

Income security for people living with HIV/AIDS in Canada

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This info sheet is one in a series of six info sheets on the disability income and other benefit programs people living with HIV/AIDS in Canada rely upon:

1. HIV/AIDS and income insecurity
2. Employment Insurance sickness benefit
3. Long-term disability insurance
4. Canada and Quebec Pension Plan disability benefit
5. Provincial and territorial social assistance
6. Overcoming the barriers to income security: recommendations for reform

HIV/AIDS and income insecurity

This info sheet explains the links between HIV/AIDS and poverty, and Canadian governments' legal obligations to promote the health and income security of people living with HIV/AIDS. It also provides a short overview of the income security program many people living with HIV/AIDS in Canada rely upon.

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HIV as a lifelong episodic disability

Over 20 years into the HIV/AIDS epidemic in Canada, advances in HIV antiretroviral medication have transformed HIV disease from a “terminal” condition into a lifelong, episodic illness for many people. With intensive health management and appropriate supports, people living with HIV/AIDS can expect to live for a longer time during which they will experience a better quality of life. 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 surpassed by the number of new infections.

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” during which the disabling effects of HIV, its treatment, and opportunistic infections are unpredictable.

Three major characteristics of HIV/AIDS, and similar episodic disabilities, which 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.

Relationship between HIV/AIDS, health, and poverty

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.”

The links between poverty and HIV/AIDS go in two directions. In one direction, poverty contributes to people’s vulnerability to HIV, exacerbates the impact HIV/AIDS has upon them, and leads to greater illness and early death. Going in the other direction, the experience of HIV/AIDS by individuals, households and communities leads to an intensification of poverty. As a result, HIV/AIDS frequently impoverishes people in such a way as to intensify the epidemic itself.

The relationship between HIV disease progression and increasing economic insecurity has been described as a downward drift. People who are not poor prior to HIV infection, often become poor as their HIV infection progresses. This phenomenon is particularly prevalent among young people

who have little or no workforce attachment, resources, or support. Nevertheless, even people living with HIV/AIDS who were previously “well off” may 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 Canada, the employment situation of people living with HIV/AIDS is generally similar to that of persons with disabilities, whose employment levels are variously estimated as 30-40% lower than those of non-disabled persons. In 1997 and 1998, the Canadian AIDS Society conducted a national survey of over 400 people living with HIV/AIDS:

- Thirty-eight percent were working.
- Among those who were working, 54 percent had not revealed their HIV status. When asked why, the majority identified the negative attitudes or fears of an employer or co-workers (56 percent) and discrimination from an employer or co-workers (45 percent).
- Twenty percent were looking for work.
- Among people looking for work, 57 percent said they would not reveal their HIV status.

Government obligations regarding income security

Canada is 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 many of the rights set out in the ICESCR. A number of those rights are particularly relevant to Canada’s obligation when it comes to the circumstances of people living with HIV/AIDS who are 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 themselves and their families.

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.

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 through their employer or private insurance are first directed to Employment Insurance (EI) sickness benefits. EI sickness benefits provide income assistance for roughly the first four months of disability leave. At the same time, if they have private long-term disability (LTD) insurance coverage they will begin the application process for that benefit. 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). People who require income assistance because of disability, but who have had only a limited or no attachment to the workforce, will generally apply to provincial/territorial social assistance programs to obtain income assistance and health benefits.

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Employment Insurance sickness benefit

This info sheet outlines the basic rules of the Employment Insurance sickness benefit and the barriers that people living with HIV/AIDS face when trying to access the benefit.

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Eligibility for the sickness benefit

Employment Insurance (EI) is a federal program which provides time-limited income support and training to people who have stopped working through no fault of their own. 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.

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 hours of insured employment during the “qualifying period” – the previous 52 weeks – or during the time since his or her last EI claim, if it occurred within the last year.

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

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

the amount that an eligible person receives.

Barriers to accessing EI

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 for persons living with HIV/AIDS report that clients may quit work rather than take time off for medical reasons and apply for the sickness benefit. They do so believing that they are not entitled to sick leave or sickness benefits, or because they are unwilling to approach their employer and ask for time off out of fear of disclosing their HIV status. They may also quit work when an employer unreasonably refuses their request for time off due to illness. People living with HIV/AIDS who quit work when

they are sick may face problems applying for EI benefits. Under EI laws, anyone who “voluntarily leaves employment without just cause” is disqualified from receiving any 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.

