Canadian AIDS Society

HIV and Poverty Information Sheet Series

Info Sheet #1

The Link Between Poverty and HIV

Since the last Canadian AIDS Society (CAS) Income Security project was completed in 1995, there have been notable changes to the Canadian social security system[1], to the number of new HIV infections[2], and to the distribution of HIV in the population[3]. Treatment regimens and disease management have also evolved, using Highly Active Anti-Retro-Viral Therapy (HAART). This therapy has succeeded in extending the life – and for many the quality of life – of numerous Canadians living with HIV. Meanwhile, infections have risen among men who have sex with men, heterosexual men and women, and Aboriginals.

In 1996 there were an estimated 40,000 people living with HIV/AIDS in Canada.[4]

In 2002 there were an estimated 56,000 people living with HIV/AIDS in Canada.

There are an estimated 5000 new infections every year.

Evidence suggests that poverty and economic insecurity play a key role in both HIV transmission and in the progression of the HIV disease. People living with HIV/AIDS, and community-based AIDS organizations, have conveyed to CAS that it is time to examine the relationship between HIV and income, and to integrate poverty prevention into the AIDS movement.

Want to learn more about poverty and HIV?
Check out the other information sheets:

The goals of these fact sheets are :

- **To illustrate why living in poverty is a key factor in causing Canadians to be vulnerable to HIV.**
- **To highlight the financial needs of people living with HIV and to identify the barriers they face when attempting to gain, maintain, or re-establish economic security.**
- **To demonstrate how living in poverty and economic insecurity negatively affects the health and quality of life of PLWHIV/AIDS**

How can you use these fact sheets?

Community Based Organizations (CBOs) and AIDS Service Organizations (ASOs)

- Use as evidence of need when seeking funds for programs and services that benefit clients living with HIV. Can also be cited in proposals and funding applications.
- Recognize that the poverty and income insecurity issues faced by people living with, and vulnerable to, HIV in one community are similar throughout Canada.
- Use to inform HIV prevention programs targeting people vulnerable to HIV infection due to their income difficulties.

Advocates and Policy Makers

- Recognize that poverty and income insecurity are human rights issues, and that they are barriers to the right of non-discrimination and the right to a high standard of health.
- Use when developing and/or evaluating disability policies and programs. These fact sheets illustrate many of the social and economic experiences that are shared by different disabilities and illnesses.

Researchers

- Use as a starting point for further research on the issues, and as a call to get involved in community-based research concerning people living with, and vulnerable to, HIV/AIDS.

- Provide ideas for researching poverty and the determinants of health, and how stigma and discrimination due to HIV/AIDS and poverty have health implications.
- Highlight community-based and qualitative research, and how it can reflect the life experiences of poverty and HIV.

Poverty is a Health Issue

Addressing poverty as part of the continuum of care and illness prevention is especially important for people living with, and vulnerable to, HIV. Poverty and income issues, as well as social and psychosocial issues, are raised when examining HIV transmission and epidemiology, treatment and disease management. When examining the evidence of the relationship between HIV and income, three trends are noticeable:

1. As a social determinant of health, living in poverty is a key factor causing Canadians to be vulnerable to HIV infection.
2. People diagnosed with HIV face many barriers when attempting to gain, maintain, or establish economic security.
3. PLWHIV/AIDS who experience poverty or economic insecurity are at risk of having their disease progress quickly, and of having a lower quality of life.

These fact sheets outline the relationship between HIV and poverty, and explore each of these trends. Understanding these trends will:

- Identify the economic structures that influence the transmission and progression of HIV, and its associated illnesses. This information can be used to advocate for a change to social and economic values and structures that perpetuate and promote poverty.
- Identify where resources need to be allocated for successful HIV prevention, care treatment and support. Canada needs an ongoing strong response to HIV that adequately addresses the unique financial needs of individuals and communities living with, and affected by, HIV.

Resource List

HIV and Poverty Position Statement. Approved by the Canadian AIDS Society's Board of Directors, September 2004.

Document available for download www.cdnaids.ca

1 Ross, David P., Katherine J. Scott & Peter J. Smith. (2000) *The Canadian Fact Book on Poverty.* Ottawa: Canadian Council on Social Development

2 *HIV/AIDS EPI Updates* (May 2004) Ottawa: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Health Canada

3 Ibid.

4 Ibid.

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Translation: Jean Dussault

Acknowledgements: Thank-you to the creative and passionate National Advisory Committee.

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Info Sheet #2

How is poverty identified in Canada?

Identifying and Measuring Poverty in Canada

There are many different methods to measure poverty. This is an important issue, since a measure that only looks at someone's ability to meet the basic needs for survival will result in policy and programs that target only those needs. Measures that include the amount of income and resources needed to fully participate in society will result in policy and programs that target and promote social inclusion.[1] Here are two examples of frequently used measures of poverty:

Low-Income Cut Offs

The Low-Income Cut Off (LICO) is the measure of income traditionally used by Statistics Canada. It is not strictly a measure of poverty, but a set of calculations that identify income "cut-offs" that indicate when a person's income is no longer able to meet their basic needs. The calculations, however, are criticised for being much lower than what is actually required to meet needs such as housing, food and transportation. Policy makers and researchers often use these measures as poverty lines, although Statistics Canada emphasises that they are not official measures of poverty.

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

The LICO lines are calculated every year, and are based on factors such as the estimated amount of income that a household spends on food, shelter and clothing, the number of family members in the household, and the size of the community.

