



# Positive Participation: People Living with HIV/AIDS in the Labour Force

Fact Sheet for Those Engaged in Policy Work

Based on the research project: *Development of a Conceptual Framework to Enhance Labour Force Participation Options for People Living with HIV in Canada*

This fact sheet provides an overview of the different barriers that often hinder a person living with HIV/AIDS (PHA) from entering or remaining in the labour force. It also identifies facilitators that can help overcome these barriers, in an effort to help policy-makers at all levels to better identify and understand the gaps in relevant legislation and policy. The content and recommendations within this fact sheet are based on a comprehensive scoping review of the evidence on HIV and labour force participation and consultations with PHAs, employers, insurers, and policy makers across Canada.

## Introduction

PHAs in Canada face significant and sometimes invisible challenges to participating in the workforce. As in other developed countries, unemployment rates among PHAs in Canada are considerably higher than those among the general population even though many would prefer to be engaged in paid employment.<sup>1</sup>

Whether seeking to keep their current jobs or find new ones, many PHAs must navigate a complex maze of employment and workplace laws, policies and guidelines that may affect them. The way in which these laws, policies and guidelines are written and applied has not caught up to the real-life circumstances and needs of PHAs.<sup>2</sup>

## Why does work matter to PHAs?

For most people — not just PHAs — employment is the main way to fulfilling the basic needs of modern life, money to obtain food and shelter, and insurance and health-care benefits to maintain a certain standard of quality of life.

Emotionally, employment can provide an increased sense of self-esteem, increased independence, social connectivity, and the opportunity to forge an identity based on one's career.<sup>3</sup> Given the ignorance and stigma that continue to surround HIV/AIDS — and the prejudice and discrimination that result — these fundamentals are often critical to PHAs.<sup>4</sup>

## What do we mean by “work”?

Depending on their career stage and their state of health, PHAs are typically in one of four employment situations:

- Maintaining ongoing employment;
- Returning to work;
- Entering the workforce for the first time; or
- Choosing not to work, or exiting the workforce.

Employment encompasses a wide range of work arrangements. It can be full-time or part-time; permanent or contract; it can include self-employment; and it can be remunerated at varying rates and in different ways.

### What's the reality for PHAs?

HIV/AIDS belongs to a group of illnesses called “episodic disabilities.” Episodic disabilities are characterized by periods of good health interrupted by periods of illness or disability. As a result, many people with episodic disabilities (including multiple sclerosis, lupus, arthritis, diabetes, some forms of cancer and mental illness) must rely on health and disability benefits.

However, the strict policies and narrow definitions of benefits programs leave many PHAs in a catch-22. The programs either exclude them from the workforce — even when they are healthy, willing and able enough to be part of it — or give them virtually no choice but to remain in it. For example PHAs who are on private extended benefits plans may have limited opportunities to move in and out of the workplace.

### What are some key problems and solutions?

PHAs (and the social service organizations that support them) must frequently make sense of numerous income security programs, including Employment Insurance (EI) sickness benefits, the Canada Pension Plan or Quebec Pension Plan (CPP/QPP) disability benefit, private long-term disability insurance, and provincial and territorial social assistance programs.

Regardless of their employment status or type of insurance coverage, PHAs and service providers frequently cite the complex rules surrounding health and disability benefits regimes as difficult to navigate. PHAs may find themselves confused or with few options. For example:

- *For PHAs contemplating employment*, the potential loss of public health benefits, coupled with the fear of inadequate private health benefits and disability coverage from a new employer, can cause anxiety and act as a disincentive for joining the workforce.<sup>5</sup>
- *For PHAs with public coverage*, returning to work from a leave of absence means running the risk of losing disability benefits and drug coverage that may still be needed. It also raises the possibility that low wages might not provide a level of income comparable to that provided by social benefits.<sup>3</sup>
- *For PHAs with private coverage*, moving from one job to another can be difficult. Having to change insurers, for example, could mean losing extended health benefits coverage — a significant barrier for PHAs in terms of career planning and development.<sup>6</sup> For those who are out of the workforce and who rely on long-term disability benefits, there are uncertainties about regaining access to benefits if returning to work is unsuccessful.

This widespread fragmentation and lack of integration among programs, services and policies frustrate PHAs, their families and the professionals who support them.

In addition to the personal impact on PHAs, these issues also generate multiple barriers at the public policy level. Public benefits providers often do not effectively collaborate with employers and support agencies, contributing to fragmentation and a lack of coordination within the system.<sup>4</sup> Again, the resulting inconsistencies within vocational and benefits programs deter labour force participation for PHAs.<sup>2</sup>

Increased flexibility of disability income supports would help address several of these barriers. Transitional benefits made available to PHAs as they manage the process of returning to work would help to minimize the financial risks they face when entering employment or changing jobs. The opportunity for automatic reinstatement to income and health benefits in the event of termination would also provide a safety net for PHAs who otherwise would not consider labour force participation.

These and other flexible disability supports are available in some jurisdictions and are successful at supporting PHAs in employment situations.<sup>7</sup>

## Conclusion

While too few studies focus on the legislative and public policy environment of labour force participation for PHAs, those that do suggest reforms to the existing public policy framework are required.<sup>6</sup> The outcomes of such reforms may include long term cost savings for insurers, decreased costs for public income support programs, tax benefits and a decreased burden on public health and social service programs. Reforms would also benefit PHAs, by encouraging better health, higher quality of life, improved self-esteem and improved sense of well-being and belonging.<sup>8,9</sup>

This fact sheet is one in a series that is part of a larger discussion on enhancing the successful workforce participation of PHAs in Canada. Policy-makers, PHAs, front-line AIDS service organizations, and employers all have critical roles to play in building a labour force that contributes to a healthier, more diverse and, ultimately, more inclusive and productive society.

## Additional resources

“Navigating the Maze: Improving Coordination and Integration of Disability Income and Employment Policies and Programs for People living with HIV/AIDS — A Discussion Paper.” Canadian Working Group on HIV and Rehabilitation, 2008. Available on-line at [http://www.hivandrehab.ca/EN/information/people\\_HIV/income\\_security.php](http://www.hivandrehab.ca/EN/information/people_HIV/income_security.php).

“Income Security for people living with HIV/AIDS in Canada.” Canadian HIV/AIDS Legal Network, 2005. Available on-line at [www.aidslaw.ca/incomesecurity](http://www.aidslaw.ca/incomesecurity) > Publications.

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This fact sheet is based on a comprehensive review of the research literature on HIV and labour force participation, supplemented with interview and focus group consultations with PHAs, employers, insurers, and policy makers as part of the research project, “Development of a Conceptual Framework to Enhance Labour Force Participation Options for People Living with HIV in Canada.”

The study team was comprised of Catherine Worthington<sup>2</sup>, Kelly O’Brien<sup>3,4</sup>, Elisse Zack<sup>1</sup>, Melissa Popiel<sup>1</sup>, and Brent Oliver<sup>2</sup>. 1. Canadian Working Group on HIV and Rehabilitation (CWGHR); 2. Faculty of Social Work, University of Calgary; 3. School of Rehabilitation Science, McMaster University; 4. Department of Physical Therapy, University of Toronto.

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Prepared by:  
Leon Mar, Communications & Human Rights Consulting  
[leon@leonmar.ca](mailto:leon@leonmar.ca)

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