



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

Fact sheet for CBOs/ASOs

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 becoming or remaining employed. It also identifies facilitators that can help overcome these barriers, in an effort to help community-based organizations (CBOs), including AIDS service organizations (ASOs), to better understand the employment needs of their clients and to identify gaps in service provision and systems level action. 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. In developed countries, unemployment rates among PHAs are considerably higher than those among the general population despite the fact that many would prefer to be engaged in paid employment.<sup>1</sup>

Whether they are seeking to keep their current jobs or find new ones, PHAs face a dearth of information on the employment and workplace laws, policies and guidelines that may affect them. Additionally, the way in which these laws, policies and guidelines are written and applied has not caught up to the needs of PHAs.

## Why does work matter?

For most people — not just PHAs — employment is the main means of fulfilling the basic needs of modern life: money to obtain food and shelter, and insurance and health-care benefits to maintain a certain quality of life.<sup>2</sup>

Emotionally, employment can provide an increased sense of self-esteem, increased independence and social connectivity, and the opportunity to forge an identity based on one's career.<sup>3</sup>

Considering the ignorance and stigma that continues to surround HIV/AIDS — and the prejudice and discrimination that result — these fundamentals are often especially critical to PHAs.

## 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. (It should also be noted that although volunteering, education and any number of other activities are valuable activities, this fact sheet addresses employment as paid work.)

## What's the reality for people living with HIV/AIDS?

Regardless of where they fall in the employment continuum, PHAs may switch back and forth between employment and unemployment. HIV/AIDS belongs to a group of diseases called “episodic disabilities.” Episodic disabilities are characterized by periods of good health interrupted by periods of illness or disability.<sup>4</sup> As a result, many people with episodic disabilities (including multiple sclerosis, lupus, arthritis, cancer, diabetes and mental illness) must rely on health and disability benefits. To be successful in the workplace in the long-term, PHAs need accessible and comprehensive health and drug benefits.

For PHAs, difficulties related to physical and mental health issues can also limit or inhibit employment. Different emotional and psychological challenges associated with HIV infection — including depression experienced by some PHAs — may influence their emotional readiness for work, even when they appear physically able.<sup>5</sup>

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.

*“It’s clear that our policies and programs are geared toward long-term ... or permanent removal from the workforce. They are not geared towards episodic or short-term kind of things.”*  
*- Episodic Disability Service Provider*

## What are the key barriers and facilitators to employment?

### **Income security, insurance and benefits**

Income security programs include Employment Insurance (EI), sickness benefits, the Canada Pension Plan or Quebec Pension Plan (CPPD/RRQ) disability benefit, private long-term disability insurance, and provincial and territorial social assistance programs.

PHAs and AIDS service organizations (ASOs) frequently find such programs difficult to navigate. Sometimes, PHAs don’t even fit into the programs to begin with, leaving them — and the ASOs that try to help — 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>4</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.<sup>6</sup> It also raises the possibility that low wages would not provide a level of income comparable to that provided by social benefits.<sup>7</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>8</sup>

Employers and insurers should be urged to provide income supplement programs and health insurance and benefits plans that are easily understood, accessible, flexible and portable.<sup>2</sup>

### **Stigma, discrimination and disclosure**

Insensitivity towards people with disabilities is an obstacle to employment for many PHAs. This is made worse by the fact that PHAs may face deeper levels of prejudice and higher rates of discriminatory behaviour compared to individuals living with other health conditions.<sup>9</sup> Some PHAs are isolated by their co-workers and excluded from the social and professional opportunities afforded to their peers. Certain sub-groups of PHAs encounter homophobia and racism that harmfully influence workplace dynamics.

*“I found myself persona non grata. I was excluded from meetings. I wasn’t allowed to carry out my role. Essentially, I found a change in how my employer was treating me after disclosure of my status and my illness.”*

*- Person Living with HIV, employed*

Regardless of whether they have personally experienced discrimination in the workplace, the fear and anticipation of such incidents is common; this expectation can negatively influence PHAs’ decisions regarding employment in general and disclosure in particular.<sup>8</sup>

At the organizational level, more education is needed to dispel the myths and misinformation surrounding HIV/AIDS and to promote safer, better-informed, and more tolerant and respectful workplaces. At the individual level, PHAs would benefit from programs that provide them with the advocacy and leadership skills necessary to contribute to cultural change within their organizations.

ASOs have firsthand knowledge that could help employers to design, deliver and evaluate such programs, or to enhance the effectiveness of existing ones. ASOs are also well positioned to provide PHAs with support for disclosure to and assistance in communicating with employers.

## **Legislation, policies and guidelines**

Existing government policies and programs can be impediments for PHAs who are interested in working; many were designed around traditional forms of disability and may not adequately meet their needs or those of people living with other episodic disabilities.<sup>10</sup>

Better legislation — as well as better organizational policies and guidelines on the part of employers — to prohibit discrimination and protect PHAs who disclose their status is necessary. Measures must also be taken to address the gaps in public policy, such as research and public education on the participation of PHAs in the workforce.

