

Canadian AIDS Society

HIV and Poverty Information Sheet Series

Info Sheet #5

HIV AND THE DOWNWARD DRIFT INTO POVERTY

WHAT ARE THE INCOME LEVELS AMONG PEOPLE LIVING WITH HIV IN CANADA?

Currently, there is no standardized way to identify the actual income levels of people living with HIV/AIDS (PLWHIV/AIDS) in Canada. Each research project and AIDS Service Organization (ASO) has its own method of collecting this information. There is no national database or mechanism that collects or stores this information, so there are no statistics that reflect the whole of Canada. So how do we know that poverty is a problem for PLWHIV/AIDS? The following is a snapshot of some of the data that has been collected in Canada by different research projects and ASOs. While it cannot be used to reflect national trends, or to generalize about a population, it does illustrate that PLWHIV/AIDS across Canada are living in poverty, and that HIV may be a key factor in their descent into poverty.

Longitudinal Projects

There is a collection of research projects in Canada, based on university-community partnerships, which collect information about income and employment as part of their demographic data. These projects are long-term research studies that track measurable indicators of risk. They tend to have a large number of participants (between 500-1200) and usually focus on a particular population in a single city, or partner with another project and compare data between cities.

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

Qualitative Research and Needs Assessments

Some studies focus on a much smaller number of participants (between 10-499) to explore how some factors, such as income, impact on their quality of life. These projects are usually conducted through interviews, focus groups and surveys, and are often used at the local level to build programs and deliver services. They may be conducted by university-based researchers through community-based research or needs assessments and program evaluation reports.

Intake Forms and Storytelling

Many ASOs collect information relating to income from new clients on their “intake forms.” These forms allow the organization to understand its clientele and direct programming to meet their needs. It is not collected by all ASOs, and it is usually marked as confidential information that cannot be shared outside of the organization. An ASO may choose to use this information when applying for funding of projects that address client poverty, or they may share and combine this data with other ASOs in their community for a stronger argument.

Experiential narratives and storytelling, while not statistically significant, is a very important part of understanding the relationship between HIV and poverty. Adding a voice to the statistics that are reported is essential. A personal description of living in poverty or applying to a particular income support program can illustrate some of the hidden ways that social and cultural values, bureaucracy, or law influence someone’s ability to secure their finances.

- Listen to people’s stories and write them down (with permission from the speaker) when recording incidents of discrimination.
- Record the date, time and name of the program administrator if there is a specific complaint about an interaction between a client and a government program.
- An opportunity for advocacy can be identified if more than one client experiences the same situation or has problems with the same individual.
- A written record is also an act of advocacy. It gives voice to an experience, so it is not silenced, forgotten or ignored by bureaucratic red tape, “objective” research and misdirected applications for funding.

National Surveys

There is only one known national survey that has been conducted with the goal of collecting information about income from PLWHIV/AIDS. The Canadian AIDS Society conducted the survey in 1998, with 9000 surveys distributed, and 1,400 completed and returned.¹

Among the respondents, 74% had a gross annual income of less than \$29,000, and 45% had less than \$12,000. This is very significant, considering the 1997 Statistics Canada LICO was \$16,565. A very large number of PLWHIV/AIDS reported living under the poverty line. Approximately 42% received income from public benefits, while only 11% received income from private insurance companies. Only 33% of respondents reported receiving income from wages, savings or salaries.

SO WHAT ARE THEY SAYING?

One New Brunswick study of PLWHIV/AIDS (57 participants) compared their levels of income at diagnosis with their current income levels². There was an increase in the number of households that received less than \$9,999 per year from the time they were diagnosed, from 10 households to 17 households.

- Among the low-income group, 47% indicated that there was a change in their financial status due to their HIV infection, and 27% of the high-income group indicated the same.
- Participants from the low-income group were more likely than the higher income group to describe themselves as too disabled to work (56% compared to 20%) or unemployed and looking for work (22% compared to 3%).
- Half of the high-income group were employed fulltime, while only 6% of the low-income group were fully employed.
- Low-income participants had a greater reliance on provincial social assistance than on income earned through employment. 67% of the low-income respondents relied on provincial social assistance, and 22% relied on CPP.
- When asked to evaluate the adequacy of their income, the low-income group was more likely to report a general or total inadequate financial situation (75% compared to 18%).
- Among the group experiencing financial instability, 20% were receiving CPP, and 20% were receiving EI – a testament to the inadequacy of these income programs to support PLWHIV/AIDS.

A 2002 study found that 50% of people living with HIV/AIDS in British Columbia are living in poverty (according to LICO calculations).³

These studies demonstrate that there is not only a need to support PLWHIV/AIDS in accessing financially adequate employment, but to also ensure that public income support programs are able to meet the needs of PLWHIV/AIDS and not put them at risk of poverty.⁴

WHAT CAN I DO?

Community Based Organizations

- Identify and use more tools to collect information about income and the experience of poverty by contacting a Community Based Research Technician in your area, or the Canadian AIDS Society for support.
- Increase the amount of information collected and recorded about what happens economically to PLWHIV/AIDS once they are diagnosed.
- Ensure that your organization has a human resource policy that addresses chronic illness, HIV and discrimination. Share this policy with partner organizations.

Researchers

- Increase the amount of research into what happens economically to PLWHIV/AIDS once they are diagnosed.
- Work with ASOs and PLWHIV/AIDS to identify what income-related research methods are acceptable and meet community standards for ethics. Consult with the community when developing ethics certificates, project designs and consent forms.
- Increase the amount of research on the barriers and facilitators to a healthy workplace environment, and on human resource policies.
- Make results from research more “user-friendly” and more easily accessed by CBOs.

Policy Makers/Analysts/Government

- Support and encourage research into what happens economically to PLWHIV/AIDS once they are diagnosed.
- Promote federal and provincial labour codes in ways that are culturally appropriate to different groups of people (taking into consideration literacy and education, culture, access to information technology and computers, etc).
- Work to include the inadequacy of the current labour market to meet the work and financial needs of Canadians (particularly those who live with an illness or disability, and those who are socially and economically marginalized) as a factor when evaluating eligibility for public income support programs, until the time that it does meet those needs.

RESOURCE LIST:

Jim Zamprelli. (1998) *Force for Change: Labour Force Participation for People Living with HIV/AIDS*. Ottawa: Canadian AIDS Society.

Document available for download www.cdnaids.ca

HIV Community-Based Research Networks <http://www.hiv-cbr.net>

Canadian Association for HIV Research <http://www.cahr-acrv.ca>



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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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Additional copies of this document may be obtained from:

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- 1 Zamprelli, Jim. (1998) *Force for Change: Labour Force Participation for People Living with HIV/AIDS* Ottawa: Canadian AIDS Society
 - 2 Olivier, Claude. (2001) Relationships Between Income Level and Healthcare, Social Well-Being and Mental Health Among Persons Living with HIV/AIDS. *Canadian Social Work. Special Issue 3* (1): 46-58.
 - 3 Gallo, Lisa. (September 1, 2004). *News Release – Almost 50 Per Cent of HIV-Positive British Columbians Living in Poverty*. Vancouver: BC Persons With AIDS Society.
 - 4 Olivier, Claude. (2001) Relationships Between Income Level and Healthcare, Social Well-Being and Mental Health Among Persons Living with HIV/AIDS. *Canadian Social Work. Special Issue 3* (1): 46-58.