



HIV & Disability Insurance in Canada: An Environmental Scan

by

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March 2005

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The Canadian Working Group on HIV and Rehabilitation

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The **Canadian Working Group on HIV and Rehabilitation (CWGHR)** is a national charitable organization working to improve the quality of life of people living with HIV/AIDS through rehabilitation research education, and cross-sector partnerships. CWGHR members include people living with HIV disease, members of community-based HIV organizations, national associations of health professionals, government agencies, private businesses and the employment sector.



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Canadian Working Group on HIV and Rehabilitation (CWGHR)
Income Support Research Project

HIV & Disability Insurance in Canada: An Environmental Scan

March 2005

Joan Anderson & Glen Brown

Executive Summary

Today, many people living with HIV/AIDS (PHAs) with access to antiretroviral treatments are living longer lives. HIV/AIDS is now understood as a lifelong and episodic illness for many people. This has enabled more people with HIV to continue working or to consider a return to the workforce.

The Canadian Working Group on HIV and Rehabilitation has commissioned this environmental scan to determine current policies and practices of the Canada Pension Plan Disability Program (CPP-D) and the private insurance industry relevant to PHAs. The environmental scan is intended to provide an overview of disability income support for PHAs and to focus further research in this area.

This project consisted of the following components:

- I. A literature review
- II. Based on the implications from the literature review, key informant interviews with individuals from the following stakeholder groups:
 - a) Fifteen people living with HIV/AIDS who have had experiences with CPP-D and/or private disability insurance;
 - b) Four policy and program staff within CPP-D and the private insurance industry;
 - c) Five AIDS service organization advocates who assist people with accessing benefits;
 - d) Five health care providers and other professionals who support people living with HIV in accessing benefits.

Key informants were recruited based on suggestions from the project advisory committee; some people living with HIV/AIDS were recruited with assistance from AIDS Service Organization (ASO) advocates; others were recruited directly by the research team. It is important to note that our recruitment strategy would bias towards PHAs who had access to advocates.

There is substantial research evidence and widespread agreement among health policy analysts that income is a key determinant of health. People with low incomes are more likely to become ill, and are likely to suffer more adverse effects from illness, than people with higher incomes. It is not surprising, therefore, that the impacts of poverty on the health of PHAs are also severe.

Insecurity about the future, and about future income security, is another determinant of health for people living with HIV, as is social inclusion or exclusion. Social inclusion, or "active living" can include many options: paid work, volunteer activities, social interactions, sports, etc.

The Canada Pension Plan, established in 1966, is more transparent & accountable to the general public than private insurance; conversely, CCP-D is more rigid in definitions and application of rules. It appears that CCP-D has made genuine attempts to be responsive to consumer issues.

In January 1998, CCP-D eligibility was restricted to those contributors who have made sufficient contributions in four of the last six years. Our key informant interviews with some ASO advocates noted that the contribution requirements are not realistic for some PHAs. Some PHAs may have contributed to CPP for many years, but if their recent work history has been erratic due to health problems, they will likely not be eligible for income replacement benefits precisely at the time they need them.

The CPP defines "disability" as a condition, either physical or mental, that is "severe and prolonged". "Severe" means your condition prevents you from working regularly at a "substantially gainful occupation" and "prolonged" means your condition is long-term or may result in your death.

From our interviews it seems that most PHA applications are accepted under this definition, although careful attention to the application documents is required for both the PHA and his/her health care providers. A number of cases were reported where the initial application was denied, but in almost every case the application was subsequently approved after further information was supplied. Few applicants need to pursue formal appeals, and the appeal process appears to work in many cases.

Many PHAs reported that they found the application process daunting, and that they relied heavily on ASO or health care provider support to understand the paperwork. ASO advocates reported that they spent considerable time assisting clients and their health care providers in filling out the applications properly. A primary care physician who works with a large number of recent immigrants reported that the application process is particularly problematic for them.

Few of our key informants relied upon CPP-D as their sole income; for many, the level of CPP-D payment was somewhat a moot point as it was deducted from their other income sources. For those who rely solely on CPP-D, the income is insufficient to support a basic healthy lifestyle. However, the indexing of CPP-D benefits to the cost of living was widely praised.

From the experience of our key informants, CPP-D reassessments of PHAs are rare. None of our informants were familiar with a case where a reassessment had led to a PHA being denied benefits. However, the fear of reassessment was a major concern of many informants (PHAs, ASO advocates, and health care providers). This fear causes some PHAs to under-report earnings, and causes others to avoid any work or training, even if it would be allowed under the CPP-D guidelines.

Key informant interviews with PHAs and advocates underlined a lack of information about CPP-D's rules for earned income, the three-month grace period returning to work, automatic reinstatement, and other flexibilities in the program.

Long-term disability insurance is available through group insurance plans, mostly available as part of a benefits package supplied by employers and individual insurance policies. Private insurance companies tend to be less transparent and accountable than CPP-D. Conversely, they may also be more flexible. Responsiveness can depend on the policy, on the individual file, on the worker handling the file, on the employer's stance and actions, and on pressure from the client or from his/her advocate.

Benefit levels of private insurers vary, but are generally tied to a percentage of pre-disability income. Very few policies have cost-of-living increases. Periodic reassessments are common for LTD recipients (unlike CPP-D). Reassessments typically occur after the first two years of disability, and annually thereafter.

Some private LTD plans do offer some flexibility for clients wishing to explore a return to work. As with CPP-D, however, it appears that many people on LTD are –understandably - so fearful about their long-term income security that they are unwilling to explore any possible flexibility for fear of losing benefits.

The environmental scan concludes that once people living with HIV/AIDS are on CPP-D or private insurance LTD, many are fearful of the possibility of reassessment leading to suspension or termination of benefits. This fear precludes many PHAs from exploring the flexibilities that their plans may offer in supporting return to active living.

The environmental scan adds further weight to the recommendations for action already voiced by many consumer advocacy groups and by the Parliamentary Subcommittee on the Status of Persons with Disabilities.

Further study is required to understand how CPP-D and private insurance disability policies and procedures, and especially the perceptions of them, may inhibit or facilitate return to active living.

Further research should also identify strategies to overcome those real and perceived barriers, and to elaborate on the recommendations already developed by other reports aimed at improving disability policies.

Section One: Background to this Report

1a) About This Environmental Scan

The Canadian Working Group on HIV and Rehabilitation (CWGHR) has commissioned this environmental scan to determine current policies and practices of the Canada Pension Plan Disability Program (CPP-D) and the private insurance industry relevant to people living with HIV/AIDS. (PHAs)

The environmental scan is intended to provide an overview of disability income support for PHAs and to focus further research in this area.

This project consisted of the following components:

- III. A literature review
- IV. Based on the implications from the literature review, key informant interviews with individuals from the following stakeholder groups:
 - e) Fifteen people living with HIV/AIDS who have had experiences with CPP-D and/or private disability insurance;
 - f) Four policy and program staff within CPP-D and the private insurance industry;
 - g) Five AIDS service organization advocates who assist people with accessing benefits;
 - h) Five health care providers and other professionals who support people living with HIV in accessing benefits.