LICOs measure "relative" poverty – how one person's level of income fits into a community, relative to the income of others around him or her.[2] Some community-based organizations and poverty rights groups challenge the LICO data that is produced by Statistics Canada. They claim that the extent and depth of poverty is not reflected in the statistics because key populations and regions are omitted from the calculations, such as Aboriginal reserves, prisons, the Yukon, Northwest Territories and Nunavut.[3] Alternatively, conservative thinkers and policy groups such as the Fraser Institute argue that the LICO data grossly overestimates the amount of poverty in Canada, suggesting that low-income seniors who own their own home and students (Canada's "future income elite") should not be identified as living in poverty.[4]

Market Basket Measure

The Market Basket Measure (MBM) is a relatively new approach being developed through a joint effort of federal, territorial, and provincial governments in response to the problems associated with the LICO measure. This strategy identifies a range of living costs/expenses for a family that go into a "basket", i.e. food, shelter and clothing. Each of these expenses has a price estimate, calculated by region. For example:

- Agriculture Canada's 'Nutritious Food Basket' calculates the cost of food
- Canadian Home and Mortgage Corporation calculates the cost of shelter
- Winnipeg Social Planning Council and Winnipeg Harvest calculate the cost of clothing (for all of Canada)[5]
- Household needs, transportation, telephone, recreation, school supplies, etc. are priced at 60% of the amount that is recommended for food and clothing
- Legally mandated expenses such as taxes, child support, alimony, as well as medical expenses for people with disabilities (PWD) are subtracted from a household's income

When used as a tool for measuring poverty, what remains of a household's income, after subtracting legally mandated expenses, determines whether or not a family is able to purchase the basket of necessities.[6]

The MBM is recognised by the National Council of Welfare as a "reasoned and reasonable definition of a minimum standard of living, with acceptable living standards based on acceptable methods".[7]

One of the challenges to this measure, however, is that the necessities included in the "basket" are based on political decisions. Some of the questions that have been asked include: Which goods and services will be included? What is the quality of these items? How often do these items get replaced? While the National Anti-Poverty Organization identifies a wide range of items to reflect the need to ensure financial independence and self-sufficiency, the Fraser Institute has a much more limited range of costs that should be included.[8]

How are measures of poverty used, and how do they affect programs, policies and advocacy?

In addition to the LICO and MBM measures, the Canadian Government, policy makers and researchers have a number of other standardized measures that are occasionally used. Many researchers also develop their own measures and criteria that reflect the focus of their research. Having a range of standardized and non-standardized measures makes it difficult to compare data, and in some cases can make it difficult to inform evidence-based decision-making.

It is important to the AIDS community to ensure that measures of poverty capture the financial consequences of living with HIV. Measures of poverty should not focus solely on statistical calculations, but incorporate personal experience and storytelling, to convey a voice and face of HIV. Any measure that is used should reflect the increased cost of living with HIV (treatment, supportive and medical devices, loss of employment) and the stigma and discrimination associated with HIV (loss of employment, reduced employment opportunities). The supports that many people living with HIV require to be fully integrated and involved in their communities according to the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) Principles should also be included. Statistical pictures alone risk creating a superficial overview of poverty among people living with HIV, and can overlook the personal agency of individuals.

There is a need to raise the profile of the relationship between HIV and poverty in a way that is responsible, and without labelling or stereotyping the people who live in poverty and who are at risk for HIV.

FAST FACTS

Percentage of persons in low-income/poverty using LICO[9]

	1990	1999
All persons	15.3% (4,181,000)	16.2% (4,886,000)
Under 18 years old	17.6% (1,195,000)	18.5% (1,298,000)
18-64 years old	13.4% (2,357,000)	15% (2,942,000)

According to Winnipeg Harvest, a food bank and advocacy organization, people with jobs are the fastest growing segment of their clients who depend on the organization for food.[10]

When examining the private income of individuals and excluding public income support, 1.6 million (21.9%) of Canadians of working age would be living in poverty. If the public income supports are calculated back in, 1.1 million (15.3%) families are living in poverty. This difference reveals how crucial public income supports are in preventing and reducing poverty.[11]

In 2003, welfare rates across Canada met neither the LICO nor the MBM poverty lines.

In 2003, people working for minimum wage everywhere but Quebec almost never reached the standards met by either measure.[12]

Why should the anti-poverty and disability communities be aware of HIV issues? Why should the AIDS community be aware of poverty and disability issues in Canada?

- Because HIV is a disability.
- Because living in poverty is a key factor in causing Canadians to be vulnerable to HIV infection
- Because people living with HIV are at risk of drifting into poverty
- Because poverty puts people living with HIV/AIDS at risk of rapid disease progression and poor quality of life
- Because many people living with HIV also live with other disabilities.
- Because many clients of AIDS Service Organizations (ASOs) are also clients of community based organizations (CBOs) that work to reduce and alleviate poverty and/or support people living with disabilities

Resource List

David P. Ross, Katherine J. Scott and Peter J. Smith. (2000) *The Canadian Fact Book on Poverty* Ottawa: Canadian Council on Social Development.

Publication available for download www.ccsd.ca

Understanding the 2000 Low Income Statistics Based on the Market Basket Measure. (2003) Ottawa: Applied Research Branch, Strategic Policy, Human Resources Development Canada.

Publication available for download www.sdc.gc.ca

Market Basket Measure Overview National Anti-Poverty Organization.

Publication available for download www.napo-onap.ca

Andrew Mitchell, Richard Shillington and Hindia Mohamoud. (2003) *A New Measure of Poverty.* Ottawa: Social Planning Council of Ottawa.

Publication available for download www.spcottawa.on.ca

WHAT CAN I DO?

Community Based Organizations (CBOs)

- Work with staff, volunteers, clients, and Board of Directors to identify how poverty and HIV is experienced in your community/among your clientele (i.e. finding a definition of *basic needs, social inclusion* and *quality of life* that meets your needs), and what barriers it poses to individuals and families.
- Identify ways to collect and preserve this information (i.e. intake forms, workshops, discussion groups, storytelling, writing down personal stories and experiences).
- Raise these issues when participating in research projects or providing input on government policies and programs.
- Examine the measures of poverty that are used when provided with information about income and poverty in your community, to gauge whether or not it is able to capture the experience of your community.

Researchers

- Work with CBOs to identify a range of ways to collect information about poverty and income.
- Include CBOs, through participatory action research, when planning research projects and include their issues in your research initiatives.
- Consult with CBOs to ensure that their experiences are reflected when developing and working with measures of poverty.
- Examine the measures of poverty that are traditionally used in your field to ensure that it captures current definitions of *basic needs, social inclusion* and *quality of life* that are accepted by the community.
- Confer with CBOs when using or developing a measure of poverty and ensure that it can capture the experience of their community.

