

## Support for survival:

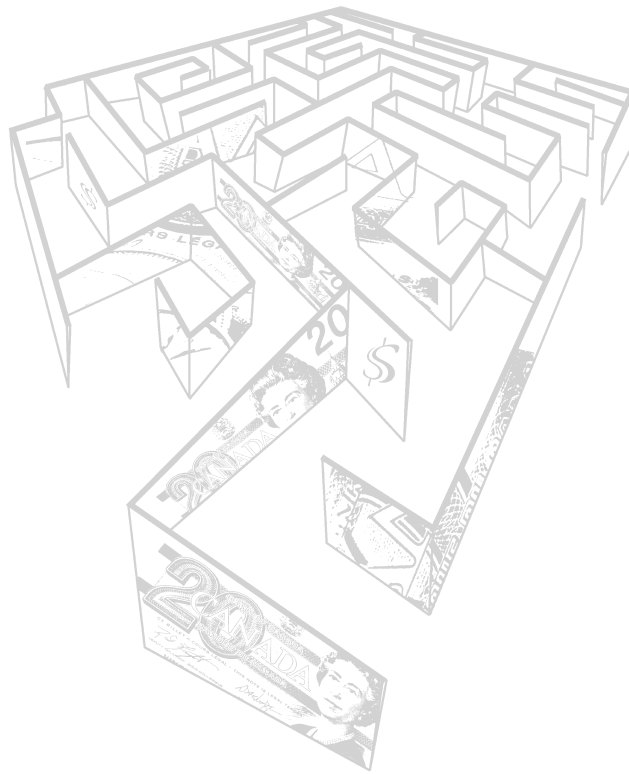
barriers to income security for people living with HIV/AIDS and directions for reform



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### **Authorship Note**

Glenn Betteridge wrote the final version of this report. Abigail Dubiniecki wrote the draft report, parts of which have been retained in this final report. Harry Beatty contributed to the report, including some of the principles and recommendations for reform that appear in the final section. Harry Beatty dedicates his work to the memory of Pat Worth – friend, colleague, advocate, and inspirational leader. This report was reviewed and edited by Richard Elliott of the Canadian HIV/AIDS Legal Network.

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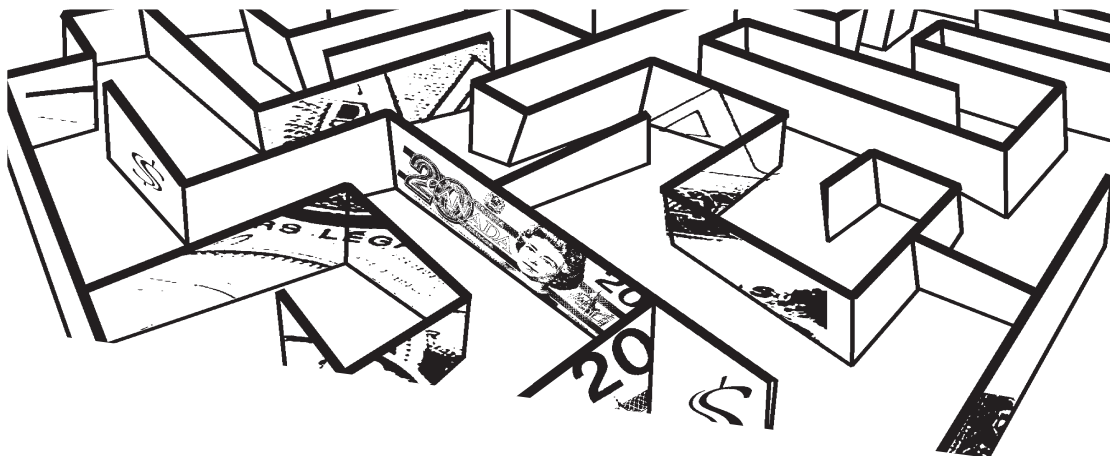


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# Executive summary

## Background

Many people experience HIV infection as an episodic disability – characterized by alternating periods of good and poor health. For people living with HIV/AIDS income is intimately tied to health. Due to significant improvements in HIV treatment since the mid-1990's many people with HIV in high-income countries are now able to live longer and experience a better quality of life. While a welcome development, this has created new issues. Maintaining an adequate level of income and access to health-related benefits, whether through employment or disability income programs, is a significant challenge for many people living with HIV/AIDS and other lifelong, episodic disabilities. Fluctuations in health can lead to fluctuations in income, and vice versa, resulting in a downward spiral for many people as their HIV infection progresses over time.

Discrimination in employment against people living with HIV/AIDS persists despite governments' human rights obligations, under both Canadian and international law, to take action against it. Discrimination and lack of accommodation for the disability-related needs of people living with HIV/AIDS makes it difficult or impossible for many to retain employment when their HIV infection results in poor health. Canada also has obligations under international human rights law to take steps towards the progressive realization of the right of everyone to work (which includes the right of everyone to the opportunity to gain a living by work which they freely choose or accept) and of the right of everyone to social security, including social insurance.

Many people living with HIV/AIDS in Canada rely on income security programs such as Employment Insurance (EI) sickness benefits, the Canada Pension Plan or Quebec Pension Plan (CPP/QPP) disability benefit, private long-term disability insurance (LTD), and provincial and territorial social assistance programs. While these programs do provide much-needed income and other benefits to people unable to participate in the workforce, some of their features also present barriers to income security for people living with HIV/AIDS.

Some of the barriers to income security faced by people living with HIV/AIDS are inherent in the individual benefit programs – both public and private. But many result from the existence of multiple programs to which people living with HIV/AIDS must apply in order to meet their needs for income (and other benefits), and the interaction and lack of coordination between and among those programs. As a result of so-called “coordination of benefits” clauses in private insurance policies and the obligation to seek other benefits under provincial/territorial social assistance programs, people are compelled to apply to programs which offer them few if any material benefits beyond what they are already receiving. Under each scheme the test for disability is different, different forms must be completed, and different adjudicators assess medical and other evidence. Despite the many different tests for disability, none adequately addresses the needs and circumstances of the many people living with HIV/AIDS and other episodic disabilities.

Benefits and programs that are intended to help people enter or re-enter the workforce are crucial to the long-term income security of people living with HIV/AIDS and those living with other episodic disabilities. Despite the fact that people may be able to work to some extent, and are permitted to do so under CPP/QPP, LTD and social assistance programs, many do not out of fear of losing benefits. In addition to lack of information and case management support, people considering working often face a range of different and potentially incompatible program rules. These disincentives to work result not only in a loss of potential income but a loss of the social interactions and sense of personal fulfillment that many people derive from work.

Access to extended health benefits, specifically prescription drug benefits, is crucial to the long-term health and survival of people living with HIV/AIDS. Some provinces offer extended health benefit programs to low income people who are not on social assistance and do not have private insurance benefits to cover such costs. However, in many provinces, people living with HIV/AIDS and other disabilities can only access such programs when they are eligible for social assistance.

People living with HIV/AIDS face “job-lock” because of the lack of portability of private insurance coverage, particularly LTD and extended health coverage. Elimination periods and pre-existing condition clauses in private insurance act as barriers to job mobility, career advancement, and greater income security. People receiving social assistance benefits may find themselves “locked” into a province, since moving from one jurisdiction to another involves reapplying for social assistance and may result in a decrease in benefits received in the short- and potentially the long-term.

Many people living with HIV/AIDS who receive disability benefits, public and private, struggle to meet their basic and health-related needs. In every province and territory, social assistance income benefits are below the poverty line and insufficient to meet the basic needs of people living with HIV/AIDS. The coordination of benefits – the process whereby a benefit from one source is deducted from a benefit from another – often results in the loss of much-needed income and undermines the objectives of programs intended to benefit people with disabilities and their children.



A fundamental rethinking and restructuring of disability income and related benefit programs is required over the next decade if these programs are to meet their objectives of providing appropriate supports and opportunities to persons living with HIV/AIDS and other episodic disabilities.

This report responds to a need identified by the membership of the Canadian HIV/AIDS Legal Network, governments, and other interested parties. When consulted, these individuals and organizations indicated that income security was an issue that has profound implications for people living with HIV/AIDS in Canada. The Legal Network conducted research on the issues involved, including legal and documentary research and consultation with key informants, and produced a draft report. A group was brought together for a two-day national workshop to provide feedback on the draft report.

The report focuses on benefits and barriers which typically will be of importance to persons living with HIV/AIDS and other episodic disabilities. It does not undertake a comprehensive review of all aspects of every disability income and benefits program in Canada as they affect all persons living with HIV/AIDS.

## **Objective and overview of this report**

With this report, the Canadian HIV/AIDS Legal Network seeks to contribute to the informed development of the laws, policies and programs people living with HIV/AIDS in Canada rely upon to provide them with income security when they are unable to meet their income needs through paid work. This goal is achieved in two ways.

- First, the report will build the capacity of people living with HIV/AIDS and people who provide services to them to advocate for improvements to income security programs. It does so by meeting the community's need for information about federal and provincial, and public and private income security programs, including the ways in which these programs, individually and in the interaction among them, result in barriers to income security for people living with HIV/AIDS.
- Second, the report makes recommendations for directions for reforms to the overall structure and approach of income security and related laws, policies and programs.

The first section of the report canvasses employment, health and rehabilitation issues affecting persons living with HIV/AIDS. This discussion provides background for the consideration of specific disability income programs which follows.

The next four sections address the four major disability income programs upon which persons living with HIV/AIDS often depend:

- the federal Employment Insurance sickness benefit;
- private long-term disability insurance;
- the Canada Pension Plan (and similar Quebec Pension Plan) disability benefit; and
- provincial/territorial social assistance benefits.

The importance of each program to persons living with HIV/AIDS and other disabilities will be discussed, together with the most significant barriers faced by people living with HIV/AIDS applying for and receiving benefits under these programs.

The sixth and final section lists principles that are central to income security reform for people living with HIV/AIDS, summarizes the barriers to income security, and makes recommendations for reform to existing federal, provincial/territorial, and private disability income programs.

Unlike previous network reports, the text of this report is not extensively referenced. Instead, at the end of each section selected bibliographic resources have been included. This is in keeping with the broad, overview approach of the report.

## **Recommendations**

The recommendations in this report respond to the barriers to income security faced by people living with HIV/AIDS when applying for and receiving benefits under income security programs, both public and private. Given the level of detail involved in the multiple programs at issue, and the need for coordination between various levels of government to improve the interaction between programs, the report sets out directions for comprehensive legislative and policy reform, rather than identifying specific changes to specific programs. If federal, provincial and territorial governments commit to undertaking this joint, collaborative effort at reforming and streamlining the various programs, it will be useful at that time to identify specific changes to specific programs that would enhance the income security of people living with HIV/AIDS and other episodic disabilities. In summary form, our analysis in this report leads us to put forward the following 15 recommendations:

### **Recommendation 1**

The Government of Canada should engage the 13 provincial and territorial governments, and the private insurance industry, in a process directed at significant reform of all laws and policies that deal with income support and benefits for persons with disabilities. This process should build on the work already being done under the Social Union Framework Agreement.

### **Recommendation 2**

The reform process should aim at a common and coordinated approach to laws and policies, without infringing on federal or provincial jurisdiction.

### **Recommendation 3**

The reform process should involve, in an ongoing, direct and meaningful way, the input of organizations representing persons with disabilities, including persons living with HIV/AIDS, in order to use their considerable expertise on these issues.

### **Recommendation 4**

Federal and provincial/territorial governments and the private insurance industry (through the Canadian Life and Health Insurance Association) should cooperate to establish a true single point of access for people living with HIV/AIDS and other disabilities in need of income support and extended health benefits in every province and territory.

**Recommendation 5**

The Public Health Agency of Canada should make long-term, sustainable funding available through the Federal Initiative on HIV/AIDS to community-based AIDS service organizations to hire and train benefits caseworkers, given that income is a key determinant of health for people living with HIV/AIDS.

**Recommendation 6**

The Public Health Agency of Canada should advocate for funding from the Department of Justice for legal services for people living with HIV/AIDS applying for, and in receipt of, benefits under public and private income security programs.

**Recommendation 7**

The reform process should work towards a test for disability that reflects the fact that people living with HIV/AIDS (and other lifelong episodic disabilities) have the capacity, yet also suffer from limitations on their ability, to function.

**Recommendation 8**

The reform process should work towards a test for disability that recognizes explicitly that a person may have a significant and legitimate need for disability-related income support despite the fact that they are capable at times of activities such as employment, study, community service, homemaking, caregiving and self-care. Ideally, the test should be the same in every jurisdiction and under every program; but at a minimum, there should be common or core elements that form part of every test.

**Recommendation 9**

The reform process should aim at coordinating eligibility determination to the greatest extent possible and should set reasonable timelines for rendering decisions under both public and private disability income support programs.

**Recommendation 10**

The reform process should seek to standardize extended health and disability support programs that will meet the essential needs of all persons with disabilities in Canada, including those living with HIV/AIDS, regardless of their province/territory of residence and regardless of whether they are eligible for social assistance. The process should build on existing provincial and territorial programs.

**Recommendation 11**

Specifically in relation to prescription drug coverage, the reform process should work towards a national catastrophic prescription drug plan. The federal and provincial/territorial governments should follow through in a timely manner on commitments made and actions undertaken in relation to catastrophic drug coverage under the First Ministers' Accord on Health Care Renewal.

**Recommendation 12**

Provincial governments should ensure through legislation the portability of private group insurance coverage. Specifically, people should be able to retain LTD and extended health benefits on reasonable and affordable terms for a reasonable period of time after an employment ends.

**Recommendation 13**

The reform process should work to better coordinate rehabilitation, vocational rehabilitation, and employment support programs offered to people living with disabilities through public and private programs.

**Recommendation 14**

The reform process should ensure that social assistance in every province and territory provides income benefits at an adequate level to enable persons with disabilities, including persons living with HIV/AIDS, to meet their essential needs for day-to-day living.

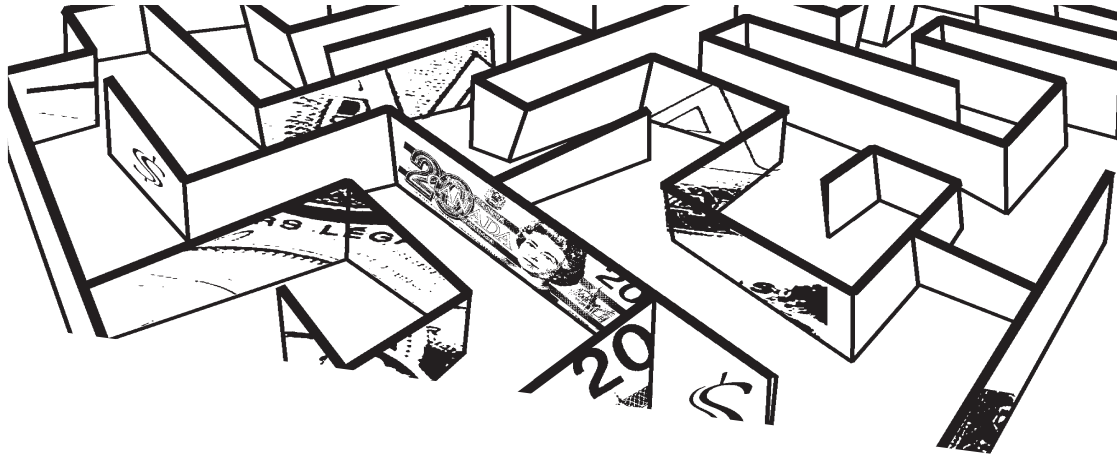
**Recommendation 15**

The reform should ensure that provincial and private insurance income support programs do not undermine federal programs through claw backs and deductions. Specifically, agreements leading to legislation should be put in place to preserve for intended beneficiaries the full value of benefits for children (National Child Benefit Supplement) and the children of disabled beneficiaries (CPP disabled contributors children's benefit), and the indexing of benefits..

**For Further Information**

Contact the Canadian HIV/AIDS Legal Network at [info@aidslaw.ca](mailto:info@aidslaw.ca); 416 595-1666.

Further copies of this report and the information sheets can be retrieved at the website of the Canadian HIV/AIDS Legal Network at [www.aidslaw.ca](http://www.aidslaw.ca), or ordered through the Canadian HIV/AIDS Information Centre, tel: 613 725-3434; fax: 613 725-1205; [www.aidssida.cpha.ca](http://www.aidssida.cpha.ca).



## Introduction and background

There are significant and well-established relationships between income (in)security and HIV/AIDS. Because of a variety of factors often associated with poverty, people living in poverty are often at significantly higher risk of HIV infection. For people who are infected with HIV, poverty is a major obstacle to accessing appropriate treatment, and those who are poor are at increased risk of HIV progression or other health problems. There are, of course, a number of other social and personal factors which contribute to both HIV infection rates and obstacles in accessing appropriate care, treatment and support – including gender inequality, racism, and other forms of stigma and discrimination, higher-risk sexual activity, and unsafe drug and alcohol use.

### HIV as a lifelong episodic disability

Over twenty years into the HIV/AIDS epidemic in Canada, advances in treatment are transforming HIV disease from a “terminal” condition into a lifelong, episodic illness for many people living with HIV/AIDS. With intensive health management and appropriate supports, people living with HIV/AIDS can now often expect to live for a longer time during which they will experience a better quality of life. Health Canada estimates that, as of the end of 2002, 56,000 people in Canada were living with HIV. Beginning in 1997, the annual number of infections has been relatively steady, with a low of 2,124 HIV-positive test reports in 2000 and high of 2,499 in 2002. However, during that same time period, Canada has seen a dramatic decrease in AIDS incidence and AIDS-related death. These statistical trends mean that the number of people living with HIV/AIDS in Canada is increasing each year, as the number of people who die from AIDS-related diseases is outstripped by the number of new infections.

While new classes and formulations of drug therapy have decreased hospitalization and mortality for people infected with HIV, they have brought with them serious, often disabling, side effects for some people. These side effects include gastrointestinal problems, lipodystrophy, hypercholesterolemia, risk of stroke and heart disease, diabetes and neurological diseases. Prolonged survival can mean higher levels of uncertainty for longer periods of time. Rather than experiencing the steady decline in health towards death

that characterized the first decade and a half of the epidemic in Canada, many people living with HIV/AIDS are now facing an uncertain life, a “roller coaster ride” in which the disabling effects of HIV, its treatment, and opportunistic infections are characterized by their unpredictability.

The three major characteristics of HIV/AIDS, and similar episodic disabilities, that create particularly challenging issues with respect to the major disability income programs and employment in Canada are:

- significant variations in disability and health status which affect the person's ability to work;
- high levels of health and other disability-related costs; and
- stigma and discrimination which can result in low labour-force participation.

