

Episodic Disability and Employment: Flexibility as Innovation



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ADELE FURRIE
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Providing data to inform change

realize FOSTERING
POSITIVE CHANGE
FOR PEOPLE LIVING
WITH HIV AND OTHER
EPISODIC DISABILITIES

réalise UN MOTEUR
DE CHANGEMENT POUR
LES PERSONNES VIVANT
AVEC LE VIH ET D'AUTRES
INVALIDITÉS ÉPISODIQUES

Who is *Realize*?

- Realize is a national non-profit with the aim of fostering positive change for people living with HIV and other episodic disabilities.
- Established in 1998, **Realize** (formerly known as the Canadian Working Group on HIV and Rehabilitation) emerged as an innovator in bridging the traditionally separate worlds of HIV, disability and rehabilitation
- **Realize** is a national charitable organization dedicated to fostering positive change for people living with HIV and other episodic disabilities
- Our vision is that the daily lives of people living with HIV and other episodic disabilities are improved in direct and meaningful ways by rehabilitation services.

Methods: Labour Force Participation & Income Support Policy Work

- National Episodic Disability Network (EDN) and Forum of health sector NGOs, government, researchers, labour, policy analysts
- Ontario Episodic Disability Network (OEDN), La Table – COCQ-SIDA
- Development of policy briefs, white papers, statements of common concern, committee presentations including:
 - Navigating the Maze, Evolving the Workplace, A Win-Win Proposition: Business Case, Episodic Caregiver Support Initiative, Episodic Disability and Post-Secondary Education in Canada, Episodic Disabilities Toolkit, Episodic Disabilities Discussion Papers, book chapters
- Presentation at UN COSP on Episodic Disability

Methods: Labour Force Participation & Income Support Policy Work cont.

- Participant in Institute for Research on Public Policy (IRPP) RoundTable: Leaving Some Behind: What Happens When Workers Get Sick
- Forum & Policy Dialogue on Workforce Participation by People Living with Episodic Disabilities in Canada
- Episodic Disabilities Employment Network (edencanada.ca)
- SSHRC/CIHR Knowledge Mobilization Partner numerous grants
- Collaborated with ILO,UNAIDS
- Accredited training for HR Professionals
- Partner on 'Learning from Each Other' project

Episodic Disability Conceptual Evolution

- CWGHR and others recognized the changing nature of treatment within HIV context
- ARTs extend life so HIV not fatal but people can have unpredictable periods of being sick and unable to work
- Difficulties fitting binary paradigm of disabled or not used by income support programs
- Since 2002, CWGHR/*Realize* has undertaken projects with other NGOs representing people with similar episodic illness trajectories