The literature review focused on articles and briefs specifically related to CPP-D and private disability insurance but also included documents that provide a broader view and analysis of Canadian income security programs. It did not include a detailed analysis of government legislation. A bibliography is provided as Appendix B to this report.

Key informants were recruited based on suggestions from the project advisory committee; some people living with HIV/AIDS were recruited with assistance from AIDS Service Organization (ASO) advocates; others were recruited directly by the research team. It is important to note that our recruitment strategy would bias towards PHAs who had access to advocates.

Further details about the project methodology, the key informant consent form and interview guide can be found in Appendix A.

Although the bulk of this environmental scan focused on CPP-D and private insurance disability, we briefly reviewed documentation relevant to the Quebec Pension Plan (QPP) and conducted four interviews with people who had experience with QPP disability benefits. The CPP and QPP programs are sufficiently harmonized that we found few distinctions between them, and they are noted within the report.

The authors are grateful to the project advisory committee and staff at CWGHR for ongoing advice and support (see Appendix C). Funding for this project was provided by Hoffman-La Roche Limited, Bristol-Myers Squibb Canada, Inc. and Social Development Canada, Government of Canada.

The authors are especially grateful to the people living with HIV/AIDS and other experts who shared their knowledge as key informants for this project.

1b) About CWGHR

The Canadian Working Group on HIV and Rehabilitation is a national, multi-sector, multi-disciplinary group that addresses issues of disability and rehabilitation in the context of HIV. CWGHR works to improve the quality of life of people living with HIV/AIDS through rehabilitation research, education and cross-sector partnerships. Its mandate includes coordinating a national

response to, facilitating and supporting the development of, and providing advice on rehabilitation issues in the context of HIV.

CWGHR was formed in 1998 and its office is located in Toronto.

CWGHR conceptualizes rehabilitation in its broadest sense of reinsertion or full return to society for those living with HIV disease and its accompanying challenges. To achieve its mandate and goals, CWGHR develops rehabilitation resources, new knowledge, and promotes awareness in a multi-sector collaboration with partners in the HIV/AIDS sector, rehabilitation professionals and with disability groups on issues of common concern. (www.hivandrehab.ca)

1c) About HIV & Rehabilitation

Today, many people living with HIV with access to antiretroviral treatments are living longer lives. The impact of this was explored in a brief prepared by CWGHR and the Canadian AIDS Society: "Throughout most of the 1980s and the 1990s, individuals diagnosed with HIV could expect to maintain their health for a limited time, after which they would see their health rapidly decline". (Canadian AIDS Society/Canadian Working Group on HIV and Rehabilitation CAS/CWGHR submission: "HIV as an Episodic Illness: Revising the CPP(D) Program: A Brief Prepared for the Sub-Committee on the Status of Persons with Disabilities", 2003) The rapid decline usually meant permanent withdrawal from the work force and for many led to life-threatening illnesses and death.

The 1990's saw advancements in drug treatments that have changed the course of HIV disease and "a large number of individuals now living with HIV are able to experience extended periods of good health" and recover from serious illnesses associated with HIV. This has enabled more people with HIV to continue working, or for some individuals after several years of not being able to work, to consider a return to the workforce. The situation is still a serious one depending upon "the effectiveness of treatment, the onset of debilitating side effects, psychosocial factors as well as the onset of new HIV related illnesses..." (CAS/CWGHR, 2003)

An understanding of HIV/AIDS as a lifelong and episodic illness has developed over time given the changes in the lives of people with HIV/AIDS. CWGHR has learned from listening to the experiences of people living with HIV/AIDS through qualitative research projects. In 2002 a cross disability research project brought together a variety of "consumer" and "provider" groups, to define common 'disability' and 'rehabilitation' issues among people living with episodic conditions and increase partnerships to affect change. During the course of this project, direction by participants led to the use of the descriptor of "lifelong and episodic" illness to best describe HIV/AIDS and other illnesses such as multiple sclerosis, mental illness, and arthritis. (Proctor, for CWGHR: "Looking Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Illnesses", 2002.)

"It is important to note that when participants (people with HIV/AIDS) discussed episodes, the ups and downs in life, that impacted their health and well-being, it was more than physical bouts of illness. Having to change treatment regimes, disclosing their status to people, change in work status, financial changes, and shifts in mental and emotional health, such as depression, also figured prominently as part of the burden of living with an episodic and unpredictable illness...Participants stories revealed that there is a cumulative impact from the stress of living with constant uncertainty that comes with HIV and its treatment". (Weir/Crook, for CWGHR: "Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS: A Qualitative Study", 2003.)

Characteristics of lifelong and episodic illness include: uncertainty, unpredictability, and alternating periods of being well/unwell/very unwell. The need for more or less support is therefore also unpredictable.

Section Two: Setting the Context: HIV, Income, Security & Inclusion

2a) HIV, Income & Health

There is substantial research evidence and widespread agreement among health policy analysts that income is a key determinant of health. People with low incomes are more likely to become ill, and are likely to suffer more adverse effects from illness, than people with higher incomes.

Dr. Gail Fawcett states, "Persons with disabilities are more likely to be poorer than those without disabilities, and there are a number of factors which affect the poverty rates of persons with disabilities. Not surprisingly, most of the factors that reduce the likelihood of persons with disabilities participating in the labor force also increase the likelihood of them living in poverty." (Fawcett, "Living with Disability in Canada: an Economic Portrait," 1996.)

A report commissioned by the Ontario HIV Treatment Network (OHTN) reached this conclusion: "It is not surprising, therefore, that the impacts of poverty on the health of people living with HIV are also severe. Inadequate nutrition, poor housing, stress, inadequate access to medications and complementary therapies, and limited social support networks can all have an adverse effect on the health of someone with a compromised immune system... Another important context of the relationship between poverty and HIV is that HIV infection can often lead to poverty. The disabling effects of the disease – or of the side effects of HIV medications – can affect employment opportunities; the cost of treatments and related therapies can also lead to poverty." (OHTN, "Deserving Dignity", 2004)

A literature review on HIV/AIDS and income security published by the Canadian AIDS Society in 1994 highlighted the following: "Recent descriptive studies substantiate an intuitive relationship between socio-economic status and the health states of people living with HIV/AIDS. Martin Schechter et al. have demonstrated a positive relationship between higher socio-economic status prior to seroconversion or enrolment in the study and the probability of being a non-progressor through the spectrum of HIV-related disease (Schechter, 1994). Supporting this finding, further study of the same cohort has demonstrated a significant relationship between low-baseline income and shorter survival time (Hogg, 1994). A comparison of the baseline socio-economic values of 122 patients in a Montreal study reinforces the credibility of these findings (Grover, 1992). A comparison of patients who had died by the end of the study (n=36) versus those who remained alive (n=86) yielded the following results: of those patients remaining alive, 19% had incomes of less than \$11,000/year; whereas, of those who had died, 36% had incomes of less than \$11,000/year (Grover, 1992). A positive association between socio-economic status and survival time has also been established among cancer patients (Ansell, 1993; Cella, 1991)." (CAS, "HIV/AIDS and Income Security: Literature Review and Annotated Bibliography", 1994)

2b) HIV, Security & Health

Insecurity about the future, and about future income security, is another determinant of health for people living with HIV. Previous surveys on PHA attitudes, and our own interviews, suggest that many PHAs experience stress about the unpredictable progression of HIV illness and the instability of income; that stress is itself a health factor.