According to the study *Unpredictable episodes of illness and the experiences of persons living with HIV/AIDS: a qualitative study* (Weir et al, 2003), living longer with HIV can mean dealing with impairments, activity limitations and restriction on participation in various social activities, ranging from moderate to debilitating. The purpose of that study, published by the Canadian Working Group on HIV and Rehabilitation (CWGHR), was to examine the reality of living with HIV/AIDS, particularly the unpredictable, episodic and fluctuating nature of the disease trajectory. People living with HIV/AIDS from across Canada participated in structured interviews and focus groups to explore their psychosocial processes over time. Most participants of the study (70%) had an HIV-positive diagnosis more than ten years prior to the advent of highly active antiretroviral therapy (HAART). Participants identified the unpredictability of the onset of illness or side effects from medication as a major source of uncertainty, often resulting in a struggle to maintain health while changing to a new medication regime. All participants identified challenges in maintaining normal participation in society, which required careful management of their personal resources (energy level, symptom control and emotional strength). Redefining self, after an HIV diagnosis, was another important issue identified in the study. Most participants said that depression was the greatest challenge encountered during the process of redefining themselves.

Many of the experiences of disability described by people living with HIV/AIDS in *Unpredictable episodes* are not unique to those with HIV/AIDS. That study was the second phase of a multi-pronged inquiry into the rehabilitation needs of people living with HIV/AIDS. The first part of the inquiry, *Looking beyond the silo: Disability issues in HIV and other lifelong episodic conditions* (Proctor, 2002), explored similarities between the experiences of people living with HIV-related disability and people living with other chronic, episodic and unpredictable illnesses. Service providers interviewed for *Looking beyond the silo* provided insight into psychological and psychiatric illnesses, multiple sclerosis, cancer, Crohn's Disease and colitis, arthritis, diabetes, cerebral palsy and other illnesses. In the report, the author developed a conceptual model based on a distinction between permanent and episodic disabilities that allowed her to identify the issues common to HIV/AIDS, permanent disabilities and episodic disabilities. Workplace and income support were identified as important issues for people with a range of disabilities. CWGHR believes that this common experience indicates that disability organizations can and should advocate together for changes in law and policy.

Changes in personal income often directly affect the health of people living with HIV/AIDS. For people living with HIV/AIDS, optimizing quality of life and independence requires a strong commitment to strengthening the immune system with rest, good nutrition, expensive and complicated drug regimens, stress management, and, increasingly, rehabilitation. Rehabilitation in the context of HIV disease involves a broad range of interdisciplinary services delivered by health care and social service professionals, including physiotherapy, social work, vocational rehabilitation, occupational therapy, psychotherapy, dietician services, complementary therapies, and others. People without a secure source of adequate income often must forego some or all of these valuable supports and services. Many aspects of treatment and maintenance of health for HIV/AIDS are expensive, and gaps in coverage for necessary services may require the person living with HIV/AIDS to choose between jeopardizing their financial position and jeopardizing their health.

## **Direct and indirect costs of HIV/AIDS**

In cost of illness (COI) studies, “direct costs” represent the value of resources used to treat the illness. “Indirect costs” represent the productivity losses (future income) of mortality and time away due to disability. Using a 1996 data set that indicated that there were 38,900 HIV-infected people in Canada, Albert and Williams estimated the annual direct costs of HIV to be \$570 million, while the annual cost per infected person was estimated at \$153,000. There are now an estimated 56,000 people living with HIV/AIDS in Canada. The direct costs of HIV disease are a “moving target” because of the steady development of new, often expensive, HIV medications and the costs of treating the side effects of such medications. In the past, funds were principally directed to hospitalization. Now, drug costs for people living with HIV/AIDS surpass hospitalization costs; at the same time, in some cases, funds spent on medications can mean avoiding hospitalization costs. Prescription drugs, including antiretroviral medications and medications used to prevent and treat other infections associated with HIV disease, can be extraordinarily expensive. Complementary therapies (such as vitamins, supplements, and massage therapy) are an important treatment source for people living with HIV/AIDS, including those who are asymptomatic. In 1997, 78.5 percent of people living with HIV/AIDS spent 10 to 20 percent of their income on complementary therapies. Direct costs of illness also extend beyond treatment to encompass other factors that impact health. Stable and adequate housing is essential to maintaining health for all people. Adequate nutrition is vital to slowing disease progression.

People infected or affected by HIV shoulder the burden of much of the direct costs of HIV disease. While lower rates of hospitalization are welcome, costs have shifted from government (through health care savings) to the individuals infected and affected by HIV (caregivers, AIDS service organizations, family members, partners, etc.). It is not surprising that most people with disabilities in Canada live in poverty.

While the direct costs of treating HIV are high, they have the potential to be offset by the increase in productivity of people living with HIV, thereby lowering the indirect costs (estimated based on the same data set to be \$600,000 per case, from diagnosis to death). The high indirect cost is partly attributed to the young age of those infected. In 1998, the



median age of HIV-positive people was 23. Albert and Williams noted that increased costs of treatment would be covered if they were to increase the period of productive life by as little as 15 percent, indicating that treatment for people living with HIV/AIDS is cost-effective. It is important to emphasize that therapy postpones, rather than prevents, the development of AIDS.

Income security programs have the potential to reduce the direct and indirect costs of HIV disease by providing adequate income support and employment flexibility to Canadians living with HIV disease. Increases to disability benefits and the improvement of return-to-work incentives and supports would likely be offset by reducing both the direct and indirect costs of HIV/AIDS. This would be a sound, long-term investment of public and private funds.

## **Relationship between HIV/AIDS and poverty**

Recent qualitative research concludes that “the long-term economic forecast for many people living with lifelong episodic illness is bleak.” Statistical evidence indicates that, in general, people with disabilities in Canada are poor. There is no reason to doubt that this is also the case of many people living with HIV/AIDS, based on qualitative research and anecdotal evidence.

The United Nations Committee on Economic, Social and Cultural Rights, in its 2001 *Statement on Poverty and the International Covenant on Economic, Social, and Cultural Rights*, defined poverty as “a human condition characterized by sustained or chronic deprivation of the resources, capabilities, choices, security, and power necessary for the enjoyment of an adequate standard of living and other civil, cultural, economic, political and social rights.” In a 2002 report commissioned by the Ministerial Council on HIV/AIDS, the expert body advising the federal Minister of Health on Canada’s response to the epidemic, Spigelman observes that “AIDS is the result and cause of poverty.” He quotes the US Center for Disease Control:

The links between poverty and HIV/AIDS are bi-directional. On the one hand, poverty contributes to vulnerability to HIV and exacerbates the impact of HIV/AIDS. On the other hand, the experience of HIV/AIDS by individuals, households and communities that are poor readily leads to an intensification of poverty. Thus, HIV/AIDS frequently impoverishes people in such a way as to intensify the epidemic itself.

Spigelman notes that people with lower incomes have a greater likelihood of being at risk for infection, contracting HIV, progressing to AIDS and dying from the disease than people with higher incomes. In an earlier literature review, Williams also found that income was a predictor of health outcomes, citing the positive association between socioeconomic status and survival time for people living with HIV/AIDS. The same correlation was shown for cancer patients.

Spigelman points out that income inequity is often a proxy for other factors, such as racism, gender inequality, and other forms of stigma and discrimination. HIV is most prevalent in marginalized and vulnerable communities. A 1999 Health Canada report highlights gender



as a factor influencing vulnerability to the disease, particularly among poor women. Women in violent relationships, prison, sex work, and those who use illicit substances are less likely to have health insurance, primary care physicians, and access to medical or social support. Prevalence is particularly high amongst women ages 16 – 24. HIV kills a disproportionate number of women and people of colour in high-income countries.

Inequities based on income, gender and race lead to social and economic exclusion, thus rendering certain populations more vulnerable to risk factors associated with HIV infection (substance use, non-consensual/survival sex, poor nutrition, stress, homelessness or inadequate housing), and to faster disease progression. In contrast, higher socioeconomic status is associated with slower disease progression. A 1997 study by Strathdee found that gay men with incomes below the poverty line were twice as likely as affluent gay men to die within ten years of contracting HIV.

The relationship between disease progression and increasing economic insecurity can be described as a downward drift. Those who are not poor prior to infection, often become poor as the disease progresses. This phenomenon is particularly prevalent among young people who have little or no workforce attachment, resources, or support. Nevertheless, even those previously “well-off” experience the downward drift into poverty.

## **Labour market participation of people living with HIV/AIDS**

People living with HIV/AIDS are much more likely to be unemployed than people in the general population. In the national survey of people living with HIV/AIDS conducted as research for *Force for Change* (1998), the Canadian AIDS Society found that only 38 percent of respondents were currently working, although virtually all respondents had been employed at some point in the past. This is similar to the employment situation for persons with disabilities generally in Canada, where employment levels are variously estimated as 30-40% lower than those of non-disabled persons.

While it is clear that persons living with HIV/AIDS, and with other disabilities, are much more likely to be unemployed than are non-disabled persons, determining the reasons for this is not a simple task. Some of the unemployment is attributable to inability to work because of the impact of the disability on health status and functioning levels. Some of the unemployment is attributable to the barriers to employment discussed next in this report. For many persons living with HIV/AIDS and other disabilities, unemployment results from a complex interaction of these factors. The individual is unable to get a job both because of health and functioning issues, and because employers will not provide appropriate accommodations, or because of other social and economic factors. People who identify themselves as “unable to work” or “unable to get a job” often could and would be working if the labour market in Canada were more accessible to them.

## **Barriers to employment faced by people living with HIV/AIDS**

### **Stigma and discrimination in employment**

Stigma refers to an unfavourable “mark” placed on a person or a group, and reflected in the attitudes, beliefs, and policies directed toward that person or group by others because of a perceived characteristic of the person or group. Stigmatization is a social process of devaluation. People devalue others or themselves because of some characteristic or characteristics they have or appear to have. Stigmatization is expressed in fear, avoidance, shame, blame, and judgment. The stigma associated with HIV/AIDS is complex. It draws on what people think and how they feel about an incurable virus, sickness, and death; about sexual activity and sexually transmitted disease; about homosexuality, sex work, drug use, gender, and race/ethnicity.

In 1997 and 1998, the Canadian AIDS Society conducted a national survey of over 400 people living with HIV/AIDS. Thirty-eight percent of respondents were working and 20 percent were looking for work. Of those who were working, 54 percent had not revealed their HIV status. When asked why they did not reveal their HIV status, the majority identified negative attitudes or fears from an employer or co-workers (56 percent) and discrimination from an employer or co-workers (45 percent). Of those who were looking for work, 57 percent said they would not reveal their HIV status.

There is also evidence from smaller studies that people living with HIV/AIDS have reason to be concerned about stigma and discrimination. A 2002 survey in Alberta found that, among 34 people living with HIV/AIDS, 29 percent had been treated unfairly by their employer or co-workers. Discrimination in employment can be subtle and people in temporary jobs are particularly vulnerable.

More recently, a 2003 survey by EKOS Research Associates entitled *HIV/AIDS – An Attitudinal Survey*, found that a quarter of the respondents had a low level of comfort in associating with people with HIV/AIDS and that forty percent had only a moderate level of comfort. Almost half of the respondents said that people with HIV/AIDS should not be allowed to serve the public as, for example, dentists or cooks. And while over three-quarters of respondents do not believe that people infected with HIV through sex or drug use have gotten what they deserve, one in ten Canadians still hold this view.

### **Employer’s duty to accommodate**

Accommodation means the steps that must be taken to permit a person with a disability to perform the essential duties of their job by removing the barriers – physical barriers, attitudes, and policies – that prevent this equal participation in the workplace. To work or continue working, some people living with HIV/AIDS may need accommodation of their disability – to manage episodic periods of fatigue and illness, to go for medical appointments, or to attend to their health in other ways. Examples of accommodation include flexible working hours, a change in shift, time off, or a switch to part-time work.

In the 1997-1998 CAS survey of people living with HIV/AIDS, those who were looking for work were asked about the benefits and accommodations they would like to have. They identified:

- no loss in financial or disability benefits (64 percent);
- reduced or flexible hours (63 percent);
- more understanding attitudes toward people living with HIV/AIDS (52 percent);
- extended sick leave (45 percent); and
- more time for medical appointments (45 percent).

The greatest concerns people expressed about returning to work were:

- losing disability benefits (70 percent);
- losing drug benefits (69 percent);
- losing extended health care coverage (59 percent);
- having time off for medical appointments without losing pay or job (51 percent); managing their treatment schedule or side effects in the workplace (51 percent); and
- disclosing their HIV status (51 percent).

Under the human rights law of every jurisdiction in Canada, people living with HIV/AIDS have a right to accommodation in the workplace. They need not disclose they have HIV/AIDS to obtain accommodation, although they may need to provide medical confirmation of their disability and the limitations it places on their ability to perform their job. According to human rights law in Canada, employers have a legal duty to accommodate the individual needs of employees with disabilities, including people living with HIV/AIDS, to the point of undue hardship. As summarized by the Ontario Human Rights Commission:

The Supreme Court of Canada has ruled that employers, unions and service providers have a legal duty to take reasonable steps to accommodate individual needs to the point of undue hardship. To substantiate a claim of undue hardship, an employer or service provider must show that they would experience more than a minor inconvenience. In many cases, accommodation measures are simple and affordable and do not create undue hardship. Undue hardship occurs if accommodation would create onerous conditions for an employer or service provider, for example, intolerable financial costs or serious disruption to business.

## **Obligations of government**

### **International human rights, HIV/AIDS and disability**

Under the *Universal Declaration of Human Rights* (Article 25), every person has the right to a standard of living adequate for their own health and well-being and that of their family, including food, clothing, housing, medical care and necessary social services, as well as the right to security in the event of unemployment, sickness, disability or other lack of livelihood in circumstances beyond their control. Inadequate income security obviously jeopardizes all of these requirements for well-being; poverty undermines the enjoyment of all other human rights.

Canada is also a party to the *International Covenant on Economic, Social, and Cultural Rights* (ICESCR). As a result, Canada has a legal obligation to take steps towards the progressive realization of the rights set out in the ICESCR. A number of rights are particularly relevant to the circumstances of people living with HIV/AIDS faced with the challenge of maintaining income security.

- Article 12 sets out the right to the “highest attainable standard of health”, which includes an “enabling environment” to secure this right.
- Article 6 recognizes the right to work, which includes the right of everyone to the opportunity to gain a living by work which is freely chosen or accepted.
- Article 9 sets out the right of everyone to social security, including social insurance.
- Article 11 recognizes the right of everyone to an adequate standard of living for himself and his family.

In 2000, the UN Committee on Economic, Social, and Cultural Rights, the expert body mandated to monitor and encourage States’ compliance with the obligations under the ICESCR, adopted General Comment 14, recognizing the interrelationship between health and other human rights including the right to work, food, housing, life, equality and privacy.

In June 2001, all 189 United Nations member states at the UN General Assembly Special Session (UNGASS) on HIV/AIDS adopted the *Declaration of Commitment on HIV/AIDS*. The Declaration represents a political commitment to a “practical blueprint for action” on HIV/AIDS related issues. Although not legally binding, it is a political-level endorsement of basic principles. The Declaration makes many references to the importance of addressing social determinants of health in order to combat the epidemic. Many of these are socioeconomic. The Declaration

- recognizes the impact of poverty on AIDS and vice versa (para 11);
- cites access to medication as a fundamental element of the realization of everyone’s right to attainment of the highest standard of living (para 15);
- notes that negative economic, social, cultural, political and legal factors hamper care, treatment and support efforts (para 21);
- recognizes that strong political leadership at the highest levels of government and the active promotion and protection of human rights helps contain the epidemic (para 27).

The *Declaration of Commitment* also sets out the need for concrete actions at the national level including ensuring the development of multi-sectoral strategies and financing plans. Under both a binding treaty and this political statement of commitment, Canada has an obligation to take steps to ensure income security for people living with HIV/AIDS, both as a matter of fundamental human rights and as a matter of necessity in responding to the epidemic.

## **Charter guarantees regarding income security**

The *Canadian Charter of Rights and Freedoms* provides a constitutional basis for challenging federal, provincial and territorial laws, and other forms of government action. The first two decades of Charter litigation have provided limited success to those seeking to establish guarantees regarding the levels of income security to which people in Canada are entitled. While there has been some recognition of equality and procedural rights for persons living in poverty, the courts have stopped well short of providing a right to enough government assistance to ensure that individuals and families have an adequate level of income.

## **Sources of disability income in Canada – an overview**

When people living with HIV/AIDS are unable to work because of their disability, those who do not have short-term sickness benefits at work are first directed to Employment Insurance (EI) sickness benefits, which cover roughly the first four months of disability leave. At the same time, if they have private disability insurance coverage they will begin the application process for the long-term disability benefit (LTD). Under most LTD policies, as a condition of receiving the benefit, people are required apply for disability benefits under the Canada/Quebec Pension Plan (CPP/QPP) if they have worked enough to make sufficient contributions.

People who require income assistance because of illness and incapacity, but who have had only a limited or no attachment to the workforce, will generally apply for provincial/territorial social assistance programs. These are needs-tested “welfare” programs, which provide relatively low levels of financial support and have detailed eligibility rules relating to income, assets and a range of other factors. Social assistance programs differ significantly among the 13 provincial/territorial jurisdictions in Canada, in terms of eligibility rules, and the income and other benefits provided. In all jurisdictions, people who are eligible for social assistance income benefits are also eligible for a range of extended health benefits, including coverage for prescription drugs. Increasingly, persons diagnosed as HIV-positive in Canada come from marginalized and economically disadvantaged groups, and so reliance on social assistance programs by persons living with HIV is becoming more common.

Social assistance may be the only disability income received by an individual, or it may be a “top-up” for a person who has only CPP/QPP disability income benefits. Under all provincial and territorial social assistance programs, applicants and recipients have an obligation to access other income to which they are entitled. Those people in need of immediate financial assistance often apply for social assistance and will, in turn, be required by social assistance authorities to apply for CPP/QPP.

To encourage people to return to the paid workforce, LTD, CPP/QPP and many social assistance programs have rehabilitation, vocational rehabilitation, employment support, and work trial components, and permit people to engage in work and earn modest amounts of income.

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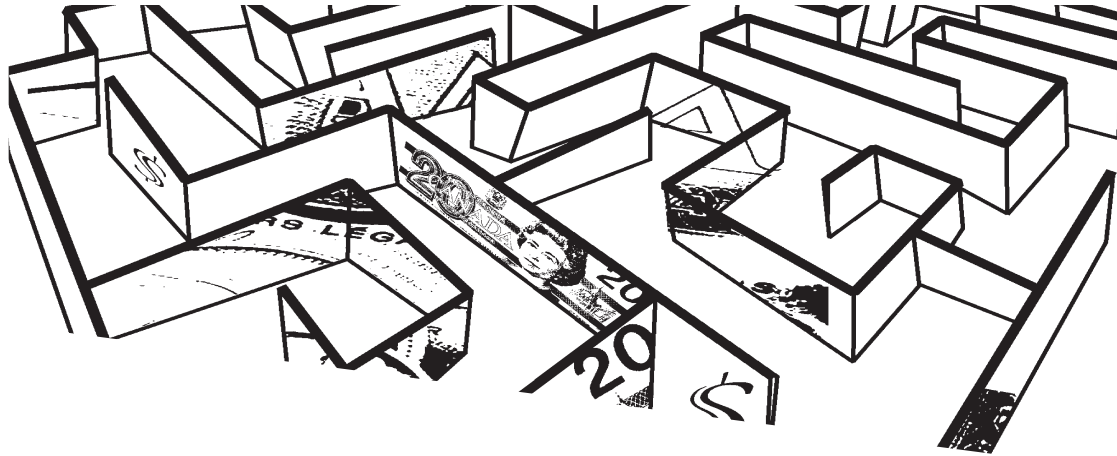
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## Employment Insurance sickness benefit

Under the authority of the federal *Employment Insurance Act* and associated regulations, Employment Insurance (EI) is a program that provides time-limited income supports and training to eligible persons who are not working. One component of the EI program is the sickness benefit, which provides income for a limited time to eligible contributors who are unable to work by virtue of illness, injury or quarantine. Some employers, especially in larger and unionized workplaces, provide either a “top-up” to the EI sickness benefit or an alternative to the sickness benefit through short-term disability coverage, either funded by the employer or purchased through an insurance carrier.

