

Canadian AIDS Society

HIV and Poverty Information Sheet Series

Info Sheet #4

LIVING WITH THE COST OF A DISABILITY

HIV AS A DISABILITY

During the 1990s, advances in treatment interrupted the quick progression of HIV and gave people living with HIV/AIDS (PLWHIV/AIDS) the chance to live longer, and sometimes healthier, lives. Unfortunately, in 2004 the treatment regimen is far from perfect. Highly Active Anti-Retroviral Therapy (HAART) is often accompanied by severe and disabling side effects (such as chronic nausea, diarrhea and pain) that force PLWHIV/AIDS to change their routines, schedules and priorities. The regimen requires adherence to a strict schedule of many pills throughout the day, and may be accompanied by multiple food restrictions. Undergoing HAART means undergoing a lifestyle change that will affect sleeping and eating patterns and influence daily tasks and schedules. HIV is a disability, and PLWHIV/AIDS are protected against discrimination based on HIV status by the Canadian Charter of Rights and Freedoms, the Canadian Human Rights Act and provincial Human Rights Codes.

HIV AS AN EPISODIC ILLNESS

For many people, living with HIV can mean living with recurring and unpredictable episodes of illness, followed by periods of health. The “episodic” nature of HIV makes it difficult to manage. With the advent of HAART and people living longer lives, many PLWHIV/AIDS face the need to regain control in their life and their place in society. However, this is not an easy task. Often, PLWHIV/AIDS must rebuild relationships, overcome stigma from loved ones or coworkers, and identify alternative ways to participate in society if they have left

Want to learn more about poverty and HIV?

Check out the other information sheets:

Info Sheet #1: The Link Between Poverty and HIV

Info Sheet #2: How is poverty identified in Canada?

Info Sheet #3: The Economics of Risk and Vulnerability

Info Sheet #4: Living with the Cost of a Disability

Info Sheet #5: HIV and the Downward Drift into Poverty

Info Sheet #6: What is the impact of poverty on the life of someone with HIV?

Info Sheet #7: Public Income and Health Related Benefits

work or changed careers. All this must be done while managing medication, unpredictable symptoms and the many other factors that are associated with a chronic illness.¹

HIV AND PAID EMPLOYMENT

There are three basic needs that must be met for employment to be an option to PLWHIV/AIDS.

- **Financial Need:** Employment must be *gainful*. Earnings and benefits from employment must meet the increased costs associated with HIV, including coverage for expensive medication.
- **Health Need:** Employment must be *flexible*. It has to accommodate the health problems and activity limitations associated with HIV and treatment regimens.
- **Psychological Need:** Employment must be *meaningful*. PLWHIV/AIDS, people living with disabilities and people living in poverty, should be able to access employment that fits their experience, skills and abilities, and provides opportunities for ongoing career development.

Stigma, Discrimination and Workforce Trends

Although discrimination based on HIV is illegal, it remains a barrier to adequate and meaningful employment. For PLWHIV/AIDS already in the workforce, disclosure of their status to an employer (accidental or otherwise) may have serious ramifications.² For some people, side effects from medication cause visible, physical symptoms such as lypodystrophy (the shifting of body fat to different areas of the body). PLWHIV/AIDS who are perceived by others to have these visible symptoms face an increased risk of stigmatization and labelling, and not being hired. If they are able to find employment, there is the risk of rumours circulating the workplace about their status. Discrimination, real or perceived, prevents many PLWHIV/AIDS from seeking support, negotiating alternative working conditions (such as flex time, shorter work weeks) or seeking alternative employment.

FAST FACTS
In a study conducted in 1998 among PLWHIV/AIDS in Canada, 50% of respondents who were working at the time had not disclosed their status, and 45% expected discrimination from their employer or co-worker. Among respondents who were not working, 65% would not reveal their HIV status to a future employer or co-worker because they feared discrimination.³

The workforce and labour trends are not supportive of people living with HIV. The type of employment that has been growing in Canada since 1990 is low-waged contracting or self-employment, and temporary work. For example, in 1996, 45% of those who were self-employed earned less than \$20,000 per year.⁴

When seeking employment, PLWHIV/AIDS not only face the physical barriers of their illness and the stigma from potential employers, but a labour market that does not even meet the financial needs of a person without an illness or disability.

Weighing Benefits and Risks of Working

Many organizations do not offer health, pharmacare or dental benefits. Narrative experiences from the HIV community indicate that organizations and companies cannot offer group insurance to PLWHIV/AIDS because the cost to the company would be excessive. Unfortunately, the cost of basic living due to the high cost of medication and assistive supports may be too expensive for the salary earned by many PLWHIV/AIDS. For these people, qualifying for public assistance programs is the only way that they can get these medical costs covered, even if the programs do not reflect the basic cost of living (i.e. rent and food). Those who are self-employed usually do not qualify for private programs due to their HIV status. Others who experience good health and/or adequate health insurance must evaluate how a leave from work will affect them financially.