"Living with HIV is living with uncertainty, and never knowing when illness will set in... Returning to work should be accompanied by the feeling of security, that if illness or other factors strike, a person's health and well-being will not be compromised by fear of poverty." (CAS/CWGHR, 2003)

A participant in a cross disability forum expressed a common fear: "I'm feeling fine now, but I am afraid of what might happen if I go back to work and then I get sick again." (Cited in a 2002 CWGHR newsletter.)

2c) HIV, Social Inclusion & Health

For many PHAs, social inclusion or exclusion is a key determinant of health. Social inclusion, or “active living” can include many options: paid work, volunteer activities, social interactions, sports, etc. All these options can promote health, confidence and dignity.

What is social and economic inclusion? Health Canada in the Atlantic region has provided leadership in promoting this framework for action on policy and programs: “The word ‘inclusion’ has an everyday meaning for most of us. To be included is to be accepted and to be able to participate fully within our families, our communities and our society. Those who are excluded, whether because of poverty, ill health, gender, race or lack of education, do not have the opportunity for full participation in the economic and social benefits of society.” (Guildford, “Making the Case for Social and Economic Inclusion”, 2000).

Health Canada recognizes social and economic inclusion as a “strategy for change...in order to reduce the inequities that exist in society” (Health Canada Population Health web-site, 2004).

It is important to recognize the experiences of stigma and discrimination many people with illness and disabilities bring when approaching income support systems – based on things like sexism, homophobia, racism, on fears of illnesses, disabilities and difference inherent in our society. This recognition can assist in reforming systems to respond in a way that gives a message of inclusion and respect.

Income support programs, public or private, can learn by analyzing their policies and procedures using an “inclusion lens”. Do they exclude or include people who are marginalized, disadvantaged, impoverished, or discriminated against? (Shookner, “An Inclusion Lens: Workbook for Looking at Social and Economic Exclusion and Inclusion,” 2002.) Social inclusion challenges service providers and policy makers to ensure their services, policies and any related changes do not reinforce or increase exclusion and isolation.

Section Three: Canada Pension Plan Disability

3a) History & Overview of CPP-D

In 2002 the Parliamentary Subcommittee on the Status of Persons with Disabilities (hereafter referred to as the Subcommittee) began a consultation process to review CPP-D. The Subcommittee reviewed the process “from the application process to the Review Tribunal”. Their work provides description, analysis and recommendations on CPP-D captured in: “Listening to Canadians – A First View of the Future of the Canada Pension Plan Disability Program - Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities”. We integrate many of the issues discussed that are relevant to the lives of people living with HIV/AIDS below. The Recommendations and are attached in Appendix D.

The Canada Pension Plan was established in January 1966 by an Act of Parliament, after a long period of debate: “The Act set up a national contributory public insurance program to provide income protection to workers in the event of a long-term interruption of earnings as a result of retirement, disability or death. The first disability benefit was paid in 1970.” (Subcommittee, 2003.)

In his history and analysis of CPP-D for the Office of the Commissioner of Review Tribunals (OCRT), Professor Michael Prince outlines the four periods of CPP disability policy development:

- “1964-1970: policy design and formation. Constitutional amendment, intergovernmental negotiations and support, and federal CPP legislation. Administrative preparation and phasing-in of CPP contributions, and retirement, survivor and disability benefits.
- 1970-1986: implementation, adaptation and reform proposals. Disability benefits were first paid in the 1970-71 fiscal year. Contribution requirements for disability pension and children's benefits eased slightly.
- 1987-1993: major reforms to the CPP. Reforms include liberalization of disability eligibility requirements and a substantial increase in disability benefits.
- 1994-2001: critique, retrenchment and reorientation of CPP Disability. Benefit changes and stricter eligibility for disability pensions.” (Prince, “Wrestling With the Poor Cousin: Canada Pension Plan Disability Policy and Practice, 1964 – 2001”, 2002.)

In the focus on fiscal belt-tightening in the 1990's, there were concerns about the increasing caseload of CPP-D and changes were made to tighten eligibility. The Subcommittee report indicates that “CPP(D)'s share (including children's benefits) of total CPP payments... reached a maximum of 18.7% in 1994-1995, and since then has declined steadily to 13.9% in 2002-2003... new adjudication guidelines emphasizing the medical basis for approval, stricter eligibility conditions and improved labour market conditions, are thought to be key contributors to the declining caseload in the late 1990s and early 2000s.” (Subcommittee, 2003.)

In her policy history of the CCP-D Benefit for the Caledon Institute for Social Policy, Sherri Torjman notes “Not surprisingly, the downward slope has raised questions about the responsiveness of the program and whether the restrictions in both eligibility criteria and program administration in recent years have gone too far in the opposite direction.” (Torjman, “The Canada Pension Plan Disability Benefit”, 2002.)

Some anti-poverty and disability advocates had called for a review that goes beyond this one program. In their brief to the Subcommittee, the Council of Canadians with Disabilities (CCD) reiterated a resolution calling for the “a comprehensive disability insurance program that would provide coverage to all Canadians.” Professor Michael Prince asserted “ a comprehensive approach is essential for addressing the fragmentation of the current system of disability income and supports in the country, and to advance the vision of full citizenship for people with disabilities”. (Prince, 2003)

Any such comprehensive reforms would be long-term and complex, in part because they would require substantive agreement from all the provinces. Therefore many advocates have focused in the short term on improving the current system.

3b) General Themes about CPP-D

CCP-D is more transparent & accountable to the general public than private insurance because all workers contribute to it and because it is a public service. Conversely, CCP-D is more rigid in definitions and application of rules. It appears that CCP-D has made genuine attempts to be responsive to consumer issues.

Torjman notes key aspects of CPP-D including:

“The Canada Pension Plan is fully indexed to inflation, so benefits keep pace with annual rises in the cost of living as measured by changes in the Consumer Price Index. Most private pensions do not ensure full inflation protection....” and

“The public provision of disability protection guarantees universal coverage with no exclusion of workers with a severe or prolonged disability who are considered ‘high risk’ or an inordinate burden to private insurers. The CPP is the only pension plan that affords this protection regardless of the medical history of the contributor. Private pension plans carry out extensive screening. They typically disallow from coverage persons with certain health-related conditions or require that these workers pay higher premiums, thereby eliminating protection for many Canadians.” (Torjman, 2002). This universal coverage is especially important for people who do not work for employers with group plans, and who are denied access to individual insurance coverage because of pre-existing conditions.