### Eligibility and eligibility review

To be eligible for the EI sickness benefit, a worker must have had an interruption in earnings, meaning a weekly decrease in earnings of 40 percent or more, because of illness, injury or quarantine. The worker must also have accumulated at least 600 insured hours of employment during the “qualifying period” – that is, employment income on which the worker was making contributions to the EI program (usually through deductions from their pay). The qualifying period is either the previous 52 weeks, or if the individual has already made a previous claim for EI sickness benefits during the past year, the time since that previous claim. Subject to certain conditions, the qualifying period may be extended to a maximum of 104 weeks on specific grounds, including inability to work because of illness or injury.

Finally, the worker must show that they “would otherwise be available to work”; in other words, their illness or injury is the cause of their inability to work. The fact that someone is HIV-positive or has a diagnosis of AIDS does not in and of itself entitle a person to the sickness benefit. Drug and alcohol dependency is recognized as a condition that may render someone unable to work.

As part of the application process, reviewed below, a person must provide a medical certificate. The medical certificate must be completed by a medical doctor or other medical professional, attest to the person's inability to work and state the probable duration of the illness, injury or quarantine. The Commission retains a medical advisor and may require a person to undergo a medical examination at the Commission's expense. However, the EI Commission makes the final determination of whether a person is unable to work and otherwise eligible for the sickness benefit.

## **Application process**

Workers who are unable to work due to illness or injury are encouraged to apply as soon as possible, either in person at an EI office or online. Once a worker's earnings have decreased by 40 percent on a weekly basis, a delay of more than four weeks in making the application may lead to a loss of benefits.

In order to apply for the EI sickness benefit, the worker must submit the following information:

- Social Insurance Number (SIN) or proof of immigration status and a work permit
- personal identification
- a record of employment (ROE) from each job held over the last 52 weeks (alternate proof of employment such as pay stubs may be submitted in certain circumstances)
- a medical certificate indicating how long the illness or injury is expected to last
- details regarding the worker's most recent employment, including gross salary received or to be received

## **Benefits**

The basic benefit rate for the EI sickness benefit is 55 percent of the worker's "average insured earnings" up to a maximum amount of \$413 per week. The sickness benefit is taxable income, meaning that federal and provincial/territorial income taxes are deducted from the amount that an eligible person receives.

## **Treatment of earned income**

Any earnings while on EI sickness benefits are deducted dollar-for-dollar from the worker's earnings. While recipients of regular benefits or parental benefits are exempt from this rule, there is no earnings exemption for recipients of EI sickness benefits.

## **Rehabilitation and return to work**

A worker who is able to take part in a training course would generally be considered able to work, and ineligible for the EI sickness benefit. However, a person living with HIV who has recovered and is fit to return to work at the end of the period of EI sickness benefits may be eligible to receive EI regular benefits if they cannot return to their previous employment.



If a worker is eligible for EI regular benefits, they may be able to qualify for a training course. Unless the worker is directed to the training course by Human Resources and Skills Development Canada (HRSDC) staff, they must show that taking a course does not prevent the worker from being available to work or from accepting any appropriate offer of employment during normal working hours.

## **Barriers to income security**

### **Lack of awareness of the EI sickness benefit**

A significant barrier to the income security offered by EI sickness benefit is the lack of awareness of the benefit among those who may be entitled to it. Anecdotally, advocates on behalf of persons living with HIV/AIDS report that clients may quit work rather than taking time off for medical reasons and applying for the sickness benefit. They do so believing that they do not have the latter option, or because they are unwilling to approach their employer and ask for time off out of fear of disclosing their HIV status. This is problematic for the person living with HIV/AIDS since under the eligibility requirements of EI a person who “voluntarily leaves employment without just cause” is disqualified from receiving any benefit under the Act based on the employment they left. There may be circumstances where an employer unreasonably refuses an employee’s request for time off due to illness. This leaves the employee with the decision to continue to work in circumstances that may be detrimental to their health, or to voluntarily leave work and risk not being eligible for the EI sickness or regular benefit. The employee who “voluntarily” leaves work or takes an unauthorized leave from work will face an uphill battle to receive an EI sickness benefit. In order to be eligible for the EI sickness benefit, they will have to show that “they had no reasonable alternative to leaving or taking leave, having regard to all of the circumstances.” All this will take time and may add to the person’s anxiety during a period in which the person is suffering from poor health. The application process may be further complicated if the person originally applied for an EI regular benefit (unaware of the sickness benefit) which requires the person declare themselves to be capable of and available for work.

### **Difficulty meeting eligibility requirements**

For many persons living with HIV/AIDS, a barrier to claiming the EI sickness benefit is that to qualify a person must have worked a minimum of 600 hours in the “qualifying period.” A person with ongoing health problems (for instance, a person living with an episodic disability such as HIV/AIDS) may have difficulty in meeting this minimum requirement. Such workers may have a significant reduction in earnings over several months which does not meet the test of a 40 percent decrease in earnings during specific weeks.

In addition, workers living with HIV/AIDS may have difficulty in getting medical documentation of their health status as required by EI, because they are responsible, almost without exception, for obtaining such documentation from their physician and paying for the required reports.

## Complexity of the program

Finally, the complexity of the *Employment Insurance Act* and regulations, and of the application process, presents a barrier to people living with HIV/AIDS attempting to access the sickness benefit. A firm grasp of the basic principles of the Act, regulations and benefit entitlement manual are necessary to understand the reason why an EI claim has been refused, and what arguments can be made to support a claim under review. While there are several levels of review and appeal provided for under the EI program, resolving a person's entitlement after an initial denial often takes time during which the person may have not access to income (and potentially other benefits associated with employment). Given the complexity of the EI program, people who do not have access to legal advice are at a distinct disadvantage in the EI review and appeals process.

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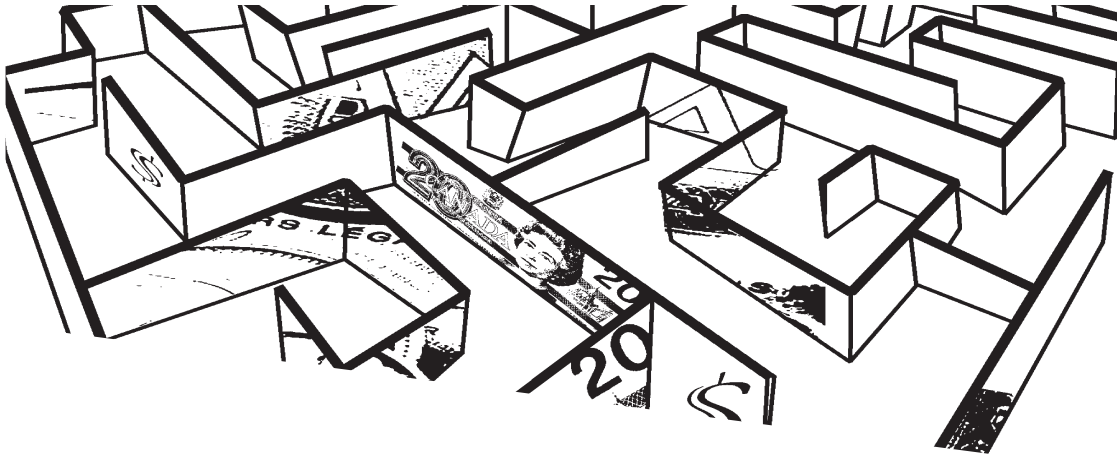
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## Private disability insurance

*In this section we describe typical provisions in long-term disability (LTD) insurance contracts. The provisions described are not necessarily included in every contract of insurance or insurance policy. The information in this section is not legal advice. Readers who have questions about a specific LTD insurance contract or policy should contact the insurer or seek legal advice.*

There are a number of different types of disability insurance plans offered by the private insurance industry in Canada, and sometimes by employers. However, all of the plans are a result of a private contract. The contract may be between the insurance company and an individual. In this case the individual is responsible for paying the premiums under the contract. However, it is more common that the contract is between an organization (such as employer or professional association) and the insurance company, entered into for the benefit of a group of persons (such as all the employees in a workplace). This is often referred to as group insurance. A group insurance plan may also be established and financed by an organization itself and administered by the organization or a benefits administration company. Under group insurance, the employer usually pays some of the premiums with the employee/member paying the rest; or the employer may pay the entire amount of the premium on behalf of the employee/member.

Disability insurance may be short- or long-term. Short-term plans typically cover the first four to six months of absence from work due to disability or illness. This period usually mirrors the waiting period for long-term disability (LTD) benefits, discussed below. Short-term disability plans are also sometimes called “weekly indemnity plans.” Often such plans are funded directly by an employer, rather than being purchased from an insurance company. Because of their variation and complexity, we shall not examine short-term disability plans in the present paper.

LTD insurance plans are also sometimes known as “monthly income replacement benefits.” The regulation, or lack thereof, of disability insurance in Canada permits a considerable variation in LTD insurance contracts among different insurers. However, there are a number of features common to most policies. LTD plans typically provide benefits after the first four

to six months of disability to those who qualify. LTD insurance policies are regulated by provincial and territorial governments, but only as regards a limited number of their most important features. LTD insurance contracts will be subject to different regulations depending on whether they are part of a contract of life insurance or part of a contract of accident and sickness insurance. Many of the provincial/territorial laws that regulate insurance contracts are based on uniform laws.

Despite the existence of provincial legislation, many of the important provisions in LTD insurance contracts are governed by industry practice and self-regulation rather than by governmental regulation. The Canadian Life and Health Insurance Association, an industry organization representing approximately 100 companies in Canada, publishes and regularly updates a set of guidelines. However, these guidelines are not legally binding on insurance companies.

### **Application for insurance coverage and proof of insurability**

Depending on whether the LTD insurance being applied for is an individual or a group policy, the applicant will be required to provide more or less information in order to be eligible for coverage. Where individual insurance is sought, in order to be considered for insurance coverage, the applicant will have to provide written information (usually by completing a form) about their current and past health and undergo a physical examination. The applicant's undertaking to provide evidence of insurability includes the obligation to disclose to the insurer every fact known to them that is "material" to assessing their insurability.

Group insurance is usually provided on a "non-medical basis," meaning that the members of the group do not have to undergo individual medical assessment. However, some group insurance coverage does require the individual members to provide evidence of insurability, which includes the legal obligation on the part of the individual to disclose all material facts to the insurer.

It is legal for an insurance company to refuse to provide LTD insurance to a person because of a pre-existing medical condition, such as HIV infection, that increases the insurance risk. Some Canadian anti-discrimination laws (i.e., human rights legislation) explicitly exempt insurers from the duty not to discriminate where the exclusion is reasonable in the insurance industry and made in good faith. Other provincial/territorial anti-discrimination laws allow an insurance company to legally discriminate if they can show that their actions were reasonable and justifiable in the circumstances or taken in good faith.

Some anti-discrimination laws explicitly provide exemptions which permit employers to exclude employees with pre-existing conditions from group LTD coverage in certain circumstances, usually depending on the number of employees. However, such legislation will often require the employer to pay the employee the premiums it would have paid on behalf of the employee had they been enrolled in the group LTD plan.

## **Coverage, pre-existing conditions, waiting periods, and conversion privileges**

The date when a person begins to be covered under an LTD policy is a matter of contract. For individual policies, the date upon which coverage begins is established according to provincial/territorial insurance legislation, which may leave it to be established in the policy. Coverage is usually contingent upon payment of the first premium by the insured, or receipt of the policy by the insured, or both. For group coverage, the master policy between the insurance company and the employer creates a program under which qualified individuals may obtain coverage. The individual is only covered as of the date they are enrolled in the program as per the terms of the master policy. As a matter of practice, this date usually coincides with the date an employee's probationary period ends and/or a certificate of insurance is delivered to the insured person.

Under most group LTD insurance policies a pre-existing condition will not prevent the person from being covered. However, for a period of time, the policy will take away the person's right to make a claim based on a medical condition for which they have sought treatment in the period prior to being enrolled in the plan. For example, the policy may state that if a person seeks medical advice or treatment within the six months prior to being enrolled in the plan, they will not be able to make a claim for the LTD benefit based on the illness or medical condition for which they sought medical attention until they have been enrolled in the plan for at least twelve months. This type of pre-existing condition clause would exclude from coverage a person living with HIV/AIDS who is taking antiretroviral medication and, depending on the frequency of medical appointments, may exclude those people whose HIV infection is regularly monitored by their physician. Courts have held that this type of limitation of coverage based on a pre-existing medical condition is not prohibited by anti-discrimination laws.

Most LTD insurance policies have waiting periods (also known as elimination periods) during which time a person is ineligible to receive an LTD benefit despite the fact that they have been enrolled under the policy. Commonly a person's disability (and period away from work due to the disability) must last for four to six months before the claimant may receive an LTD benefit. During that time the employee may be eligible for payments from their employer, short-term disability insurance, or EI sickness benefits.

LTD plans usually provide insurance coverage to the insured person during a specified period of time. For example, people enrolled under a group policy will be covered by the insurance contract so long as they continue to be part of the group – in other words, as they remain with the employer through whom they access a group insurance plan. Some policies may extend a person's coverage for a set period of time after they leave the group (often 31 days).

A person who is leaving an insured group may have the privilege of converting the group insurance to individual insurance without evidence of insurability (i.e., without providing medical information or undergoing a medical examination). The most common situation in which a person would leave a group would involve an employee whose employment is

terminated either by the employee or the employer. Typically, the conversion privilege must be exercised within a short period of time (usually 30 days), but this will depend upon the terms of the contract.

## **Accessing the LTD benefit**

### **Eligibility and eligibility review: the definition of disability**

In order to receive LTD benefits, claimants must demonstrate that they have a “total disability” that prevents them from working. The meaning of “total disability” typically changes, however, after the recipient has been receiving the LTD benefit for a set period of time. The change in the definition of “total disability” is a critical issue in determining continued eligibility for many recipients.

The definition of disability in an LTD policy should be examined carefully as it may vary from plan to plan. Although a number of standard disability forms are used, there is some variation among them and there are some unique terms. However, “total disability” usually refers to an inability to perform the “essential duties” of one’s pre-disability job in an initial period (typically two years), but then the test changes to an inability to perform the essential duties of “any job for which the person is reasonably fitted by education, training, or experience.” The shift from the “own occupation” test to the “any occupation” test makes a big difference to many LTD recipients, because while it may be clear that the person cannot do his or her usual job, it is much easier for the insurer to argue that there is alternative employment the person could perform.

Until the advent of new classes of medication used in combination to treat HIV disease, most insurance companies approved disability benefits for people living with HIV/AIDS based simply on an HIV-positive diagnosis. Since the introduction of such medications, insurance companies require more evidence of disability. People living with HIV/AIDS must demonstrate that they are under the active care of a physician or specialist and provide objective evidence of clinical and physical symptoms that prevent them from working (e.g., viral load test results, disabling complications such as dementia, diarrhoea, fatigue).

Once a person’s claim has been accepted (i.e., they have been found to be disabled according to the terms of the insurance policy), the insurance company may provide the LTD benefit to age 65, or the benefit may be time-limited. The precise length of time for which the benefit will be paid is specified in the insurance contract.

To continue receiving the LTD benefit for the permissible duration under the terms of the contract of insurance, a claimant is obliged to provide proof of continuing disability. In practice, this eligibility review may happen at set intervals, or it may be triggered by external events or investigations. The history of the HIV epidemic and treatment advances in Canada illustrate the different ways in which reviews have been handled over time. In the early days of the epidemic when there was no approved medication for treating HIV infection, and then when only one class of approved medications existed, the medical situation of most people living with HIV/AIDS was not subject to reviews. After 1996, with the advent of new classes



of medication used in combination, many of those people who had survived HIV infection until that time had their LTD claims reviewed. Today, as a general rule, those people whose claims for LTD are accepted will have set review dates at which time they will have to prove ongoing eligibility for LTD benefits. Throughout Canada, insurers who have previously paid benefits and cease to pay them, alleging that a disability no longer exists, have the legal burden of proving that the claimant's situation has changed.

Where an employee is receiving the LTD benefit under a group policy, the termination of their employment does not affect their entitlement to continue receiving the benefit. Likewise, despite the termination of the group insurance contract between the insurer and the employer, an employee who is in receipt of the LTD benefit will continue to receive the benefit so long as they meet the definition of disability.

### **Claims process**

The purpose of LTD insurance is to insure against the inability to work due to disability that lasts over the long-term. In order to successfully make a claim for the LTD benefit, a person must demonstrate their inability to work due to disability. The person and their medical provider(s) will have most of the information required to assess whether they meet the definition of disability set out in the insurance contract. The person wishing to make a claim for the LTD benefit (often referred to as the claimant) sets the application process in motion by notifying the insurer or employer of their intention to make a claim. The person will be provided with the standard claim forms, normally consisting of a section to be completed by the claimant and a section to be completed by the claimant's physician. The claimant is also asked to sign a release of information form permitting the insurance company to verify the claimant's employment and medical information with the employer and physician, respectively.

It may take several weeks or even several months for the insurance company's "adjudicator," the person responsible for making a decision about the claim, to assemble the documents they require to reach a decision. An internal assessment of the medical evidence, conducted by the insurance company's own medical professionals, is typically part of the adjudication process. If the claim is denied, the claimant will be sent a letter which will usually include the reasons for the denial. If the claim has been denied due to inadequate evidence of disability the claimant will usually be given the opportunity to provide additional information or evidence to support their claim. This additional information and evidence will then be assessed and a decision rendered, followed by a letter denying or accepting the claim. Where a claim is accepted, the insurer will pay a lump sum benefit owing, which typically covers benefits for the period of time between filing the claim and the date of the decision, and initiate payment of periodic benefits (usually paid weekly or monthly).

Courts have held that insurance companies have an obligation to deal with claims (and the people submitting the claims) in good faith. In the *Clarfield v Crown Life Insurance Company* case in 2000, an Ontario Superior Court judge interpreted this to mean that failure to deal with a disability claim with reasonable promptness during each step of the process (such as taking measures to advise claimants of missing information required to expedite the process), and to treat claims fairly (in the manner in which the claim is processed and in the final decision),

could be in and of itself the basis for a lawsuit against the insurance company. The court recognized that the timely processing of claims is especially important in disability insurance claims cases:

Although an insurer may be responsible to pay interest on a claim paid after delay, delay in payment may nevertheless operate to the disadvantage of an insured. The insured, having suffered a loss, will frequently be under financial pressure to settle the claim as soon as possible in order to redress the situation that underlies the claim.

This obligation arises from the nature of the insurance, which the court characterized as “peace of mind” insurance, which, when withheld, aggravated the financial and emotional vulnerability of claimants.

