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Advanced Grant Research Report

# Disability in the Context of HIV: Building a Foundation for an Instrument to Describe Disability Experienced by Adults Living with HIV

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## Disability in the Context of HIV: Building a Foundation for an Instrument to Describe Disability Experienced by Adults Living with HIV

Since the advent of new medication therapists, individuals may be living longer with the day-to-day health-related consequences of HIV and the potentially adverse effects of treatments. An initial working term that may be used to label these health-related consequences is disability. Currently, health providers cannot measure the prevalence or burden of disability because the experiences of these individuals are complex and not well understood. Understanding the meaning and experience of living with HIV is first necessary to know what is important and how to approach measuring these consequences before we can evaluate interventions to improve HIV care and treatment.

**Purpose & Objectives:** To determine what disability means from the perspective of people living with HIV in order to facilitate the development of an instrument to describe disability experienced by adults living with HIV. Specific objectives were: 1) to develop a conceptual framework of disability from the perspective of adults living with HIV; and 2) to evaluate how well existing HIV-specific health status instruments describe disability as experienced by adults living with HIV.

**Methods:** This research consisted of two phases. For objective #1 we conducted a series of focus groups and face-to-face interviews with men and women living with HIV. We asked participants to describe their health-related challenges, their physical, social and psychological areas of life affected, and impact on their overall health. We analyzed data using grounded theoretical techniques, a systematic set of procedures used to develop theory to describe and explain a phenomenon. For objective #2 we conducted a content analysis to determine how well existing HIV-health status instruments captured dimensions of disability.

## Results

**Objective #1:** We recruited 38 participants (21 men, 16 women, 1 transgendered individual) for 4 focus groups and 15 face-to-face interviews at the AIDS Committee of Toronto and Voices of Positive Women in Toronto. We also completed two validity check focus groups with 7 returning participants. Participants conceptualized disability as multi-dimensional and episodic in nature characterized by unpredictable periods of wellness and illness due to HIV and its treatments. The Episodic Disability Framework consists of 3 main components: a) dimensions of disability that include: impairments / symptoms, difficulties carrying out day-to-day activities, challenges to social inclusion, and uncertainty that may fluctuate on a daily basis or over the course of living

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with HIV, b) contextual factors that include extrinsic factors (level of support and stigma) and intrinsic factors (living strategies and personal attributes) that may exacerbate or alleviate disability, and c) triggers that mark momentous or major episodes of disability - examples include starting and/or changing medications, receiving an HIV diagnosis, experiencing a 'serious illnesses' and suffering a loss of others.

**Objective #2:** We conducted a document analysis matching items from existing instruments with categories of the Episodic Disability Framework. We reviewed 4274 abstracts, from which 30 met the inclusion criteria and were retrieved. Instruments were evaluated for their ability to capture major dimensions of disability in the newly developed framework. Of the 4 major dimensions of disability, symptoms/impairments and difficulties with day-to-day activities were characterized in greatest depth while uncertainty and challenges to social inclusion were less well represented.

**Conclusions:** The Episodic Disability Framework presents a new way to conceptualize disability based on the perspective of adults living with HIV. Existing instruments do not fully capture the disability experience, but do provide a foundation from which to build a future measure of disability for adults living with HIV.

## Project Outcomes

This research resulted in various program, policy and partnership outcomes. This research was guided by a community advisory committee which helped to foster program and policy partnerships. The committee consisted of four members including persons living with HIV, representative(s) from the Canadian Working Group on HIV and Rehabilitation (CWGHR), AIDS Service Organizations (ASOs) and the AIDS Bureau, Ontario Ministry of Health and Long Term Care. The committee specifically was involved with recruitment of participants, analysis of data including formulation and refinement of the conceptual framework, content analysis of instruments, and translation of research findings to relevant stakeholders in the HIV community. One advisory committee member was also involved in the write-up and publication of results.

Through our community partnerships, we were invited to participate in a Labour Force and Income Support Strategizing Session in March 2007. This goal of this session (conducted by CWGHR in partnership with the Wellesley Institute) was to brainstorm strategies on how to positively shape labour force and income support programs and policies to better meet the needs of people living with episodic illnesses. This research was highlighted as empirical evidence demonstrating the episodic nature in which disability is experienced by people living with HIV and the resulting challenges of trying to engage in the labour force.