## **Career services**

Although many ASOs provide PHAs with programs and services that may facilitate employment, very few of them receive dedicated resources to provide career services.

This leaves many PHAs to seek help from more general social-service organizations and employment agencies, many of which are inadequately prepared to address the specific needs of PHAs, or to evaluate the potential risks and benefits of employment. In the worst-case scenario, discriminatory attitudes and negative stereotypes about PHAs — including the belief that they are unemployable — can result in the dissemination of incorrect information and misleading advice.<sup>11</sup>

This general lack of access to quality career services for PHAs is exacerbated by a lack of coordination and information-sharing among the various service providers to which PHAs turn for social services, such as addictions counselling, child-care assistance, education programs and support groups.<sup>11</sup>

Providing PHAs with access to pre-employment training — job searching, resumé writing and interviewing skills, for example — without risking their eligibility for income support or disability benefits would serve as a crucial facilitator to employment. Such an approach would include the opportunity to assess individuals' emotional readiness for employment.

Improved knowledge sharing between ASOs and vocational and career-services agencies (for example, to give ASO staff better career coaching skills and to give vocational agency staff better insight into the specific needs of PHAs) would also improve the quality of services provided to PHAs.

## **Access to information**

Poor access to relevant and accurate information regarding job accommodation and employee rights is a significant barrier to employment for PHAs.

Specific and accessible information regarding workplace disclosure and support programs would help PHAs to make better-informed career decisions. Pre-employment awareness of and access to information regarding employers' policies and group insurance coverage would benefit PHAs who are considering a return to work or contemplating a job change, as would information regarding the legal workplace accommodation obligations of potential employers.<sup>2</sup>

Providing this sort of information would support PHAs who are anxious about employment or who are fearful of losing their existing disability supports and health care insurance.

## Conclusion

The issues outlined in this fact sheet are part of a larger discussion on enhancing the successful workforce participation of PHAs in Canada. Front-line AIDS service organizations, people living with HIV/AIDS, employers and policy-makers all have critical roles to play in reforming outdated schemes that overlook or ignore the challenges faced by PHAs, and in building workforces that contribute to a healthier, more diverse and, ultimately, more 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.

Persons With Disabilities Online: <http://www.pwd-nline.gc.ca/pwdh.4m.2@.jsp?lang=eng>

Job Accommodation Network: <http://askjan.org/>

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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.”

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For further information, contact the CWGHR at [info@hivandrehab.ca](mailto:info@hivandrehab.ca).  
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## References

1. Worthington C, Krentz HB. Socio-economic factors and health-related quality of life in adults living with HIV. *International Journal of STD and AIDS*. 2005;16(9):608-614.
2. Ferrier S, Lavis J. With health comes work? People living with HIV/AIDS consider returning to work. *AIDS Care: Psychological & Socio-Medical Aspects of AIDS/HIV*. Jun 2003;15(3):423-435.
3. Braveman B, Kielhofner G, Albrecht G, Helfrich C. Occupational identity, occupational competence and occupational settings (environment): Influences on return to work in men living with HIV/AIDS. *WORK: A Journal of Prevention, Assessment & Rehabilitation*. 2006;27(3):267-276.
4. Escovitz K, Donegan K. Providing effective employment supports for persons living with HIV: the KEEP project. *Journal of Vocational Rehabilitation*. 2005;22(2):105-114.
5. Conyers L, Boomer KB. Factors associated with disclosure of HIV/AIDS to employers among individuals who use job accommodations and those who do not. *Journal of Vocational Rehabilitation*. 2005;22(3):189-198.
6. Nixon S, Renwick R. Experiences of contemplating returning to work for people living with HIV/AIDS. *Qualitative Health Research*. Nov 2003;13(9):1272-1290.
7. Paul-Ward A, Braveman B, Kielhofner G, Levin M. Developing employment services for individuals with HIV/AIDS: participatory action strategies at work. *Journal of Vocational Rehabilitation*. 2005;22(2):85-93.
8. Brooks RA, Klosinski LE. Assisting persons living with HIV/AIDS to return to work: programmatic steps for AIDS service organizations. *AIDS Education and Prevention*. Jun 1999;11(3):212-223.
9. Conyers L, Rumrill Jr PD. A comparison of equal employment opportunity commission case resolution patterns of people with HIV/AIDS and other disabilities. *Journal of Vocational Rehabilitation*. 2005;22(3):171-178.
10. Maticka-Tyndale E, Adam BD, Cohen JJ. To work or not to work: combination therapies and HIV. *Qualitative Health Research*. Dec 2002;12(10):1353-1372.
11. Ciasullo E, Escovitz K. Positive futures: the need for paradigm shift in HIV/AIDS services. *Journal of Vocational Rehabilitation*. 2005;22(2):125-128.