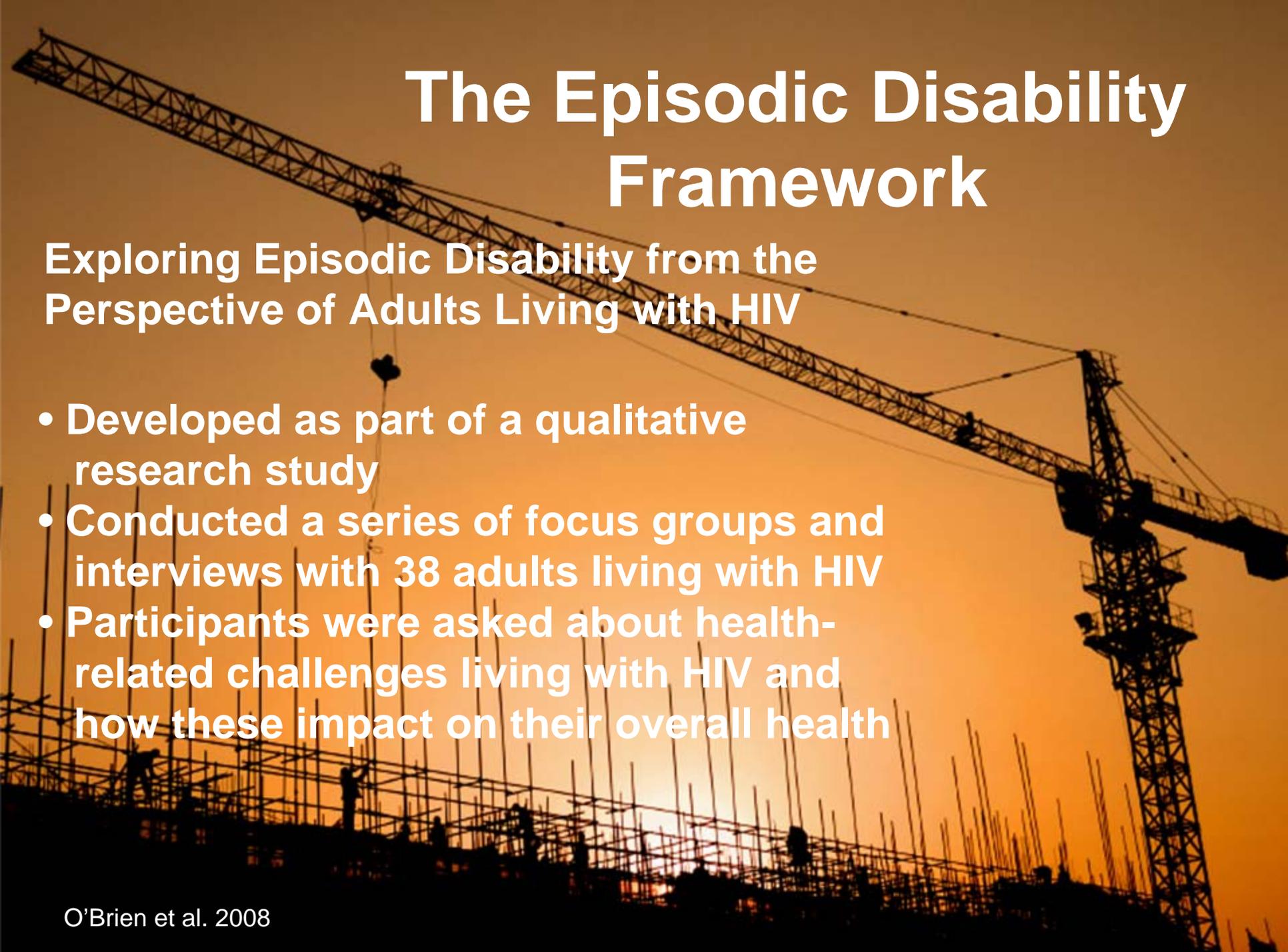
- ‘Disability’ as it is generally understood: lifelong & relatively consistent
- ‘Episodic disability’ issues: unpredictable, intermittent periods of good & not so good health, presents challenges for active labour force participation, insurance benefits, income security, vocational rehabilitation & social inclusion

The Great Wave
Hokusai (1760-1849)