In the *Clarfield* case, the judge awarded extra damages partly on the basis that the claimant suffered anxiety, stress, and financial pressure because the insurance company delayed processing his claim and then rejected it. Likewise, the judge dismissed the “extra-contractual” payments that the insurance company paid to him as negating the purpose of disability payments to provide “solace and security to the insured” as they “in fact exacerbated his feelings of anxiety and uncertainty about the future” because the company threatened the insured with the possibility of reclaiming the payments at their will (since they were not “disability” payments but “extra-contractual” payments). The judge noted that the underlying purpose of those payments was to prevent the insured from disputing the rejection of his claim. Finally, the insurance company had sent letters that tried to have him “sign away” his rights, and had failed to consider other possible benefits under the plan or to make him or his spouse aware of them – all of which represented a failure to deal with the claim in a balanced and reasonable manner and constituted a breach of the insurance company’s duty of good faith toward the claimant.

## **Benefits and the coordination and taxation of benefits**

As a general rule, under provincial/territorial legislation, an insurer must pay the benefit within 30 or 60 days after the claim for benefits has been proven and periodically after that time. However, it may take an extended period of time for the insured person to provide the information to prove their claim, and for the insurer to review that information. This can have the effect of delaying the payment of the benefit even where the claim is approved, sometimes for extended periods of time.

The amount of the benefit is usually a percentage of the pre-disability employment income (e.g., typically between 60 and 70 percent), but may be a set amount, paid weekly or monthly. Questions may arise as to what counts as employment income (e.g., tips, bonuses, commissions). These will be resolved by reference to the terms of the LTD insurance policy and their interpretation.

Most private LTD insurance policies contain a clause that requires a recipient to apply for other benefits to which they may be entitled. This type of clause, known as a “coordination of benefits” clause, states that income benefits received from other sources are deducted



from the amount of the LTD benefit paid by the insurance company. Insurers will require that people who are disabled as a result of their medical condition and who have a history of employment, apply for the CPP/QPP disability benefit. (The CPP disability benefit will be reviewed in detail in the next section of this report). According to the typical coordination of benefits clause, the total amount of all other benefits will be deducted from the LTD insurance benefit. For example, the CPP/QPP disability benefit is usually deducted dollar-for-dollar from the LTD benefit, although the deduction may vary from policy to policy. In practice, a person who is eligible for both an LTD benefit and a CPP/QPP disability benefit will receive a cheque from CPP/QPP and a cheque from the LTD insurer on a monthly basis – the total amount of the two cheques will equal the amount of the maximum LTD benefit under the terms of the insurance policy. While the coordination of benefits provides no financial gain for the benefit recipient, and creates additional administrative burdens for the recipient, it saves the insurance industry a significant amount of money that it would otherwise have to pay out in benefits.

There may be tax implications of receiving an LTD benefit, depending on the terms of the policy. Where the employee pays the insurance premiums in full, they will not have to pay income tax on the benefits received. Where the employer pays all or part of the premiums, the insurance coverage is considered a taxable benefit provided by the employer, and so any LTD benefit received by an employee with a disability is taxable as income. (However, if the employee pays some part of the premiums, the employee can deduct the premiums they have paid when calculating their taxable income on their tax return.)

Under some plans, the benefit amount is indexed to inflation, meaning that the benefit amount will increase to keep up with inflation, preserving the real dollar amount of income the person receives. Where the benefit is not indexed, the benefits will not keep up with inflation, meaning the amount of the benefit in real dollars will erode over time. For some long-term survivors of HIV/AIDS, this has resulted in a substantial decrease in their standard of living during the time they have been receiving LTD benefits.

## **Rehabilitation, return to work, and recurrence of disability**

Private insurance companies have a long-term financial interest in assisting people who are receiving LTD benefit return to work. Most LTD policies require recipients to make reasonable efforts to return to work. To assist people receiving LTD to return to the workforce, insurers may offer counselling, vocational rehabilitation training and other resources.

Significantly, most policies or insurers have provisions which allow an employee to return to work while continuing to receive benefits at a reduced rate to account for work earnings. This is sometimes called rehabilitative employment. Claimants must be careful to engage only in paid work that has been prearranged and approved with the insurer under the terms of contract of insurance; otherwise, they risk losing eligibility for the LTD benefit. An approved rehabilitation arrangement, including potential return to work, usually continues for an agreed upon period of time up to two years. If, at the end of the agreed upon period of time, the insured person cannot return to work on a full-time basis as a result of their disability, they may have their LTD benefit reinstated.

The situation of a worker who has returned to work full-time and who is not (or is no longer) covered by a return to work agreement is more complicated. If the person becomes disabled as a result of the same or a related medical condition within a specified period of time, they can apply to have their LTD benefit reinstated immediately. The period of time during which a person can be reinstated is set out in the insurance contract, and may be subject to provincial law. Once the period of time has elapsed, the disability will no longer be considered a recurrence and the person will have to reapply for the LTD benefit – but can only do so after the elimination period has elapsed.

## **Barriers to income security**

### **Psychological impact of declaring total disability**

The decision to claim private insurance benefits may be an extremely difficult one for people living with HIV/AIDS. LTD insurance is structured as an all-or-nothing proposition at the initial stage when a claim is made. There is no possibility of applying for a partial LTD benefit. A person living with HIV/AIDS must declare that they are “totally disabled” and unable to work in order to claim the LTD benefit. A person who is unable to work full-time at their job may not consider themselves to be totally disabled, and as a result may be hesitant or unwilling to state such in order to receive the LTD benefit. For some people, the fluctuating nature of the symptoms associated with HIV infection – with alternating periods of good and poor health – may reinforce their feeling that they are not totally disabled. Declaring oneself to be totally disabled may be extremely destructive to a person’s sense of self, especially for those people whose self-perception is intimately linked with their employment or profession. At the same time the choice to continue working though illness may result in diminished performance and absences that threaten job security. A further psychological barrier to claiming LTD may be the fear of disclosing one’s HIV status. “Outing” themselves as HIV-positive in order to make a claim may involve coming to terms with their HIV infection and, potentially, pressure to disclose the nature of their disability to those in their workplace, including supervisors.

### **Access to information**

One of the significant barriers to accessing benefits under LTD insurance is lack of access to information, both in terms of documents and in terms of what to expect from insurance company representatives responsible for processing claims. This barrier is most acutely experienced by people covered under group LTD plans. As a result of inadequate access to information, employees are at a distinct disadvantage when pursuing the LTD benefit to which they may be entitled.

Members of a group plan are rarely provided with a copy of the contract of insurance under which they are insured. Individuals in the non-unionized sector insured under a group plan will likely not be given a copy of the contract of insurance. Instead it is standard industry practice for group members to receive a benefits booklet. This booklet is intended to summarize and set out the essential terms of the contract of insurance.

Employers and insurance companies are often unwilling, at least initially, to provide employees with a copy of the contract of insurance (i.e., the policy) under which an employee is insured, leaving the employee in the dark about their rights and entitlements and the claims adjudication and resolution process under the contract. Most often employees get limited access to the terms of the contract of insurance, and then only by way of excerpts from the contract quoted or paraphrased in letters sent from the insurance company to the employee. Regarding the processing of claims, rarely does the benefit booklet state in detail the process for making applications or for resolving disputes about coverage and accessing benefits. Most if not all insurance companies have an ombudsperson whose role it is to accept and attempt to resolve complaints by members of the public. In addition, some provincial government regulatory agencies that supervise the insurance industry have a similar function.

### **No fixed timelines for adjudication**

Under most policies of insurance, the adjudication of an LTD claim has no fixed timeline. Applicants do not know how long they can expect to wait before receiving a decision on their claim. Delays in assessing claims may result if the applicant or their physician has not submitted information to the insurer in a timely manner – which is not the fault of the insurer. However, even when evidence is submitted in a timely manner, insurers rarely conduct an initial file review within a fixed time after receiving the information (e.g., 10 days). If insurers did so and found that crucial information (such as medical test results or consultation notes) was missing, the applicant could be immediately advised to provide this information. As it stands, there are often delays between the time of application and when a decision is rendered. In most cases the applicant is invited to submit further information to support the claim only after the decision is rendered. Where the applicant does submit further information (most often medical information sent to the insurance company by their physician), they must then wait for a further adjudication of the claim – with no fixed timeline for a decision.

The lack of a fixed timeline for rendering decisions, and the lack of an initial file review process, present barriers to income security for people living with HIV/AIDS. It may take weeks or months for the insurer to render a decision on an application for an LTD benefit. People who have no savings to draw upon to meet their basic needs during that time may be forced to apply for social assistance in order to survive. In all provinces and territories, social assistance benefit amounts are below the poverty line, and may not provide people with sufficient income to pay for rent/mortgage, food, utilities and other basic necessities.

### **Reliance on objective medical evidence and physicians as gatekeepers**

The reliance on objective medical evidence and on physicians' assessments to establish initial and ongoing eligibility for an LTD benefit may present a barrier to income security for some people. In the claims adjudication process the general practitioner is the gatekeeper of the medical information needed to establish "disability." To establish that they meet the definition of "disability," the insurance company will require the applicant to provide a medical diagnosis, the basis for the diagnosis, a summary and interpretation of test results, current or proposed treatment and the prognosis. Applicants must rely on their physician, usually their general practitioner/primary care physician, to provide this information to their insurance company. To arrive at a diagnosis, the primary care physician will usually

send the patient for tests or to specialist physicians for consultations. The results of any tests or consultations are held by the primary care physician in the patient's medical file. If the physician has not sent the patient for the tests or consultations necessary to arrive at a diagnosis, their LTD claim may be refused for lack of sufficient objective medical evidence to establish "disability." In other cases, despite the existence of objective medical evidence (i.e., test results and consultation reports) in the patient's medical file, the primary care physician may not effectively convey this information to the insurance company. Most if not all insurance companies provide physicians with standardized forms to complete on behalf of patients applying for an LTD benefit. A primary care physician may not adequately detail the patient's medical condition(s) on the form, or may not send the insurance company copies of the relevant test results and consultations reports. This may result in a delay in processing or refusal of the claim.

The cost of obtaining objective medical information is also a factor that might limit access to the LTD benefit. Under LTD insurance policies, the claimant is responsible for providing the medical evidence to support their claim. Provincial and territorial government health care programs set out a list of insured services. Physician referrals and common diagnostic tests required by people living with HIV/AIDS are insured. However, under most provincial and territorial health plans, physicians cannot bill the plan for the time it takes to complete forms or reports on behalf of a patient who is applying for an LTD benefit.

Finally, physician shortages might limit the accessibility of the LTD benefit. For people living in areas underserved by primary care and specialist physicians it may be difficult to obtain the objective medical evidence necessary to prove disability. Increasingly people in Canada are unable to find primary care physicians who are accepting new patients, are faced with waiting times for appointments with specialist physicians, and encounter waiting lists for sophisticated diagnostic tests.

### **Proof of insurability and pre-existing condition clauses**

Proof of insurability and pre-existing medical condition clauses act as barrier to LTD insurance coverage and benefits for people with HIV/AIDS. A person living with HIV/AIDS would certainly be refused coverage if they applied for individual LTD insurance. Barriers also exist for people living with HIV/AIDS enrolled in group LTD plans where individual proof of insurability is not required. As set out above, people living with HIV/AIDS who are under the regular care of a physician will likely face a initial period of time after enrolment during which they will be excluded from making a claim for the LTD benefit (by virtue of a pre-existing condition clause).

### **The problem of "job-lock"**

"Job-lock" occurs when a person living with HIV/AIDS, or another disability, stays in a job for fear of losing or interrupting their LTD coverage. Four main factors create a situation of job-lock for people living with HIV/AIDS:

1. the requirement of evidence of insurability when applying for individual LTD insurance coverage;
2. pre-existing condition clauses in group LTD insurance policies;
3. the uncertainty of the course of HIV infection, which may result in prolonged, unexpected periods of illness; and
4. group LTD policies that do not give employees a conversion (to individual benefits without proof of insurability) option.

If a person living with HIV/AIDS has LTD coverage in their current job and is beyond the period during which the pre-existing condition clause would exclude a claim, and has no conversion option under their policy, to give up that job would likely mean foregoing LTD coverage for a prolonged period of time. This would be the case even if they were hired by an employer who had a group LTD plan under which the person was eligible for coverage without proof of insurability. For example, if there was a waiting period for enrolment of three months and the pre-existing condition clause effectively excluded a claim of disability based on HIV status for 12 months, they would be without LTD coverage for 15 months. A conversion option for LTD coverage could bridge this gap, assuming that the person could afford to pay the individual premiums. Without a conversion option, the possibility of leaving a job to become self-employed – a trend in many types of jobs – while maintaining LTD coverage is virtually non-existent. The risk of going without LTD coverage for an extended period of time may be too great for some people living with HIV/AIDS to seriously consider changing jobs. Job-lock can lead to feelings of frustration and powerlessness, seriously limit career options, and may result in a stalled career path.

As a means of addressing this problematic situation, the United States Congress passed the *Health Insurance Portability and Accountability Act of 1996*. It was a lengthy and detailed piece of legislation – 169 pages – which amended numerous laws. The purpose of the Act was to:

1. increase people's ability to get health coverage for themselves and their dependents when starting a new job;
2. lower people's chance of losing existing health care coverage, whether they have that coverage through a job, or through individual health insurance;
3. help people maintain continuous health coverage for themselves and their dependents when they change jobs; and
4. help people buy health insurance coverage on their own if they lose coverage under an employer's group health plan and have no other health coverage available.

There is no comparable legislation in Canada. In September 2002, a member of the Ontario Legislative Assembly introduced private member's Bill 176 (*An Act to provide for some continuation of benefit plans of employees after the end of their employment*) for first reading. In comparison to the US *Health Insurance Portability and Accountability Act of 1996*, Ontario's Bill 176 was extremely concise – less than two pages. The Bill proposed to amend the provincial employment standards legislation to provide that when the employment of a person who had been employed for at least 12 months with an employer ended, the person was entitled to have the employer continue to provide, offer or arrange for the group insurance

benefit coverage the employee had while working. The period of continuation was to last for six months following the end of employment or whatever shorter period the employer and employee agree to. The employee was to be responsible for the full cost of all benefit plans that were continued. The Bill did not become law.

### **Risk associated with returning to work**

The significant risks associated with returning to the same job for people who are receiving disability benefits can result in a situation where recipients are “trapped” on the LTD disability benefit. The risk arises, in part, from the potential that a person will have to re-qualify for the LTD benefit if they suffer a recurrence of their disability. Some LTD policies have “recurrent disability” clauses that allow for a person’s LTD benefits to be quickly restarted if the person’s disability recurs within a set period of time after returning to work. Once outside that period, a person who is unable to work due to a recurrence of their disability will have to go through the entire LTD application process again.

People also run a great risk of losing insurance coverage (which in the case of group insurance may include life, LTD and extended health coverage) if their employment is terminated after they return to work. In the case of people with HIV/AIDS, many of whom rely on expensive HIV antiretroviral medications and other extended health benefits to maintain their health, the prospect of losing insurance coverage if they were to get terminated from their employment is daunting. People who are considering returning to a different job than the one they had before qualifying for the LTD benefit face the prospect of have an interruption in their LTD and extended health benefits insurance coverage, or not being eligible for such coverage.

The prospect of having to reapply for the LTD benefit or of losing insurance coverage can act as a significant disincentive to returning to work for people living with HIV/AIDS. But remaining on the LTD benefit means living on just a portion of pre-disability income and experiencing the stigma associated with being “totally disabled,” and often feelings of frustration and powerlessness seriously limit career options and result in a stalled career path.

### **Lack of coordination of benefits**

When it comes to coordinating LTD and CPP/QPP disability benefits, the use of the phrase “coordination of benefits” to describe the deduction of other benefit income from an LTD benefit is misleading. In reality, a lack of coordination of benefits leads to income insecurity for some recipients. This issue is examined below in the section on the CPP/QPP disability benefit.

### **LTD coverage not a realistic option**

People who do not work for companies, who are not members of a union or association, or who hold part-time or seasonal employment likely will not have access to LTD coverage. The main source of LTD insurance is group plans provided through an employment benefits package, union, or association. Given the changing demographics of those becoming infected with HIV/AIDS, many people (living with HIV/AIDS or who may become HIV-positive)



will not have access to private disability insurance because they are either unemployed, underemployed, or employed in low-wage, unstable jobs. Although the highest incidence of HIV infection in recent years has remained among men who have sex with men, women, people who inject drugs and people from endemic communities are an increasing proportion of those becoming infected. Members of these groups have lower labour force participation, or have been relegated to low-wage, unstable employment. Individual coverage is too costly to be accessible to the working poor and even many people at lower middle class income level. Less expensive plans boast lower premiums, but beneficiaries get what they pay for. Lower premiums usually translate into longer waiting periods between filing a claim and receiving the first payment, and the benefit may replace a smaller proportion of earnings than under group plans.

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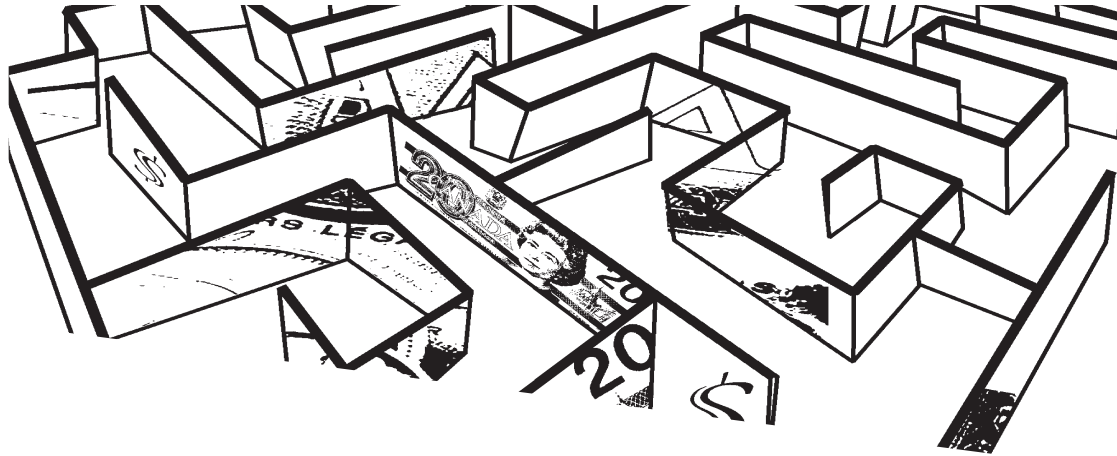
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## Canada Pension Plan and Quebec Pension Plan disability benefit

The Canada Pension Plan (CPP) was established in 1966 as a national program for workers whose earnings are interrupted for a long period or ended due to retirement, disability, or death. Quebec used the “opt-out” provision in the CPP to create its own system – the Quebec Pension Plan (QPP). Under CPP and QPP, workers and employers make mandatory contributions to the program from insurable employment, which are held by the respective governments in investment funds. Benefits for retirement, disability and death are paid from the investment funds.