Not enough hours worked to qualify

To qualify for the EI sickness benefit, a person typically must have worked a minimum number of hours (600) in the preceding year, or since their last EI claim. A person with ongoing health problems (for example, a person living with an episodic disability such as HIV/AIDS) may have difficulty meeting this minimum requirement. If, over an extended

period of time, a person’s health is poor, this may result in many absences from work, and many hours of work lost to illness.

Complexity of the program

The complexity of the EI act and its regulations presents a barrier to people living with HIV/AIDS when they attempt to access the sickness benefit. A firm grasp of the basic principles of the EI act, regulations and benefit entitlement manual are necessary to understand the reason why an EI claim has been denied, and what arguments can be made to support a claim once it has been refused. 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 not have access to income

(and, potentially, other benefits associated with employment). Given the complexity of the EI program, people who are unable to access legal advice are at a distinct disadvantage in the EI review and appeals process.

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Long-term disability insurance

This info sheet describes typical provisions in long-term disability (LTD) insurance contracts (also known as policies), and some of the ways in which these provisions may act as barriers to income security. The provisions described are not necessarily included in every insurance contract.

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Background

An insurance policy is a 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 an employer or professional association) and the insurance company, and 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.” Under group insurance, either the employer pays some of the premiums and the employee/member pays the rest, or the employer pays the entire amount of the premium on behalf of the employee/member.

Long-term disability (LTD) insurance policies are also known as “monthly income replacement policies.” LTD policies 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. The lack of more extensive regulation permits a considerable degree of variation among different LTD insurance policies. However, there are a number of features common to most policies. 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 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. Group insurance is usually provided on a “non-medical basis,” meaning that members of the group do not have to undergo individual medical assessment. 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, where the medical condition increases the risk that the insurance company will have to pay benefits.

Pre-existing conditions, waiting periods, and conversion privileges

Under most group LTD insurance policies, a pre-existing condition will not prevent the person from being covered. However, the policy will take away, for a period of time, 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 in 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 that pre-existing illness or medical condition until they have been enrolled in the plan for at least 12 months.

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 are enrolled in the policy. Typically, 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 the LTD benefit.

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).

Test for disability

The test for disability in a LTD policy should be examined carefully. Although a number of standard disability tests are used, there are some variations among them and some unique terms. Typically, "total disability" refers to an inability to perform the "essential duties" of a person's pre-disability job for an initial period (typically two years). After that initial period, a person must be unable 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.

While it may be clear during the initial period that the person cannot do his or her usual job, after that time it is much easier for the insurer to argue that there is an alternative job that the person could do.

If a person's LTD claim is accepted, so long as the person continues to meet the test for disability, the insurance company will provide the LTD benefit. Typically, the benefit will be paid until age 65, but may be time-limited (e.g., for 10 years).

The amount of the benefit is usually a percentage of the pre-disability employment income (typically between 60 to 70 percent), but may be a set amount, paid weekly or monthly.

"Coordination of benefits" clauses

Most, if not all, 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 is known as a "coordination of benefits." 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, a person who receives the CPP or QPP disability benefit will have that benefit deducted dollar-for-dollar from the LTD benefit. While the coordination of benefits provides no financial gain for people living with HIV/AIDS, it saves the insurance industry a significant amount of money.

Rehabilitation, return to work, and recurrence of disability

Private insurance companies have a financial interest in seeing

LTD benefit recipients return to work. Most LTD policies require recipients to make reasonable efforts to return to work. To assist people receiving LTD benefit in a return to the workforce, insurers may offer counselling, vocational rehabilitation training, and other resources. An approved rehabilitation arrangement typically continues for an agreed upon period of time up to two years. At the end of the agreed upon period of time, if the insured person cannot return to work on a full-time basis as a result of the disability, his or her benefits will likely be continued or reinstated (if they were interrupted by the attempted return to work).

Barriers to income security

While LTD benefits provide many people living with HIV/AIDS with much-needed income, they do not necessarily provide income security. Aspects of LTD policies, either alone or as a result of interaction with other benefit programs, act as barriers to income security.