富嶽三十六景 神奈川
浪裏

以舟の浪の二平

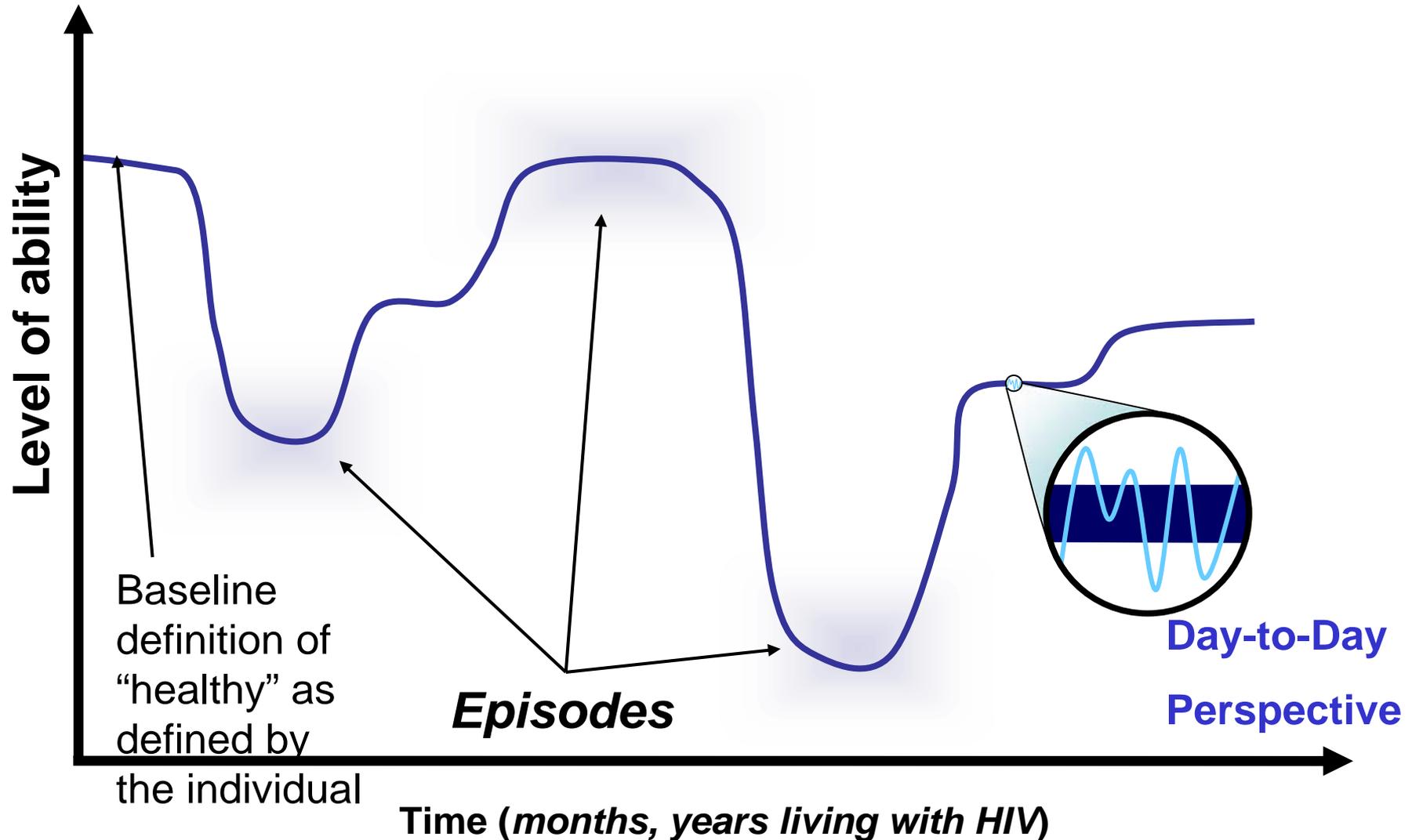


The Episodic Disability Framework

Exploring Episodic Disability from the Perspective of Adults Living with HIV

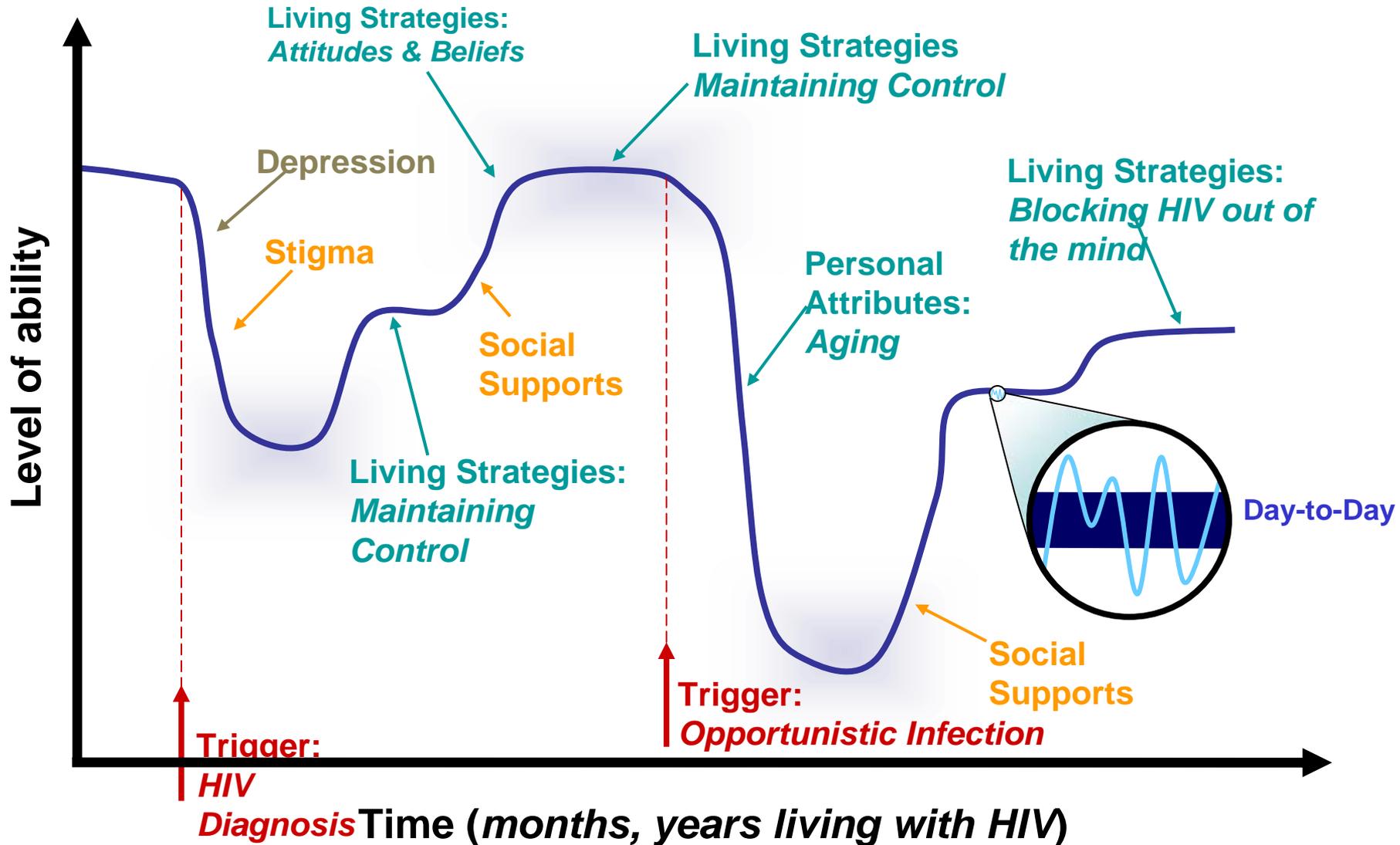
- Developed as part of a qualitative research study
- Conducted a series of focus groups and interviews with 38 adults living with HIV
- Participants were asked about health-related challenges living with HIV and how these impact on their overall health

Episodic Disability Framework



Note: Episodic paths are not the same for every individual

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

Front-line Care Providers
Can use it to ask questions about health challenges

Policy Makers
Can use it to help guide programs & policies





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
 - Two 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 Initiation of the Episodic Disability Movement

HIV

Mental Illness

Multiple Sclerosis

Arthritis

Episodic Disability Initiatives

OEDN

EDN

Collaborating for
Capacity

National Policy
Dialogue

Managing Episodic
Disabilities course

The Challenges Facing People Living with Episodic Disabilities



We need access to services.

