



# 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



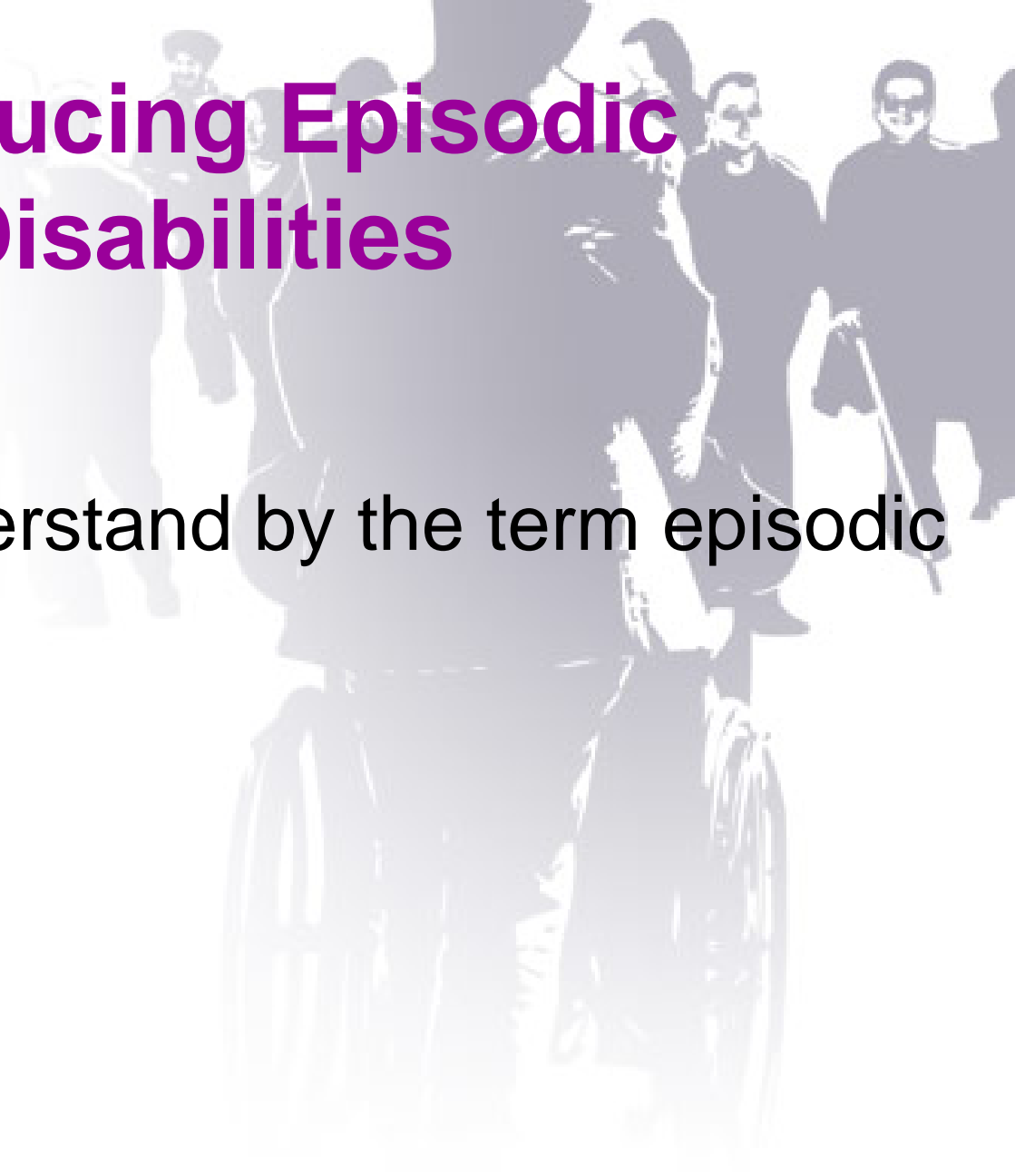
# Canadian Working Group on HIV and Rehabilitation