The CPP and QPP are “quasi-insurance” schemes. They offer unique features that distinguish them from private insurance. The CPP and QPP provide universal coverage to those with some workforce attachment. The benefit amount is indexed to inflation and adjusted according to the consumer price index. Unlike private LTD insurance, the CPP and QPP (both contributions and benefits) are “portable” between jobs and provinces and there are no “pre-existing condition” exemptions to exclude potential claimants. Finally, both CPP and QPP take into account the impact on the family of a person unable to earn income through work because of disability: benefits are provided to minor children of people who receive a CPP or QPP disability benefit, and to adult children up to the age of 25 so long as they are in school.

CPP/QPP provides a basic and modest level of income support. The program was not intended to replace 100 percent of lost income. Rather, it was designed to provide reasonable levels of income to supplement other sources, including private insurance, personal savings and investments, and provincial/territorial social assistance (welfare).

The discussion that follows will focus on the CPP disability benefit. Although the CPP and the QPP are similar, they differ in important respects. First and foremost, while Quebec has the freedom to amend the QPP, the government of Canada must have provincial and territorial consent in order to amend certain important provisions of the CPP. Readers with an interest

in the QPP can access information about the features of that program on the Government of Quebec Website at [www.rrq.gouv.qc.ca](http://www.rrq.gouv.qc.ca).

## Eligibility

To qualify for the CPP disability benefit a person must establish that they:

- are less than 65 years of age;
- are not receiving a CPP retirement pension;
- meet the test for disability under the CPP Act; and
- have made sufficient contributions to the CPP within a pre-determined contribution period.

## Test for disability

The CPP does not define the term “disability.” Rather, it sets out the test that a person must meet in order to be found eligible to receive the CPP disability benefit. The test has remained virtually unchanged in the legislation since 1971. However, the way CPP adjudicators, tribunal members and courts have interpreted and applied the test has varied over time. Effectively, the disability test has been used by those responsible for administering the CPP as a valve to regulate CPP disability benefit case load over time, depending in part on the fiscal climate. In times of fiscal restraint, it has been much more difficult for people to qualify for the benefit. The tribunals and courts responsible for hearing appeals related to the CPP disability benefit have also played a role in turning on and off the valve. At times they have interpreted the test for disability in a restrictive manner, and at other times they have given the test a large and liberal interpretation that favours people seeking the benefit.

The test for disability is set out in section 42(2) of the CPP Act. According to the test “a person shall be considered to be disabled only if he is determined in prescribed manner to have a **severe** and **prolonged** mental or physical disability.” Note that the disability must be shown to be both severe and prolonged.

### *“Severe” disability*

The CPP states that a disability is “severe” if the person “is incapable regularly of pursuing any substantially gainful occupation.” According to CPP policy guidelines, the person’s medical condition is the “prime indicator” in determining whether the person is disabled under the legislative test. The most important aspect of a person’s medical condition is whether, and if so in what ways, it prevents the person from working. The adjudicator should examine the nature of the medical condition, the functional limitations that result from that condition, and the impact of treatment on the person’s capacity to work.

The test for disability was considered in detail in the 2001 Federal Court of Appeal decision in *Villani v Canada (Attorney General)*. The Court rejected the notion that a disability has to be “total” in order for an applicant to receive benefits. Rather, disability should be assessed in terms of its impact on a person’s employability. The Federal Court of Appeal noted that previous tribunal cases demonstrated an unjustified and unfounded inconsistency in the

application of the “severe” requirement, despite the fact that social benefits legislation such as the CPP Act should be interpreted in a broad and generous manner such that any doubt is resolved in favour of the applicant. The Federal Court of appeal adopted a “real world” approach to determining whether an applicant’s disability is severe. The Court quoted the following passage from the 1988 Pension Appeal Board decision in *Leduc v Minister of National Health and Welfare*, as support for this approach:

The Board is advised by medical authority that despite the handicaps under which the Appellant is suffering, there might exist the possibility that he might be able to pursue some unspecified form of substantially gainful employment. In an abstract and theoretical sense, this might well be true. However, the Appellant does not live in an abstract and theoretical world. He lives in a real world, people [sic] by real employers who are required to face up to the realities of commercial enterprise. The question is whether it is realistic to postulate that, given all of the Appellant’s well-documented difficulties, any employer would even remotely consider engaging the Appellant. This Board cannot envision any circumstances in which such might be the case. In the Board’s opinion, the Appellant, Edward Leduc, is for all intents and purposes, unemployable.

Placing the disability analysis in the “real world” context involves examining whether the applicant is incapable regularly of pursuing any substantially gainful occupation, not whether the applicant is incapable at all times of pursuing any conceivable occupation. In *Villani*, the court ruled that disability is “severe” when it renders the applicant incapable of pursuing with consistent frequency any truly remunerative employment, and as such, must be linked to the personal circumstances of the applicant, rather than limited to objective medical criteria (par 38). These particular circumstances include age, education level, language proficiency, past work and life experience, and functional limitations. The “real world” approach must be distinguished from the use of socioeconomic factors such the availability of work in a specific geographic area (which is expressly prohibited by the CPP regulations).

According to CPP policy guidelines, earnings are “substantially gainful” when they are more than token. Profitability is the most important indicator of whether a person is regularly engaging in a “substantially gainful” occupation. Profitability is determined using a “substantially gainful occupation” (SGO) benchmark set at 25 percent of the average Year’s Maximum Pensionable Earnings (YMPE). In 2005 the YMPE was \$41,100, resulting in a SGO benchmark of \$10,275. According to policy guidelines, an individual working to full capacity but earning less than SGO benchmark would be presumed not to have the capacity for work. A person earning twice the SGO benchmark would be presumed to have the capacity to work. A person earning between the SGO benchmark and twice the benchmark must present very strong evidence to support their eligibility for the CPP disability benefit. Two other factors are taken into account when determining whether occupation is “substantially gainful” – performance (i.e., actual effort) and productivity (i.e., the amount of work produced).

#### *“Prolonged” disability*

According to the test set out in the CPP Act, a disability is prolonged if it “is likely to be long continued and of indefinite duration or is likely to result in death.” The “prolonged” requirement has not been precisely defined by the courts.

## **Sufficiently recent contributions**

In order to be eligible for the CPP disability benefit a person must not only meet the test for disability but also must satisfy the contributory requirements. The contributory requirements are set out in the CPP Act. The rules relating to the contributory requirements are extremely complex; a detailed analysis is beyond the scope of this report. Stated simply, an applicant for the CPP disability benefit must have made sufficient contributions to the plan within a sufficiently recent period of time. People who do not earn more than a certain amount of money (called the “Year’s Basic Exemption” and set at \$3,500 for 2005) in a calendar year, are not permitted to make CPP contributions in that year. According to the CPP Act, to be eligible for the disability benefit, a person must have made contributions in at least four of the six calendar years immediately prior to the date on which they became disabled.

## **Application and appeal process**

The regulations under the CPP Act establish the broad strokes of the application processes for the CPP disability benefit. Applicants for the CPP disability benefit must provide information about their disability, how it restricts their ability to function, and their vocational profile. The medical report, which is completed by a physician using a standard form, provides CPP medical adjudicators with information as to the nature, extent and prognosis of the physical or mental impairment, the findings upon which the diagnosis and prognosis were made, any limitation resulting from the impairment, and any other relevant information (including information about further diagnostic work or treatment). The applicant must provide a statement of their occupation and earnings for the period prior to the commencement of their disability. The applicant must also provide a statement of their education and employment experience and their activities of daily life. CPP authorities may require the applicant, at CPP’s expense, to undergo special medical examinations in order to determine whether the applicant is disabled.

Successful applicants will be granted the CPP disability benefit, with payment of benefits retroactive to the fourth month after the applicant’s date of disability. The date of disability can only be back-dated to a maximum of 15 months prior to the actual date of application for the benefit. The actual amount of the retroactive payment will depend upon the date of application, the date of disability, and how long it took to process the application.

Unsuccessful applicants have recourse to three levels of appeal under the CPP (reconsideration/administrative review, a three-member Review Tribunal, and the Pension Appeals Board), and can also apply to the Federal Court of Appeal for permission to have the decision of the Pension Appeals Board judicially reviewed.

The first level of appeal under the CPP is a reconsideration. Applicants may seek reconsideration within 90 days of the refusal to grant the CPP disability benefit, or to challenge the amount of the benefit. The reconsideration is a paper review process decided by a different medical adjudicator to keep the case distinct from its original assessment. Often applications are rejected because of insufficient evidence to establish whether the person meets the test for disability. On reconsideration, applicants may supply new evidence to

supplement their original application. In recent years, close to 30 percent of applicants who have filed reconsiderations have had the denial of their CPP disability benefit reversed.

The next level of appeal under the CPP is made to the Review Tribunal – an impartial three member panel composed of a medical professional, a lawyer acting as chair, and a person from another profession or occupation. The Review Tribunal hears appeals relating to all categories of CPP benefits (e.g., retirement pension, survivor’s pension) and appeals relating to benefits under the *Old Age Security Act*. At the Review Tribunal the applicant and the CPP authorities have a right to present their case, both in writing and orally. Historically, approximately 95 percent of appeals to the Review Tribunal were brought by people who were denied the CPP disability benefit. Since the late 1990’s, the proportion of disability benefit decisions appealed to the Review Tribunal continues to grow, despite a decrease in the number of appeals during the same period. Since the mid-1990’s, the Review Tribunal has been allowing an increasing proportion of CPP disability benefit appeals, echoing similar trends in decisions by the CPP adjudicators. There was a sharp increase in the proportion of decisions in favour of after 2001/2002, partly attributable to the Federal Court of Appeal judgment in *Villani* released in 2001. In 2003/2004, the last year for which statistics are available, approximately 53 percent of CPP disability appeals were granted. This rate has increased every year since 1992/1993 when the success rate was slightly above 17 percent.

People whose appeals are refused by the Review Tribunal may seek leave to appeal that decision to the Pension Appeals Board, a tribunal where judges of provincial superior courts and the Federal Court hear cases. Unlike the case of an appeal to the Review Tribunal, an applicant for a CPP disability benefit does not have the right to have their case heard. It is up to the Pension Appeals Board, applying a legal test, to decide whether to hear a case.

## Benefits

The CPP disability benefit is paid monthly and is comprised of two portions:

- a fixed, flat-rate amount (\$388.67 in the year 2005), plus
- an amount based on a percentage of contributions equal to 75 percent of the retirement pension a contributor would have received at age 65 (to a maximum of \$621.56 in 2005).

When added together, the maximum monthly payment in 2005 is \$1,010.23 per month. The average CPP disability benefit is \$749.08. The flat rate allows those workers, particularly women, who have been “underemployed” (employed mostly in contract or seasonal work) to receive a guaranteed minimum benefit provided they meet eligibility criteria.

Dependent children of people who receive the CPP disability benefit are eligible to receive a children’s benefit as well, which enhances the income security of the family as a whole. Minor children, and adult children between the ages of 18 and 25 who attend school full-time, are eligible. In 2005, the amount of the children’s benefit is \$195.96 a month.

CPP disability benefits are subject to income tax in the year they are received. It is possible for recipients to have the tax deducted from the benefit on a monthly basis.

CPP disability benefits are indexed to inflation and adjusted annually based on the consumer price index for Canada, as published by Statistics Canada.

## **Allowable earnings**

In 2001, CPP adopted a policy guideline on allowable earnings. This was a positive development for people living with HIV/AIDS and other episodic disabilities who receive the CPP disability benefit. The policy recognizes that a “significant minority” of people receiving the CPP disability benefit will have an opportunity and the desire to engage in some form of paid work. It also explicitly recognizes the needs of people with severe illnesses of a “cyclical nature” who may alternate between periods of work activity and periods when they cannot work.

The allowable earnings policy permits a person to work and earn up to a certain amount of money (i.e., allowable earnings) in a calendar year without having to report the money to CPP, and without having it affect their eligibility for the CPP disability benefit. For the purposes of counting allowable earnings, the year starts on January 1<sup>st</sup> and a person’s earnings balance returns to zero on January 1<sup>st</sup> of each year. For 2005, the allowable earnings amount is set at \$4,100.

The allowable earnings policy is intended to complement other CPP policies aimed at removing the disincentives to returning to work. Once a person earns more than the allowable earnings amount they are obliged to contact CPP administrators and provide information about their earnings. The CPP administrators will then discuss with the person whether it would be appropriate for them to start a three-month flexible work trial. The flexible work trial and other initiatives designed to reduce the disincentives to a return to work are examined below in “Rehabilitation, return to work and automatic reinstatement.”

## **Eligibility review**

A person who is receiving a CPP disability benefit may have their eligibility reviewed or reassessed. According to the regulations under the CPP Act, authorities can require a person receiving the CPP disability benefit to submit medical reports, undergo a medical examination, and provide a statement of his or her occupation and earnings for any period. The authority to conduct a review includes a review of the on-going eligibility of a person who has been granted benefits as a result of a tribunal or court order.

According to CPP policy guidelines, in the absence of strong evidence to the contrary, a decision to grant or continue benefits must be respected. CPP administrators must obtain evidence of a change in the person’s circumstances – in other words, evidence that the person no longer has a severe and prolonged disability as of a certain date – in order to terminate a CPP disability benefit. As with an initial adjudication of disability, both medical and non-medical evidence will be taken into account. CPP authorities will verify whether there is any indication of improvement of the person’s medical condition or ability to regularly engage in substantially gainful occupation.



## **Vocational rehabilitation, return to work, automatic reinstatement, and fast-track reapplication**

### **Vocational rehabilitation**

Under the CPP Regulations, the CPP authorities can require a beneficiary to undertake reasonable rehabilitation measures if they are of the opinion that the beneficiary may benefit vocationally. The regulations permit the disability benefit to be terminated where a person fails to comply with this requirement, unless they have “good cause,” which means a “significant risk to a person’s life or health.” However, the policy guidelines and CPP practice offer a less rigid approach to rehabilitation, based on client needs, personal attributes, assessments and individually-tailored rehabilitation plans, and cost. Personal attributes include level of education, work history, official language skills, motivation to return to work, years until retirement, commitment to rehabilitation, medical condition and prognosis, and special equipment and needs. Candidates for vocational rehabilitation are identified through file review and by self-referral. The guidelines outline a process focussed on individual assessment to determine whether a person is suitable for vocational rehabilitation. CPP bears the cost of vocational rehabilitation and contracts with private sector rehabilitation specialists. As a guide, the policy states that the total cost of vocational rehabilitation should not exceed the average yearly disability benefit (approximately \$8,989 in 2004). The policy makes it clear that the authorities cannot terminate a person’s CPP disability benefit merely because they have completed a vocational rehabilitation program. The termination will only be justified where the vocational rehabilitation has restored the capacity to work to the extent that the person no longer meets the test for disability under the Act.

### **Return to work incentives**

In 1995, CPP introduced a policy designed to remove work disincentives experienced by people receiving the CPP disability benefit. At that time, one percent of recipients had benefits terminated because they returned to work, five percent because of death, and nine percent because of retirement. The policy introduced four work incentive measures to assist benefit recipients with community participation and economic re-integration, and allowed for:

1. volunteer activity, which does not in itself indicate a regained capacity to work;
2. three-month trial work periods during which the full CPP disability benefit is paid;
3. educational upgrading and rehabilitation rules to clarify how participation in these activities affects eligibility; and
4. fast-track reapplication for people who return to work and subsequently suffer a recurrence of the same disability within five years.

Each of these incentives was intended to encourage people to take steps towards returning to work without risking the loss of their CPP disability benefit. With the exception of volunteer activity, the policy setting out the work incentives must be read in light of more recent policies or changes to the law.



The three-month work trial now operates hand-in-hand with the policy on allowable earnings. Under the allowable earnings policy, a CPP disability benefit recipient is obliged to report their earnings only after they have reached a certain level in a 12-month period (\$4,100 in 2005). This reporting triggers the CPP authorities to consider discussing with the benefit recipient possible participation in a three-month work trial. As the first step, the authorities must determine whether the person has a capacity for substantially gainful occupation, based on the amount of the person's earnings in a given month. The threshold amount is the annual substantially gainful occupation (SGO) benchmark (\$10,275 in 2005) divided by 12 (i.e., approximately \$856 per month).

The three-month work trial begins in the month after the month in which the client earns more than the monthly SGO amount. It is possible for a recipient to exceed the allowable earnings threshold (\$4,100 in 2005) and never exceed the monthly SGO benchmark in a given month (\$856 in 2005). Where a person does exceed the allowable earnings level but does not meet the monthly SGO benchmark, they may nonetheless be required to participate in a three-month work trial if the CPP authorities believe they have regained the capacity to perform regularly, profitably and productively in employment.

The work trial policy allows a person to return to work (potentially full-time) and maintain full CPP benefits for three months. Under CPP policy guidelines, CPP staff should follow up with the benefit recipient a week or so before the end of the three-month period to determine if the person is working regularly, productively and profitably. If so, the benefit will be terminated at the end of the third month. If not, the benefit will continue. It is also possible that CPP administrators will suspend the benefit while determining whether the person continues to meet the test for disability under the Act.

### **Automatic reinstatement and fast-track reapplication**

The fast-track reapplication process outlined in the 1995 policy guidelines has been superseded to a great extent by legislative changes to the CPP which provide for "automatic reinstatement." Automatic reinstatement applies to CPP disability recipients who had their benefits terminated as a result of returning to work as of 31 January 2005 or later. Under the changes to the CPP and Regulations, a person with a disability may within two years of re-starting work, apply to have their benefits reinstated if they are not able to work because of their original or a related disability. The application for automatic reinstatement must be made within 12 months of the month in which the person again became incapable of working. Where a person's disability benefit is reinstated, the disabled contributor's child benefit will also be reinstated if there is a child who meets the eligibility criteria for that benefit. The amount of the disability benefit that the person will receive on reinstatement cannot be less than the amount of the benefit the person received in the month prior to returning to work when their benefits were terminated for that reason (adjusted for inflation). A person who is denied automatic reinstatement can avail themselves of the various levels of reconsideration and appeal available to other applicants under the CPP.

The fast track reapplication process set out in the 1995 policy guidelines is still in place. It will benefit people who return to work and have a recurrence of the same disability within five years. It creates an expedited reapplication process for people who are outside the two year

time-frame for rapid reinstatement, and who last received a CPP disability benefit five years ago or less. To be eligible for fast track reapplication a person must:

- apply within six months of stopping work;
- have stopped work due to the same disability; and
- meet the earnings and contributory requirements.

The CPP authorities have committed to processing fast track reapplications quickly and have developed a reapplication form to allow them to do so.

## **Charter challenges**

Challenges under the *Canadian Charter of Rights and Freedoms* to the denial of CPP disability benefits have not succeeded. There are two reported court cases where a person has challenged the denial of a CPP disability benefit, alleging that an aspect of the CPP Act infringes on section 15 of the *Charter*. *Charter* section 15 guarantees people with disabilities equal protection and benefit of the law.

In the 1997 case of *Xinos v Canada (Attorney General)*, an applicant was denied the CPP disability benefit because he had not made sufficiently recent contributions to the plan. He argued that the “recency test” set out in the CPP denied the equal benefit or equal protection of the law guaranteed by section 15 of the *Charter*, since the recency test applied only to people applying for the disability benefit and not the other benefits under the plan (i.e., retirement, survivor, or death benefits). The Federal Court of Appeal dismissed the case. It concluded that the section 15 guarantee of equal benefit and equal protection of the law did not require that every beneficiary under the CPP be entitled to identical benefits or identical conditions of eligibility. The Court reasoned that it was not surprising that a scheme designed to replace loss of employment income due to disability required some evidence of a certain level of recent income from employment in the years immediately prior to the disability. The Court concluded that even if discrimination could be found, the use of the recency test to meet the objective of maintaining a viable income replacement program was legitimate and thus such discrimination was justified.

