



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

Fact sheet for Employers

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 workplace barriers that often hinder an employee living with HIV/AIDS from working to his or her full potential. It also identifies facilitators that can help overcome these barriers, in an effort to help employers to retain qualified, experienced staff, and build a healthy, diverse and productive workplace. 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

Human capital can be both an organization's greatest asset and its biggest expense. Whether your organization is large or small, recruiting and retaining the best workforce possible is fundamental to its success.

Many employers face significant and sometimes invisible recruitment and retention challenges with regard to PHAs — challenges that, when left unaddressed, have a negative impact on organizational culture, productivity, competitiveness and reputation.

Often, employers are unaware of such problems because HIV-positive employees choose not to disclose their HIV status, fearing a number of negative consequences, including being discriminated against, losing their benefits or even losing their job.<sup>1</sup> For employers who do know their workforce includes PHAs, ascertaining how to retain these valuable employees — and the expertise, experience and institutional memory they possess — often remains uncharted waters.

## HIV/AIDS, episodic disabilities and work

To better understand the needs of their HIV-positive employees and to identify gaps in organizational policies and guidelines, employers need to have a clear understanding of HIV/AIDS.

Given current medications, HIV/AIDS now belongs to a group of illnesses called “episodic disabilities.” Episodic disabilities — including multiple sclerosis, lupus, arthritis, diabetes, some forms of cancer and mental illness — are characterized by periods of good health interrupted by periods of illness or disability. These periods can be unpredictable and vary in severity and length from one person to another.

As a result, the levels of accommodation required to help people with episodic disabilities to sustain employment range from none to significant, with most cases falling somewhere in the moderate range. Despite their episodes of illness, many PHAs are willing and able to function successfully in the workplace.<sup>2</sup>

## Key barriers and facilitators

For people with episodic disabilities, common barriers to employment include difficulties related to medication (such as side effects, or medication scheduling) and a lack of flexible workplace policies and guidelines that acknowledge their physical and emotional realities.<sup>3,4</sup>

For HIV-positive employees in particular, ignorance and fear of HIV/AIDS by co-workers and managers remain among the biggest barriers to employment.<sup>5</sup>

In such cases, introducing or improving workplace support and education programs are examples of facilitators that could tackle the problems and, ultimately, contribute to more equitable, transparent and accountable workplaces.<sup>6</sup>

To do so successfully, leadership from the top is critical. Rather than pigeonholing such issues as the responsibility of one department — usually, human resources — issues should instead be integrated into organization-wide strategic planning. If the solutions are to benefit the entire organization, the entire organization should be made responsible for developing and implementing them — ideally with the full and direct participation of employees with episodic disabilities, including PHAs.

Below, we list five recommendations from the literature for employers to consider in addressing some of the most common barriers and facilitators.

- **Support respect and understanding in the workplace**

Insensitivity is an obstacle to employment for many people with episodic disabilities.<sup>7</sup> For PHAs, this is made worse by the fact that they generally face deeper levels of prejudice and higher rates of discriminatory behaviour in comparison to other disability groups.<sup>8</sup> Many 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.<sup>9</sup>

Regardless of whether PHAs have personally experienced discrimination in the workplace, the fear and anticipation of such incidents are common and can negatively affect a PHA's performance at work.<sup>10</sup>

At the organizational level, more education of management and staff is needed to dispel the myths and misinformation surrounding HIV/AIDS and to promote safer, better-informed and more respectful workplaces. Organizational policies and guidelines to prohibit discrimination and protect those who disclose their HIV-positive status are also necessary.

At the individual level, PHAs would benefit from training to provide them with the advocacy and leadership skills necessary to contribute to cultural change within their organizations. Such leadership training could eventually allow for peer-support programs directed at co-worker education and mentorship of new employees with episodic disabilities.

- **Consider a wide range of innovative ways to work**

Flexible work schedules, working remotely and job-sharing are just some examples of alternatives to traditional models of full-time employment that can facilitate improved employment options for and lead to better performance by people with episodic disabilities, including PHAs.

- **Improve access to relevant, accurate and comprehensible information**

Poor access to relevant and accurate information regarding confidentiality of employee records and reasonable job accommodation leaves many employees with episodic disabilities in the dark about existing workplace initiatives that could be of benefit to them.<sup>11</sup>

Specific and accessible information regarding workplace disclosure and support programs could help PHAs to make better-informed career decisions. Information regarding the legal workplace accommodation obligations of employers could also help both the employee (in terms of accessing relevant programs) and the employer (in terms of ensuring efficient and effective delivery of such programs, and accurate accountability reporting to government, where necessary).

- **Provide health insurance and benefits plans that are more accessible and flexible**

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.

Even when they appear physically able, different emotional and psychological challenges associated with HIV infection may negatively influence PHAs' emotional readiness for work. For example, depression experienced by some PHAs is often an invisible barrier — in some cases, a PHA's staff, peers and managers may not even know their colleague is living with HIV.<sup>12</sup>

For the PHA, having accessible and flexible benefits to address such invisible challenges could help to improve his/her overall performance in the workplace. Improved coordination among benefits programs and stable access to benefits could assist PHAs with the challenges associated with moving in and out of the workplace.

- **Engage with community-based organizations and social services**

Living successfully with HIV/AIDS imparts a unique combination of life management skills and abilities that are transferrable to the workplace. Employers should enable this skill development and knowledge transfer. For example, employers should engage not only with their HIV-positive employees, but also with the front-line AIDS service organizations (ASOs) that serve them. Many ASOs can provide up-to-date information resources on emerging issues related to HIV and employment; in some instances, they may also have public speakers who can provide insights on the needs of people living and working with HIV. Resources available from ASOs can help employers to reach out to HIV-positive employees.

## Conclusion

As employers pay increasing attention to socially responsible business practices, the opportunity exists to re-evaluate and address internal barriers and facilitators to employment for people with episodic disabilities such as HIV/AIDS. By addressing such issues, employers will benefit from a workforce that is more tolerant and appreciative of diversity, more flexible in its

approaches to both colleagues and clients, and more engaged and responsible to communities of which its people are a part — all of which are increasingly important to building an organization that can recruit and retain the best and brightest.

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

## Additional resources

“Persons with Disabilities Online.” Government of Canada. Available on-line at [www.pwd-online.gc.ca](http://www.pwd-online.gc.ca). Links to services and information commonly used by employers to support people with disabilities in the workplace are available on this website.

“Opportunities Fund for Persons with Disabilities.” Human Resources and Skills Development Canada. Available on-line at [www.hrsdc.gc.ca](http://www.hrsdc.gc.ca) > Disability Issues > Funding Programs > Opportunities Fund for Persons with Disabilities.

“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.”

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Funding for this study was provided by the Canadian Institutes of Health Research (CIHR). The opinions expressed in this publication are those of the authors and do not necessarily reflect the official views of CIHR.



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