- 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



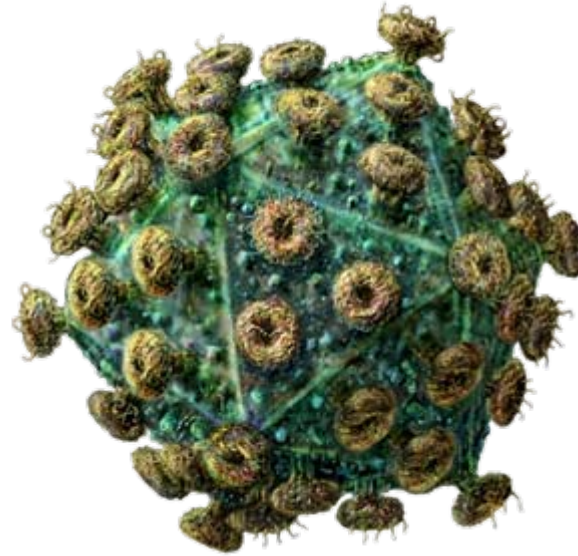
# Introducing Episodic Disabilities

- What do you understand by the term episodic disability?





# Introducing Episodic Disabilities Cont.



**Body Function  
& Structural  
Impairments**



**Activity  
Limitations**



**Participation  
Restrictions**

***Disability***



# What is an Episodic Disability?

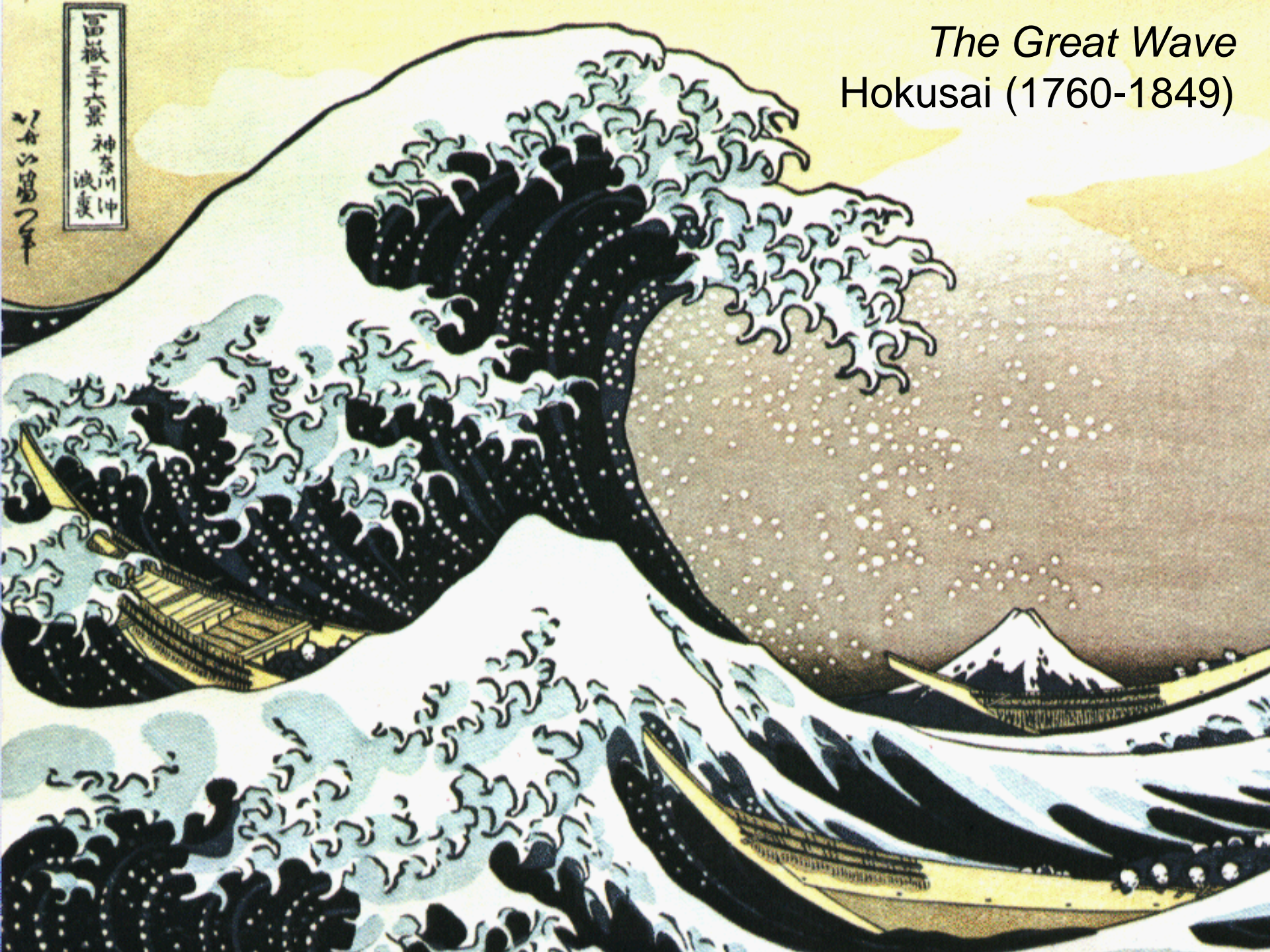
- Marked by fluctuating periods and degrees of wellness and illness
- Unpredictable
- Episodic disabilities include: some forms of mental illness, HIV/AIDS, multiple sclerosis, diabetes, arthritis, lupus and some forms of cancer