Portability is also an important aspect of CPP-D (and the Quebec Pension Plan), which means that people can carry their benefits with them across Canada unlike strictly provincial income security programs that vary a great deal. Many private insurance plans are also portable.

3c) Getting on CPP-D

1. Eligibility

The Subcommittee identified early in its process in 2002 that eligibility criteria is a major issue. It sought input and found substantive support for greater flexibility in the interpretation of the definition especially for people with “degenerative diseases, as well as mental, episodic chronic, episodic and invisible illnesses”.

Contribution Requirements

The following CPP-D information is taken primarily from the CPP website.
(www.sdc.gc.ca/en/isp/cpp)

To qualify for the CPP Disability benefit a person must “be under 65; have earned a specified minimum amount and contributed to the CPP while working for a minimum number of years; and have a disability as defined by the CPP legislation. To remain eligible, a person must continue to have a disability according to the CPP legislation.”

Eligibility for CPP Disability is limited by how recent the CPP contributions were. Eligibility to CPP is not “vested” (banked indefinitely) when CPP Disability is concerned, unlike for CPP retirement benefits.

Contributions and minimum level of earnings requirement:

“If your disability (as defined in CPP legislation) began after December 31, 1997, you must have contributed to the CPP in four of the last six years. In 2004, the minimum level of earnings [after which contributions must be made] is \$4,000”. Normally, if someone does not

meet this contribution criteria, it would mean that they would not qualify for a CPP disability benefit. However, CPP-D goes on to explain: "you may still qualify if:

- you delayed applying (that is, you had enough years of contributions when you first became disabled and you have been continuously disabled since then, but you don't have enough now);
- your CPP contributions stopped or were reduced because you were raising your children under seven years of age;
- you have obtained enough CPP credits from a former spouse or common-law partner to make you eligible;
- you worked in another country with which Canada has a social security agreement. Your contributions to that country's pension plan, when added to your CPP contributions, may be enough for you to meet the requirement;
- you were medically incapable of applying."

If the applicant does not meet the contributions criteria, then the application does not go on to a medical adjudicator to assess for the CPP-D definition of disability. People who have not contributed sufficiently to the plan (according to the criteria) do not receive benefits from it.

Several organizations representing people with disabilities identified former changes made to the contributions requirement as too restrictive:

"Effective in January 1998, eligibility was restricted to those claimants who have contributed in four of the last six years. Previously, the threshold was five of the last ten years, or two of the last three. Therefore, a person must now work for a longer period of time in order to qualify for benefits.... these legislative changes have had a significantly adverse effect on persons with serious mental illness. Many are still striving to create a work history and tend to have a limited attachment to the labor force." (Canadian Mental Health Association CMHA, "Position Paper on Federal Income Security Programs", 2003.)

"Taken together, the various reforms (of the 90's) have the effect of tightening up the disability benefit. The longer contributory requirements will keep some workers off the disability caseload even if they meet the definitional requirements." (Torjman, 2002)

Organizations and policy analysts decried the circumstances that deny CPP-D benefits to people who meet the definition and had made contributions sufficient under the old rules. They have called for restoration of a greater flexibility to the contributory requirement that would recognize "the episodic and degenerative nature of many disabilities as well as the challenges of finding and keeping employment when living with a disability" (Prince, 2002.)

The contribution requirement affects people with HIV/AIDS, especially people affected by HIV/AIDS at younger ages, who may not have the work and contributions history required to qualify under the tighter rules. The episodic nature of HIV/AIDS "can mean that an individual is required to enter and leave the workforce multiple times throughout his or her working life. While cumulative contributions to CPP over 10 or 20 years may be substantial, they may not have been made in a recent period of consecutive years. Under current guidelines, many people living with HIV have difficulty maintaining long term work and contribution requirements." (CAS/CWGHR, 2003.)

Some review tribunal members supported the arguments of advocacy groups. As a result, the Subcommittee said it "agrees with the panel members of the Review Tribunals who told us that the four-out-of-six rule actually introduces a type of systematic discrimination against people who have certain episodic illnesses where there are ups and downs. Over the course of these illnesses, periods of wellness may become shorter and periods of illness longer. As a result, many of these people do not qualify for CPP(D) eligibility based on the contributory criteria" (Subcommittee, 2003).

Our key informant interviews with some ASO advocates also noted that the contribution limits are not realistic for some people living with HIV/AIDS. Some PHAs may have contributed to CPP for many years, but may not be eligible for benefits if their recent work history has been erratic due to health problems.

Definition of Disability

The CPP defines "disability" as a condition, either physical or mental, that is "severe and prolonged". "Severe" means your condition prevents you from working regularly at a "substantially gainful" occupation and "prolonged" means your condition is long-term or may result in your death."

Although many people (and some CPP documents) interpret the "severe" part of the definition to mean that one is unable to perform any job, court interpretations have rejected this extreme interpretation. As interpreted in the Villani case, the decision-maker must consider whether the person is "incapable regularly of pursuing any substantially gainful occupation".

To qualify, the applicant must meet both the "severe" and "prolonged" criteria according to the CPP legislation. Medical adjudicators assess the severity of the disability first. If the applicant does not meet the "severe" criteria, (CPP-D) cannot consider the question of whether the disability is prolonged.

A CPP disability benefit is not approved on the basis of which disability or disease an applicant has, but on how the medical condition and its treatment affect the applicant's ability to work at any job on a regular basis.

Many view the definition of 'severe and prolonged' as a restrictive definition. Service organizations and individuals living with disabilities have seriously challenged the definition and its interpretation. Michael Mendelson, speaking to the Subcommittee from the Caledon Institute of Social Policy, expressed many people's frustrations: "... at its heart, the Canada Pension Plan Disability is a kind of program working by binary categorization. By this I mean you set up a fence. On the one side of the fence are the people who are entitled to the program, who acquire the label of being disabled or of having a certain kind of disability; and on the other side of the fence are those who don't manage to make it through that barrier. We know that people don't come in categories.... We know that people come in spectrums, if we can call it that. These are not even one-dimensional spectrums, but very complicated multi-dimensional ones." (Subcommittee, 2003)

The disability rights movement has changed the understanding of disability but the language of CPP-D policy has remained much the same. The Subcommittee observed: "It is hard for us not to believe that it affects the approach of those who administer CPP(D) if they are dealing in an environment that uses archaic language unsuited to today's circumstances (Subcommittee, 2003)

Several sources in the literature also noted the program no longer recognized that people live in the 'real world', and people were being denied benefits because they may be judged able to do "any job" regardless of socio economic factors (for example, employment opportunities in area of Canada you live, education, age, literacy).

"The issue of how to interpret the meaning of disability under the legislation was addressed in 2001 by a Federal Court of Appeal decision in Villani v. Canada. In this case, the Federal Court noted that the CPP is social legislation with a benevolent purpose of conferring benefits and, therefore, the legislation should be interpreted in a broad and generous manner, with any ambiguity resolved in favour of a claimant for disability benefits. The Court adopted a 'real world' approach to determining severity of disability, within the meaning of the Plan, as against a 'strict abstract' approach. Real world details such as a person's age, education level, employment experience and language proficiency were all relevant, the Court argued, in determining whether an applicant suffers from a severe disability under the CPP." (Prince, 2002). It is also important to note the 2002 Federal Court of Appeal decision in Canada v Rice. In this case the Federal Court of Appeal ruled that socio-economic factors such as

regional employment opportunities or the availability of work are not factors than can be considered in the determination of eligibility for CPP-D.