Policy Makers/Analysts

- Examine the measures of poverty that are traditionally used to inform your policies and programs to ensure that it captures current and relevant definitions of *basic needs*, *social inclusion* and *quality of life*.
- Consult with CBOs when using or developing a measure of poverty to ensure that it can capture the experience of their community.

1 Mitchell, Andrew, Richard Shillington and Hindia Mohamoud. A New Measure of Poverty. Social Planning Council of Ottawa, Ottawa: 2003.

2 Ross, David P., Katherine J. Scott & Peter J. Smith. (2000) *The Canadian Fact Book on Poverty.* Ottawa: Canadian Council on Social Development

3 Morris, Marika. (2002) *Women and Poverty Fact Sheet* Ottawa: Canadian Research Institute for the Advancement of Women.

4 Sarlo, Christopher A. (1996) *Poverty in Canada* (2nd ed).Vancouver: The Fraser Institute

5 Ross, David P., Katherine J. Scott & Peter J. Smith. (2000) *The Canadian Fact Book on Poverty.* Ottawa: Canadian Council on Social Development

6 Ibid.

7 *Income for Living?* (2004) Ottawa: National Council of Welfare, Government of Canada

8 Mitchell, Andrew & the Community Social Planning Council of Toronto. (May 2000) *The Market Basket Measure – Update.* Toronto: Social Planning Network of Ontario.

9 *Percentage and Number of Persons in Low Income/Poverty by Age, Sex and Family Characteristics, Canada, 1990 & 1999.* (2002) Ottawa: Canadian Council on Social Development.

10 *The Minimum Wage Should be Increased-Fact Sheet.* Just Income Coalition. www.just-income.ca

11 Ross, David P., Katherine J. Scott & Peter J. Smith. (2000) *The Canadian Fact Book on Poverty.* Ottawa: Canadian Council on Social Development

12 *Income for Living?* (2004) Ottawa: National Council of Welfare, Government of Canada

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Info Sheet #3

The Economics of Risk and Vulnerability

Risk and Vulnerability

When attempting to understand how HIV is transmitted within a community, understanding the concepts of risk, vulnerability and impact can be a useful approach.[1]

RISK: Risk refers to the factors that create a direct opportunity for HIV transmission. This includes sharing needles, not using condoms during sexual activity, and mother-to-child transmission. Risk factors are those that can expose someone to HIV infection.

VULNERABILITY: Vulnerability is the combination of social factors that lead to risk. It also can be used to explain why some groups of people are exposed to higher risks than others. The list of social factors that create vulnerability are the *determinants of health*. One specific factor in this list of determinants that includes issues relating to poverty is *Income and the Economic Environment*, (sometimes called *Income and Social Status*).[2]

IMPACT: Impact explains how HIV/AIDS affects the physical, mental and social well-being of individuals, and how individuals and communities experience the disease.

Living in poverty limits choice options to attain economic security which may increase individuals risk of HIV infection. The social consequences and economic constraints of living in poverty include exclusion, stigma, marginalisation, inability to meet living

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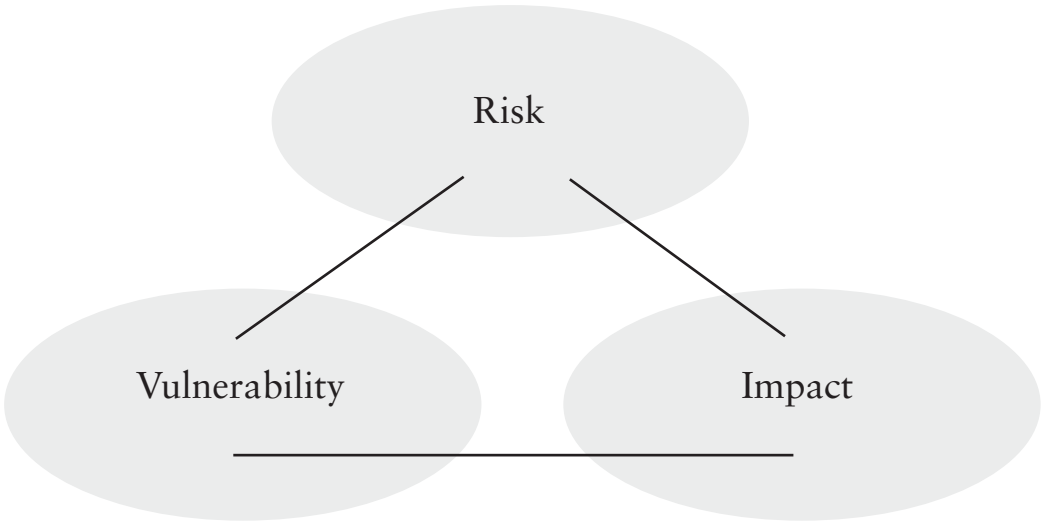
Info Sheet #7: Public Income and Health Related Benefits

needs or to participate in the community, etc. These consequences limit the options and choices that individuals have in attaining economic security and a decent or adequate standard of living. Many people who live in poverty experience economic and social exclusion, including:

- A lack of respectable, non-judgemental, responsive services
- A lack of housing, shelter, transportation and clothing
- A lack of nutritious food
- A lack of access to preventative health care, medical treatment and medication
- A lack of childcare
- A lack of opportunities for adequately paying employment
- A lack of access to adequate education and training
- A forced dependence on abusive partners and family

Studies that show that people with low incomes are more likely than those with higher incomes to be exposed to the risk of HIV infection due to their increased vulnerability.[3] So what causes this vulnerability?



Social and Economic Exclusion

Many people who experience poverty often become excluded and marginalized from different areas of social, economic and community life.[4] Social exclusion can refer to the ways that individuals are excluded from employment, a secure income, adequate housing, educational opportunities, health, citizenship, and integration in the local community. Social exclusion can also be the result of additional stigma and marginalization associated with other factors such as gender, ethnicity, low-education, occupation, etc.[5]

Many of the processes that lead to social exclusion are economically/financially based. For example:[6]

- Changes in the economy of a community (e.g. increasing unemployment and job insecurity)
- Demographic changes in a community (e.g. an increasing number of single-parent households and elderly persons)
- Cuts and reforms to social assistance programs that exclude certain individuals and groups (e.g. caregivers or people with certain types of illness/disability)
- Stigmatization and marginalization of groups or communities that lead to the segregation of minorities (based on ethnicity, substance use, type of employment or source of income, gender, age, etc.)

