



Canadian Working Group on HIV and Rehabilitation

Groupe de travail canadien sur le VIH et la réinsertion sociale



Different but Equal: Workforce Participation of People Living with Episodic Disabilities

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Presentation Overview

About CWGHR

What is an Episodic Disability?

Episodic vs. Traditional Understanding of Disability

The Business Case for Hiring and Retaining People Living with an Episodic Disability



Presentation Overview

Why income security is often a challenge

Workplace Supports

Call to Action!



Canadian Working Group on HIV and Rehabilitation

**Established
in 1998**

**Centred on
the needs of
people living
with HIV**

**Addresses
rehabilitation
issues in the
context of
HIV**

**Collaborative
work on
cross-
disability
issues**



Three Life Stories



Sadie



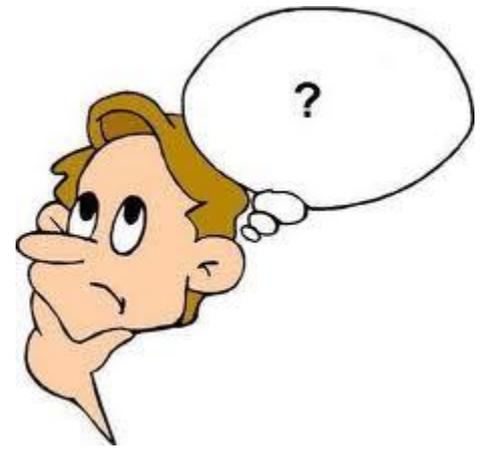
Bill



Lisa



What is a Disability?



What is a disability?





What is a Disability?

“disability” means,

(a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical coordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,



What is a Disability (Cont'd)?

- (b) a condition of mental impairment or a developmental disability,
- (c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
- (d) a mental disorder, or
- (e) an injury or disability for which benefits were claimed or received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997*; (“handicap”)



What is a Disability (Cont'd)?

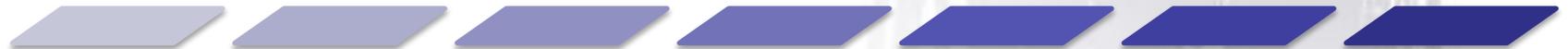
- Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Convention on the Rights of Persons with Disabilities)
- The challenge of defining the definition!



Introducing Episodic Disabilities

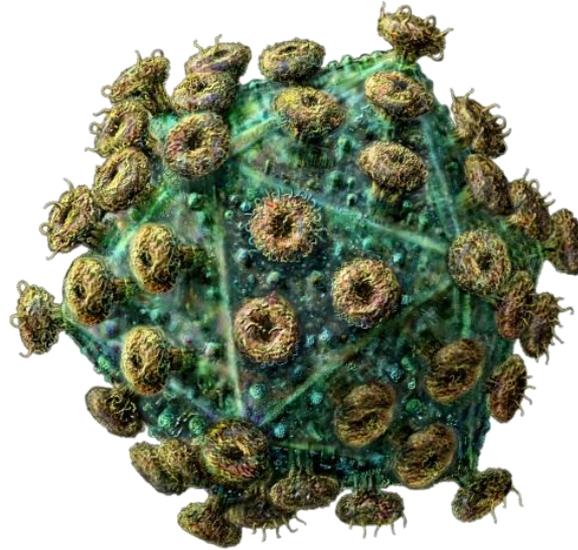


What do you understand by the term episodic disability?