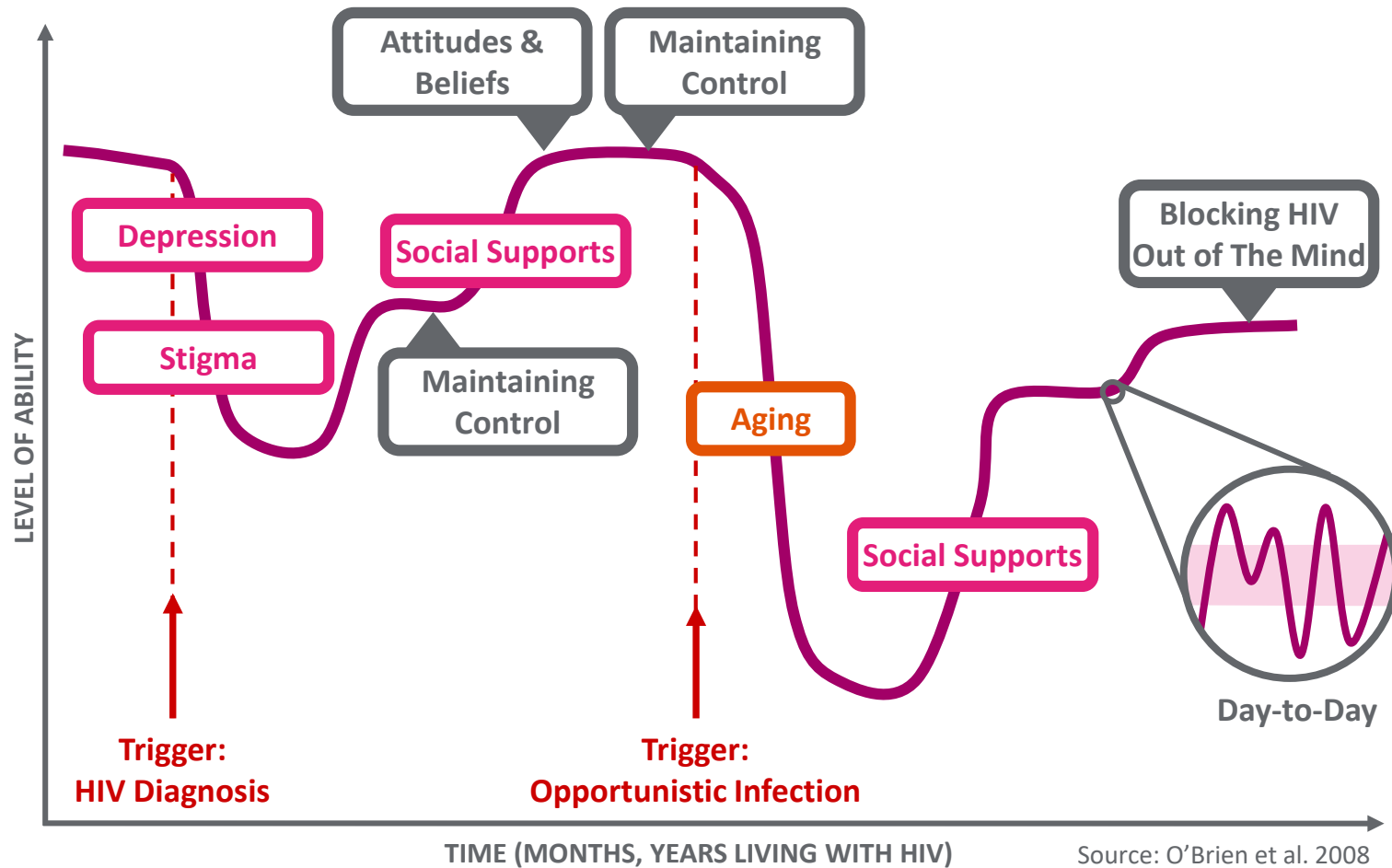
What is an Episodic Disability?

- “Episodic disabilities are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability from one person to another.”
- Unpredictability has a negative impact on meaningful community participation, employment, income security, social inclusion and access to care
- At work, this can result in “intermittent work capacity” (IWC)
- *What is accommodation in the context of intermittent work capacity?*

EDN List of Episodic Conditions (2015)

- Arthritis
- Asthma
- Some forms of Cancer
- Chronic Obstructive Pulmonary Disease including:
 - Chronic Bronchitis
 - Emphysema
- Chronic Fatigue Syndrome*
- Chronic Pain
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
- Crohns & Colitis
- Diabetes
- Epilepsy
- Fibromyalgia*
- Hepatitis C
- HIV/AIDS
- Lupus
- Mental Health Conditions including:
 - Depression
 - Anxiety
 - Bi-Polar Disorder
 - Schizophrenia
- Meniere's Disease
- Multiple Sclerosis
- Migraines
- Parkinson's Disease
- Systemic Exertion Intolerance Disease (SEID)*