Some of the ways that social exclusion is manifested include:[7]

- Legal exclusion – many individuals do not have access to the same legal rights as others (e.g. people who do sex work, who are homeless, or who have problems with substance use)
- Failure of governments, programs and services to provide basic needs/social goods (e.g. physical supports for the people with disabilities, language services, preventative medical treatment and housing for people who are homeless)
- Exclusion from social production/contribution to society (e.g. the systematic arrest of street-involved youth or the tendency to not accommodate people with disabilities)
- Economic exclusion (e.g. not allowing an individual access to a bank account because of a lack of permanent housing, or restricting people on welfare from accumulating savings)

The implications of social and economic exclusion are serious, since the longer a person lives in poverty, the less likely it will be that they will ever exit that poverty. The people less likely to exit poverty are more likely to experience social and economic exclusion. These individuals include:

- Single parents
- Persons with disabilities
- Persons in a visible minority group
- Recent immigrants
- Persons who are single
- Persons with lower levels of education

FAST FACTS

- **One in five women are living in poverty in Canada (approximately 2.8 million), and make up the majority of the people living in poverty in Canada.**
- **Of single parent families, 56% of women-headed families are living in poverty (while 24% of male-headed families are living in poverty).**
- **49% of women over 65 who are single, widowed and divorced live in poverty, as do 41% of single women under 65.**
- **Aboriginal women have an average annual income of $13,300 (compared to $18,200 for Aboriginal men).[8]**
- **While 19% of all women in Canada experience poverty, 37% of women who are visible minorities experience low incomes. These women earn an average of $3000 less per year than women who are not visible minorities, and $7,000 less than men who are.**
- **Some data show that 42% of women over 65 and who are lesbian live in poverty, while only 14% of men who are gay have low incomes.**
- **Among all aboriginals living off a reserve, 44% live in poverty, while 47% of aboriginals living on a reserve have less than $10,000 annual income[9].**

Mapping Poverty and HIV through Research

The shift from a Health Promotion framework to a Population Health Framework in Canadian Health Policy has allowed more focus on the social determinants of health. It has also increased concentration on the mid- and long-term effects of these determinants, and has encouraged relationships between sectors, communities and groups. One of the challenges of this shift, however, is that the focus on evidence-based, quantitative decision-making renders it difficult to portray trends and experiences that cannot be captured with statistics.[10] It is also important to recognise the validity of qualitative research, as well as the role of community-based expertise to inform immediate action when there is a lack of long-term research studies tracking measurable indicators.[11] Some researchers in Canada have noted that it is difficult to conduct research on poverty and HIV because income is so closely connected to other determinants of health such as social support, education and literacy, gender, etc.[12] The lack of an adequate measure of poverty was explicitly identified as a barrier to making income and poverty based research a priority. This could be an explanation for why there is very little data on this relationship in Canada.

Resource List:

Richard Wilkinson and Michael Marmot. *Social Determinants of Health: The Solid Facts* 2nd Editon. Denmark: World Health Organization

Document available for download: http://www.who.dk/document/e81384.pdf

Ottawa Charter for Health Promotion (1986) Ottawa: World Health Organization, Health and Welfare Canada, and the Canadian Public Health Association.

Document available for download: http://www.hc-sc.gc.ca/hppb/phdd/pdf/charter.pdf

What is the Population Health Approach? Population Health Approach, Health Canada.

Document available for download: http://www.hc-sc.gc.ca/hppb/phdd/

Martin Spigelman Research Associates (2002) *HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action*. Ottawa: Ministerial Council on HIV/AIDS, Government of Canada.

Document available for download: http://www.hc-sc.gc.ca/hppb/hiv_aids/can_strat/ministerial/discussion_paper /

Lia DePauw. (2004) *Behind the Pandemic: Uncovering the Links Between Social Inequity and HIV/AIDS*. USC Canada, AIDS Vancouver and the Interagency Coaliton on AIDS and Development.

Document available for download: http://www.aidsvancouver.org/pdf/usc-behindthepandemic.pdf

What Can I do?

Community Based Organizations

- Work with staff, clients, and Board of Directors to identify the *economic* factors that increase the vulnerability of your clients to high-risk activities.
- Build alliances with other organizations working in HIV, disability and/or poverty in your community to identify which *economic* factors are being experienced across different communities and client groups.
- Integrate strategies to acknowledge and respond to the *economic* factors that increase vulnerability to HIV infection as part of HIV prevention campaigns.
- Examine where stigma and bias may be reflected in your programs and service delivery.
- Examine where your programs and services supports an individual's autonomy over their financial decision-making, and identify ways to make a shift to allow clients more control over the financial services that they can access within your organization.
- Put poverty and HIV on your research agenda. Ethical community-based research that reveals the complex relationship between poverty and HIV will help create tools, initiatives and policies that contribute to the prevention, care, treatment and support of HIV.

Researchers

- Increase collection of quantitative and qualitative data on income and social status as it relates to the prevention of HIV.
- Validate the use of qualitative data, community-based research and experiential narratives when conducting research.
- Increase the participation of CBOs in research projects.
- Examine where stigma and bias may be reflected in your research.
- Put poverty and HIV on your research agenda. Ethical community-based research that reveals the complex relationship between poverty and HIV will help create tools, initiatives and policies that contribute to the prevention, care, treatment and support of HIV.