Psychological impact of declaring total disability

The decision to make a claim under a LTD insurance policy may be an extremely difficult one for people living with HIV/AIDS. 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 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 one's sense of self, especially for those whose self-perception is intimately linked with their work or profession.

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 the insurance company representatives responsible for processing claims. Under group LTD plans, employers and insurance companies are often unwilling, at least initially, to provide employees with a copy of the contract of insurance under which an employee is insured, leaving them in the dark about their rights and entitlements. As a result of inadequate access to information, employees are at a distinct disadvantage when advocating for the LTD benefit to which they may be entitled.

Reliance on objective medical evidence and physicians as gate-keepers

In the LTD claims adjudication process, the person's family physician is typically the gatekeeper of the medical information needed to establish "disability." If the physician has not sent the patient for the tests or consultations necessary to arrive at a clear 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 physician may not effectively convey this information to the insurance company.

No fixed timelines for adjudication

It may take weeks or months for the insurer to render a decision on an application for a LTD benefit. Under most policies of insurance, the adjudication of a LTD claim has no fixed timeline. People living with HIV/AIDS often do not know how long they can expect to wait before receiving a decision on their claim.

The problem of "job-lock"

"Job-lock" occurs when a person stays in a job for fear of losing or interrupting his or her LTD coverage. Four main factors create a situation of job-lock for people living with HIV:

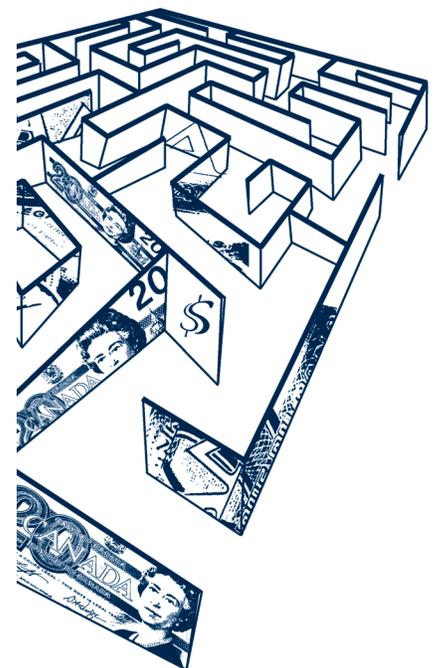
- 1) the requirement of evidence of insurability when applying for individual LTD insurance coverage;
- 2) pre-existing condition clauses in group LTD insurance policies;
- 3) the uncertainty of the course of HIV infection, which may result in unexpected or prolonged periods of illness; and
- 4) group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

As a means of addressing this problematic situation, the federal government in the United States passed the **Health Insurance Portability and Accountability Act of 1996**. The purpose of the Act was to

- increase people's ability to get health coverage for themselves and their dependents when starting a new job;

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

There is no comparable legislation in Canada.



Risk associated with return to work

For people who are receiving disability benefits, the significant risk associated with returning to the same job is that it can result in a situation where recipients are “trapped” on the LTD disability benefit. The risk arises, in part, from the possibility 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 the return 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 group insurance coverage (which may include life, LTD and extended health coverage) if their employment is terminated after they return to work. 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 with their new employer.

The prospect of having to re-apply for the LTD benefit, or losing LTD or extended health insurance coverage can act as a significant disincentive to return 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.” Indeed, as a result of “job-lock,” people living with

HIV/AIDS may feel frustrated and powerless in the face of limited career options and a stalled career path.

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Canada and Quebec pension plan disability benefits

This info sheet describes the Canada Pension Plan disability benefit and some of the ways in which the Plan's rules may act as barriers to income security for people living with HIV/AIDS.

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The Canada and Quebec pension plans

The Canada Pension Plan (CPP) was established in 1966 as a national program for workers whose earnings were interrupted or came to an end due to disability, retirement 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. However, they offer unique features that distinguish them from private insurance. The CPP and QPP provide universal coverage to those with some workforce attachment. Unlike private long-term disability (LTD) insurance, the CPP/QPP (both contributions and benefits) are “portable” between jobs and provinces and there are no “pre-

existing condition” exemptions to exclude potential claimants. Finally, CPP and QPP take into account the impact of the inability to earn income through work due to disability on a disabled person’s family. 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.