In May 2004, CPP-D introduced a comprehensive policy to provide direction to disability decision-makers in determining eligibility for CPP-D benefits. This policy provides an analytical framework for decision-making relating to administrative law principles and the CPP definition of disability.

Many applicants to CPP-D have little alternative but to apply to CPP-D, as their application to CPP-D is a precondition of eligibility for private LTD plans or for provincial disability support programs.

Our key informant interviews provided a variety of experiences related to the CPP-D definition of disability. Our interviews would suggest that this definition has not resulted in many denials of CPP-D benefit for people living with HIV/AIDS. However, it is important to note that our recruitment strategy for this study would bias towards PHAs who had access to advocates. It is possible that a number of PHAs may have never applied for CPP-D because of the definition of disability, or were refused on first application and did not seek a review.

From our interviews it seems that most PHA applications are accepted by CPP-D under this definition, although careful attention to the application documents is required for both the PHA and his/her health care providers. A number of cases were reported where the initial application was denied, but in almost every case the application was subsequently approved after further information was supplied. We heard of only one case where the initial application was denied (in this case, under the Quebec Pension Plan) and the client decided not to pursue the issue, based on advice from his doctor.

The definition of disability may be a practical and psychological barrier to some PHAs who never consider applying. Some of our PHA key informants told us of their own fears of declaring a "prolonged and severe" disability, and of their worries about proving it.

"To be eligible for CPP Disability, clients believe that they have to declare that they are 'no longer able to work.' Some of our clients won't go there." – ASO case worker

2. Application Process

In the literature review, several consumer groups and advocates identified barriers such as language, literacy and visual impairment. The BC Coalition of People with Disabilities (BCCPD) calls "the five-part application...intimidating and confusing". Their website provides guides to assist people through the application, in particular the section that applicants need to fill out themselves. (<http://www.bccpd.bc.ca>) Finding advocates to assist applicants is generally encouraged.

A recent study on cancer patient access to disability insurance found similar barriers: "There is an enormous burden on patients to learn about and coordinate the claims process, and it is often difficult for patients to find help and/or information in order to be successful in this process." (Sunnybrook & Women's College Health Sciences Centre, "Investigating Cancer Patient Access to Long-term Disability Insurance Coverage: A Study from Multiple Perspectives," 2004.)

Several sources also identified the high rate of reversals on appeal points to a problem in the first stage of the application. The Subcommittee found that "the CPP(D) program receives over 50,000 applications each year. There are almost 20,000 appeals each year for applications that have been rejected. It is estimated that over 30% eventually succeed." While eventual acceptance onto CPP-D shows the system can work, it creates time delay and stress upon individuals who are living with a disability and all that this involves.

"The [Multiple Sclerosis] Society has found that the majority of people with MS who appeal with our assistance are eventually granted benefits. It appears that within the appeals process, people have an opportunity to provide more detailed information to the medical adjudicator. This suggests there is a flaw in the system from the beginning, making the process inefficient and wasteful of taxpayers' money and leaving people who are struggling

with disabilities without a way to make ends meet.” (Multiple Sclerosis Society of Canada, “A Brief to the Sub-Committee on the Status of Persons with Disabilities, Multiple Sclerosis and CPP(D) Issues,” 2003.)

The Canadian AIDS Society and the Canadian Working Group on HIV/AIDS and Rehabilitation challenge a narrow medical approach to the initial judgment on applications from people living with HIV/AIDS: “There are objective medical criteria that help evaluate whether a person living with HIV is eligible for disability, namely tests for CD4 cells and viral load. However, CD4 cells and viral load are not accurate indicators of strength and physical stamina, do not predict each individual’s vulnerability to illness, do not account for side effects produced by treatment, and do not provide indication of psychological and emotional health and well being.” (CAS/CWGHR, 2003.) CWGHR has provided educational sessions for some CPP-D and private insurance adjudicators that have resulted in new understandings of the complexities of living with HIV.

Our key informants strongly affirmed the need for accessible entry to the CPP-D system. Many PHAs reported that they found the application process daunting, and that they relied heavily on ASO or health care provider support to understand the paperwork. ASO advocates reported that they spent considerable time assisting clients and their health care providers in filling out the applications properly. A primary care physician who works with a large number of recent immigrants reported that the application process is particularly problematic for them.

PHAs who had access to advocates (ASO case workers, social workers, well-informed doctors, etc) reported few barriers to accessing CPP-D. PHAs who attempted to access the system on their own were more likely to have to provide additional information on request, or to pursue an appeal.

CPP-D staff reported that just over 50% of applications from claimants with HIV are denied on first application (which is in line with the overall trend for applications)

This research suggests that a more user-friendly application process may improve access to CPP-D. [CPP-D is currently developing a lower-literacy application form]. The research also strongly suggests that access to an informed advocate (ASO, social worker, etc) is a key component to efficient entry to CPP-D.

A number of informants noted that CPP-D information services such as the 1-800 line were easily accessible (a real person answered) and very helpful to PHAs or advocates seeking information on the application process.

“We urge clients to see us before, not after, they’ve applied. We can help save a lot of hassle.” – ASO advocate

3. Timeliness

Several groups representing people living with disabilities identified a disconnect between the timelines sought by CPP-D and reality: “Human Resources Development Canada (HRDC) has set forth clear service standards regarding application and appeals processing timelines (e.g. 62 working days to decide on an initial application; 71 days to decide on a reconsideration –appeal level I) The reality is that consumers’ lives are put on hold for far greater time periods than these standards allow for”. (CMHA, 2003)

The Subcommittee acknowledged that “The experience of a significant number of individuals who shared their stories indicate that it actually takes 4 to 5 months for an application to be processed and a minimum of two to three years to go through the appeal process.” (Subcommittee, 2003.)

Key informants for this project reported mixed experiences with the timeliness of CPP-D responses. Most PHAs and their advocates reported that the process to receive benefits took

three to six months. In some cases, delays were the result of delayed paperwork from physicians. Although payments are routinely retroactive, ASO advocates urged vigilance to ensure the calculations are correct. In a number of cases, PHAs had alternate sources of income (private insurance or provincial disability plans) during the waiting period, and were legally required to reimburse these plans for any amount they received from CPP-D. In cases where this “clawback” was unexpected, it created additional stress for the PHA who had made financial commitments expecting extra income.

4. Refusals, Reconsiderations & Appeals

Our interviews suggest that many initial refusals from CPP-D are changed when further information is provided, and that few applicants may need to pursue formal appeals.

As noted above, the appeal process appears to work in many cases. Advocacy groups encourage applicants to turn to advocates and legal clinics where possible, as the rate of overturn of rejections is significant – over 30%.