Policy Makers/Analysts/Government

- Validate the use of qualitative data, community-based research and experiential narratives when making evidence-based policy and programs.
- Integrate strategies to acknowledge and respond to the economic factors that increase vulnerability to HIV infection as part of HIV prevention campaigns.
- Examine where stigma and bias may be reflected in your programs and service delivery.
- Examine where your programs and services supports an individual's autonomy over their financial decision-making, and identify ways to make a shift to allow clients more control over the financial services that they can access.
- Put poverty and HIV on your research agenda. Ethical community-based research that reveals the complex relationship between poverty and HIV will help create tools, initiatives and policies that contribute to the prevention, care, treatment and support of HIV.
- Resources need to be available to the different stakeholders working in HIV, poverty prevention and social integration. This includes:
    - Community Based Organizations and AIDS Service Organizations
    - University- and community-based research initiatives that advance knowledge of poverty and HIV
    - Medical and health disciplines
    - Government programs that target the elimination of poverty

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1 DePauw, Lia. (2004) *Behind the Pandemic: Uncovering the Links Between Social Inequity and HIV/AIDS.* USC Canada, AIDS Vancouver and the Interagency Coaliton on AIDS and Development.

2 Federal, Provincial and Territorial Advisory Committee on Population Health. (1999) *Towards a Healthy Future: Second Report on the Health of Canadians* (1999) Ottawa: Minister of Public Works and Government Services Canada

3 Martin Spiegelman Research Associates. (2002) *HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action.*

4 Shaw, Mary, Danny Dorling & George Davey Smith. (1999) *Determinants of Health*, Michael Marmot and Richard G. Wilkinson eds. New York: Oxford University Press

5 Ibid.

6 Ibid.

7 Ibid.

8 Ibid.

9 Morris, Marika. (2002) *Women and Poverty Fact Sheet* Ottawa: Canadian Research Institute for the Advancement of Women.

10 Ryan, Bill. (2000) *Framing Gay Men's Health in a Population Health Discourse*. Saskatoon: Gay and Lesbian Health Services of Saskatoon

11 Wong, Chris. (1997) *Paradigms Lost: Examining the impact of a shift from health promotion to population health on HIV/AIDS policy and programs in Canada.* Ottawa: Canadian AIDS Society.

12 Chapman, Ainsley and Nichole Downer. (2004) Survey conducted with Canadian HIV Researchers. Ottawa: Canadian AIDS Society.

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?
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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.

FAST FACTS

A survey of 44 ASOs[8] 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.cdnaids.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.cdnaids.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.cdnaids.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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Acknowledgements: Thank-you to the creative and passionate National Advisory Committee.

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:

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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.

FAST FACTS

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 levels[2]. 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 demonstrates 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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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.

Canadian AIDS Society

HIV and Poverty Information Sheet Series

Info Sheet #6

What is the impact of poverty on the life of someone with HIV?

A Decrease in Quality of Life

"Quality of life" has a range of definitions and measures, each to describe the personal feelings that someone has towards their life. This is an important measure since the quality of life that a person with HIV/AIDS experiences is directly related to their degree of poverty.

Quality of life has been defined as "the degree to which a person enjoys the important possibilities of his/her life in three broad domains – being, belonging and becoming".[1] Quality of life is how much a person can take part in, and enjoy, a range of life experiences. This can include life experiences relating to one's physical, psychological and spiritual being. Someone who has a high quality of life is able to enjoy his or her physical body, psychological state and spirituality. An individual's quality of life also depends on how he or she is able to enjoy and experience activities that help fulfill his/her personal goals, hopes and wishes. One of the most important components to a high quality of life and well-being is how someone "belongs" or fits into his/her environment. PLWHIV/AIDS not only have the physical limitations that impact how positively or negatively they experience their life, but stigma and discrimination compounds these limitations. Illness and disability can be supported when there are a range of employment options, secure income, and a supportive network of family, friends and community members. The experience of illness and disability become much more difficult when stigma and discrimination reduce or eliminate these supports.

In a study of women living with HIV in British Columbia (110 participants), 30% reported incomes of less than $10,000, and 21% reported an income between $10,000 and $19,000.[2] The impact of economic instability on this particular group of women illustrates how poverty plays a large role in the psychosocial stressors that diminish a person's quality of life.

Want to learn more about poverty and HIV?
Check out the other information sheets:

For example, from a list of fourteen potential psychosocial stressors that were experienced "quite often or most of the time", six were directly related to poverty or a lack of economic security. The number one stressor, reported by 61% of the participants, was "not having enough money". Among the other income related stressors that the participants experienced,

- 40% were concerned about insufficient money for medications and therapies
- 38% were concerned about the lack of affordable housing
- 34% were concerned about the lack of transportation
- 24% feared losing their job *(only 25% were employed)*
- 13% were concerned about inadequate childcare *(only 51% had children)*

A number of issues were indirectly associated with poverty. Many were the result of a lack of resources in the health system, which could cause financial problems for the women in the future:

- 52% feared rejection or discrimination
- 41% were concerned about her own health/medical problems
- 30% were concerned about dealing with illness in the family
- 29% were concerned about not having enough emotional support

Similar experiences were reported from a group of participants in a 1998 study of PLWHIV/AIDS in New Brunswick (57 participants)[3]. Among this group, 33% reported incomes of less than $14,999 (the Statistics Canada LICO for 1998), while 53% were in a higher income bracket of $15,000 or more. In this study, the most significant difference between the low-income group and the higher-income group was their quality of life and their experience of living with HIV.[4] Among a list of twenty-three problems and feelings, the low-income group identified all but three items on the list as something they experienced more frequently than the high-income group. The five items that were particularly significant were:

- Feelings of depression and hopelessness
- HIV-related discrimination
- Family tensions because of HIV/AIDS
- Alcohol or drug use
- Rejection by family or friends

Faster Disease Progression

Evidence suggests that living in poverty not only leads to a lower quality of life, but can also speed up progression of HIV infection. A study of men living with HIV in Canada found that those who lived in poverty became sicker and died more quickly. This is despite a universal health care system where individuals have access to diagnostic and emergency medical care, HIV specialists, and in this case, equal access to, and use of, HIV treatment.[5]

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.

Researchers

- Increase the amount of research into the relationship between HIV, quality of life and disease progression in Canada.
- 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.