In 2000, the Supreme Court of Canada decided *Granovsky v Canada (Minister of Employment and Immigration)*, another challenge to the recency requirement under section 15 of the *Charter*. Granovsky, who claimed to be suffering from an intermittent and degenerative back injury, had been denied a CPP disability benefit because he did not satisfy the recency test for contributions – having only contributed in one year of ten in the relevant period prior to his disability. At the time of his original injury he applied for the CPP disability benefit, but did not meet the test for disability. He continued to work sporadically for many years, and applied again for the CPP disability benefit. He was refused the benefit because, although he met the test for disability, he did not meet the contributory requirements. He claimed that in the years he had not made contributions to the CPP program from his earnings, he was unable to meet the level of earnings required to make contributions because of his back condition. Granovsky argued that the CPP infringed section 15 of the *Charter* because the contribution requirement fails to take into account the fact that persons with temporary disabilities may not be able to

make contributions for the minimum qualifying period because they are physically unable to work. Granovsky asserted that the recency test effectively discriminates against people with temporary disabilities by treating them differently from able-bodied people whose ability to work without interruption allowed them to make sufficient contributions.

The Supreme Court unanimously denied the appeal. The Court's reasons draw on a part of the CPP contributory test that allows applicants to "drop out" from the calculation of contributions any years in which they are disabled according to the CPP test for disability. Granovsky did not benefit from the "drop-out" provisions during the years prior to applicant since he did not meet the CPP definition of disability.

In the Supreme Court's view, Granovsky failed to show a convincing human rights dimension to his complaint. He failed to show that the government's response to his condition, through the design of the CPP or its application, demeans the dignity of persons with temporary disabilities or casts any doubt on their worthiness as human beings. The "drop-out" provision relates to the health status of applicants in each of the 10 years prior to the application (i.e., the relevant contribution period) during which time Granovsky enjoyed a health advantage relative to the permanently disabled. The differential treatment afforded by the "drop-out" provision assists the position of those with a history of severe and permanent disabilities. It does not assist more fortunate people such as Granovsky, who had only temporary disability. However, in the context of a contributory benefits plan, Parliament is inevitably called upon to target the particular group or groups it wishes the CPP to benefit. Ultimately, the Supreme Court decided that Parliament did not violate the purpose of the *Charter's* equality rights section by seeking to benefit individuals with a history of severe and prolonged disability.

## **Barriers to income security**

### **Psychological barriers**

As with applicants for an LTD disability benefit, the psychological impact of declaring oneself disabled and unable to work may be a barrier to applying for and receiving the CPP disability benefit. Many people may conceive of applying for and receiving CPP benefits as tantamount to "dropping out" of the workforce, a move that has emotional and psychosocial repercussions for many.

A further psychological barrier is the perception by some that CPP authorities are concerned primarily with limiting the number of people receiving benefits, rather than the income security and well-being of people who apply for and receive benefits. The prospect of re-assessment is frightening for many people living with HIV/AIDS who are receiving disability benefits. This fear discourages recipients from initiating contact with CPP authorities and may lead to under-reporting of earned income. The mistrust of the motives of CPP authorities can effectively undermine many of the potentially beneficial aspects of the CPP disability program for recipients. Remarkably few CPP disability benefit recipients have taken advantage of the flexibility in the measures aimed at assisting with return to work and other social reintegration, such as removing disincentives to work and vocational rehabilitation. Over the years, the perception has become that CPP is solely an all-or-nothing income

program, rather than a program with built-in flexibilities that can benefit people living with HIV/AIDS and other episodic disabilities. This has left recipients with a hearty scepticism of the motives of CPP administrators.

The recent legislative and regulatory amendments to permit automatic reinstatement is a welcome development which could foster a greater understanding of the CPP disability program and start to earn the trust of benefit recipients. The importance of enshrining “incentives” to return to work in legislation, thereby giving recipients a right to such measures and the right to the reconsideration and appeal process if denied, cannot be underestimated. Also, recently the CPP authorities have made an effort to communicate the changes to recipients, both through direct communications with CPP benefit recipients and via their Website. It also appears that CPP authorities are now taking an active case management approach to working with recipients who unsuccessfully attempt to return to work and need to use the automatic reinstatement mechanism.

### **Access to information**

The barriers to income security associated with access to information under the CPP are different from those associated with LTD insurance. Unlike LTD policies, the fundamental rights, obligations and entitlement under the CPP are set out in legislation. This legislation is publicly available to applicants, recipients and their advocates. In addition, many details of the CPP program are available online. However, CPP policy guidelines are not published or publicly available via the internet. In this respect, the CPP is lagging behind programs such as Employment Insurance and many provincial social assistance programs which post their policies and procedures on the internet in the interests of transparency and accountability.

The different case management approaches between CPP and LTD insurers have an impact on access to information. Most LTD claims are assigned to an individual to manage the case. This person is the claimant’s point of contact with the insurance company, and also serves as the point of contact for the claimant’s physician and advocate. The LTD case manager is usually readily accessible by phone, mail and email, and is available to discuss the details of the claim including what information is required to support the claim. CPP, however, is a huge bureaucracy. It is virtually impossible to discuss the details of an application with a CPP employee. All correspondence is with the office responsible for CPP claims processing. Throughout the entire CPP applicant and appeals process, it is unlikely that a claimant will ever speak with the person who has been responsible for adjudicating and processing their claim. This paper process makes for a very impersonal experience, one in which the claimant is given the impression that their claim is not receiving the attention it deserves.

### **No fixed timelines for adjudication**

Similar to LTD claims, the initial adjudication of CPP claims has no fixed timeline. Applicants do not know how long they can expect to wait before receiving a decision in their claim. Nor is there an initial file review process within a fixed period of receiving the information (e.g. 10 days) to ensure that crucial sources of information (such as medical test result or consultation notes) are not missing. The applicant is invited to submit further information to support the

claim only at the reconsideration stage. If the applicant does submit further information, they must then wait for a further adjudication of the claim – with no fixed timeline for a decision.

The lack of a fixed timeline for rendering decisions, and the lack of an initial file review process, present barriers to income security for people living with HIV/AIDS, for the reasons described above in the section on LTD benefits.

### **Disability test does not reflect episodic disabilities**

The “prolonged” requirement in the CPP test for disability fails to consider the unique circumstances of people living with episodic disabilities, including HIV/AIDS. By requiring a “severe” condition to last a minimum of one year, the definition does not accommodate people with episodic disabilities that may keep them from the workforce for less than one year, but whose condition nevertheless is ongoing. The prolonged requirement may be tempered by the condition that being able to work intermittently does not qualify as “regular” employment. However, adjudicators typically first assess whether the disability is prolonged, and then whether it is severe, which reverses the legislative requirements. There is no apparent legislative justification for this approach. Nevertheless its effects may serve to limit eligibility for people with recurring or cyclical illnesses.

The fact that the disability definition is tied to employability is helpful in that it allows for a “real world” approach to disability adjudication focused on actual ability to work rather than relying solely on medical criteria. However, equating disability and unemployability poses particular problems for people living with HIV/AIDS and others with episodic disabilities, and serves to undermine the stability of the CPP. If the CPP allowed applicants to continue to work the amount that they were able to, while providing a top-up or a guaranteed minimum earnings amount, people with disabilities could work when possible, but take much needed time off when their conditions required it. When working, they would continue making contributions to the plan.

A less rigid test for disability, combined with a higher threshold for allowable earnings and income deductibility, would provide income security and the necessary flexibility to accommodate the people with unpredictable illnesses. At the same time, it would help generate revenue for the program and sustain it.

### **Recency requirement**

Regardless of the amount of money or the number of years that a person has contributed to the CPP, a person might not fulfill the contributory requirement if they have not made sufficiently recent contributions. Despite the CPP disability benefit’s unique recency requirement, and the detrimental effect it has on claimants with recurring, progressive, or sporadic disabilities, *Charter* challenges to the more onerous eligibility criteria have been unsuccessful.

In effect, the overly strict definition of disability combined with the recency requirement sets people with episodic disabilities up for income insecurity. As HIV disease progresses, people with symptoms of HIV participate in the workforce to the extent that their health permits. Yet

if their participation is truly minimal, they risk not being able to meet the requirement for recent contributions even as they meet the test for disability.

The situation of many people living with HIV/AIDS is somewhat different from Granovsky, the man who was seeking the CPP disability benefit in the Supreme Court case. First, there is a history of stigma that people living with HIV/AIDS have faced due to their illness. This stigma continues today and sometimes manifests itself in job losses due to disclosure of HIV status. Second, it is debatable whether people for whom HIV is an obstacle to steady earnings are “more advantaged” than people with permanent disabilities that result in stable impairments.

Depriving people living with HIV/AIDS, and other episodic disabilities, of the CPP disability benefit has long-term detrimental effects and is at odds with Canada’s stated commitments – manifested at various United Nations sessions on HIV/AIDS and in binding international human rights treaties – to improve the standard of living of people with HIV/AIDS.

### **Reliance on objective medical evidence and physicians as gatekeepers**

As in the case of the LTD benefit, the reliance on objective medical evidence and physicians to establish initial and ongoing eligibility for a CPP disability benefit may present a barrier to income security for some people. This has been discussed above in more detail in relation to LTD benefits.

### **Lack of coordination between CPP disability and LTD benefits**

The lack of coordination between the LTD benefit and the CPP disability benefit operates as a barrier to income security for people living with HIV/AIDS in a number of ways.

First, the deduction of the CPP disability benefit amount from the LTD benefit amount can have negative financial consequences for a person receiving both sources of income. The CPP disability benefit is indexed to inflation and thus the amount of the benefit increases annually to reflect increases in the cost of living. However, LTD benefits may or may not be indexed to keep pace with inflation or increases in the cost of living. For people whose LTD benefit is not indexed, the real amount of money they receive will decrease year after year since any increase in the CPP disability benefit will be deducted from their fixed LTD benefit. A further financial barrier to income security for people with disabilities and their families was the practice, by some insurance companies, of deducting the amount of the disabled contributor child benefit from the LTD benefit. In 2003, in *Hennig v Clarica Life Insurance Company*, the Alberta Court of Appeal found this practice illegal. The fact that this practice went on for many years, to the detriment of many people with disabilities and their families, indicates the lack of responsiveness of government regulators to the ways in which interactions between income security programs can lead to income insecurity. Rather than legislators taking the initiative to correct the situation, it was left to an individual recipient to litigate the matter.

Second, there is no established mechanism to coordinate vocational rehabilitation under LTD and CPP. While it is in the interest of the private insurer and CPP, and may be in the interest of the person receiving benefits, for that person to undertake vocational rehabilitation, there



is currently no mechanism to coordinate or share the costs of a rehabilitation program. In most circumstances it would be left to the client or someone acting on behalf of the client to negotiate a vocational rehabilitation plan and coordinate the flow of information with the various parties involved. Presumably both CPP and the private insurer would have to approve of the rehabilitation program, failing which the person could lose one or other of their benefits.

Third, return to work is treated differently under LTD policies and the CPP disability program. The difference in programs may have adverse effects on a recipient's eligibility, and the different rules and obligations may be extremely confusing. Under CPP, a recipient has no obligation to report earned income until the amount exceeds the allowable earnings threshold. Once recipients exceed the threshold and report their income, they may be invited to start a three-month paid work trial during which time they will receive their full CPP disability benefit and the earned income. At the end of the three-month work trial, recipients must decide if they are ready to return to work and discontinue their CPP disability benefit. Under many LTD policies, recipients have an obligation to report all earned income and any change in their circumstances (such as returned capacity for work). When recipients report income, they will likely be invited to participate in a period of rehabilitative employment which can last up to two years without affecting the recipient's eligibility for LTD benefits (although any income earned during that time is deducted).

### **Eligibility by reconsideration and appeal**

The CPP provides "second chances" to applicants who are initially denied the CPP disability benefit. The success rates at the reconsideration and appeal stages indicate that too many applicants who are entitled to receive benefits are not granted benefits at the initial application stage. While it is encouraging that many people do eventually receive benefits to which they are entitled, such high rates for reversing the initial decision to deny benefits highlight a problem with the initial processing of applications. The problem may be the quality of the adjudication, or the lack of information clients are able to put before adjudicators. If the problem is with the quality of adjudication, better training of adjudicators is in order. If adjudicators do not have sufficient information before them to make "good" decisions, which evidence is then made available on reconsideration and appeal, it would make sense to have more intensive case management to ensure that this information is brought forth at the application stage. Increasing the resources at the initial application stage could result in significant resource savings at the reconsideration and appeals stage, and perhaps an overall saving for the CPP. Consider that the Review Tribunal spent \$4.28 million in the year ending 31 March 2002 just on per diems for panel members. What would be the cost savings of cutting the number of appeals in half through better up-front claims processing and adjudication?

The various levels of appeal and reconsideration also potentially represent a period of financial disaster and emotional frustration for applicants. Financially, people who are refused CPP disability are forced to spend savings or to apply for provincial social assistance to meet their living needs (if they are not already receiving social assistance). Unlike the CPP disability benefit, provincial social assistance benefits are asset-tested, meaning that people who have more than a certain amount of assets must spend those down in order to qualify



for social assistance benefits. So a person could be forced to spend the savings they have accumulated over years while disputing a denial of the CPP disability benefit, and end up on social assistance with only limited savings. The fact that people who are eventually found eligible by a Review Tribunal or the PAB will be paid the CPP disability benefit retroactively and receive it in a lump sum is unlikely to compensate them for the stress associated with living with income insecurity in the interim and having to pursue various reconsiderations and appeals. In the extreme, for people living with HIV/AIDS, this stress can have a detrimental impact on their health.

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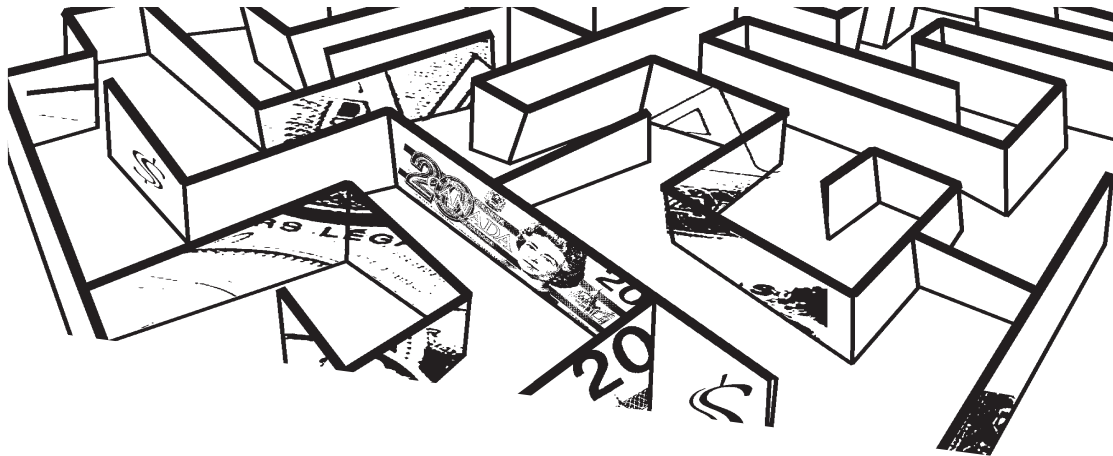
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## Provincial and territorial social assistance

*The features of the social assistance programs described in this section are not necessarily part of every provincial/territorial program. Specific provincial/territorial programs are referred to as examples; programs in other provinces/territories may have the same or a similar feature. Readers who have questions about social assistance in their province/territory should contact the provincial or municipal office responsible for social assistance, or seek legal advice.*

Social assistance programs, sometimes referred to as welfare, are provided as a last resort to those who are unable to meet their basic financial needs through other sources of income. People rely on social assistance only when they have exhausted virtually all of their other options and resources. Social assistance is administered by the provinces and territories, some of which have granted a degree of administrative control to regional and local governments (including Aboriginal governments). Funding for social assistance programs is shared between the federal government and provinces/territories. In some provinces and territories, post-secondary students can qualify for assistance if they meet stringent requirements; in others, students are categorically ineligible for assistance. Jurisdictional divisions add an additional layer of complexity for many Aboriginal people. Conflicts and confusion over which level of government (federal, provincial/territorial, or band council) has jurisdiction to provide a particular Aboriginal applicant with benefits can send Aboriginal people with disabilities (particularly those in urban areas) on endless trips between various offices. During times of economic recession, nearly 10 percent of the Canadian population has been in receipt of social assistance.

Social assistance is most often the only source of income for those people with disabilities who do not have significant employment history. As the burden of HIV infections in Canada has shifted to populations that have traditionally been marginalized in society and in the labour force (e.g., injection drug users, immigrants to Canada, young women, Aboriginal people), more and more people living with HIV/AIDS rely on social assistance as a source of income and, where available, other supports and benefits.

There is only one national standard for social assistance programs – applicants cannot be denied assistance because they come from outside the province or territory where they are seeking assistance. Programs vary widely among the provinces and territories. It is beyond the scope of this report to examine each of the 13 provincial and territorial social assistance programs in detail. Instead we provide an overview of some typical features of the programs that are most relevant to people living with HIV/AIDS.

## **Overview of social assistance programs for people with disabilities**

People with disabilities living in Alberta, Ontario, or British Columbia have access to disability-specific income security programs. These programs are “separate” from regular social assistance in that they have been specifically designed to meet the needs of people with disabilities. People with disabilities in the other provinces and the territories must rely on the general social assistance programs. These provinces and territories provide income assistance to all eligible people, usually supplemented by a range of extended benefits available only to people with disabilities.

## **Eligibility and eligibility review**

All applicants for social assistance benefits must submit personal and financial information about family members with whom they live and have a relationship of interdependence, including proof of age, citizenship/immigration status, proof of income, a bank statement, and proof of address.

### **Basic eligibility: the “needs” test**

Social assistance programs are “needs” tested – social assistance authorities compare the budgetary needs of an applicant and any dependants with their income and assets. Budgetary needs are intended to include items such as food, shelter, clothing, household expenses, transportation and personal grooming items as fixed by government regulation. However, the budgetary needs amount as established under regulations does not correspond to the actual cost of these items, and certainly does not correspond to the amount of income needed to maintain health and well-being. Assets are broadly defined, but most jurisdictions do not count the following in assessing eligibility:

- assets that cannot be easily converted to cash;
- household items;
- principal residences; and
- a small amount of liquid assets.

Income is also broadly defined. To qualify for social assistance an applicant’s household needs must be greater than the household’s resources, or their budget surplus must be insufficient to meet the cost of special needs such as medications or disability-related equipment.