However, the Subcommittee expressed its concerns about the appeal process: “Generally, we found that the application and appeal process is financially and emotionally stressful for those who have to go through it at a time when they are struggling to cope with physical or mental disabilities as well as a change in life circumstances...Despite the level of satisfaction with staff during the appeal process, the Subcommittee is extremely concerned that the rigours of the process itself discourage many people from even starting it. The Office of the Commissioner of Review Tribunals (OCRT)’s client satisfaction survey found that almost 80% of people who did not appeal cited stress involved in the appeal as a factor in their decision. To us, this means that many people who are entitled to CPP(D) benefits are probably not receiving them.” (Subcommittee, 2003.)

Cost is a key issue that affects access. Applicants and appellants must pay for copies of medical records. Those appealing decisions may pay fees for legal assistance or representation. Some provinces include CPP-D appeals in its legal clinic coverage and others do not.

The CPP-D web-site describes its process for informing people if their application has been accepted or not as: “We will telephone you to explain how and why we made the decision on your application before we mail you a letter confirming the decision. The phone call and letter will tell you if your application has been approved and what your appeal rights are. If your application is approved, we will also tell you the date that your benefit begins and the amounts you will receive.”

CPP-D is committed to conveying initial refusal information via a phone call rather than a form letter. Our informants reported a mixed record on that commitment; it appears that some refusals are still communicated by letter. For those who did receive phone calls, however, they were described as very helpful. The calls provided opportunities to rectify any missing or inaccurate information in the application that might prompt a refusal.

There were few examples of formal appeals found within our key informant group. ASO advocates who had supported appeals found the process to be reasonably fair and transparent.

“The appeal process is a bit unwieldy and takes time, but people generally get on CPP-D if they should” – ASO advocate

5. Information/Education for Clients

The Council of Canadians with Disabilities (CCD) drew attention to the need for non-governmental groups to provide accessible information: “Many advocacy groups have developed excellent materials and supports for those going through appeals and clients could

be referred to these organizations” (CCD, “Presentation to The Sub-Committee on the Status of Persons with Disabilities,” 2003.)

These resources include websites of the BC Coalition of People with Disabilities <http://www.bccpd.bc.ca/> which contains guides to the applications and appeals; HIV/AIDS specific resources include the Canadian AIDS Society (<http://www.cdnaids.ca>) and the Ontario AIDS Network (www.ontarioaidsnetwork.on.ca) that provide information on public and private plans.

The Subcommittee “wonders why the community has been left to perform the job that the CPP(D) program should be carrying out itself in terms of providing assistance to those who need help.” The Subcommittee noted that “many participants (in their consultation) believe that a large number of persons with disabilities are unaware of the existence of the CPP(D) program and do not know that benefits may be available to them.” (Subcommittee, 2003.)

Several groups raised the issue of the need for plain language. “All application processes for CPP(D) must be made accessible by addressing language and cultural adaptation, education and literacy, cognitive and learning capacities.” (CAS/CWGHR, 2003.)

Data from key informant interviews suggests that the issue of education – both for PHAs and for the community organizations and professionals who support them - is a significant one. PHAs spoke of the crucial role advocates played in helping them fill out applications and access benefits. Advocates spoke of the complexity of the application process and the need to coach both PHAs and doctors in filling them out properly. Health care providers spoke of the learning curve to properly fill out the required paperwork. CPP-D staff spoke of the time needed to solicit proper information from clients and doctors. Information about CPP-D income security policies is difficult to access.

Few PHAs understood the rules and regulations concerning earned income, vocational rehabilitation, or reinstatement to CPP-D after trial periods of working. As a result, some PHAs may fail to report earnings or fail to explore possibilities for part-time work or for trial periods of full-time work.

3d) Being on CPP-D

1. Benefit Levels

The real life experiences and information that came forward at the Subcommittee put into question one of the foundation stones of CPP-D. From the beginning of the program there was an underlying assumption that Canadians would have other resources to also draw upon.

One of the great positive aspects of CPP-D is its universality. However, this sense of universality can be undermined: “Because part of disability payments is based on an earnings-related calculation, not all recipients receive the same monthly benefit. This is particularly important when considering gender. Due to the overall higher earnings of men, women as a whole receive fewer benefits. For example in 2000, the average disability benefit for men was \$737.21 per month, compared to \$625.15 per month for women.” (CAS/CWGHR, 2003)

The CPP-D benefit is based on a two prong calculation: an earnings-related calculation and a flat rate amount; the flat rate amount for 2004 is \$382.17.

“The architects of CPP(D) fully anticipated that beneficiaries would also have access to other sources of income to replace their earnings in the event that a severe disability precludes work... Suffice it to say that the expectations of CPP(D)'s architects have only partially been met, since a recent estimate suggests that less than one-half of CPP(D) recipients receive disability income support from another source. Members of the Subcommittee are also concerned that the proportion of CPP(D) beneficiaries with access to multiple sources of income support seems to have declined in recent years, since Statistics Canada estimated in 1995 that 60% of CPP(D)

recipients received disability income support from another source. The low and declining incidence of multiple sources of disability income support among CPP(D) beneficiaries and the absence of a well integrated disability income support system is of great concern to us and raises the issue of the adequacy of the level of income support provided under CPP(D).” (Subcommittee, 2003.)

Some clients are surprised to learn that there is no drug benefit coverage associated with CPP-D.

Few of our key informants experienced CPP-D as their sole income; for many, the level of CPP-D payment was somewhat a moot point as it was deducted from their other income sources. For those who rely solely on CPP-D, the income is insufficient to support a basic healthy lifestyle. However, the indexing of CPP-D benefits to the Consumer Price Index was widely praised.

2. Reassessments

From the experience of our key informants, reassessments of PHAs are rare. None of our informants were familiar with a case where a reassessment had led to a PHA being denied benefits. However, the fear of reassessment was a major concern of many informants (PHAs, ASO advocates, and health care providers). This fear causes some to under-report earnings, and causes others to avoid any work or training, even if it would be allowed under the CPP-D guidelines.

“The ‘party line’ among the PHA community was: do not initiate any contact with CPP, or you’ll start a reassessment.” – PHA key informant.

3. Interactions with CPP-D Staff

Few key informant interviews needed to interact with CPP-D, but of those who did they report rare, but largely positive interactions with CPP-D staff. Staff are seen to be helpful and supportive.

4. Access to education, vocational rehabilitation

In 1996, a proposal was approved to establish a Vocational Rehabilitation Program as an integral component of the CPP disability program. The following year, the CPP introduced a policy guideline concerning vocational rehabilitation. The program is based on the premise that vocational rehabilitation is more likely to be successful if undertaken as quickly as possible after the onset of a disability. It recognizes that new training techniques, assistive devices and medical technologies enable many individuals with disabilities to return to work even in the presence of a severe and prolonged disability. While the disability must be severe and prolonged, the medical condition must be stable. (Torjman, 2002.)