Policy Makers/Analysts/Government

- Recognise that the health care system alone is not enough to create health in Canada.
- Include more discussions of the role of poverty as a key component of improving the health of Canadians, particularly those living with disability and illness.
- Develop strategies to address poverty as part of the continuum of public health care and illness prevention.
- The Canadian Government needs to show leadership and keep its commitment to the international conventions, declarations and commitments that it has signed as a member of the United Nations.
    - Declaration of Commitment on HIV/AIDS (2001)
    - International Guidelines on HIV/AIDS and Human Rights (1998) and Revised Guideline 6 (2002)
    - Universal Declaration of Human Rights (1948)
    - International Covenant on Economic, Social and Cultural Rights (1976)
    - International Covenant on the Rights of the Child (1989)
    - Declaration on the Rights of Disabled Persons (1975)
- The Canadian Government must commit to reducing economic disparities in Canada (absolute and relative poverty), and ensure that wealth in Canada is redistributed more equally.

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Translation: Jean Dussault

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1 Raphael, Dennis. (2001) "From Increasing Poverty to Societal Disintegration: How economic inequality affects the health of individuals and communities." In Pat Armstrong, Hugh Armstrong, and David Coburn.(Eds) *Unhealthy Times: Political Economy Perspectives on Health and Care.* Toronto: Oxford University Press

2 Kirkham, Colleen, and Daphne J. Lobb. The British Columbia Positive Women's Survey: a detailed profile of 110 HIV-infected women. *Canadian Medical Association Journal* 158(3):317-323.

3 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

4 Ibid.

5 Martin T. Schechter, Robert S. Hogg, Bruce Aylward, Kevin J.P. Craib, Thinh N. Le and Julio S.G. Montaner Higher Socioeconomic Status is associated with Slower Progression of HIV Infection Independent of Access to Health Care. Journal of Clinical Epidemiology. 47(1) 59-67 1994

Info Sheet #7

Public Income and Health-Related Benefits

Disability and Canada's Current Social Safety Net

Disability and its social and physical implications are seen though a variety of perspectives from different groups and communities (i.e. people with disabilities, advocacy groups, medical practitioners, the general public).[1] How disability is perceived will affect how it is defined, how programs are developed, and how programs decide eligibility. The different components of Canada's social safety net reflect different attitudes and ways of understanding disability. This can influence the goals, definitions and eligibility criteria of these groups. These perspectives, however, do not necessarily match those that are promoted by the community sector and advocates of people with disabilities or people living with HIV/AIDS (PLWHIV/AIDS).

Defining Disability

Understanding how disability has been defined sheds some light onto why the current income system exists the way it does, and how community organizations can advocate for change. Here are three ways to look at disability[2]:

Impairment Perspective

This medical model identifies disability as a health problem. It has been criticized for emphasizing the physical or mental "defect," and is used to support arguments that

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

a person with a disability is abnormal or inferior. Until 2001, this approach was promoted by the World Health Organization, and has influenced many models of care and support.

Functional Limitation Perspective[3]

This perspective attempts to expand the medical model to include the social and physical environment. It measures disability by the number of limitations, or restrictions, a person has against what is considered standard for humans. Some limitations include those that restrict the ability to fulfill a social role, such as lifting and carrying a child.

Social and Human Rights Perspective

This perspective views disability not as a disability itself, but how it negatively impacts on someone's interaction with their social or physical environment (such as work, home or school). Definitions that fit into this perspective tend to see a person's disability as a result of his/her environment not being able to adapt to his/her needs. Disability is seen as a social concept and reflects society's inability to account for, and adapt to, these needs. The human rights model views someone living with a disability as a human being who, because of his or her medical condition are not being given the same legal and social rights as others. The current definition of the WHO International Classification of Function, Disability and Health (ICF) illustrates this perspective, however it has only been in existence since May 2001.

How does HIV fit into models and definitions of disability?

The model increasingly adopted by both the medical and rehabilitation communities, as well as PLWHIV/AIDS and community-based organizations, is the ICF model. The team or multi-sector approach to understanding HIV as a disability incorporates a person's physical health and their social environment.

The community-based AIDS movement in Canada also promotes the human rights model of disability and HIV. This approach recognizes that PLWHIV/AIDS are a social group that are stigmatized, marginalized and discriminated against because of their disability. One way that this approach deals with the social consequences of having HIV is to focus on the Canadian Charter of Rights and Freedoms.

Federal Income Support Programs for People With Disabilities

The Federal, Territorial, Provincial and Municipal governments provide different types of benefits. Each program has its own goal and mandate, and may (or may not) be coordinated to work in conjunction with other programs. They can be broken down into three primary types of benefits:

1. **Cash-based payments and monthly allowances:** Payments are provided either monthly or bi-weekly, and are usually intended for food, housing and living expenses. While they may include vouchers, they are usually cash based and how they are spent are up to the recipient's discretion. The amount is usually calculated by using a general formula that is developed by the host program, and often does not reflect the unique social and financial circumstances of each individual.

2. **Tax Relief:** Some programs provide monthly, quarterly or annual cash-back on tax that has been paid, while others allow a range of tax deductions for qualified individuals.

3. **Assistance Programs:** These programs provide loans and other resources to help sustain vocational training, supported living and health benefits, and housing supports to improve basic living conditions.

What about Provincial and Private Programs?

Each province has its own set of programs that work in conjunction with what is offered at the federal level. Provincial programs and services may also include cash-based "allowance" programs targeting people with low-incomes and disabilities, as well as financial resources to pay for rehabilitative and medical supports, assisted living, some forms of complementary and alternative therapy, as well as pharmacare.

Some people have access to private programs (sometimes called Long-Term Disability programs) through a group insurance plan, or a private plan subscribed to before they were diagnosed. These plans also provide varying amounts of cash-based allowances and health-related benefits. Most private plans, and some provincial programs, consider federal programs like Canada Pension Plan (Disability) and the National Child Tax Benefit as the "first-payer". This means that these plans will often "clawback" or deduct a partial or whole amount of what is paid by the federal government when calculating a claimant's entitlement to benefits. As a result, many claimants will receive a smaller provincial benefit when it is combined with the other sources of income.

With all of these income supports, why are people living with HIV still living in poverty?

