



Understanding Episodic Disabilities and Employment A presentation to RBC

By: Martine Mangion, MSc

Melissa Popiel, MSW

Richard Chenier, Mood Disorders Society of Canada



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



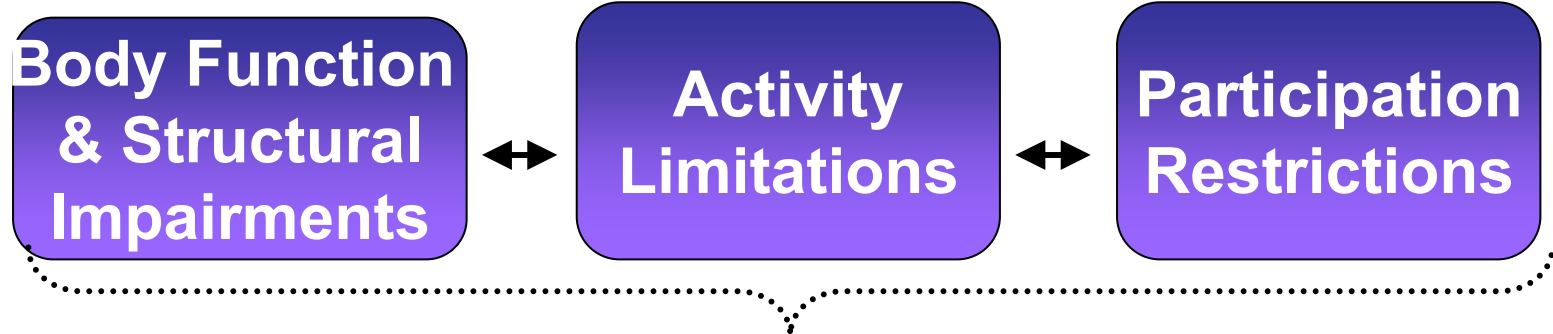
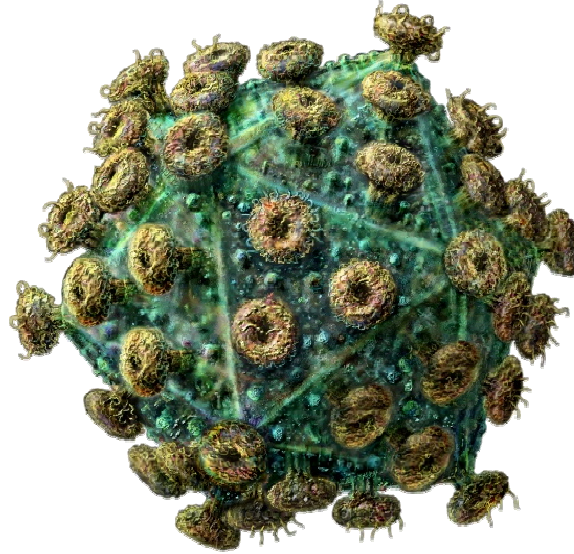
Introducing Episodic Disabilities

- What does the term episodic disability mean to you?





Introducing Episodic Disabilities Cont.



Disability



What is an Episodic Disability?