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## Dissemination

We are in the stage of translating and disseminating research knowledge to persons living with HIV, researchers, future and current health care providers, government representatives, insurance and employment representatives and policy makers. With the advisory committee we have had opportunities for knowledge translation among community-based AIDS service organizations (Toronto PWA Foundation and AIDS Committee of Toronto) and a primary health care centre (Maple Leaf Medical Clinic). We presented this research at the Annual Canadian Conference on HIV/AIDS in 2006 and 2007 and the Centre for Addiction and Mental Health (CAMH) Qualitative Research Meeting in May 2006. Further modes of dissemination will include publications in peer-reviewed scientific journals (see appendices) and fact sheets made available on the Wellesley Institute, Centre for Research on Inner City Health at St. Michael's Hospital, and CWGHR websites. Additional translation will include collaborations with CWGHR through their provision of educational workshops to multiple stakeholders across Canada, and through the Episodic Disability Network to inform policy and program development related to return to work and disability income support policy issues for people living with episodic illnesses.

Below is a list of dissemination activities related to this research:

*Community Presentations:* Development of a Framework of “Episodic Disability” from the Perspective of Adults Living with HIV.

- Centre for Addiction and Mental Health (CAMH) Qualitative Research Meeting – May 2006
- Canadian Working Group on HIV and Rehabilitation AGM – June 2006
- Maple Leaf Medical Clinic Rounds – March 2007
- AIDS Committee of Toronto Staff Meeting – March 2007
- Persons with AIDS Society Staff Meeting – July 2007

*Conference Presentations*

- The Canadian Association of HIV Research (CAHR) Conference, Toronto, ON– May 2006
  - Exploring Disability from the Perspective of Adults Living with HIV: Development of a Conceptual Framework
- The Ontario HIV Treatment Network Conference – November 2006

- Exploring Disability from the Perspective of Adults Living with HIV: Development of a Conceptual Framework
- World Congress of Physical Therapy Conference, Vancouver, BC – June 2007
  - Putting Disability into Context: Factors that Influence the Experiences of Disability for Adults Living with HIV/AIDS
- Health Policy, Management and Evaluation Research Day, Toronto, ON – May 2007
  - Putting Disability into Context: Factors that Influence the Experiences of Disability for Adults Living with HIV/AIDS
- The Canadian Association of HIV Research (CAHR) Conference, Toronto, ON–April 2007
  - How do Existing HIV-Specific Instruments Measure Up? Evaluating the Ability of Instruments to Describe Disability Experienced by Adults Living with HIV
- The Ontario HIV Treatment Network Conference – November 2007
  - Putting Disability into Context: Factors that Influence the Experiences of Disability for Adults Living with HIV/AIDS
  - How do Existing HIV-Specific Instruments Measure Up? Evaluating the Ability of Instruments to Describe Disability Experienced by Adults Living with HIV

## Next Steps & Future Research

The next step is to develop fact sheets that summarize the findings of this research so that we can more widely disseminate these findings to health providers and people living with HIV. We will devise three versions of these fact sheets that will be targeted to different audiences including: people living with HIV, health and social service providers, and stakeholders in the labour force and income support field. We will also continue to work towards submitting manuscripts for publication of this research in peer reviewed journals. We are preparing four manuscripts to submit for publication related to this research. We will also continue our collaborations with CWGHR so that this research may be used to inform policy and program development related to return to work and disability income support policy issues for people living with HIV.

This study provides a foundation for future research that will include development and psychometric testing of a new measure of disability for adults living with HIV. This instrument

may be used to measure the impact and prevalence of episodic disability and evaluate the effectiveness of rehabilitation interventions to reduce disability experienced by people living with HIV. Future research may also include investigating whether the Episodic Disability Framework is relevant to persons living with other types of lifelong episodic illnesses (e.g. multiple sclerosis, mental health, cancer, etc.) in partnership with CWGHR. Results of this and future research may inform allocation of resources and inform program and policy development for people living with HIV and more broadly, people living with episodic illnesses in Ontario.

## Lessons Learned

In the early phase of this research, we faced challenges of recruiting participants, particularly women. After receiving funding (enabling us to offer an honorarium for participation) and formalizing partnerships with community-based organizations, we were successful at recruiting a range of men and women participants for this study. Overall, we learned the benefits of embarking upon an academic-community partnership for this research. Community advisory committee members were integral in all phases of this project, particularly the interpretation of the findings, refinement of the Episodic Disability Framework, and translating this research with other stakeholders in the community.