What about unemployment?

We need a definition

Income security is essential

The Challenges Facing People Living with Episodic Disabilities Cont.

- **Disability income programs are critical supports**
- **Government spent an estimated \$28 billion dollars in 2008/2009**
- **Lack of comprehensive oversight exists of programs**

The Challenges Facing People Living with Episodic Disabilities Cont.

- **Lack of interjurisdictional coordination**
- **Varying program definitions, policies and practices**
- **Designed for different purposes and by different jurisdictions**
- **People with episodic disabilities struggle to navigate the maze of policies and programs**

The Challenges Facing People Living with Episodic Disabilities Cont.

- **Definitional inconsistencies and incompatibilities may present barriers to stable income**
- **People living with episodic disabilities may be in a worse financial position if they return to work part-time or work intermittently**



The Lived Experience

By :Deanna Matzanke





The Lived Experience Cont.

- My experience (briefly)
- My employer and me

What have I done?

Must be pro-active in communication and have a back-up plan for absences; keep files meticulously up to date

What have they done?

Flexible work options are critical; change in thinking when and where work needs to be done; flexibility to attend medical appointments.

***Always coloured by access to care issues



The Lived Experience Cont.

What can organizations do to support employees with episodic disabilities in the workplace?

- Have a flexible work policy and mean it.
- Actively help your employees develop a back-up plan for unpredictable absences.
- Don't forget co-workers in the back-up plan.
- Understand that on-going management of the episodic disability is dependent upon access to care.



The Lived Experience Cont.

Do some of the challenges and issues discussed so far resonate with you?

What other workplace accommodations challenges do you face?



Episodic Disability Research

- Using multi-sector & cross-disability perspectives:
 - Undertook an international policy review
 - Developed recommendations for optimal labour force engagement, income and benefit supports
 - Cost-benefit analysis of public policy change
 - Surveyed HR professionals about episodic disabilities
 - National consultation with multi-sector stakeholders



Lessons Learned

Research revealed a need for:

- Multi-sector coordination among all relevant private & public sector stakeholders (The Netherlands, Germany, Sweden)
- Partial disability income support integrated with employment earnings when a person with an episodic disability works part-time
- Significant cost savings to the insurance carrier



Lessons Learned Cont.

- More labour force participation options for people with episodic disabilities
- Flexibility in policies & programs to accommodate episodic participation in the labour force (*'flexicurity'*)
- Knowledge & training on episodic disabilities for human resources professionals
- More insurance options that remove disincentives to participate in the labour force to one's potential



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



Episodic Disabilities in the Workplace: Questions for Consideration

- What personal and health issues need to be resolved prior to returning to work?
- What limitations/restrictions might the employee have in the workplace?
- What will the employee do to maintain a healthy work/life balance?
- Does the employee have access to good healthcare?



Questions for Consideration Cont.

- What is the employee's plan to maintain good health?
- How comfortable is the employee in communicating accommodation needs to an employer?
- How can good communication with the employee be maintained?
- Is the employee experiencing challenges with coworkers?



How to Support the Employee

- With the employee:
 - Show understanding for the person and their need to have good healthcare and employment supports in place
 - Explore ways to open channels of communication
 - Explore a variety of accommodation options
 - Take a long-term view to accommodation planning



How to Support the Employee Cont.

- With coworkers:
 - Discuss accommodations practices
 - Educate about the impact of episodic disabilities on the workplace
 - Encourage to support others living with episodic disabilities



Building Strong Coworker Relationships

- Coworkers are vital to active employment involvement
- Express genuine interest in the welfare of the coworker & get to know the person
- Ask if there is something that can be done to help
- Recognize that the illness is part of the person's life and not what the person is
- Avoid questions that make the person feel that there is something wrong with him/her



What Additional Supports are Available?