The discussion that follows focuses on the CPP disability benefit. Although the CPP and the QPP are similar in many respects, they also differ in important respects. Readers with an interest in the QPP can access information about the features of that program on the Government of Quebec Web site at www.rrq.gouv.qc.ca.

Test for CPP disability benefit

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, and
- have made sufficient contributions to the CPP within a pre-determined contribution period.

The CPP act 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. According to the test “a person shall be considered disabled only if he is determined in prescribed manner to have a severe and prolonged mental or physical disability.” The CPP act 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. And the most important aspect of the medical condition is: How does it prevent the person from working? Under the act, a disability is prolonged if it

“is likely to be long continued and of indefinite duration or is likely to result in death.”

In order to be eligible for the CPP disability benefit, a person must also meet the contributory requirements. The rules relating to the contributory requirement are extremely complex. Stated simply, an applicant for the CPP disability benefit must have made sufficient contributions to the plan within a sufficiently recent period of time.

According to CPP policy guidelines, CPP authorities must obtain evidence of a change in the person's circumstances – in other words, evidence that the person has ceased to be disabled at a certain date – in order to terminate a person's CPP disability benefit.

Benefit and allowable earnings

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 an earner would have received at age 65 (to a maximum of \$621.56 in 2005). The average CPP disability benefit was \$749.08. Dependent children of people who receive the CPP disability benefit are eligible to receive a benefit as well. 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 and are indexed to inflation and adjusted annually based on the consumer price index.

In 2001, CPP adopted a policy guideline on allowable earnings. This was an extremely positive development for people living

with HIV/AIDS and other episodic disabilities. The allowable earnings policy permits a person who is receiving the CPP disability benefit to work and earn up to a certain amount of money (i.e., allowable earnings, set at \$4,100 in 2005) in a calendar year without having to report the money to CPP, and without having it affect their eligibility for the benefit.

Vocational rehabilitation, return to work incentives, and automatic reinstatement

Under the **CPP Regulations**, authorities can require a person receiving a disability benefit to undergo reasonable rehabilitation measures if they believe the person may benefit vocationally. In practice, CPP authorities have adopted a more flexible approach to rehabilitation, based on a person's needs and attributes, individual assessments and tailored rehabilitation plans, and cost. Personal attributes include the person's level of education, work history, official language skills, motivation to return to work, years till retirement, commitment to rehabilitation, medical condition and prognosis, and special equipment and needs.

In 1995, CPP introduced four work-incentive measures to assist benefit recipients with community participation and labour market re-integration, allowing 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 re-application for people who return to work and subsequently suffer a recurrence of the same disability within five years.

With the exception of volunteer activity, the 1995 policy setting out the work incentives must be read in light of recent legal and policy changes. Most significantly, the fast-track reapplication process has been superseded to a great extent by legislative changes to CPP which provide for “automatic reinstatement.” CPP disability recipients who had their benefits terminated as a result of a return to work as of 31 January 2005 or later may be eligible for automatic reinstatement. 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. Disabled contributor's children's benefits can also be automatically reinstated.

Barriers to income security

Although the CPP disability benefit provides many people living with HIV/AIDS with much-needed income, it does not necessarily provide them with income security. Aspects of the CPP disability benefit, either alone or as a result of interaction with other benefit programs, act as barriers to income security.

Psychological barriers

The psychological impact of declaring oneself disabled and unable to work may act as 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 – akin to an admission of defeat.

A further psychological barrier is the perception among benefit recipients 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.

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 severe disabilities that recur, but that may only keep them out of the workforce for less than one year at a time. The severe criterion, which equates disability with unemployability, poses a further barrier for people living with episodic disabilities who may retain some capacity for work. 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. Whenever they worked, they would make 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 those with unpredictable illnesses. At the same time, it would help generate revenue for the program and sustain it.

Recency requirement

Practically speaking, the requirement of recent contributions means that a person’s entitlement to a CPP disability benefit never vests: 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. In effect, the overly strict definition of disability, combined with the recency requirement, sets people with episodic disabilities up for income insecurity. As HIV infection progresses, people with symptoms of HIV participate in the workforce to the extent that their health permits. Yet if their participation is minimal, they risk not being able to meet the recency of contributions requirement at a point in time when they meet the test for disability.