Canada's income support system/social safety net appears to be plagued by a number of problems that prevent many PLWHIV/AIDS from accessing income support programs. Since each program has its own legislative and administrative policies, each one will have elements that are more flexible and progressive as well as those that are more rigid and problematic. However, there are trends to the flaws and shortcomings of each program. Some of the problems regularly faced by people living with HIV, and other episodic illnesses, when attempting to access income support programs are discussed below.

Accessibility

One example of the problems PLWHIV/AIDS have in accessing social programs is their dependency on the level of knowledge held by the program administrator. Administrators that are aware of the details of programs, and have knowledge of HIV, seem to be capable and willing to match the needs of the client with the corresponding benefits.[4] Access to knowledgeable staff is not guaranteed however, as there still remains a large portion of the population that lacks even basic information about HIV. Stigma and discrimination remain a reality for many Canadians.

Another challenge that has been identified with public income support programs is the fact that there is no standard or consistently used definition of "disability" and corresponding eligibility criteria across the various programs and government departments. While someone's illness or level of disability may qualify them for one program, it does not guarantee them access to another program, even if both programs target people living with disabilities. Community-based organizations have made recommendations that these definitions be more closely aligned, both to increase the ease in applying for benefits, and to expand eligibility.[5]

A report produced by the Government of Canada in 2003 attempted to identify the barriers that it faces in unifying definitions of disability.[6] They argue that a single definition may not be possible or desirable, as each program has created eligibility criteria that meets a unique goal and targets a specific population. A single definition, and streamlined eligibility, would require changing the goals and functions of programs. The reality, from the perspective of the Canadian AIDS Society, is that moving towards unified definitions and eligibility would result in a significant increase in the number of qualified applicants who could benefit from each program, allowing PLWHIV/AIDS access to many supports that they are currently denied. This would be a positive shift.

Adequacy

Taking into account the increased cost of living with a disability such as HIV, these programs are unlikely to meet the physical, psychological, social and economic consequences of the illness. For many programs, the amount of money that is paid to a recipient has not increased – or has only increased marginally in the last five to fifteen years – and does not reflect the increased cost of living. The current purchasing power of these benefits has dropped. Furthermore, programs tend to contribute to the marginalization and stigmatization of people with disabilities by promoting a "victim" stereotype instead of responding to the fact that each person is autonomous with his or her individual needs and capacities.[7] There has been some movement by poverty and disability advocacy groups to move the system towards individualized funding policies[8].

Individualized Funding: A system of delivering services that supports self-determination by providing funds directly to individuals or families so that they can identify the services and supports they need and choose where and how they obtain those services and supports[9].

B.C. Association for Community Living

The guiding principles of individualized funding[10]:

1. **People with developmental disabilities and their families have a right to choose individualized funding as a way to meet their needs for services and supports and to achieve greater self-determination.**
2. **It is the public's collective responsibility to provide the services and supports needed by people with developmental disabilities to participate fully in community life.**
3. **Individualized funding is simply a mechanism for disbursing public funds, not a way for the government to relinquish public responsibility for supports and services, and to pass it on to the private sector.**
4. **Individualized funding must be based on the reasonable assumption that recipients are trustworthy and negotiating for funding in good faith.**

Individualized funding (and planning supports) must be flexible and responsive to the culture, values and preferences of each person and their family.

Administration

This is one of the most perplexing and challenging aspects of income support programs. HIV is among a collection of disabling illnesses that are "episodic". Unfortunately, the social safety net is not equipped to deal with episodic illnesses as a disability.[11] PLWHIV/AIDS feel the brunt of this through a variety of problems found in the ways that programs are administered, including[12]:

- Policies and regulations that are inconsistently applied by each worker, office and region
- Administrators who have judgmental attitudes towards youth, street involved youth, substance users and ethnic minorities
- Administrators who have a lack of knowledge about HIV and related issues

People living with HIV/AIDS and other episodic illnesses experience many of the same physical, social and economic consequences as someone who lives with a disability most or all of the time. The difference, however, is that they are not treated equally by these programs.

The Government of Canada has also indicated that there are challenges with the administration of programs[13]:

- Medical personnel have reported that they have difficulty filling out forms and understanding the different eligibility criteria. They also have difficulty trying to assess the type and severity of their patient's disability.
- The forms and assessment processes do not effectively measure the disabilities associated with mental illness.
- There is a need to clarify program eligibility requirements both to staff and to clients.

Policy, Legislation and Administration

When a federal or provincial government builds an income replacement program it creates an "Act," or statute, that becomes legally binding once it has been passed by its governing body (such as a provincial legislature). This Act outlines the legal obligations of the government and the users of the program. The government department responsible for implementing this Act develops a set of policies that describes how the Act is to be implemented. Departmental staff use these policies to make decisions about who qualifies for the program and how much they are eligible to

receive. The staff, or "administrators" become the front-line contact with the applicants and administer the policies. Anecdotal evidence from people who live with HIV, and from benefits counsellors, suggests that somehow, what is written in the legislation or Act does not always correspond with how it is implemented. People who appear to be legally entitled to a program do not qualify, or must go through an appeal before they can access their benefits. Currently, no one can be exactly sure why this might happen. Some of the reasons might include:

- Not enough staff employed by programs to adequately manage the caseload of applicants
- Too many staff responsible for a single applicant/client, and details about an application are lost or overlooked
- Staff may have stigma and negative attitudes towards people who live in poverty or who live with a disability/HIV, and do not try to find ways to help them
- Policies may be poorly written and difficult for staff to understand clearly
- Policies may be written in a way that reflects stigma and negative attitudes towards people who live in poverty or who live with a disability/HIV
- Staff may not be properly trained on how to read and implement the policies, or the training may reflect stigma

Between 2005-2006, CAS will be speaking with PLWHIV/AIDS, benefits counsellors and program administrators/staff about how policies are implemented across Canada. The results of this research will be available to the public, to PLWHIV/AIDS and to benefits counsellors. It will also inform a Canada-wide advocacy strategy to create transparent and fair implementations of income support programs.

How can public income support programs improve?