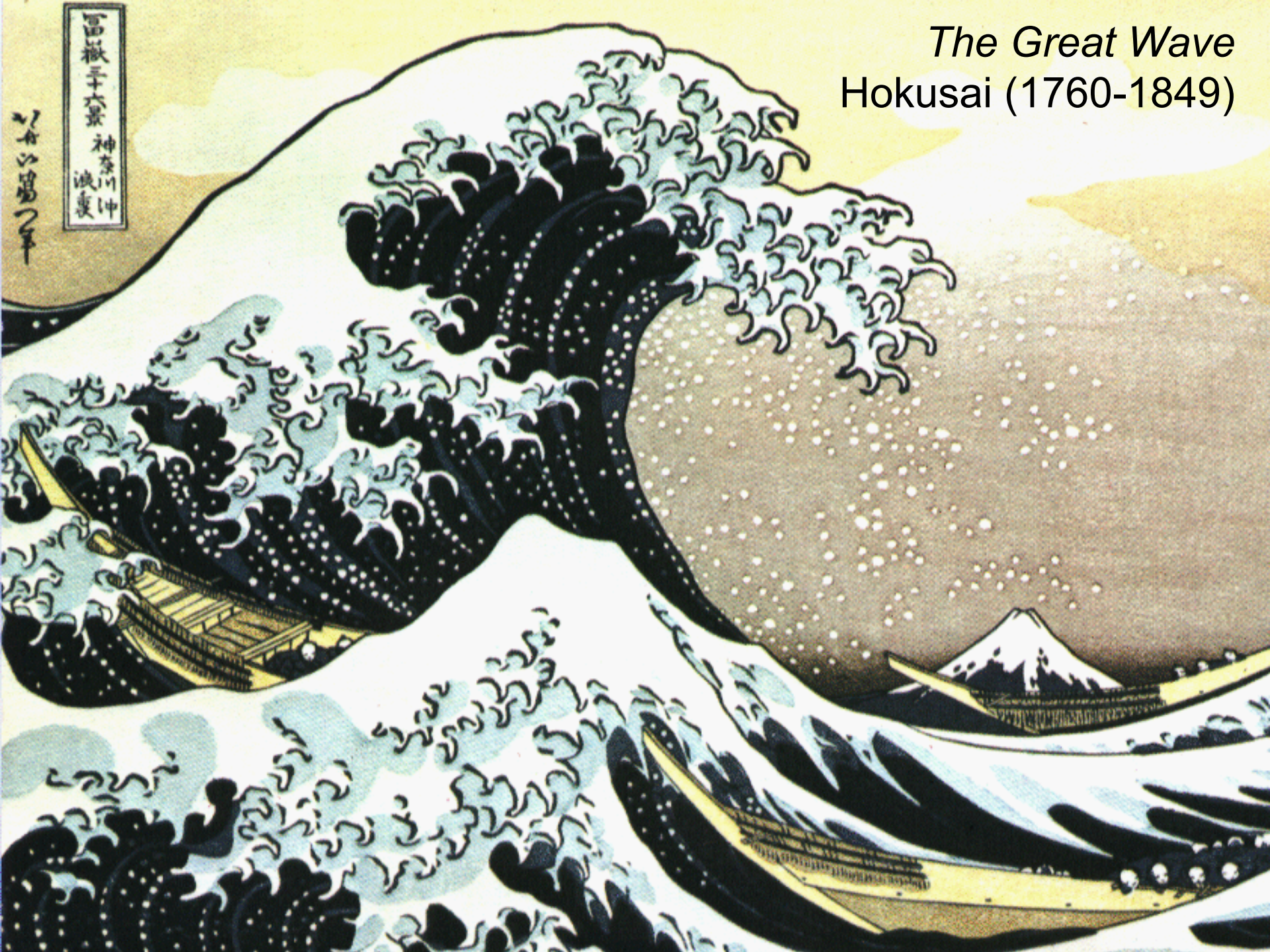
- Marked by fluctuating periods and degrees of wellness and illness
- Unpredictable
- Episodic disabilities include: some forms of mental illness, HIV/AIDS, multiple sclerosis, diabetes, arthritis, lupus and some forms of cancer