Lack of coordination between CPP disability and LTD benefits

The lack of coordination between the CPP disability benefit and LTD benefits operates as a barrier to income security for people living with HIV/AIDS in a number of ways. For more information on LTD insurance, see info sheet 3 in this series.

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 so, the amount of the benefit increases annually to reflect 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 their CPP disability benefit will be deducted from their LTD benefit. A further financial barrier to income security for people with disabilities and their families was the practice of some insurers to

deduct the amount of the disabled contributor’s child’s benefit from the LTD benefit. In *Hennig v Clarica Life Insurance Co*, a 2003 decision, the Alberta Court of Appeal found that this practice was illegal.

Second, there is no established mechanism to coordinate vocational rehabilitation under LTD and CPP. In most circumstances, it is left to the person who is receiving benefits (or someone acting on their behalf), to negotiate a vocational rehabilitation plan and coordinate the flow of information among CPP, insurance, medical and rehabilitation workers.

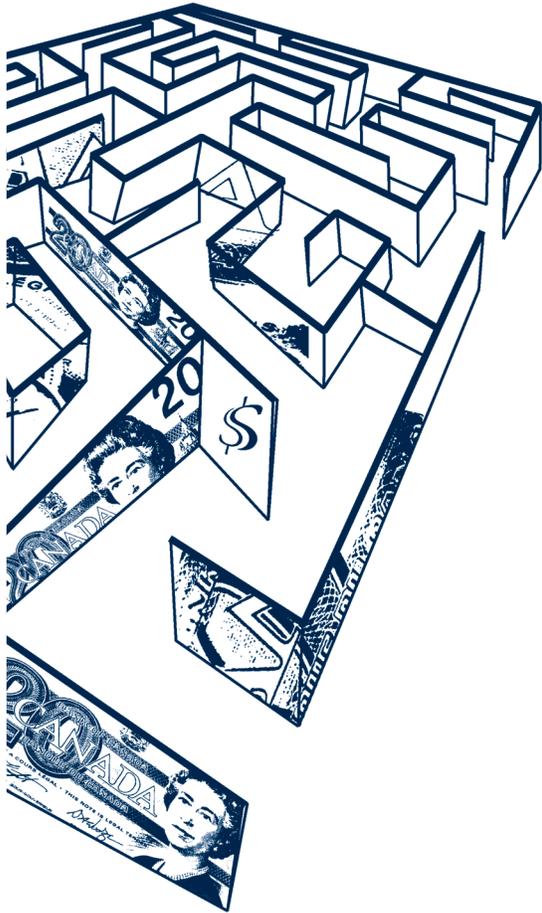
Third, a return to work and employment earnings are treated differently under LTD policies and the CPP disability benefit. Rules related to income reporting, paid work trials, and the period during which a person can renew a claim for benefits based on a recurrence of disability all differ. The difference in programs may have adverse effects on a recipient’s eligibility, and the different rules and obligations can be extremely confusing to people living with HIV/AIDS and their advocates.

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Income security for people living with HIV/AIDS in Canada

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- 5. Provincial and territorial social assistance**
6. Overcoming the barriers to income security: recommendations for reform

Provincial and territorial social assistance

This info sheet describes typical provisions in provincial and territorial social assistance programs, and some of the ways in which those provisions may act as barriers to income security for people living with HIV/AIDS. The provisions described are not necessarily part of every provincial or territorial program.



A provincial and territorial responsibility

Social assistance programs, sometimes referred to as welfare, are provided as a last resort to people 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). The involvement of various levels of government adds an additional layer of complexity for Aboriginal people trying to access social assistance. Conflicts and confusion over which level of government (federal, provincial, 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.

Social assistance is most often the only source of income for people with disabilities who do not have a 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 workforce (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 source of income and, where available, other supports and benefits.

Programs vary widely among the provinces and territories. This info sheet provides an overview of some typical features of the programs, and related barriers to income security, most relevant to people living with HIV/AIDS.

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 established under regulations does not correspond to the actual cost of these items, and certainly does not add up to the actual amount of money needed to maintain health and well-being. Assets are 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.

Tests for disability

People with disabilities applying for social assistance must provide medical confirmation of their disability. Medical evidence is reviewed by provincial or territorial

adjudicators, 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. Typically, the final decision about whether a person meets the test for disability is left to the administrator of the program.