In provinces/territories where people with disabilities receive benefits under the general social assistance program, applicants can usually be divided into four categories:

- employable persons
- single-parent families with young children
- the elderly
- persons with disabilities

Different rules of eligibility (at the time of application and on an ongoing basis) apply to each group. As a condition of applying for social assistance, most provinces and territories require applicants to show that they have looked for and are unable to find employment. As a condition of ongoing eligibility, most provinces and territories require people to actively look for employment or participate in “workfare” activities. Workfare activities usually include one or more of the following: basic literacy education, work placements, job counselling or structured job searches. People applying for and receiving benefits because of a disability, those who have temporary medical conditions which make them unable to participate in workfare activities, the elderly, and parents with young children are often exempted from job search and other workfare requirements.

People with disabilities applying for social assistance must provide medical confirmation of their disability. This medical evidence is reviewed by medical professionals hired by the province or territory as adjudicators/assessors, who provide an opinion on the person’s degree of impairment based on their medical condition, ability to function in the workplace, and ability to undertake other activities of daily living. However, under most if not all programs, the ultimate decision about whether a person meets the test for disability is left to the administrator of the program, not the medical adjudicator/assessor.

### **Tests for disability**

The tests for disability vary among the provincial and territorial social assistance programs. All of the tests for disability are based, at least in part, on a person’s inability to work because of their medical condition. In this way, the social assistance disability tests are similar to the tests under the CPP and LTD policies. However, none of the provincial/territorial tests for disability is the same as the LTD tests and only one provincial test incorporates the CPP test. Under the Ontario Disability Support Program (ODSP), an applicant for benefits who is already eligible for the CPP disability benefit is automatically considered to be a “person with a disability” for the purposes of the Ontario program. In effect, the Ontario test for disability incorporates the test set out CPP, and CPP disability benefit recipients do not have to go through the detailed disability adjudication process to qualify for income support under the Ontario program.

Also under the Ontario Disability Support Program, a person who is disabled solely because of an addiction to drugs or alcohol is categorically ineligible. This exclusion arguably infringes upon the human rights of those applicants for ODSP who suffer from an addiction, under both the Ontario Human Rights Code and the *Canadian Charter of Rights and Freedoms*.

## **Coordination of benefits and deduction of the CPP/QPP disability benefit**

Applicants and recipients of social assistance have an obligation to seek out other sources of income, including other government and private benefits. If people who apply for social assistance on the basis of disability and who have a history of workforce attachment are not already receiving a CPP/QPP disability benefit, the social assistance authorities will likely require them to apply for CPP/QPP as a condition of receiving social assistance. Provincial and territorial programs deduct the amount of the CPP/QPP disability benefit dollar-for-dollar from the amount of social assistance income benefit. In practice, a person who is eligible for both a CPP/QPP disability benefit and social assistance will receive a cheque from CPP/QPP and a cheque from social assistance – the total amount of the two cheques will equal the total social assistance income benefit to which they are entitled. While the coordination of benefits provides no financial gain for the person receiving benefits, it saves the province or territory a potentially significant amount of money.

For some people, the amount of the CPP disability benefit may exceed the amount of the social assistance income to which they are entitled – which would make them ineligible for social assistance income benefits. However, some provinces will continue to provide people receiving CPP with other social assistance benefits, including prescription drug benefits, under certain circumstances.

It is unlikely that many people who receive an LTD benefit would also be eligible to receive income from social assistance. The amount of the LTD benefit is likely to exceed the amount of the social assistance income benefit a person would be entitled to – i.e., the person's budgetary needs as determined under the social assistance program. For example, assuming a social assistance benefit of \$1,000 per month, and an LTD benefit of 66% of gross pre-disability earnings, the person would have had to have earned less than \$18,200 annually to be financially eligible for an income benefit from social assistance. In reality, few jobs at or below that pay level offer employees LTD coverage.

### **Eligibility review**

People receiving social assistance have an ongoing obligation to report any change in their circumstances. Recipients must advise social assistance authorities of any change that is relevant to their eligibility for benefits or the calculation of the amount of their benefits. Usually recipients can fulfill this obligation by reporting on changes in employment income, other income, rent, living arrangements and family composition on a monthly basis. Some provincial and territorial programs also have file review procedures and protocols under which cases are reviewed at regular intervals or based on “red flags.”

Some provincial and territorial programs review a person's medical condition at set intervals to determine if they continue to satisfy the test for disability under the program. Under other programs a date for medical review may be established during the initial medical assessment (or during a prior medical review).

## **Income assistance benefits and earnings exemptions**

Income assistance under social assistance programs is intended to meet the budgetary needs of recipients. The calculation of the budgetary needs of, and the resulting amount of benefits provided to, people in similar circumstances varies widely among the provinces and territories. Yet in all provinces and territories the amount of the disability benefit is below the poverty line. According to the National Council of Welfare, in 2004 annual social assistance income benefits to which a single person with a disability was entitled ranged from \$6,584 in Alberta to \$11,380 in Ontario.

People receiving social assistance are permitted to work and earn money, but must report employment income to social assistance authorities. Most if not all provinces and territories encourage people to work by exempting employment income from the general rule that income should be deducted from benefits dollar-for-dollar. In some provinces/territories a person can earn a set amount of money without any deduction, in others only a portion of earned income is deducted, and other provinces/territories use a combination of these exemptions.

## **Extended health and other benefits, including prescription drug benefits**

In addition to an income benefit, social assistance programs offer a range of other benefits to recipients. The exact benefits offered and the criteria for eligibility vary widely among the provinces and territories. For people living with HIV/AIDS, the most important non-income benefit is prescription drug coverage under provincial and territorial prescription drug programs. Typically, people who receive social assistance are automatically eligible to have their prescription drugs paid for by the provincial and territorial prescription drug program.

Other benefits that may be available to social assistance recipients include:

- special diet and nutritional supplement allowances
- dental care
- vision care
- hearing aids
- guide dogs
- mobility devices
- day care
- prenatal benefits
- back-to-school and winter clothing
- school start-up allowance
- burial or cremation expenses
- medical and other transportation costs
- medical supplies



- benefits to establish a new residence
- co-payment under other government benefit programs

People living with HIV/AIDS, like other people receiving social assistance, will have a need for the full range of other benefits available under the provincial and territorial social assistance programs. For people taking HIV antiretroviral medications, the value of the prescription drug coverage alone can exceed by far the income assistance they receive. Not having access to some or all of these other benefits can have a detrimental impact upon the health of people living with HIV/AIDS.

Increasingly, financially well-off provinces are separating eligibility for extended health benefits from eligibility for social assistance. This means that people with disabilities who leave social assistance (because they return to paid employment, or because they are financially ineligible as a result of other benefits such as the CPP disability benefit) are still able to keep their extended health benefits. Ideally, such an approach would be taken in each jurisdiction.

## **Internal reviews and appeals**

Provincial and territorial social assistance programs have internal review or appeal mechanisms available to people who disagree with a decision of the social assistance authorities. The exact internal review and appeal system differs in each province/territory. In general, social assistance applicants or recipients can ask for an internal review (i.e., internal to the ministry or department responsible for administering social assistance) of a decision relating to their eligibility for, or the amount of, a benefit. Applicants or recipients who are unsuccessful on an internal review generally have a right to appeal their case to a specialized administrative tribunal or a court in the province/territory.

In most jurisdictions, where an application for benefits is refused or benefits are terminated, the person may be able to receive assistance pending the outcome of their appeal. However, if they lose their appeal they have an obligation to repay the benefits they received while the decision in their appeal was pending.

## **Supports to return to work and rapid reinstatement**

Provinces with disability-specific programs such as Alberta, Ontario and British Columbia encourage people to participate in competitive employment by offering education or employment supports. In these three provinces, participation in such programs is voluntary for people who continue to meet the test for disability and are otherwise eligible for benefits. In Alberta, if a file review demonstrates that a person is capable of earning a livelihood by pursuing full-time employment, the authorities have discretion to compel participation in such programs as a condition of receiving ongoing benefits.

For example, Ontario offers eligible recipients the following support:

- employment or self-employment planning assistance;

- employment or self-employment preparation and training;
- mobility, speech, vision, hearing, reading and writing aids and devices;
- prosthetics and orthotics;
- adaptive technology;
- interpreter, reader and note taker services;
- travel, route and orientation training for those who require assistance with directions;
- job coaching and assistance with job searches;
- transportation subsidies relating to employment;
- intervention with employers where disability affects job retention;
- on the job training; and
- child care.

In some provinces and territories, under certain circumstances, a person with a disability who has previously received benefits under the provincial/territorial social assistance program may be eligible for rapid reinstatement without a new medical adjudication. Whether or not a person is eligible for rapid reinstatement may depend upon the reason the person left the program, and whether the previous medical assessment of their circumstances is still valid.

## **Barriers to income security**

### **Benefit levels inadequate to maintain health**

As reported by the National Council on Welfare, social assistance rates in all Canadian provinces and territories and total welfare income levels (including GST and HST rebates) are well below the poverty line. According to the National Council on Welfare, in 2004 the total social assistance incomes (including income tax rebates) of single persons with a disability ranged from 39 percent of the poverty line in Alberta (\$6,584) to 59 percent of the poverty line in Ontario (\$11,380). Total welfare incomes for single people with disabilities were further below the poverty line all provinces in 2004 than they were in the late 1980's or early 1990's - despite increases in the cost of living over time. As a result, the value of most provincial and territorial social assistance income benefits continues to decline year over year.

It can be costly to live with a disability such as HIV infection, and current social assistance rates do not provide people with sufficient financial means to meet their health and basic needs. People living with HIV/AIDS likely will have, at some point, extraordinary health-related needs that are not provided for by social assistance or related benefits. People living with HIV/AIDS may rely on non-prescription medications and complementary and alternative therapies to manage HIV infection, opportunistic infections and the side effects of prescription medications. If they are unable to obtain these medications and therapies for free (e.g., from AIDS service organizations, student clinics, samples from physicians) they must pay for them out of their meagre social assistance income at the expense of meeting other needs (e.g., nutritious food) or go without. Neither option promotes good health for the individual and will likely lead to increased sickness with significant direct health care costs for government.

## **Complexity of the programs**

Many of the provincial and territorial social assistance programs are complex mazes composed of statutes, regulations, and policy guidelines. While most such documents are available on the internet, these documents are not written in plain language and contain numerous mathematical formulas and rules for determining benefit entitlements. The complexity is compounded for people whose first language is not English or French – mostly immigrants – who make up an increasing proportion of newly diagnosed cases of HIV in Canada.

In recent years, provincial and territorial governments have created plain language brochures about various aspects of their social assistance programs. In some jurisdictions, the brochures are available not only in English or French, but also in other languages reflecting provincial/territorial demographics. These plain language brochures do not provide full details on the programs and the benefits available. Caseworkers, who have a great deal of decision-making power, are effectively the gatekeepers of benefits. Whether or not a person will receive a benefit to which they are entitled may depend to a large extent on whether the case worker is aware of the benefit, and if so, whether they advise the person about the benefit. It is very difficult to estimate the number of people country-wide who are not receiving all of the benefits they are legally entitled to receive under provincial and territorial social assistance programs.

The complexity of many provincial and territorial social assistance systems also makes them administratively unwieldy and prone to administrative errors. One program area where this occurs frequently is in reporting employment income. Recipients have an obligation to report employment income. But the rules about deducting income from the person's total benefits entitlement are often complex. As a general rule, people must report income at the end of the month in which they receive it. Yet this income will have an impact on the amount of benefits not in the month they earn it, but in the month it is deducted from their social assistance cheque, which may or may not be the next month depending on how long it takes the authorities to act on the income reported. For people with episodic disabilities such as HIV, their ability to work and earn income may vary greatly from month-to-month. High earnings in one month can result in a small amount of social assistance income in the next month, at which point the person may be too sick to work. Unless the person has been able to save some of their earnings, they will suffer a severe budget shortfall at a time when their health is poor.

## **Disability tests and adjudication – a barrier to mobility**

While LTD and CPP benefits are portable across provincial boundaries, provincial/territorial social assistance benefits by their very nature are not. Each provincial or territorial social assistance program has its own legislative requirements, including different tests for disability, different forms that must be completed, and different adjudicators. The fact a person has qualified for social assistance on the basis of disability in one province or territory is not relevant to their eligibility for disability assistance in another province or territory. Like all people, people living with HIV/AIDS may wish to move from one province or territory to another to be closer to family and friends, to pursue employment opportunities, or to access better community services and supports. However, for people receiving social assistance

because of their disability, an inter-provincial/territorial move can result in uncertainty and economic hardship.

Take for example a person living with HIV/AIDS and receiving disability benefits under the Alberta Assured Income for the Severely Handicapped program (\$950 per month in 2005) who wants move to Ontario to access a better range of community support services and to be closer to family. Upon moving to Ontario, she would have to apply for social assistance under the Ontario Works program – the general (i.e., non-disability) social assistance program in Ontario if she needed benefits right away. She would then be referred to apply for benefits as a person with disability under the Ontario Disability Support Program. She would have to submit the required forms, including a medical form completed by her physician. Assuming that she could find a family physician in Ontario (or a physician in Alberta who was a member of the College of Physicians and Surgeons of Ontario), this physician would likely have no knowledge of the person's medical condition unless she had brought a copy of her medical file from Alberta. If she had not, then she would have to request a copy, which she would have to pay to have copied and sent, and which would take time to get to her new physician. Once her application was complete, she would have to wait a number of weeks or months to get a decision on whether she met the test for a person with a disability under the ODSP. If she were eligible, then the relevant file information would be transferred from the Ontario Works office to the ODSP office for processing, which could take a number of weeks. All the while she would be living with the uncertainty of not knowing if she would qualify for ODSP, and would be receiving income under the Ontario Works program (\$536 per month in 2005).

### **Reliance on objective medical evidence and physicians as gatekeepers**

Similar to the LTD benefit and the CPP disability benefit, the reliance on objective medical evidence and physicians to establish initial and ongoing eligibility for social assistance may present a barrier to income security for some people. See the discussion above in the sections on LTD and CPP disability benefits.

### **Provincial/territorial deductions undermine federal government benefits**

Receiving other government benefits often puts social assistance recipients in a worse financial position than people receiving the same benefits who are not on social assistance. They are worse off financially because other benefits are deducted from their social assistance income, without proper regard for the legislative intent behind these other benefits or the indexing built into the other benefits.

In every province and territory, families on social assistance have had the National Child Benefit Supplement “clawed back” (i.e., deducted from their social assistance benefit) by provincial and territorial governments for some period of time since 1998. Since 1 July 1998, the federal government has paid a National Child Benefit to all low-income families and many middle-income families with children under 18. The benefit consists of two components: the Canada Child Tax Benefit and the National Child Benefit Supplement. As of 1 July 2004, the maximum Canada Child Tax Benefit goes to families with an annual net family income of \$35,000 or less, and is not considered income for the purposes of calculating social assistance eligibility. The maximum National Child Benefit Supplement goes to families with

net incomes below \$22,615, and partial supplements go to families with incomes between \$22,615 and \$35,000. As of early 2004, only Newfoundland, Nova Scotia, New Brunswick, Quebec, Manitoba and Alberta did not claw back the National Child Benefit Supplement. In all other provinces, the children of people receiving social assistance are worse off than the children of low- and middle-income families with working parents. In reality, the impact of the claw back is felt by the entire family, not just the child(ren).

People on social assistance who receive other, indexed government benefits do not receive any benefit from that indexing. For example, as the amount of the National Child Benefit Supplement has increased year by year to take into account increases in the cost of living, the amount of money clawed back by provinces and territories has also increased. As a result, the amount of money received by families on social assistance has decreased in real dollar value since social assistance rates have not similarly kept pace with increases in the cost of living. This same dynamic characterizes the deduction of the CPP disability benefit from provincial and territorial social assistance. Each year, the amount deducted on account of the CPP disability benefit is greater, and in constant dollar value, is a greater proportion of the fixed social assistance income benefit. What is effectively occurring is an ever-increasing transfer of funds from federal government programs into provincial and territorial accounts as they pay less and less each year to those social assistance recipients receiving indexed federal benefits. Leaving aside the federal-provincial/territorial budgetary implications, the provincial and territorial social assistance programs are undermining key aspects of federal government programs designed to provide much-needed assistance to vulnerable groups of people, such as children and people with disabilities.

### **Extended health benefits tied to social assistance**

For people living with HIV/AIDS, access to extended health benefits including prescription drug benefits is a matter of survival. Without HIV antiretroviral medications many people living with HIV/AIDS would face increased chances of illness and pre-mature death. There is no standard way in which extended health benefits are provided to people living with HIV/AIDS. The vast majority of people living with HIV/AIDS in Canada do not have access to specialized government programs which provide HIV/AIDS drugs, or catastrophic drug programs which pay most of the costs of medications for people with exceptionally high prescription drug costs.

In a few provinces and territories, extended health benefits are tied to ongoing receipt of social assistance income benefits. In those jurisdictions, only those people who are receiving social assistance income benefits are eligible for prescription drug and other extended health benefits. Many people living with HIV/AIDS in these jurisdictions who have been prescribed antiretroviral medications simply cannot afford to work and pay for their basic needs and the cost of their medications. They must stop working in order to get government-funded prescription drug coverage.

Some provinces or territories permit people to continue to receive government-funded extended health benefits even if their income (either from employment or from sources such as CPP) exceeds their budgetary needs such that they do not receive social assistance income benefits. However, the person must have been eligible for and in receipt of a social assistance

income benefit to continue to access the extended health benefits. Many people in low wage jobs that do not include extended health benefits as part of the remuneration must leave their jobs in order to become eligible for social assistance and access to extended health benefits. Once they are receiving social assistance they can then look for work and, if they find a suitable job, return to paid employment and continue to receive extended health benefits.

### **Lack of coordination between social assistance and CPP disability benefits**

As with CPP and LTD, the lack of coordination between the CPP disability benefit and provincial/territorial social assistance benefits operates as a barrier to income security for people living with HIV/AIDS in a number of ways.

First, the deduction of the CPP disability benefit amount from the social assistance benefit amount can have negative financial consequences for a person receiving both sources of income. As explained above, any financial gain from the indexing of the CPP disability benefit is lost because of its deduction from the social assistance benefit.

Second, the deduction of the CPP benefit can result in loss of eligibility under the social assistance program. Because of indexing, the CPP disability benefit increases each year. There may be a point at which the amount of the CPP benefit, counted as income under social assistance programs, exceeds a person's budgetary requirement – i.e., under the social assistance rules. They are no longer in need of income support because they have sufficient income to meet their budgetary needs. People who live in provinces or territories that have not increased their social assistance rates for many years are at the greatest risk of losing their eligibility in this way.

In some provinces and territories, a person who is not eligible for social assistance income benefits also loses eligibility for extended health and other benefits offered under the social assistance program. In recent years, some provincial and territorial governments have reformed programs to prevent the loss of extended health benefits where a person is ineligible for an income benefit under the social assistance program. In general, this has been accomplished in one of two ways: First, some jurisdictions now offer extended health and other benefits for eligible persons with disabilities separate from the social assistance program. Second, some jurisdictions take into account health care costs, including prescription drug costs, in determining people's eligibility for extended health benefits. If a person's income is less than their health care costs plus their other budgetary needs, they retain eligibility for extended health benefits. Both types of reforms are of great benefit to people with HIV who rely on costly antiretroviral medications to maintain their health.