Introducing Episodic Disabilities



Body Function
& Structural
Impairments



Activity
Limitations



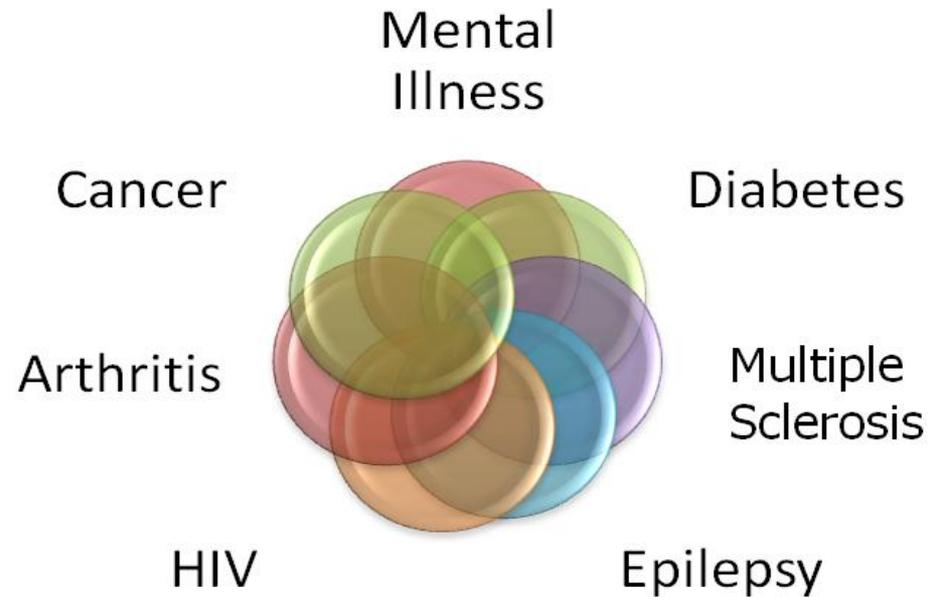
Participation
Restrictions

Disability



What is an Episodic Disability?

Episodic disabilities are lifelong and chronic conditions. It is often difficult to predict when episodes of disability will occur, how severe they will be, and how long they will last.





Episodic vs. Traditional Understanding of Disability

A person can simultaneously live with both permanent and episodic disabilities

Unlike a permanent disability which is relatively consistent, an episodic disability is marked by fluctuating periods and degrees of illness and wellness

For people living with episodic disabilities, this unpredictability can have a negative impact on meaningful community and employment participation, income security, social inclusion and access to care



The Numbers ... Did you know?

6,800,000 – Mental Illness

9,000,000 - Diabetes

55,000 to 75,000 - MS

65,000 - HIV

5,500,000 - Arthritis



The Episodic Disabilities Framework

Exploring Episodic Disability from the Perspective of Adults Living with HIV



Qualitative research study

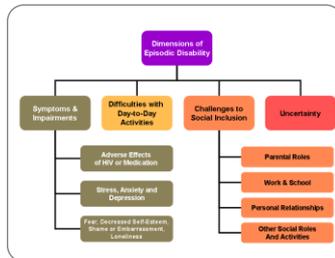


Conducted a series of focus groups

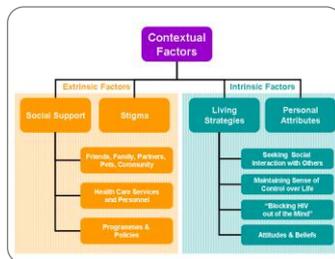


Questions on health related challenges

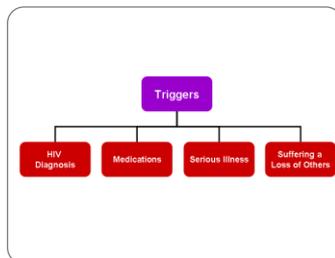
Components of The Episodic Disability Framework



1) **Dimensions of Episodic Disability**



2) **Contextual Factors** can influence the experiences of disability



3) **Triggers** can initiate a major or momentous episode of disability

Dimensions of Episodic Disability

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graph TD; A[Dimensions of Episodic Disability] --- B[Symptoms & Impairments]; A --- C[Difficulties with Day-to-Day Activities]; A --- D[Challenges to Social Inclusion]; A --- E[Uncertainty];
```

Symptoms & Impairments

Difficulties with Day-to-Day Activities

Challenges to Social Inclusion

Uncertainty

Dimensions of Episodic Disability

Symptoms & Impairments

Difficulties with Day-to-Day Activities

Challenges to Social Inclusion

Uncertainty

Adverse Effects of HIV or Medication

Stress, Anxiety and Depression

Fear, Loneliness



Dimensions of Episodic Disability

Symptoms & Impairments

Difficulties with Day-to-Day Activities

Challenges to Social Inclusion

Uncertainty



Dimensions of Episodic Disability

Symptoms & Impairments

Difficulties with Day-to-Day Activities

Challenges to Social Inclusion

Uncertainty



Parental Roles

Work & School

Relationships

Other Social Roles & Activities

Dimensions of Episodic Disability

Symptoms & Impairments

Difficulties with Day-to-Day Activities

Challenges to Social Inclusion

Uncertainty



Contextual Factors

Extrinsic Factors

Social Support

Stigma

**Friends, Family,
Partners**

**Health Care Services
and Personnel**

**Programmes &
Policies**

Intrinsic Factors

**Living
Strategies**

**Personal
Attributes**

**Interaction
with Others**

**Maintaining Sense of
Control over Life**

**“Blocking HIV
out of the Mind”**

Attitudes & Beliefs

Triggers can initiate a major or momentous episode of disability

Triggers

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graph TD; A[Triggers] --- B[HIV Diagnosis]; A --- C[Medications]; A --- D[Serious Illness]; A --- E[Suffering a Loss of Others];
```