# 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

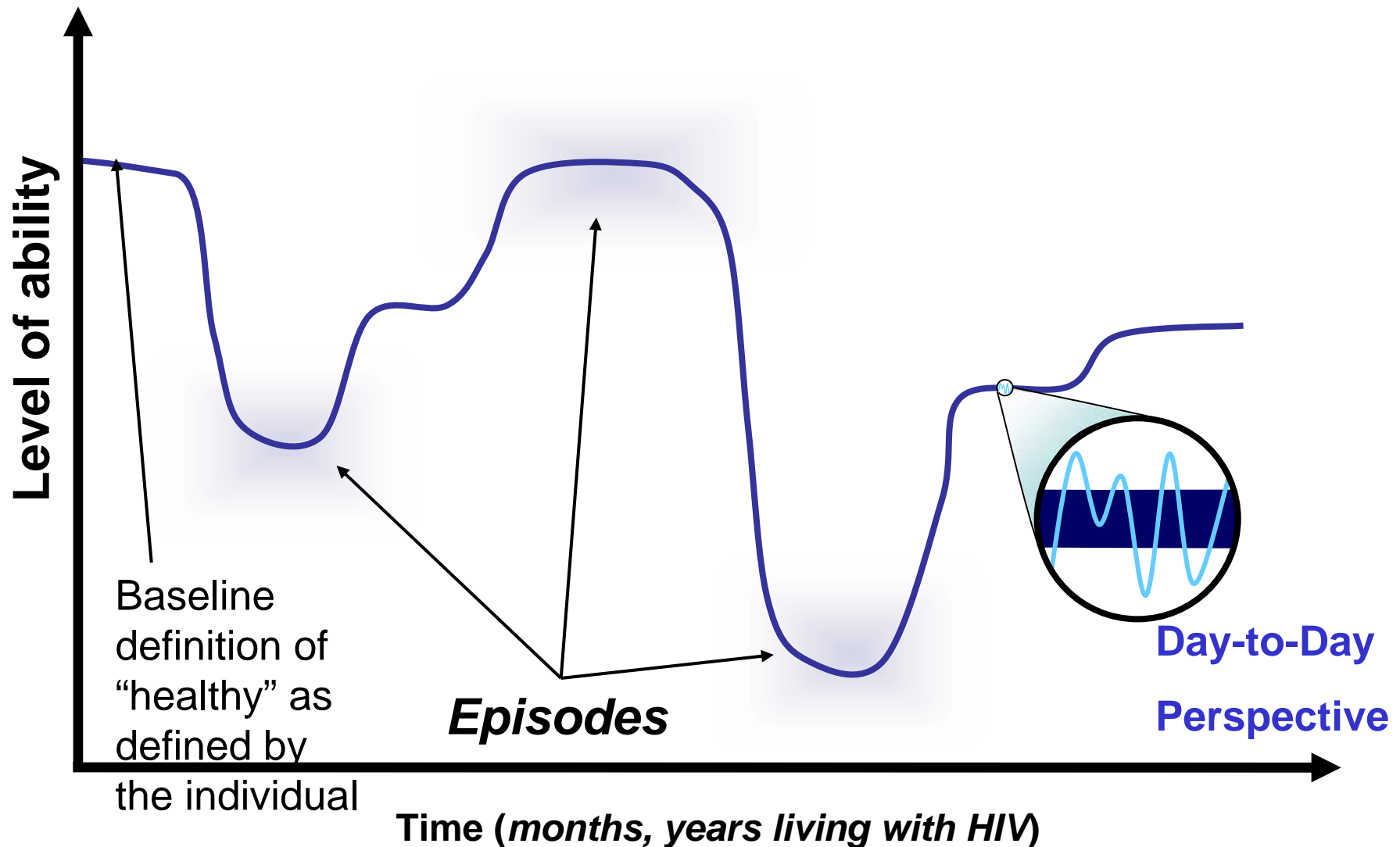


# The Episodic Disability Framework

## Exploring Episodic Disability from the Perspective of Adults Living with HIV

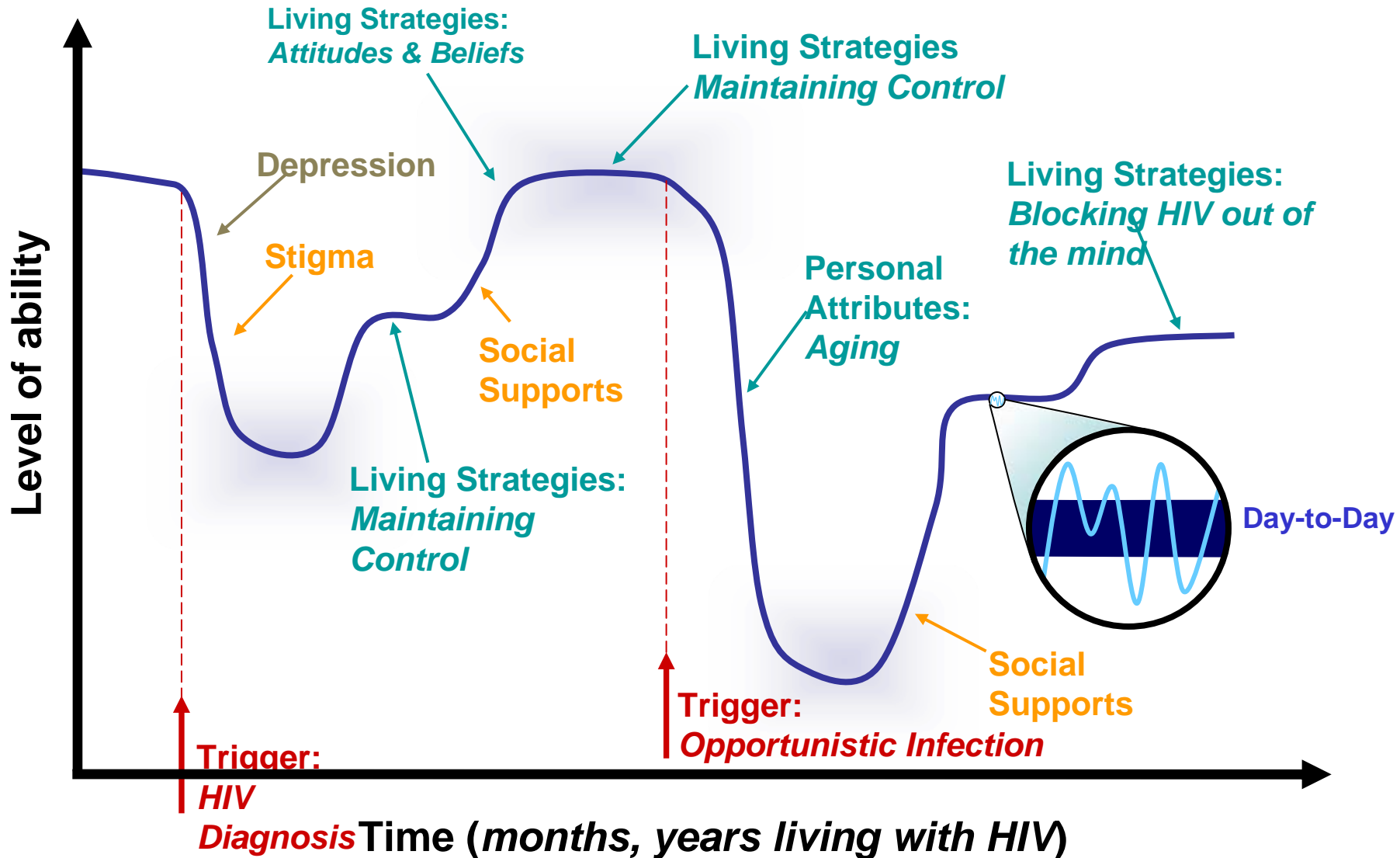
- Developed as part of a qualitative research study
- Conducted a series of focus groups and interviews with 38 adults living with HIV
- Participants were asked about health-related challenges living with HIV and how these impact on their overall health

