Canadian AIDS Society

HIV and Poverty Information Sheet Series

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

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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.

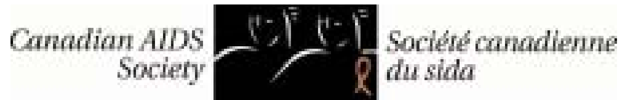
- Work towards significantly increasing rates of income support benefits across all programs, including those that are not directly targeting people living with disabilities.

- 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.



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

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

3 Sometimes called the Ecological Perspective.

4 SP Research Associates. (1991) *"We have no time to waste fighting…" Meeting the Income Support Needs of Persons Living with HIV and AIDS* Ottawa: National Welfare Grants Division, National Health and Welfare Canada

5 Chapman, Ainsley. (2003) *HIV and Disability Policy: Evaluating the Disability Tax Credit and Medical Expense Tax Credit* Ottawa: Canadian AIDS Society

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

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9 Ibid.

10 Ibid.

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12 Gilmour, J.M. and D.L. Martin. (2001) *Women's Poverty, Women's Health: The role of access to justice* Toronto: Osgood Hall Law School, York University

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

14 Thomas, Hilda.(1994) Breaking Down the Barriers: A Paper on Disability Issues as the Pertain to the Proposed Reform of Canada's Social Security System. B.C. Association for Community Living.

15 Ibid.

16 Ibid.

The HIV and Poverty Information Sheet Series is published by the Canadian AIDS Society. This project is funded by the Government of Canada's Social Development Partnerships Program. The opinions and interpretations in this publication are those of the author and do not necessarily reflect those of the Government of Canada.

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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Translation: Jean Dussault

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

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