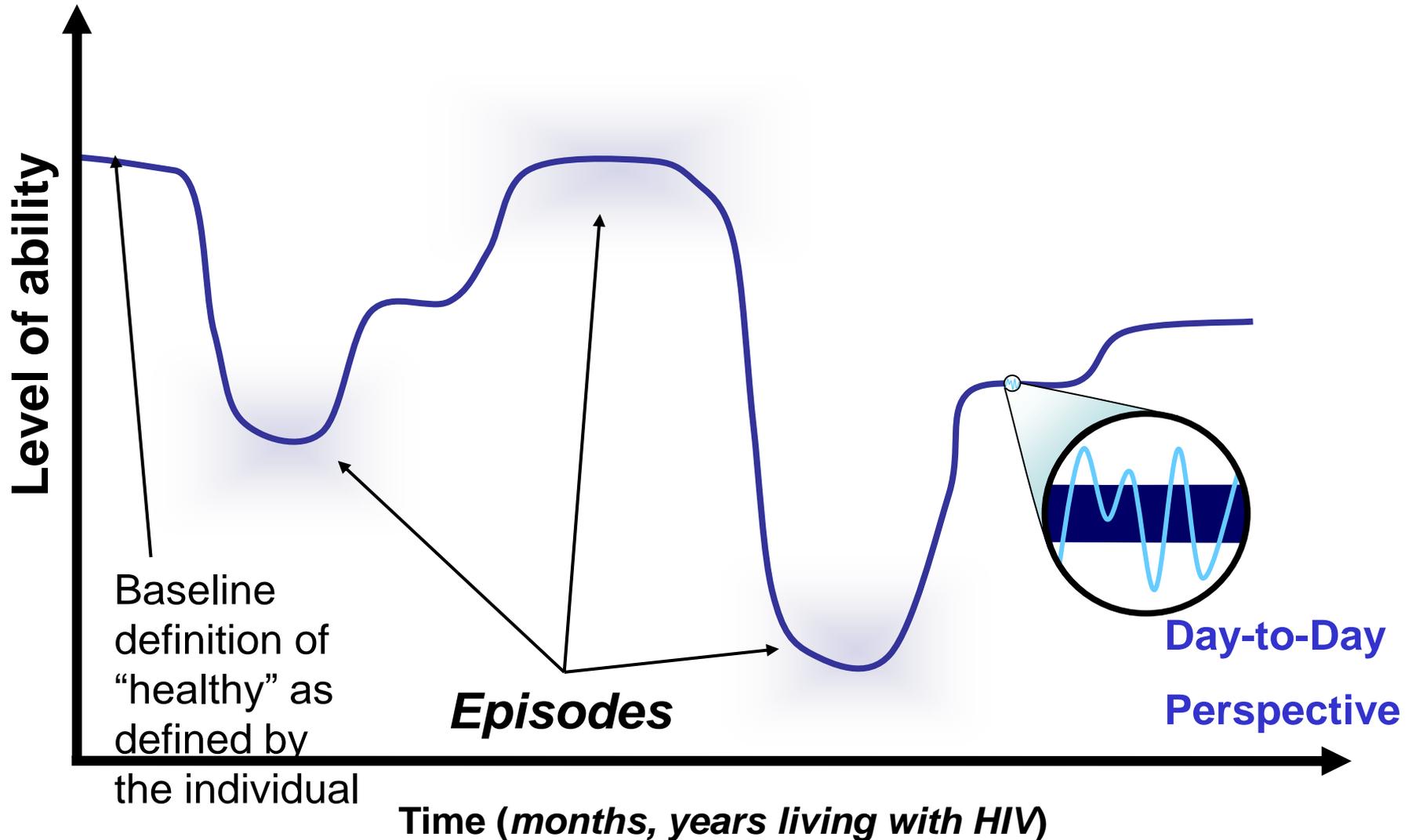
**HIV
Diagnosis**

Medications

Serious Illness

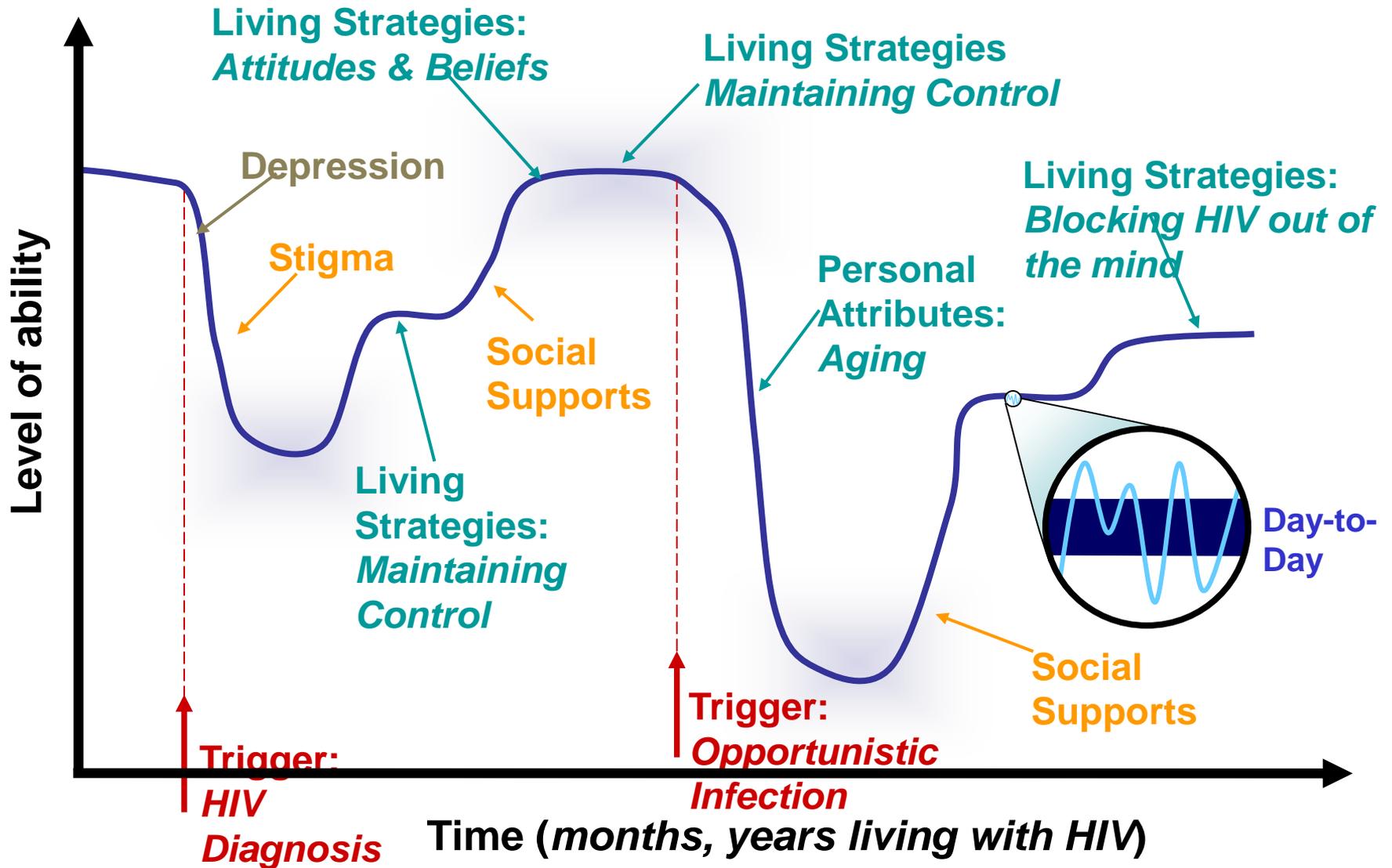
**Suffering a
Loss of Others**

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





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



The Business Case for Hiring and Retaining People Living with Episodic Disabilities