# 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

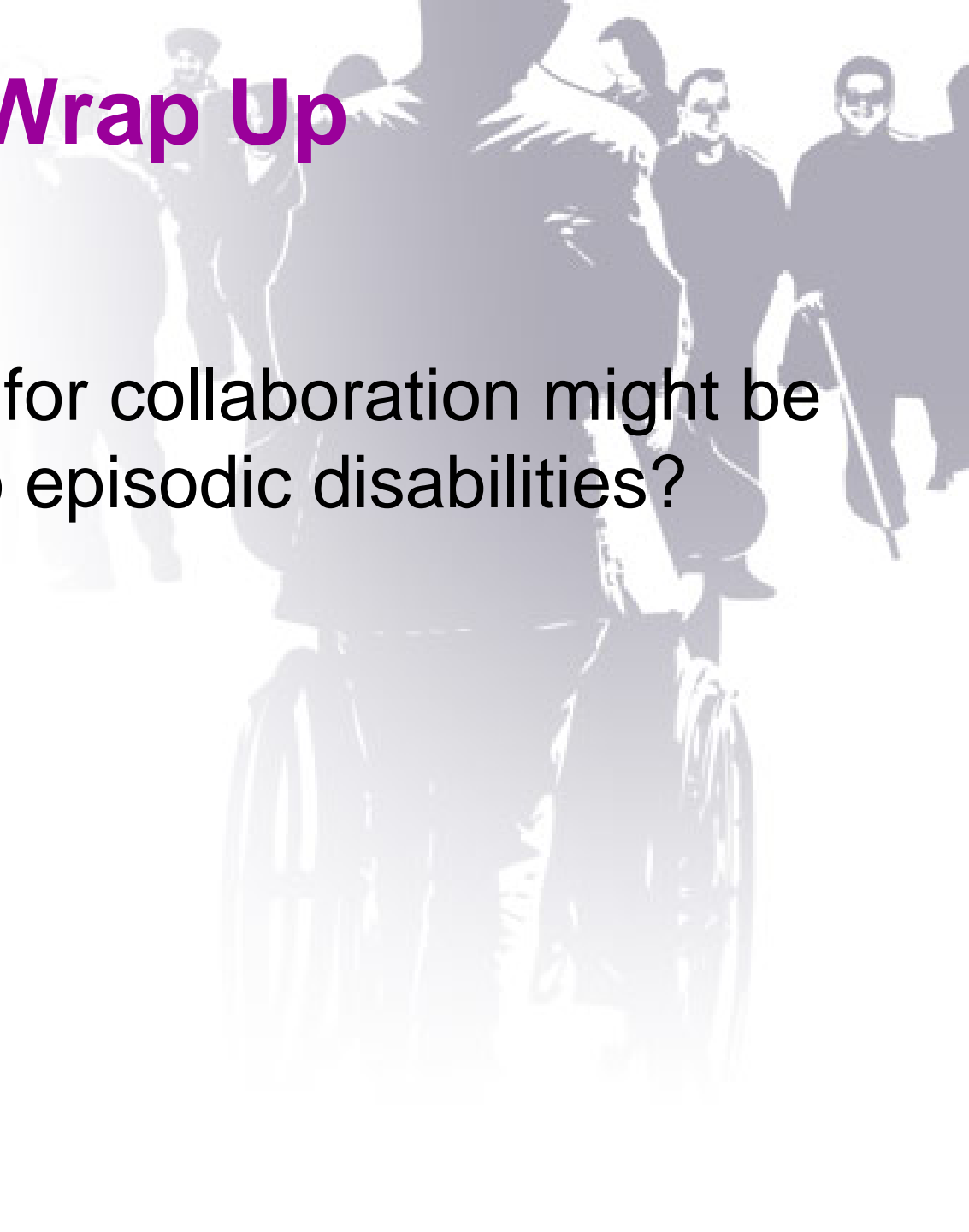
- Factor social determinants of health into any comprehensive program
- Include in policies: episodic nature of illness and individual nature of illness course
- Develop a workplace culture that focuses on the full integration of all staff
- Include strong communications protocol between management/HR 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 pushing a wheelchair. Other people are visible in the background, some standing and some walking, creating a sense of a community or a group of people.

**Thank You**

For more information see  
[www.hivandrehab.ca](http://www.hivandrehab.ca)

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**Canada** 