Third, there is no established mechanism to coordinate vocational rehabilitation and employment supports under CPP and social assistance programs. As with CPP and LTD, in most circumstances, it is left to the client or someone acting on behalf of the client to negotiate a vocational rehabilitation plan with, and coordinate the flow of information between, the relevant federal and provincial/territorial authorities.

Fourth, return to work may be treated differently under social assistance programs and the CPP disability program. The difference in programs may have adverse effects on a recipient's

eligibility, and the different rules and obligations may be extremely confusing and perhaps overwhelming for the person living with HIV/AIDS.

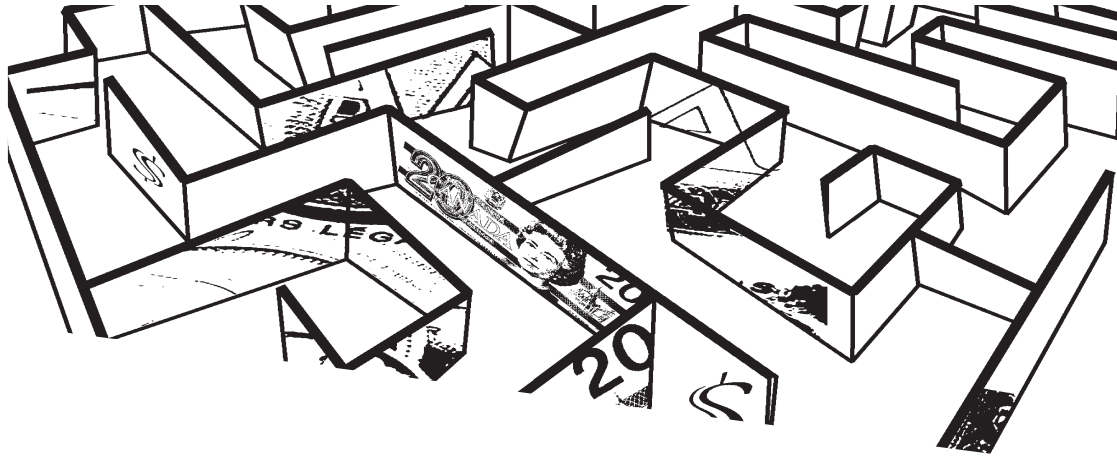
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# Recommendations for a coordinated approach to disability benefits

## Principles and observations central to reform

A number of basic principles and observations underpin the analysis of disability income programs in relation to the lives of persons living with HIV/AIDS, and effective reform of social and economic policy in Canada and how it can most effectively be changed:

- Canada has an obligation under international human rights law to take steps towards the progressive realization of the right of everyone to work, which includes the right of everyone to the opportunity to gain a living through work which is freely chosen or accepted, and the right of everyone to social security in the event of unemployment, sickness or disability.
- Because of medical advances, many people living with HIV/AIDS in Canada can now expect to live longer than would have been expected a decade ago, and many can work and otherwise contribute to their communities if appropriate supports and accommodations are available to meet their needs.
- Increasingly, people newly diagnosed as HIV-positive in Canada are from socially and economically marginalized and disadvantaged groups.
- People living with HIV/AIDS differ from one another in their health, economic and disability status, just as the broader community of persons with disabilities do.
- The economic inclusion of persons living with HIV/AIDS and other disabilities in Canadian society is a critically important social objective, not only because of the personal and social costs of exclusion, but because their skills and contributions are highly valuable. This is more the case now than ever because of the projected need for a skilled and knowledgeable workforce in Canada over the next three decades to replace retiring workers.
- There will continue to be people living with HIV/AIDS and other significant disabilities whose health status and economic circumstances will require them to be economically

dependent on disability income programs, and reforms must equitably address their needs, as well as the needs of those who can and want to work.

- Effective reform of disability income programs as they affect people living with HIV/AIDS will require the broad support of disability and health organizations throughout Canada.

## **Need for leadership from the federal government**

Some of the barriers to income security faced by people living with HIV/AIDS are inherent in the individual benefit programs – both public and private. But most result from the existence of multiple programs to which people living with HIV/AIDS must apply in order to meet their income and benefit needs, and the interaction and lack of coordination between those programs. Better coordination amongst programs such as private LTD, the CPP disability benefit, and social assistance will likely not happen so long as governments and private insurers continue to set program rules and administer programs separately. The federal government must take a leadership role, building on federal-provincial/territorial proposals for reform to programs for people with disabilities. Federal-provincial/territorial cooperation on issues related to people with disabilities is already underway. In 1996, federal and provincial/territorial governments created the Federal-Provincial-Territorial Council on Social Policy Renewal. The Council, guided by the Social Union Framework Agreement, is responsible for piloting efforts to renew and modernize Canadian social policy, with a focus on the pan-Canadian dimension of health and social policy systems, based on the recognition that reform is best achieved in partnership. The Council has identified children in poverty and persons with disabilities as the priority areas for social policy reform. To date, the Federal-Provincial-Territorial Council on Social Policy Renewal has published two documents on policy reform for people with disabilities. These documents, listed in the references to this section, should be the basis for further action. The federal government must also encourage the private insurance industry to be part of the reform process.

### **Recommendation 1**

The Government of Canada should engage the 13 provincial and territorial governments, and the private insurance industry, in a process directed at significant reform of all laws and policies that deal with income support and benefits for persons with disabilities. This process should build on the work already being done under the Social Union Framework Agreement.

## Recommendation 2

The reform process should aim at a common and coordinated approach to laws and policies, without infringing on federal or provincial jurisdiction.

## Recommendation 3

The reform process should involve, in an ongoing, direct and meaningful way, the input of organizations representing persons with disabilities, including persons living with HIV/AIDS, in order to use their considerable expertise on these issues.

## Removing barriers to income security

### Single point of access to information about programs

As it stands, there is no single source that can provide people living with HIV/AIDS with information about the range of programs they may need to access to provide them with assistance and extended health benefits. While the federal government is moving forward with single point of entry services (i.e., the Government On-Line Initiative; Service Canada Access Centres Initiative), many Canadians living with HIV/AIDS and other disabilities many not benefit from these programs to a great degree. With respect to the Government of Canada On-Line initiative, low income people are least likely to have access to advances in information technology, and technology may not meet the needs of people living with perception or sensory-related disabilities. Moreover, the exclusive focus on creating a single point of access for federal government services, while important, will be of limited benefit. As indicated in this report, the reality is that people living with HIV/AIDS typically rely on a complex mix of federal and provincial/territorial, and public and private programs to meet their needs for income security and extended health benefits. Greater coordination beyond a single point of access for federal programs is needed.

## Recommendation 4

Federal and provincial/territorial governments and the private insurance industry (through the Canadian Life and Health Insurance Association) should cooperate to establish a true single point of access for people living with HIV/AIDS and other disabilities in need of income support and extended health benefits in every province and territory.

## **Advocacy services for people living with HIV/AIDS**

Each disability income program reviewed in this report is complex. The interactions between the programs add a further level of complexity for people living with HIV/AIDS applying for and receiving benefits. Yet no program provides advocates to people living with HIV/AIDS applying for and receiving benefits under the programs, and there is no coordinated case management for people who must contend with the rules of more than one program. This lack of information and support can act as a significant barrier to people's ability to maximize their income security under the programs, and can act as a barrier to accessing supports to return to employment. While some larger community-based AIDS service organizations have benefits support workers for clients, many do not have these resources. While some provinces/territories provide legal assistance to people applying for and receiving benefits under legal aid programs, others do not.

### **Recommendation 5**

The Public Health Agency of Canada should make long-term, sustainable funding available through the Federal Initiative on HIV/AIDS to community-based AIDS service organizations to hire and train benefits caseworkers, given that income is a key determinant of health for people living with HIV/AIDS.

### **Recommendation 6**

The Public Health Agency of Canada should advocate for funding from the Department of Justice for legal services for people living with HIV/AIDS applying for, and in receipt of, benefits under public and private income security programs.

## **Rationalizing tests for and assessments of disability**

Despite myriad different tests for disability, none adequately addresses the needs and circumstances of many people living with HIV/AIDS and other episodic disabilities. People with episodic disabilities may be reticent to categorize or label themselves as “totally disabled” or “totally unable to work” for an indefinite or prolonged period, as is required under current tests for disability. Their reticence may stem from the fact that they may not be totally disabled and unable to work for prolonged periods. Some people living with HIV/AIDS may be unable to continue working full-time as a result of illness or side effects from medication, but can continue to work if their disability is accommodated through reduced work hours. Other people may experience episodes of illness which render them incapable of functioning in the workplace, followed by an episode during which they can work part-time or full-time, followed by an episode of incapacitating illness, and so on. The

categorical nature of current tests for disability results in the social marginalization of many people with disabilities.

To a certain extent, LTD, CPP, and social assistance programs permit people to work, study and/or engage in volunteer activities. These are important opportunities for people living with HIV/AIDS; however, the rules are not well known and there may be a sense of distrust. As a result, people who may be able to work to some extent, do not attempt to do so out of fear of losing benefits. In doing so, they forego the social interactions and sense of personal fulfillment that many get from working. Moreover, these aspects of the programs only temper the tests for disability; they do not fundamentally change the test for disability that people must meet at the time of application and on an ongoing basis in order to receive benefits.

Many people with disabilities apply for benefits under more than one disability income security program, often not by choice. Under each scheme, the test for disability is different, different forms must be completed, and different adjudicators assess medical and other evidence. Under public disability income insurance programs, there are at least 14 distinct tests for disability, excluding the test for the EI sickness benefit which is short-term in nature. Under private LTD insurance policies, the test for disability usually changes at some point (e.g., at the two year mark); prior to that time, people must show they are unable, by reason of disability, to perform in their “own occupation” and after that point, people must show that they are unable to perform in “any occupation.” And because private LTD insurance is a matter of contract, the definitions of disability often vary from contract to contract. The medical and personal information upon which decisions regarding eligibility are made is essentially the same under each program, yet the applicant and their doctors must complete a different application for each program to which they apply.

As a result of so-called “coordination of benefits” clauses in private insurance policies and the obligation under provincial/territorial social assistance programs to seek other benefits, people are compelled to apply to programs which offer them few if any material benefits beyond what they are already receiving. The lack of coordination – both in terms of the different tests for disability under different programs and the assessment of whether a person meets each test – results in significant personal and social costs. People living with disabilities must complete forms, go to medical appointments, have their health care providers complete forms, submit the forms, and wait for a determination for each program to which they apply. This process takes time and energy, can be extremely stressful, and can potentially result in increased health problems at a time when a person is seeking benefits because of already poor health. People living with disabilities often bear the cost of repeatedly proving their disability, especially when their initial application is turned down and further information is required. The absence of fixed timelines for rendering decisions adds to the uncertainty faced by people applying for disability benefits. Even if they are entitled to more than one benefit, they rarely if ever realize any financial gain from a successful application to a second program – after the off-set of one benefit from another, people end up with the same or less income to meet their needs.

People living with HIV/AIDS who receive social assistance benefits may find themselves “locked” into a province, since moving from one jurisdiction to another involves reapplying for social assistance. There is no guarantee that a person who is eligible under one provincial/

territorial social assistance program will be eligible under the program in another province/territory. Moreover, the level of income assistance and range of other benefits differs dramatically among the provinces and territories.

The social cost in terms of wasted resources is evident. Given the shortage of family physicians, physicians should not be called upon to fill out a series of often lengthy forms for the same patient for different disability programs, especially when it will likely have no benefit for patient's health or well-being. Private insurance companies, provincial and territorial governments, and CPP all have disability adjudication staff assessing whether people (in many cases, assessing whether the *same* people) are too disabled to work. Common or shared adjudication, based on tests for disability with common or shared elements, would likely result in administrative cost-savings.

### **Recommendation 7**

The reform process should work towards a test for disability that reflects the fact that people living with HIV/AIDS (and other lifelong episodic disabilities) have the capacity, yet also suffer from limitations on their ability, to function.

### **Recommendation 8**

The reform process should work towards a test for disability that recognizes explicitly that a person may have a significant and legitimate need for disability-related income support despite the fact that they are capable at times of activities such as employment, study, community service, homemaking, care giving and self-care. Ideally, the test should be the same in every jurisdiction and under every program; but at a minimum, there should be common or core elements that form part of every test.

### **Recommendation 9**

The reform process should aim at coordinating eligibility determination to the greatest extent possible and should set reasonable timelines for rendering decisions under both public and private disability income support programs.

## **Untying extended health and income benefits**

Access to extended health benefits, specifically prescription drug benefits, is crucial to the long-term health and survival of people living with HIV/AIDS. Some provinces offer extended health benefit programs to low income people who are not on social assistance and

who do not have private insurance benefits to cover such costs. However, in many provinces, people living with HIV/AIDS and other disabilities can only access public extended health benefits programs if they are or have been receiving social assistance. The high cost of HIV antiretroviral medications alone means that many people have little choice but to rely on social assistance for income and extended health benefits, even though they might otherwise remain in the labour force if they could access such benefits. The issue of government coverage for exceptionally high prescription drug costs associated with medical conditions is already being studied. In September 2000, the federal and provincial/territorial governments agreed on a vision, principles and action plan for health system renewal, known as the First Ministers' Accord on Health Care Renewal. Under the Accord, the federal and provincial first ministers agreed to take measures by the end of 2005/2006 to ensure that Canadians will have reasonable access to catastrophic drug coverage. While the issue of catastrophic drug coverage has been part of the February 2003 First Ministers' Accord on Health Care Renewal and September 2004 Ten-Year Plan to Strengthen Health Care, it remains at the "study" stage and leadership is needed to ensure that much-needed reform takes place sooner rather than later.

#### **Recommendation 10**

The reform process should seek to standardize extended health and disability support programs that will meet the essential needs of all persons with disabilities in Canada, including those living with HIV/AIDS, regardless of their province/territory of residence and regardless of whether they are eligible for social assistance. The process should build on existing provincial and territorial programs.

#### **Recommendation 11**

Specifically in relation to prescription drug coverage, the reform process should work towards a national catastrophic prescription drug plan. The federal and provincial/territorial governments should follow through in a timely manner on commitments made and actions undertaken in relation to catastrophic drug coverage under the First Ministers' Accord on Health Care Renewal.

### **Legislating portability of private insurance benefits**

People living with HIV/AIDS face "job-lock" because of the lack of portability of private insurance coverage, including most significantly LTD and extended health coverage. Elimination periods and pre-existing condition clauses act as barriers to job mobility, career advancement, and greater income security. For the vast majority of the people who have employment-related group benefits, leaving a job means leaving benefit coverage. For low to middle income workers, the absence of public prescription drug benefit plans (in some provinces and territories) or individual private plans under which a person living with



HIV/AIDS could qualify likely means they would have to go without prescription drug coverage for months. Similarly, people living with HIV/AIDS would certainly be excluded from individual LTD extended health coverage, and would have to rely solely on CPP disability coverage or social assistance if they became sick between jobs or while waiting for the elimination or pre-existing conditions clauses to end.

### **Recommendation 12**

Provincial governments should ensure through legislation the portability of private group insurance coverage. Specifically, people should be able to retain LTD and extended health benefits on reasonable and affordable terms for a reasonable period of time after an employment ends.

### **Coordination of rehabilitation, vocational rehabilitation, and employment support programs**

Benefits and programs that are intended to help people enter or re-enter the workforce are crucial to the long-term income security of people living with HIV/AIDS and those living with other episodic disabilities. Such rehabilitation, vocational rehabilitation, and employment support programs offer important incentives for people to take concrete steps to move to employment income and, potentially, income self-sufficiency. They are also a good investment of public and private resources. Not only do such programs potentially decrease the amount of public and private expenditures of disability income benefits, but they also foster social integration of people living with disabilities through labour force participation.

However, as currently structured, these programs do not fulfill their potential, and often act as a barrier to people living with HIV/AIDS meeting their need for income security and fulfilling their personal aspirations. The individual programs are complex, and people are not given the information and case management support they need to access and succeed in these programs. The challenges are greater for people who are receiving benefits under two programs. In addition to lack of information and case management support, people likely face a range of different and potentially incompatible program rules. Following the rules (e.g., earned income, income reporting, work-trials) under one program may put a person's eligibility under another program at risk.

### **Recommendation 13**

The reform process should work to better coordinate rehabilitation, vocational rehabilitation, and employment support programs offered to people living with disabilities through public and private programs.

## **Income sufficient to meet needs and respect for federal benefit programs**

In every province and territory, social assistance income benefit rates are below the poverty line and insufficient to meet the basic needs of people living with HIV/AIDS. Furthermore, the real value of these benefits is decreasing over time because year after year many provinces and territories fail to increase benefits. The coordination of benefits – the process whereby a benefit from one source is deducted from a benefit from another – is also a significant barrier to income security. By deducting the entire amount of the CPP disability benefit, provincial social assistance programs and those LTD programs that do not have indexed benefits, undermine the federal government’s intention of providing insurance against increases in the cost of living. Provincial/territorial social assistance programs that claw back the federal National Child Benefit Supplement impoverish children in the most economically disadvantaged families in Canada – those families in greatest need of the benefit.

### **Recommendation 14**

The reform process should ensure that social assistance in every province and territory provides income benefits at an adequate level to enable persons with disabilities, including persons living with HIV/AIDS, to meet their essential needs for day-to-day living.

### **Recommendation 15**

The reform should ensure that provincial and private insurance income support programs do not undermine federal programs through claw backs and deductions. Specifically, agreements leading to legislation should be put in place to preserve for intended beneficiaries the full value of benefits for children (National Child Benefit Supplement) and the children of disabled beneficiaries (CPP disabled contributors children’s benefit), and the indexing of benefits.

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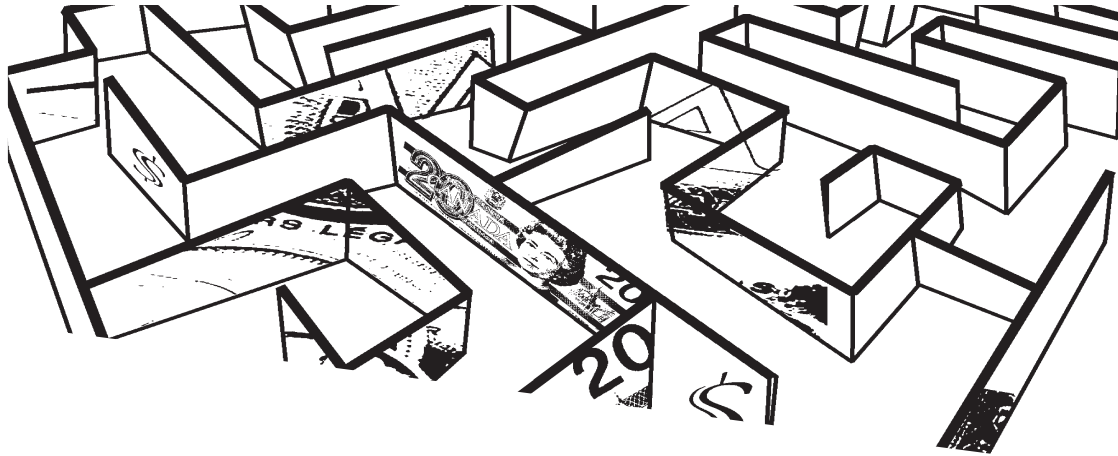
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## Appendix: Key informants and consultation participants

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