“Since disability is equated with permanent unemployability, individuals on CPP-Disability are highly reluctant to do anything that even resembles work or the pursuit of employment. For instance, people who are interested in vocational rehabilitation are afraid to make the call to seek information through formal CPP channels because it may trigger a reassessment of their medical condition resulting in the fear that their benefits could be lost. Some individuals have even been encouraged to participate in rehabilitation measures only to discover later on how difficult it was to get back on CPP Disability. Essentially, people are penalized for trying to improve their condition even if they are not capable of participating in regular work again.” (CMHA, 2003.)

“Between 1998-1999 and 2002-2003, HRDC’s aggregate allocation to the Vocational Rehabilitation Program totaled \$21 million or an average of \$4.2 million annually. In our opinion, this is a very small effort for a program that pays out more than \$2.5 billion in disability benefits each year. This effort seems even smaller considering the testimony we received that outlined

the significant benefits from vocational rehabilitation, provided the intervention is early and comprehensive.” (Subcommittee, 2003)

Individuals evaluating their ability to remain in the workforce or to reintegrate after a period of illness want assurance that they will be entitled to have their benefits reinstated should they need to withdraw from the workforce. A need was identified for continued “accurate, independent advice and information” Clearly there is a feeling on behalf of applicants that they do not have enough information about the program and their eligibility under different circumstances to be assured that they will be provided financial security. (CAS/CWGHR, 2003.)

In order to access vocational rehabilitation, clients must attain a statement from their physician stating that their health had improved and that they were capable of rehabilitation. Many PHAs fear that this statement would lead to an eventual loss of CPP-D benefits. CPP-D staff, however, note that they are aware of the cyclical nature of some illnesses and that clients would continue to be eligible should their health take a turn for the worse.

Key informant interviews confirmed that many PHAs are reluctant to engage with vocational rehabilitation services for fear that this would trigger a reassessment or denial of benefits. And, although CPP-D staff interviews indicate that educational pursuits do not trigger reassessments, our interviews with PHAs and ASO advocates suggest a strong fear of this possibility.

(The Quebec Pension Plan has no vocational rehabilitation program.)

3e) Returning to Work

1. Barriers/Inhibitions to Returning to Work

Many PHAs in our interviews expressed profound fears about considering returning to work. They worry about failing health, about reentering a changed workforce, and about regaining access to CPP-D or private disability insurance. (See also Ferrier & Lavis, “With health comes work? People living with HIV/AIDS consider returning to work,” 2003)

With CPP-D, at application the client and his or her doctor must prove that the client is too disabled to work. To be accepted into the CPP Vocational Rehabilitation (VR) program, the client and his or her doctor must then say that the client is motivated to return to work full time and that the doctor supports (agrees with) participation. If as a result of participation in VR, the client regains capacity to work—even if a job is not secured--benefits can be discontinued.

Furthermore, the CPP website states that the VR program is for those clients “whose medical condition has stabilized and who will likely become ineligible for benefits...”

There are many challenges for people with HIV/AIDS considering or attempting a return to work: “Discrimination and the inability of small organizations to sustain HIV positive employees are indirectly associated with the disease, and can not be alleviated with improved health and rehabilitation training. While these are factors beyond the control of the individual, they can play a large role in the ability of an individual living with HIV to remain in a position or to seek new employment. This is also an issue that can not be ignored when examining the effectiveness of CPP (D) policy and programs.” Furthermore, “many women experience additional barriers when considering seeking employment. These include family and relationship issues, having children, sexual abuse and poverty.” (CAS/CWGHR, 2003). Women may also have the role of caregiver to an HIV+ partner or child/children.

2. Earned Income, Part-Time or Contract Work

Several organizations have raised the issue of an increase in the limit to earned income. In particular, groups representing people with episodic illnesses where individuals may have

periods of wellness alternating with illness and the unpredictability does not allow them to return to the work force: “For many individuals, periods of health are not long enough to sustain a long term employment contract. By increasing the earnings exemptions, people living with HIV are able to participate in employment when they are healthy, and are able to participate in the workforce without jeopardizing their benefits. Increasing the earnings exemption is a way of removing work disincentives.” (CAS/CWGHR, 2003)

Key informant interviews with CPP-D staff clarified that the “allowable earnings” amount (currently \$4,000, usually increased annually) is not an earning ceiling, but is intended to trigger a report to CPP-D. Clients can earn the allowable earnings amount every year.

Clients are not reassessed by CPP-D when they report allowable earnings. The intent, according to CPP-D, is to initiate a discussion about the client’s ability to return to a substantially gainful occupation. In addition, CPP-D staff say that this provides them with the opportunity to provide support to clients who are returning to work whether or not they return to a substantially gainful occupation. When a client has earnings between allowable earnings and the substantially gainful amount, CPP-D offers support to clients such as regular telephone contact to identify services available, including vocational rehabilitation.

For 2004, the income defined as “substantially gainful occupation” is \$9,770 annually. This would trigger a reassessment, but even if a client was found to be employed/employable they would still receive CPP-D benefits for three months. They may also be eligible for automatic reinstatement to CPP-D should the return to work prove unsuccessful within two years. Automatic reinstatement will be in force by January 2005.

In the words of one senior CPP-D manager, “the Program recognizes that a significant minority will have the opportunity and desire to participate in some form of work activity because it gives them a connection to the community and a feeling of self-worth. Some will experience an improvement in their medical condition (or their ability to adapt to their limitations), return to work and no longer require income support. Others, without any change in their medical condition, will adapt to their limitations and want to participate in a minimal level of work. Still others, particularly those with severe illnesses of a cyclical nature, may alternate between periods of work activity and periods when they cannot work. The program encourages clients who cannot work on a regular basis to continue working without losing their CPP-D benefits.”

Key informant interviews with PHAs and advocates, however, underlined a lack of information of CPP-D’s rules for earned income, and a palpable fear that any report to CPP-D of earnings could lead to cancellation of benefits.

“The rules on earnings aren’t understood by anyone. Are you reassessed after \$4 thousand income? Should you report only after 3 months earning income? When are you already over the level? All this prompts people to be dishonest, since they are scared shitless about losing CPP entirely.” – ASO Advocate

3. Trial Period

The allowance for a three-month trial period for re-employment while CPP is still paid is not well known. It also may not be long enough for some PHAs interested in exploring returning to work.

“We’d also like to see the program increase the trial period. Currently, the trial period when you go back to work is three months. We don’t feel that is enough time for someone to evaluate their new work environment, to be able to evaluate the skills that are going to be required, whether this is a high-stress job, as well as what kind of physical capacity is going to be required of them. This is especially important for people who have been out of the workforce for a number of years. Currently, many people living with HIV have been on disability for five to ten years, and to return to the workplace is going to take quite a bit of

training and rehabilitation.” (Ainsley Chapman, Canadian AIDS Society, cited in the Subcommittee report, 2003.)

4. Automatic Reinstatement

CPP-D policies (to be in force by January 2005) will allow clients to be eligible for automatic reinstatement to CPP-D should their return to work prove unsuccessful within two years of the benefit being stopped. There is no requirement to make contributions to CPP to qualify for automatic reinstatement. Clients will be automatically put back on CPP-D if they have the same or similar disability, as documented by their physician in an updated medical report, and can no longer work.