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

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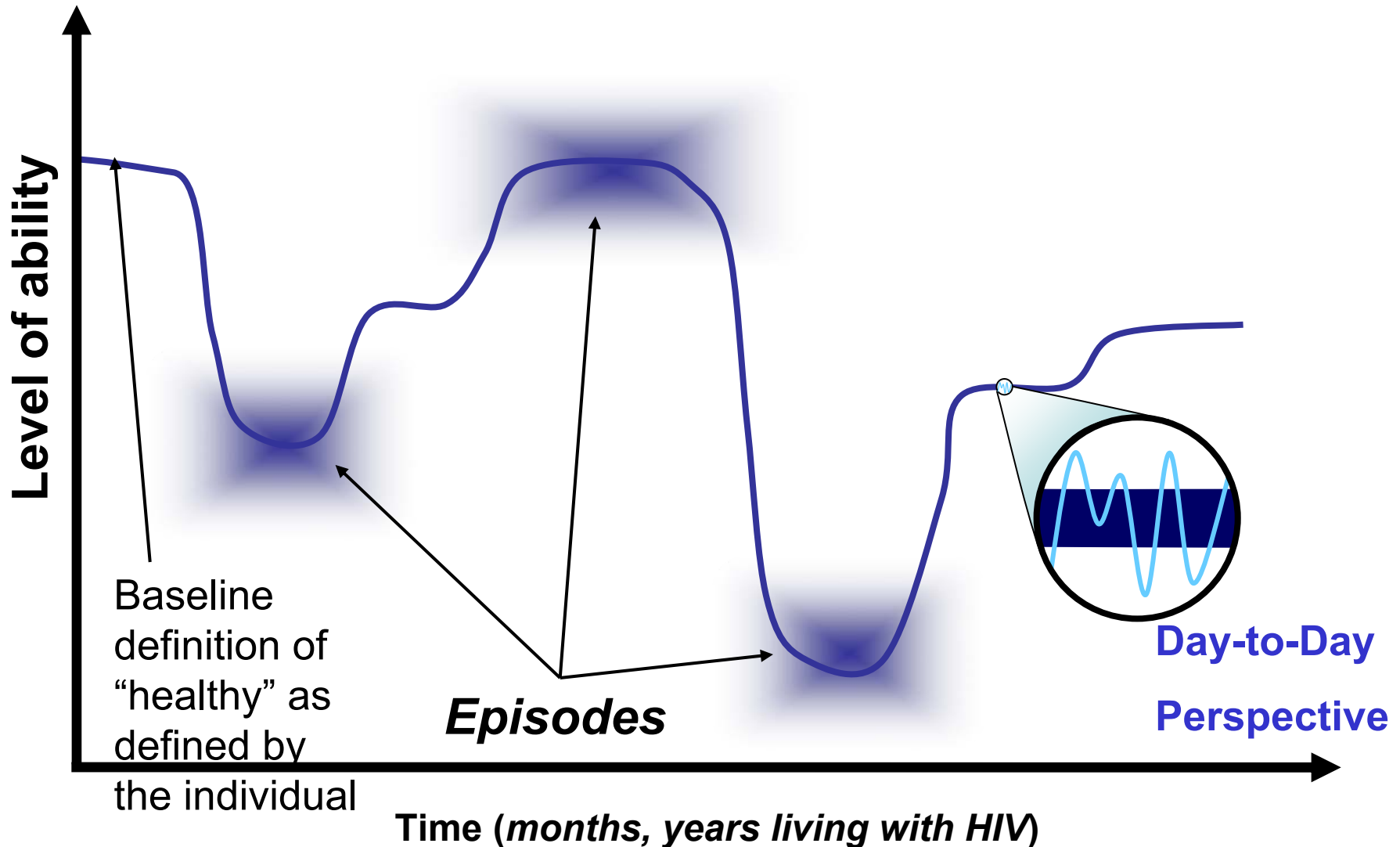


The Episodic Disability Framework

Exploring Episodic Disability from the Perspective of Adults Living with HIV

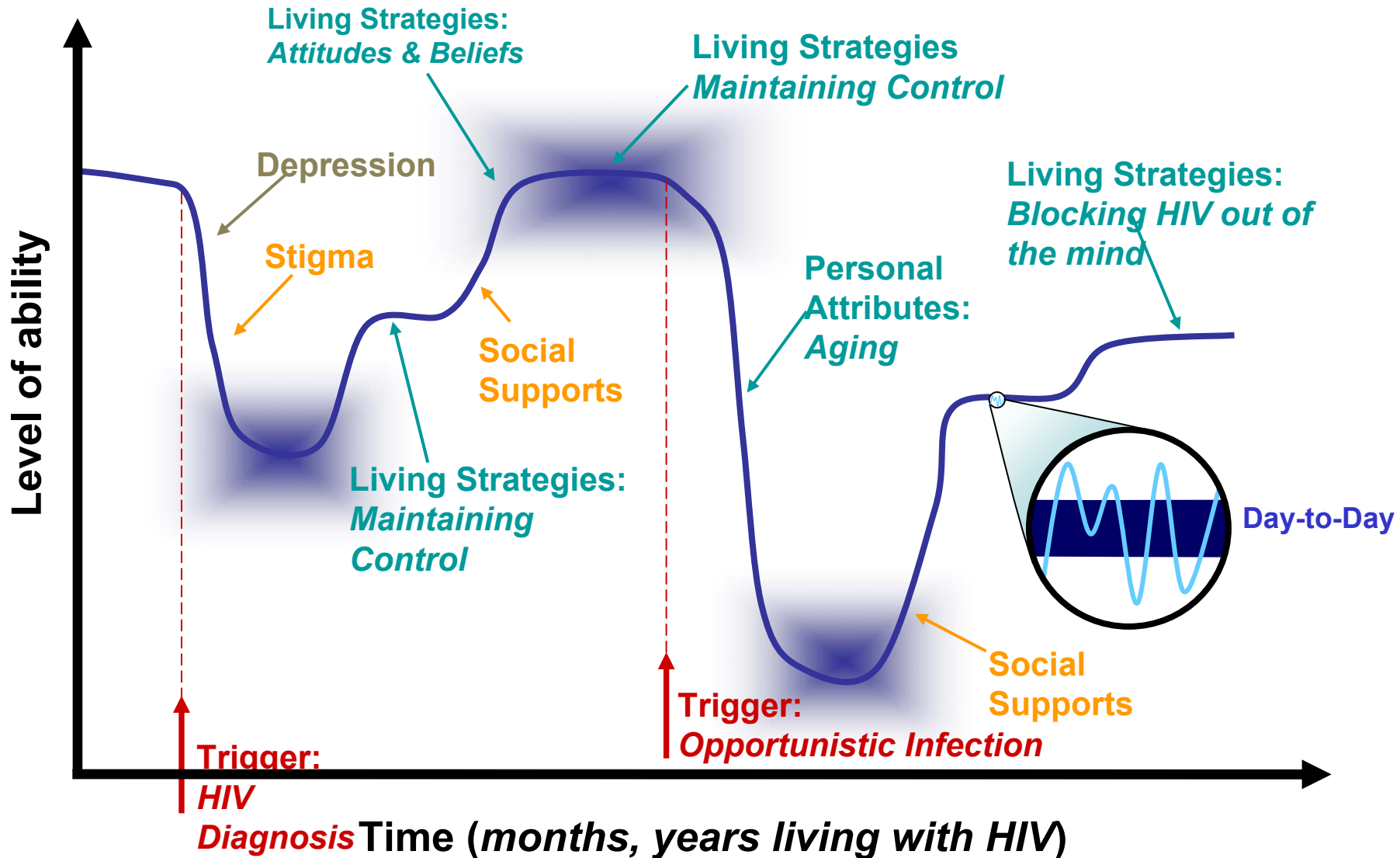
- Developed as part of a qualitative research study
- Conducted a series of focus groups and interviews with 38 adults living with HIV
- Participants were asked about health-related challenges living with HIV and how these impact on their overall health