Episodic Disability Framework



Learning From Each Other Project

- Funding from Centre for Research on Work Disability Policy (CRWDP) & Office for Disability Issues, Employment and Social Development Canada
- Question: Who are people living with episodic disabilities and what are their experiences in the workplace?
- Partners included **Realize**, Adele Furrie at Adele Furrie Consulting Inc., Dr. Rebecca Gewurtz at McMaster University, Maureen Haan at CCRW, John Stapleton at Open Policy

Two Methods

- Queried Canadian Survey on Disability (CSD) 2012 data looking for Episodic Conditions (EPI) and Work Disability (WD)
 - EDN list of 21 conditions; plus mental health condition and/or Pain noted as “sometimes” or “often”
 - Intermittent Work Capacity indicated as “Sometimes” or “Often”
- Online Survey asking about individual experiences with episodic disability
 - Snowball sampling through episodic disability organizations
 - In French and English
 - 953 Canadians completed the survey

Who are People with Episodic Disabilities?

- Using our definition 1,882,490 individuals, or 82.4% of the adult population was classified as having an **episodic disability** according to CSD data
- Not all people with episodic disabilities experienced intermittent work capacity, but many did
- Population of people with episodic disabilities more likely to be female, older and living alone

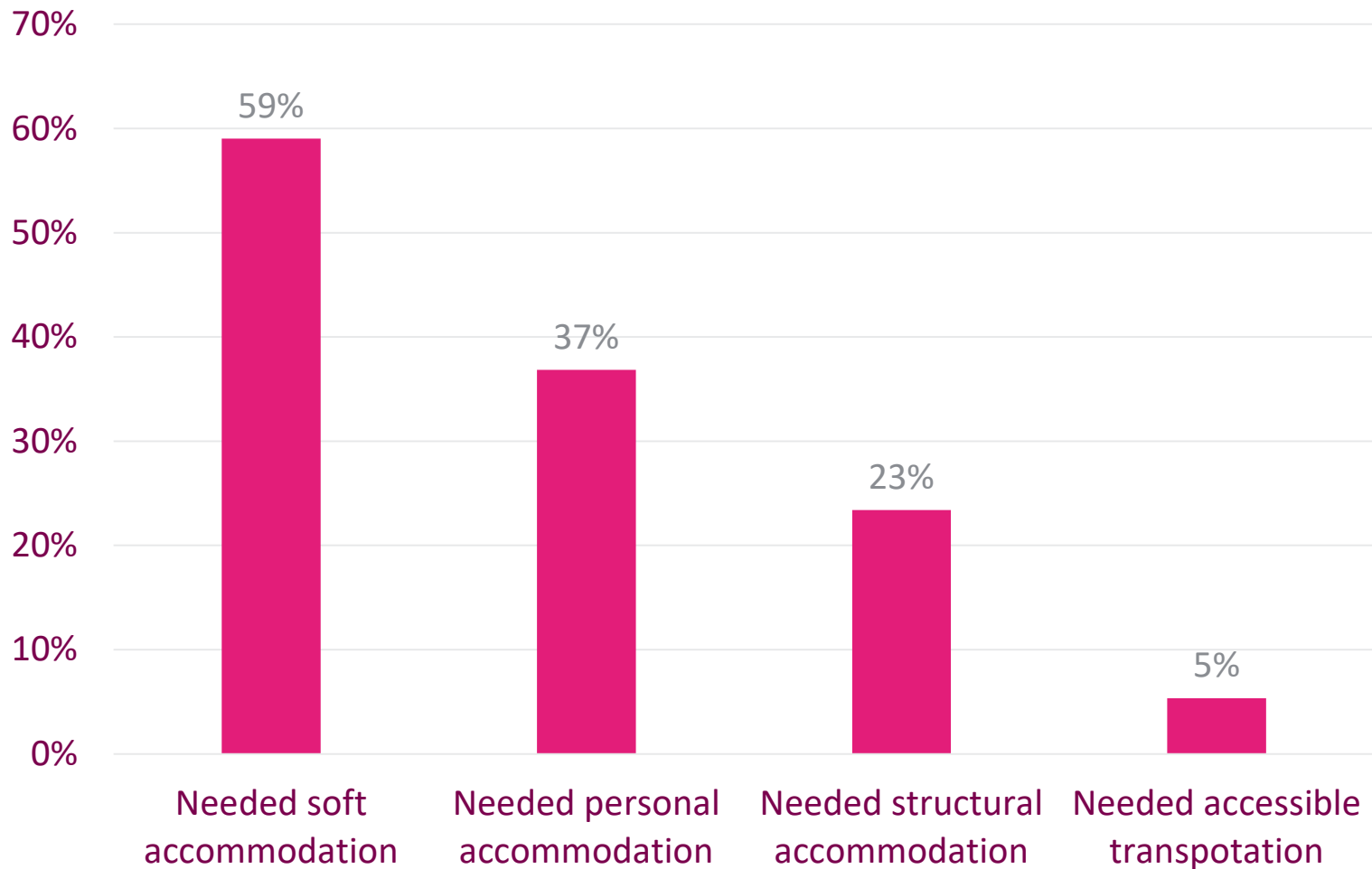
What is the Impact on Employment?