The precise test for disability varies 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 long-term disability (LTD) insurance policies and the Canada Pension Plan (CPP) disability benefit. However, none of the provincial/territorial tests for disability is the same as the LTD or CPP tests.

Under the Ontario Disability Support Program, an applicant for benefits who is already eligible for the CPP disability benefit is 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 in CPP. This means that CPP disability benefit recipients do not have to go through the detailed disability adjudication process to qualify for income support under the Ontario program.

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. People who have a history of workforce attachment who are not already receiving a CPP or Quebec Pension Plan (QPP)

disability benefit will be required by social assistance authorities to apply for CPP or QPP. Provincial and territorial programs deduct the amount of the CPP or QPP disability benefit dollar-for-dollar from the amount of the social assistance income benefit.

Income assistance benefits and earnings exemptions

The amount of income assistance varies widely among the provinces and territories. According to the National Council of Welfare, in 2004 the 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. In all provinces and territories, the amount of the benefit was, and continues to be, below the poverty line.

Most if not all provinces and territories encourage people to work by providing an employment earnings exemption for employment income: a certain amount of employment earnings are not deducted from the amount of the social assistance income benefit. The amount of income a person can earn without having it deducted, or the rate at which earnings are deducted, varies among the provinces and territories.

Extended health and other benefits, including prescription drug benefits

In addition to income assistance, social assistance programs offer a range of benefits to recipients:

- 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

The exact benefits offered and the criteria for eligibility vary widely among the provinces and territories. In most, if not all, provinces and territories, people who receive social assistance are automatically eligible to have their prescription drugs paid for by the provincial and territorial prescription drug program.

In some provinces/territories, 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) can continue to receive extended health benefits.

Supports to return to employment and rapid reinstatement

Provinces/territories encourage people to participate in competitive employment by offering education or employment support. Some provinces offer educational or employment support programs for

people receiving social assistance because of their disability.

Barriers to income security

Although provincial and territorial social assistance programs provide many people living with HIV/AIDS with much-needed income and other benefits, they do not necessarily provide them with income security. Aspects of social assistance programs, either alone or as a result of interaction with other benefit programs, act as barriers to income security.

Inadequate benefit levels

It can be extremely 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 will likely at some point have extraordinary health-related needs that are not provided for by social assistance or related benefits.

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). In 2004, in all provinces, total welfare incomes for single people with disabilities were further below the poverty line than they were in the late 1980s or early 1990's, despite increases in the cost of living over time. As a result, the value of most

provincial and territorial welfare and related benefits continues to decline year over year.

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 social assistance statutes, regulations and policy guidelines 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 new HIV infections in Canada.

Disability tests and adjudication – a barrier to mobility

While LTD and CPP benefits are portable across provincial boundaries, provincial and territorial social assistance, 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. That a person has qualified for social assistance on the basis of disability in one province or territory has no bearing on whether they will qualify for 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 an interprovincial/territorial move can result in uncertainty and economic hardship.

Extended health benefits tied to income 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 will face increased chances of illness and premature 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, people must be eligible for and receiving social assistance income benefits to receive extended health benefits. In these jurisdictions, many people living with HIV/AIDS who have been prescribed antiretrovirals 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.

Other provinces or territories permit people to continue to receive government-funded extended health benefits, even if their income (either from employment or from sources like CPP) exceeds their budgetary needs, such that they are no longer eligible for social assistance income benefits. However, the person must

have been eligible for, and in receipt of, social assistance 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, including 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.

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.

Third, there is no established mechanism to coordinate vocational rehabilitation and employment supports under CPP and social

assistance programs, respectively. 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.

See info sheet 3 in this series for more information on LTD benefits. Info sheet 4 contains information on the CPP/QPP disability benefits.

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Income security for people living with HIV/AIDS in Canada

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4. Canada and Quebec Pension Plan disability benefit
5. Provincial and territorial social assistance

6. Overcoming the barriers to income security: recommendations for reform

Overcoming the barriers to income security: Recommendations for reform

This info sheet presents recommendations for reform to the income support programs, both public and private, that many people living with HIV/AIDS rely upon to meet their basic needs. The recommendations are intended to address the barriers to income security identified in info sheets 2, 3, 4 and 5.