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

Managing Episodic
Disabilities course

EDEN

The Challenges Facing People Living with Episodic Disabilities

- A person potentially moves in and out of the labour force in an unpredictable manner
- Income support plans and workplace policies do not always accommodate the episodic nature of these disabilities
- Income support plans and workplace policies have varying program definitions, policies and practices
- People with episodic disabilities struggle to navigate the maze of policies and programs



The Lived Experience

**By: Richard Chenier
Founding Member of the Mood
Disorders Society of Canada**



Mental Illness in the Workplace

- Economic
- Social
- Health
- **QUICK FACTS: MENTAL ILLNESS AND ADDICTION IN CANADA - MDSC**



Personal History of Mental Illness in the Workplace

- Post Traumatic Stress Disorder
- Bi-Polar Disorder
- Hospitalized on eight occasions (against my better judgment!!)
- Hallowed halls of the Manitoba Legislature to the streets of Winnipeg in a few short years



Examining Mental Illness in the Workplace Through my Lens

- Mental Illness from the perspective of a:
 - Senior Manager
 - Human Resources Professional
 - Consumer/Employee
 - 12 years experience consulting in mental health (1998 to present)



Critical First Step

- **Mental Health Literacy has been defined as knowledge and beliefs about mental disorders which aid their recognition, management or prevention.**
- **Improving mental health literacy in the workplace confers early recognition and intervention, prevention and the reduction of stigma and discrimination.**

Mental Health Literacy in Canada

www.camimh.ca



Mental Health Literacy Consists of:

- Knowledge and beliefs about risk factors and causes
- Knowledge and beliefs about interventions and recovery
- Attitudes which facilitate recognition and appropriate help-seeking
- Knowledge of how to seek mental health information



Factors Common to Recovery

- Hope
- Medication/Treatment
- Empowerment
- Support
- Education/Knowledge
- Self-help
- Spirituality
- Employment/Meaningful Activity



A Call To Action

- Don't mask or hide mental health issues in your workplace. They seldom go away and the impact on your organization can have lasting negative effects
- Provide your managers and staff with the necessary training and tools to deal with mental health issues in the workplace
- Employers should develop workplace mental wellness plans and policies to ensure that their approach is systematic, thorough and equitable to all staff



- Plans should also include policies aimed at accommodating employees with a mental health issue
- Think outside of your organizational box: more effective utilization of resources available in your community



A few Questions

- 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?

- Intra-organizational programs
- 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

Martine Mangion: Manager of Episodic Disabilities Initiatives

mmangion@hivandrehab.ca

416-513-0440 x.244

Melissa Popiel: Coordinator of HIV and Episodic Disabilities Initiatives

mpopiel@hivandrehab.ca

416-513-0440 x.235



Thank You

For more information see
www.hivandrehab.ca