When considering a permanent or temporary leave from work during illness (planned or unplanned), there are a number of fears that are experienced by PLWHIV/AIDS:

- Not qualifying for public income support and disability benefits
- Not being able to have their benefits reinstated if they leave work temporarily
- Benefit payers (i.e. insurance company) using lab data (CD4+ count) alone to justify revoking a benefit
- Being forced back to work due to unrealistic expectations by benefit payers
- Losing drug benefits
- Losing extended health care coverage
- Losing access to child care

The complexity of income support programs and the serious financial and health consequences of a decision to leave or return to work make this process extremely challenging. The level of technical knowledge and access to current information about all of these policies requires specialized expertise and training that exceeds the capacity of most Canadians. As a result, many AIDS Service Organization (ASOs) and Community Based Organizations (CBOs) are offering “Benefits Counselling”. A benefits counsellor is a staff member (or volunteer) who is trained and experienced with these policies. They work with clients to help them understand their options, and the risks and benefits of each decision.

A study conducted by the Canadian AIDS Society in 1998 identified the following challenges for PLWHIV/AIDS attempting to calculate the benefits and risks of returning to, or entering, the workforce:⁵

- A need to protect confidentiality when making inquiries and seeking information about different private and public support benefits (without risk of raising suspicions and prompting a review of their file).
- A need for assistance in balancing the different pros and cons, and to understand the financial implications of each option.
- A need for qualified, trained persons that have access to accurate and up to date information, to assist them in making decisions.

THE COMMUNITY'S STRUGGLE TO SUPPORT PLWHIV/AIDS

The ability of ASOs and service providers to offer this support is also a challenge, since they face a number of barriers:⁶

- A high level of expertise, training and/or experience is required for benefits counselling
- Liability for wrong information or advice they provide
- The complexity and variety of support programs require a high level of knowledge, resources and ongoing technical advice
- A lack of awareness and knowledge of HIV among administrators and staff working in the programs as well as in workplaces
- There is a need to advocate with existing insurance programs and build alliances with other disability groups to ensure they meet the needs of PLWHIV/AIDS and PWD. Unfortunately local organizations often do not have time, resources or expertise to do this.

The AIDS community has been experiencing a lack of adequate funding, and this has resulted in a lack of ability to support PLWHIV/AIDS experiencing, or at risk of, poverty.⁷ Narratives from members of the Canadian AIDS Society tell us that many ASOs have cut important positions within their organizations (such as education and volunteer coordinators), have reduced operational funding and in some cases, lost funding completely. Current funding structures promote short-term and unsustainable projects that require excessive administration and management requirements. High staff turnover and concern for the health of staff (stress, reduced salaries, health and pension plans) were also identified as major problems. While the need for services and overall AIDS awareness is increasing, organizations are overstretched, and some are considering reducing the scope of their mandate. These barriers are impeding the ability of the AIDS community to respond to the poverty experienced by its clients, and of others in the community at risk of infection.

EAST FACTS

A survey of 44 ASOs⁸ asked what services they provided to target the income-related needs of their clients:

- 71% provide benefits counselling, 30% provide benefits workshops, and 48% provide financial planning
- Only 16% provide emergency loans, but 68% of these provide non-repayable emergency funds
- 46% provide a food bank and 14% provide a community garden
- 18% provide workplace sensitivity/outreach and 18% provide work-related training to clients
- 68% provide support in finding housing
- 75% do advocacy to increase access to treatment
- 68% do general advocacy activities, while 82% advocate on behalf of their clients
- 86% provide support to clients filling out forms when applying for government programs, and 66% accompany their clients to appointments and appeals
- Only 56% indicated that the needs of their ASO were met, while 34% indicated that their needs were not met, or only slightly met.

When asked for reasons why their program needs were not met, 92% indicated that there was a lack of funding and 45% said there was not enough staff to run the program. 11% indicated that they could not respond to the demand that was generated by the inadequacy of government-based income programs.

Shared Concerns

There have been many calls for multi-sector collaborations and partnerships between community-based groups working in different fields. One area where this has been an increasingly successful endeavour is through alliances between the AIDS community and other illness and disability communities. Many of these individuals have shared concerns.⁹ Currently, CAS is also encouraging and supporting alliances with the anti-poverty movement in Canada, as both movements share a number of concerns. However, a lack of resources is not only experienced by the HIV community, but also by the anti-poverty and disability movements. A lack of operational funding and infrastructure in one community will impact on the ability of other communities to respond to the needs of shared clients and target populations. ASOs do not have the resources nor expertise to respond to all of the poverty and disability related needs of their clients, and need the support of other communities. Other communities cannot respond to all of the HIV prevention, care, treatment and support of their clients without the assistance of the AIDS community. All three communities must have the resources that they need to support their own clients, and to build meaningful, sustainable partnerships and collaborations with other organizations and agencies.