While hundreds of recommendations have been made over the last decade on specific ways to make programs more flexible, inclusive and relevant, a few have targeted the underlying philosophy and structure of the social safety net. For example:[14]

- Replace the "charity" approach to social security with a human rights model, and end the marginalization and stigmatization of clients.
- Replace the medical model with a holistic approach to disability that takes into account the social, psychological, developmental and physical needs of clients.

- Replace the cause-based system of eligibility (the cause of the disability) with an inclusive definition established on the actual needs of clients.

Another strategy that has been suggested by advocacy groups (B.C. Association for Community Living, B.C. Coalition of PWD, Canadian Mental Health Association, B.C. Division) is to replace the fragmented and unequal system with a National Disability Income Plan[15]. This income tested, Canada-wide plan would be cost-shared with provincial/territorial governments. It would:

> Establish minimum levels of income security (perhaps linked to the poverty line in each region) and a "cost of disability" supplement to cover the additional expenses of disability – housing, transportation, personal support services, technical devices, medication and so on.[16]

Other features the current delivery system requires include:

- Independent planning
- Choice in services and flexibility
- Control over how supports and services are provided
- Portability (to maintain eligibility and access to benefits if relocation within a province or between provinces occurs)

Until there is room for the full integration of marginalized populations, with PLWHIV/AIDS and other disabilities included in the labour force, the Canadian government must recognize the social and financial consequences of living with a disability in Canada. Individuals are punished by discrimination in the workforce, and again by income security programs that exclude them for not being able to find employment that meets their health and financial needs.

WHAT OTHER SUPPORTS ARE NEEDED TO ENSURE INCOME SECURITY, INDEPENDENT LIVING AND QUALITY OF LIFE?

Direct income support (cash) is only one component to ensure that PLWHIV/AIDS have the resources they need to manage their illness and remain active in their lives. While Canada is proud to have a public health care system, we have seen how a variety of services and programs that are integral to the health of individuals are not available. Access to HIV and other medical specialists and innovative hospital-based technology does little to support someone with a chronic illness if prevention and medicine is not available. There is a need for basic health-related benefits that cover the cost of treatment (i.e. medical procedures and preventative measures) that are not

covered in Canada's health care system. For example, pharmacare, dental and vision care, physiotherapy, complementary and alternative therapy, occupational therapy, home care, and assistive devices are provincially administered. Each province has its own regulations, policies and programs that are inconsistent across the country. Coverage for some medications and other health products and services are provided only to those who fit a narrow definition of "need". Childcare and safe, accessible housing are also central to building and maintaining health, however they are rarely included in discussions about illness prevention and healthcare.

Resource List:

For more information on Federal programs, departments and relevant application forms, visit the Canada Benefits Website: www.CanadaBenefits.gc.ca

Defining Disability: A Complex Issue. (2003) Gatineau, Quebec: Office for Disability Issues, Human Resources Development Canada.

Document available for download: http://www.sdc.gc.ca/en/hip/odi/documents/Definitions/Definitions.pdf

Office of the United Nations High Commissioner for Human Rights http://www.ohchr.org/

International Law, Conventions, Declarations and other Instruments found in General Assembly Resolutions (since 1946): http://www.ohchr.org/english/law/index.htm

Janet Freedman and Marie Howes. (2003) *Hit by an Iceberg: Coping with Disability in Mid Career*. Victoria: Trafford Publishing.

What Can I Do?

Community Based Organizations

- Identify who are allies/advocates in your community for the poverty and income issues that you and your clients are facing. Build relationships with them and keep them informed/updated about your issues.
- Identify who can address issues at the provincial, territorial and/or national level and keep them informed/updated about your issues.
- Work to ensure that your programs and policies reflect the 2001 World Health Organization's definition of disability and activity limitation, and that they reflect a human rights approach to disability. Approach organizations that can help you.
- Promote the value of volunteer and non-paid work (including activism) as valuable contributions to society.

Researchers

- Work to ensure that your research reflects the 2001 World Health Organization's definition of disability and activity limitation, and that they reflect a human rights approach to disability.
- Increase the involvement of community-based organizations in the planning and implementation of your research projects.
- Increase the amount of available research on the consequences of reforms to social assistance and the problems associated with public income support programs.
- Increase the amount of research into how poverty and economic marginalization affects HIV prevention, care, treatment and support, and use this research for policy change.

Policy Makers/Analysts/Government

- Efforts must be made by the federal, provincial, territorial and municipal governments to provide adequate resources to programs, services and community-based organizations that work towards the prevention of poverty for all people who live in Canada, particularly for people living with illness, disability and/or who are socially and economically marginalized. This is particularly crucial

given the need for increased compensation to community-based organizations working in poverty prevention and alleviation, that have incurred increased pressure on resources due to government "downloading."

- Federal, provincial, territorial and municipal governments must ensure that there are adequate resources provided to AIDS Service Organizations and community-based organizations. These organizations have been increasing their caseloads to respond to the increasing number of PLWHIV/AIDS, and many of them experience concurrent disabilities and consequently more complex financial and social situations, without an increase in financial resources.
- Federal, provincial, territorial and municipal governments must increase their efforts to better coordinate and partner between each other's cash, tax relief, housing, medical and social service support programs.
- Ensure that programs and policies reflect the 2001 World Health Organization's definition of disability and activity limitation, and reflect a human rights approach to disability.
- Ensure that government-based income and health benefit programs adopt a consistent definition of disability (the WHO definition), not just to make the application process easier, but to also expand eligibility.
- Work towards significantly increasing rates of income support benefits across all programs, including those that are not directly targeting people living with disabilities.
- Work to shift income support programs towards an "Individualized Funding" model that empowers individuals to make choices about how their money is spent, what health care services are accessed, and by whom these services are provided.
- Work towards establishing a minimum level of standards that include access to information, level of service and amount of benefit that all government-based programs should meet, regardless of where they are administered.
- Work towards increasing financial and non-financial resources, and support to family and non-family caregivers, for persons living with disabilities and chronic/episodic illnesses.
- Increase the involvement of community-based organizations in the planning of government based policies and programs.

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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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