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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 – the Employment Insurance sickness benefit, long-term disability insurance benefits, Canada Pension Plan disability benefit, and provincial/territorial social assistance. But most result from the fact that people living with HIV/AIDS often must apply to more than one program in order to meet their income and benefit needs. There is a marked lack of coordination between these programs. The federal government must take a leadership role, building on federal-provincial proposals for reform to programs for people with disabilities (e.g., Social Union Framework Agreement), and must 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 a 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.

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 for their income support and extended health benefit needs. 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 co-operate 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 and applying for and receiving benefits. Yet no program provides advocates for people living with HIV/AIDS and 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 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, many 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 and applying for, or in receipt of, benefits under public and private income security programs.

Rationalizing tests for and assessments of disability

Despite the myriad of different tests for disability, none adequately addresses the needs and circumstances of the many people living with HIV/AIDS and other episodic disabilities. People

with episodic disabilities may be reluctant 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. The categorical nature of current tests for disability results in social marginalization for many people with disabilities.

Many people living with HIV/AIDS must apply to at least two programs to obtain the income and extended health benefits they need. This results in a significant waste of public and private resources. Different programs with essentially the same purpose have different tests for disability, different adjudication processes with different forms to be completed by physicians, different adjudicators to review the medical evidence, and different authorities to process the applications.

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 survival and long-term health of people living with HIV/AIDS. In most provinces and territories, people living with HIV/AIDS can only access public extended health benefits programs if they are or have been receiving social assistance. The high cost of HIV medications alone means that many people have little choice but to rely on social assistance for income and extended health benefits, even though they would be able to continue to work if they could access such benefits.

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.

Recommendation 10: The reform process should seek to standardize extended health and disability supports 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 with HIV/AIDS face “job-lock” because of the lack of portability of private insurance coverage, including most significantly long-term disability (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 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 coverage, and would have to rely solely on Canada Pension Plan (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 are important incentives for people to take concrete steps to move towards 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 on disability income benefits, but they also promote social integration of people living with disabilities through work force participation.

However, as currently structured, these programs do not fulfill their potential, and 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 people’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 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. And the real value of these benefits

is decreasing over time because year after year, many provinces and territories fail to increase benefits, even to offset the effect of inflation. 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.

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.

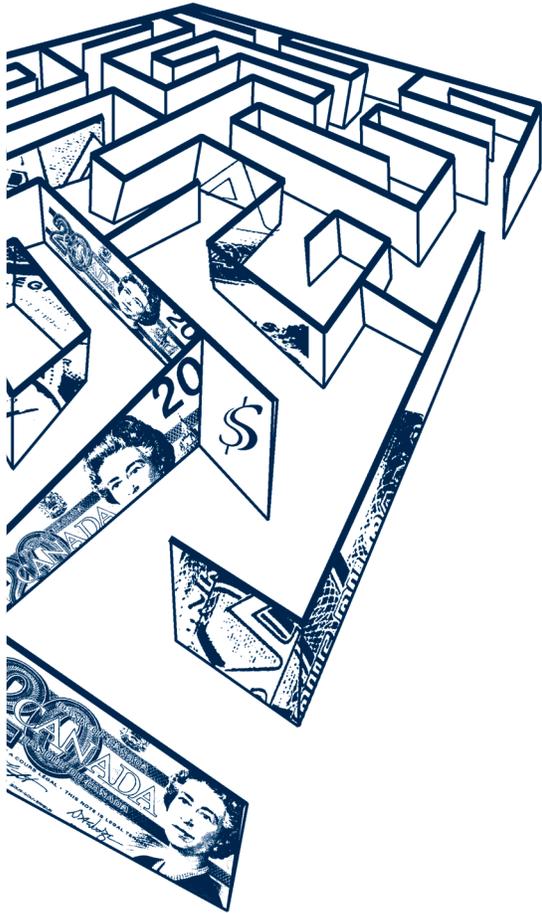
Recommendation 15: The reform should ensure that provincial and private insurance income support programs do not undermine federal programs through claw backs and deductions. Specifically, agreements leading to legislation should be put in place to preserve, for intended beneficiaries, the full value of benefits for children (National Child Benefit Supplement), the children of disabled beneficiaries (CPP disabled contributors children’s benefit), and should provide for the indexing of those benefits.

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