- 52.7% of people in the EPI/WD population who were working part-time said that **it was their disability /health condition that prevented them from working more hours**
- Almost half of the EPI population reported that **they had changed jobs because of their health condition**
- People in the EPI/WD group were more likely to be **engaged in teleworking or flexible work or be self-employed**
- People in the EPI/WD group experienced significant concerns associated with rejoining the workforce including **worries about losing their access to drugs plans and subsidized housing**

Accommodations

- The majority of people with episodic disabilities who are working and need an accommodation are receiving at least *some* of the accommodations they need
- People with episodic disabilities reported the **most benefit from “soft” accommodations** like:
 - job redesign (modified or different duties)
 - telework
 - modified hours or days or
 - reduced work hours

Type of accommodation needed



What is the most challenging element of living with an episodic disability?

- *“The **unpredictability**: I don't consider myself as someone who is ill until I have a flare up but when they do occur, they can be quite severe. In the future, having a severe flare up while employed could pose as a challenge as some flare ups have lasted up to 6 months”*
- *“**Unpredictability** of symptoms; feeling like I am letting my co-workers / students down because of fatigue; feeling frustrated because I want to do more with my job, and outside of work; disappointed because this is not the career direction I planned to stay in”*

What is the most challenging element of living with an episodic disability?

- *“The **uncertainty** of day-to-day living. Will I be able to eat or do anything today. If I can for how long....”*
- *“The **unpredictability** of the disease. And people not understanding that I'm ill because "I don't look sick“*
- *“**Unpredictability**, trying to parent, missing out on social events, stigma, "faking" it on bad days, difficulty connecting with others at times*

What is the most important service or support to persons with disabilities to maximize their employment potential?

FLEXIBILITY

- Flexible Work Practices are the most important support for people with episodic disabilities, including:
- Flexible work schedules
- Ability to change shifts
- Time off to attend medical appointments or adjust to side-effects of medication
- Reassignment to work that is less physically or mentally demanding
- Opportunity to shift from full to part-time work
- Banked hours or compressed work weeks
- Job sharing
- Teleworking

Operationalizing Flexible Work Practices

- Can be accessed as “accommodation” through formal HR processes
- Can be available as standard work policies, available to all employees without need to engage in accommodations process. For ex. Federal Gov’t considering changes to the Canadian Labour Code to include “Flex Work”
- Can be arrived at through informal discussion with managers/co-workers (see: *“Building the business case for employers to actively recruit and retain people living with mental illness”* report funded by MHCC)

Questions for Reflection

- Do you include people with episodic disabilities in your definition of ‘people with disabilities’?
- Does your workplace see people with episodic disabilities as eligible for disability related employment supports?
- Does your workplace provide avenues for accessing Flex Work?

For More Information

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