- Employee Assistance Programs (EAP)
- Peer Associations
- Variety of disability associations (e.g. National Network on Mental Health (NNMH), Arthritis Society)



Summary

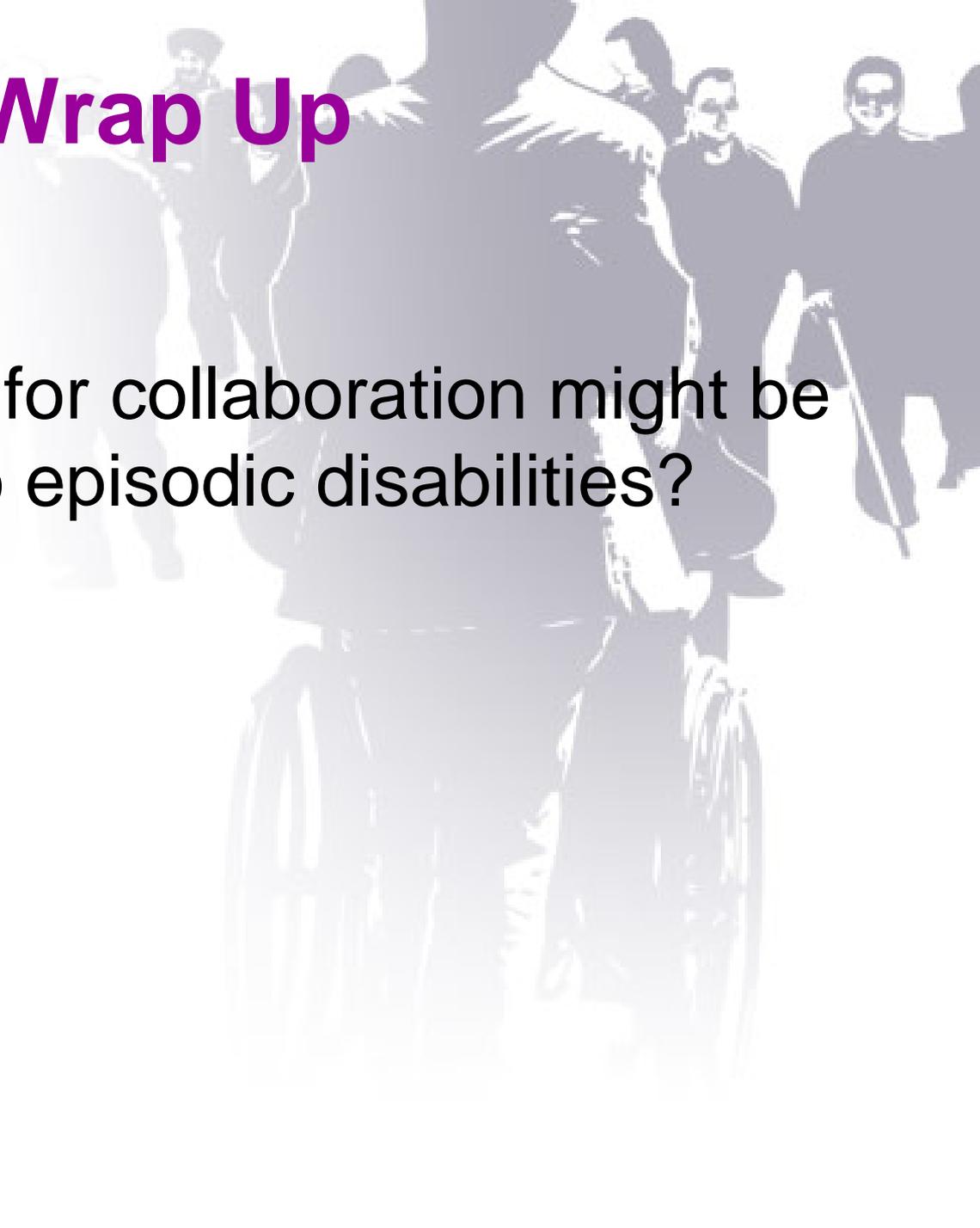
- Factor social determinants of health into any comprehensive program
- Include in policies: episodic nature of illness and individual nature of illness course
- Develop a workplace culture that focuses on the full integration of all staff
- Include strong communications protocol between management/HR and staff in policies and procedures



Wrap Up

What opportunities for collaboration might be created related to episodic disabilities?

Other questions?





Additional Information

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A large, faded background image of a group of people. In the foreground, a person is seen from behind, wearing a dark jacket and a hat, pushing a wheelchair. Other people are visible in the background, some standing and some walking. The image is semi-transparent, allowing the text to be read over it.

Thank You

For more information see
www.hivandrehab.ca

This project is funded in part
by the Government of Canada.

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