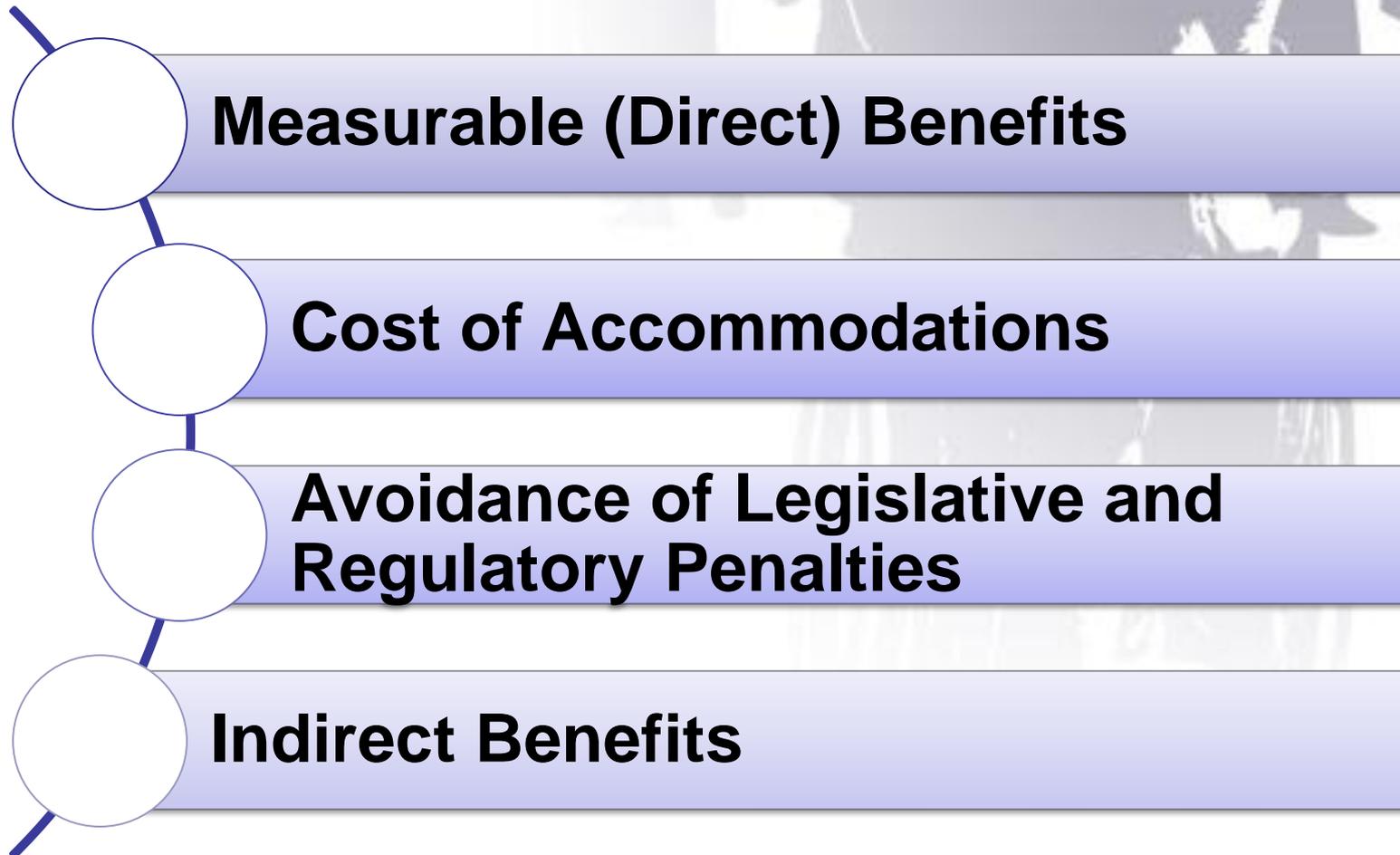


What is the economic argument?





The Business Case for Hiring and Retaining People Living with Episodic Disabilities





A WIN-WIN PROPOSITION:

The Business Case for Actively
Recruiting and Retaining People
with Episodic Disabilities





The Insecurity of Income Security for People Living with Episodic Disabilities

- What's the purpose of an income support program?
- The broad category of income support/replacement programs in Canada
- The lack of integration of income support programs



Building an Inclusive Workplace Culture

- Practice equality of treatment, not sameness
- Educate 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
- Be proactive in communicating

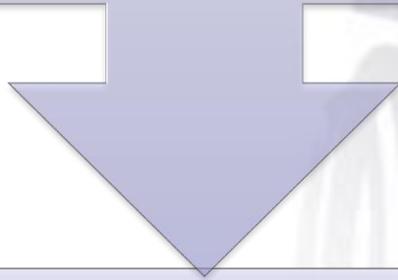


Additional Workplace Supports

- Employee Assistance Programs (EAP)
- Peer Associations
- Variety of consumer driven associations (e.g. National Network on Mental Health (NNMH), Arthritis Society, Canadian AIDS Society (CAS), MS Society etc.)
- Episodic Disabilities Employment Network (EDEN) website

Call to Action!

**Change the conversation
around disabilities**



**Share what you now know
about episodic disabilities with
everyone you know**



***... Because everyone
knows someone
living with an
episodic disability***



Reflection





Reflection

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”
(Author, Margaret Mead)



Additional Information

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A faded, grayscale background image showing a group of people in a public setting. In the foreground, a person is seen from behind, pushing a wheelchair. Other individuals are standing and talking in the background.

Thank You

For more information see
www.hivandrehab.ca