WHAT CAN I DO?

Community Based Organizations

- Pursue or expand partnerships, alliances and collaborations with organizations and community-based movements to include ASOs, anti-poverty organizations and organizations supporting people living with disabilities. Identify common issues, share knowledge and skills, and support each other's work.
- Make the income needs of PLWHIV/AIDS a priority within your own work, as well as within the work of government, research and community-based partners.
- Ensure that the voice and experience of PLWHIV/AIDS is reflected in all of your work related to income security.

Researchers

- Pursue or expand partnerships, alliances and collaborations with organizations and researchers to include ASOs, anti-poverty organizations and organizations supporting people living with disabilities. Identify common issues, share knowledge and skills, and support each other's work.
- Make the income needs of PLWHIV/AIDS a priority within your own work, as well as within the work of government, research and community-based partners.
- Ensure that the voice and experience of PLWHIV/AIDS is reflected in your work related to income security.

Policy Makers/Analysts/Government

- Pursue alliances with organizations and community based movements that work to end poverty and discrimination against economically marginalized individuals
- Make the income needs of PLWHIV/AIDS a priority within your own work, as well as within the work of government, research and community-based partners.
- Ensure that the voice and experience of PLWHIV/AIDS is reflected in work related to income security.
- Increase the resources to the anti-poverty and disability movements, supporting the infrastructure and operations of local, provincial, regional and national community based organizations.
- Provide financial resources to support partnerships between the AIDS, Disability and anti-poverty movements. A lack of human resources is one of the most significant barriers to meaningful and sustainable collaborations.

RESOURCE LIST:

Jim Zamprelli. (2004) *Providing Benefits Counselling To PLWHIV/AIDS: A Resource Guide and Train -the-Trainer Manual*. Ottawa: Canadian AIDS Society.
Document available for download www.cdn aids.ca

Proctor, Peggy (2002) *Looking Beyond the Silos: Disability Issues in HIV and other Lifelong Episodic Conditions*. Toronto: Canadian Working Group on HIV and Rehabilitation.
Document available for download www.hivandrehab.ca

Jim Zamprelli. (1998) *Force for Change: Labour Force Participation for People Living with HIV/AIDS*. Ottawa: Canadian AIDS Society.
Document available for download www.cdn aids.ca

Bacon, Jean. (2004) *HIV is Still at Work: Is your HIV policy up to date?* Ottawa: Canadian AIDS Society.
Document available for download www.cdn aids.ca

Canadian Charter of Rights and Freedoms. Department of Justice Canada.
Document available for download laws.justice.gc.ca/en/charter

The Canadian Human Rights Commission. www.chrc-ccdp.ca



- 1 Weir, Robin, Joan Crook & Christine Vanditelli-Chapman. (2003) *Unpredictable Episodes of Illness in the Experience of Persons Living with HIV/AIDS: A Qualitative Study* Toronto: Canadian Working Group on HIV and Rehabilitation.
- 2 De Bruyn, Theodore. (1998) *HIV/AIDS and Discrimination: A Discussion Paper*. The Canadian AIDS Society and the Canadian HIV/AIDS Legal Network.
- 3 Zamprelli, Jim. (1998) *Force for Change*. Ottawa: Canadian AIDS Society
- 4 De Wolff, Alice. (2000) "The face of Globalization: Women Working". *Canadian Woman Studies* 54-59
- 5 Zack, Elisse. (1998) *Benefits Counselling Issues for People Living with HIV and AIDS who are Considering Entering or Re-entering the Workforce: A report on current work on these issues and strategy for future work in Canadian AIDS Service Organizations*. Ottawa: Canadian AIDS Society
- 6 Ibid.
- 7 Martin Spigelman Research Associates. (2003) *Getting Ahead of the Epidemic: The Federal Government Role in the Canadian Strategy on HIV/AIDS 1998-2008* Report Prepared for Health Canada and the Five Year Review.
- 8 Survey was conducted in 2004 by the Canadian AIDS Society, as part of the Income Support Project, 2003-2006.
- 9 Proctor, Peggy. (2002) *Looking Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Conditions* Toronto: Canadian Working Group on HIV and Rehabilitation

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The Canadian AIDS Society (CAS) is a national coalition of more than 115 community-based AIDS organizations across Canada. CAS is dedicated to increasing the response to HIV/AIDS across all sectors of society, and to enriching the lives of people and communities living with HIV/AIDS.

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