Key informant interviews with PHAs and advocates underlined a lack of information of CPP-D’s rules for earned income, and a palpable fear that any report to CPP-D of earnings could lead to cancellation of benefits. Some advocates fear that the two-year limit for automatic reinstatement may not be sufficient for someone with an episodic illness like HIV, where ill health can sometimes return after lengthy periods of good health.

According to some advocates, the mechanisms currently in place require unreasonable waiting periods for evaluation and decision-making. Many people who are on disability do not have a pool of personal financial resources, either through cash, credit or assets, and are not in a position where they can rely on savings to be reimbursed if approved. (CAS/CWGHR, 2003)

Section Four: Private Long-Term Disability Insurance

4a) History & Overview of LTD

Long-term disability insurance is available through group insurance plans, mostly available as part of a benefits package supplied by employers. While individual plans also exist, the vast majority of those who have access to disability insurance do so via group plans. The group insurance plans are sold by private insurance companies (or brokers who sells these companies policies), which are subject to some provincial and federal government regulation. A group disability income insurance plan involves three primary parties: the plan members (individuals covered by the plan – either working or on disability); the plan sponsor (usually the employer); and the plan carrier (usually the insurance company). In many cases, the employer plays some role in assisting (or resisting) employees with access to LTD and other benefits.

The industry has been the site of many mergers and acquisitions in recent years. One result is that the details of many group insurance plans may have changed if the plan was taken over by a new company.

4b) General Themes about Private Insurance

“Current Disability Issues in Canada: a Background Paper”, (2002) prepared for the Subcommittee notes: “In 1997, about 50% of employed people were covered by long-term disability (LTD) plans provided by private insurance companies. These usually replace about two-thirds of earnings, but their total payout is low because they are generally second payers (i.e., after EI sickness payments cease, and LTD payments are reduced by any C/QPP or WCB benefits).”

Individual disability benefit plans vary widely. As the Ontario AIDS Network web-site (www.ontarioaidsnetwork) section on benefits points out, “LTD is a unique contract between your employer and their insurance company” and there are significant variations in terms of eligibility, benefits, rehabilitation programs, re-assessments and other policies and procedures. Understanding the particular implications of a given policy can be difficult for anyone on their own.

The British Columbia Persons With AIDS (BCPWA) Society’s Michael Bromm advises in a legal memo that people understand – or get help to understand - the particular terms of their own insurance policy and individual contract, or more likely, the contract between their employer and the insurance company. It is important to understand what will or won’t be covered. Employees often do not have access to the actual text of the contract between their employer and the insurer.

Private insurance companies – because they are private, and because their contracts are with employers – tend to be less transparent & accountable than CPP-D. Conversely, they may also be more flexible. Our key informant interviews revealed some illustrations where insurers had been very supportive and flexible in responding to the client. Responsiveness can depend on the policy, on the individual file, on the worker handling the file, on the employer’s stance and actions and on pressure from the client or from their advocate.

A number of key informants from within and outside the industry suggested that the industry has in recent years become more aware of the episodic nature of HIV, and interested in exploring options that would support a return to work.

As with CPP-D, however, it appears that many people on LTD are –understandably - so fearful about their long-term income security that they are unwilling to explore any possible flexibility with their insurer for fear of being cut off benefits.

One basic problem with private insurance is that many workers are not covered by LTD insurance, and the percentage of the workforce covered is shrinking. Another problem, particularly for AIDS Service Organizations, is that LTD costs are applied to an individual

employer, not across sectors; this serves as a disincentive to hire people with chronic disabilities. It also creates an incentive for employers to discourage employees from accessing LTD.

Another potential problem is the insecurity of the LTD benefit in the event the employer changes or cancels insurance plans.

4c) Getting on LTD

1. Eligibility

Most private insurance plans require a minimum length of workplace service and have restrictions on part-time workers. The definition of disabled is usually less restrictive than CPP-D: the disability is recognized if one is unable to perform one's existing job (not ANY job) for the first two years of disability. The complications of medications, diarrhea, exhaustion, depression, stigma, etc. seem to be recognized by many plans.

BCPWA's Bromm notes: "Eligibility conditions under LTD plans are typically less onerous than those for CPP(D). In addition, benefits are restricted to those who are unable to work in their own job for two years and, thereafter, in a comparable occupation. This is vastly different from CPP(D)'s requirement that, in addition to having a severe and prolonged disability, one must be unable to be employed in any substantially gainful occupation."

Key informant interviews suggest that many private insurance plans will accept medical documentation of HIV similar to CPP-D documentation as evidence of disability.

2. Application Process

The application process varies widely by insurer and employer. Assistance from employer Human Resource departments or from an ASO advocate can be very important for many.

Some key informants expressed concern that the functional assessments required by some plans may not recognize the reality of HIV, though this does not appear to be an insurmountable barrier.

"It feels like there are 10 doors with 100 keys and you have to figure out which key opens which door." – social worker.

3. Timeliness

Timeliness varies by policy, insurer and employer. Key informant interviews have reported satisfactory response and payment times.

4. Refusals & Appeals

Appeal processes – where they exist at all – vary widely from policy to policy. They appear in general to be less consistent, less available and less transparent than CPP-D. The support of the employer in pursuing an appeal is important. The ultimate appeal would be to a court of law, based on the private contract of insurance. It is not clear from our research whether clients in all provinces would have access to legal aid in the event of a legal course of action.

5. Information/Education for Clients

Information about private insurance varies widely. Many employees are not allowed access to the insurance contract. Some plans appear to rely heavily on employer Human Resource departments to be the conduit of communication with employees.

Key informant interviews suggest that there are significant gaps in recipient's knowledge about issues such as allowed earnings, access to training, etc. This lack of knowledge,

combined with a reluctance to raise issues with insurance company representatives for fear of being reassessed or cut off, may inhibit many people on LTD from exploring flexibilities to return to active living.

4d) Being on LTD

1. Benefit Levels

Benefit levels of private insurers vary, but are generally tied to a percentage of pre-disability income. Very few policies have cost-of-living increases. The employees may have to pay income tax on their benefits if the premiums were paid by their employer.

Extended health and dental benefits do not necessarily continue when someone leaves work and goes on disability; this comes as an unwelcome surprise to some PHAs.

“An important aspect of STD and LTD plans is their commitment to assisting recipients to return to the workplace, preferably in their own occupations, or—if this proves to be not feasible—in another. Consistent with this orientation, disability income insurance plans are designed to ensure that the recipients have a financial incentive to return to work in the sense that their disability income replacement benefits do not exceed their pre-disability employment income.” (Canadian Life and Health Insurance Association CLHIA, “The Role of Disability Income Insurance Plans in Canada’s Disability Income System,” 2003.)

Private insurance contracts stipulate that people must apply also to CPP-D and will deduct the CPP-D benefit from their payments. Applying to CPP-D and appealing any refusal is often required by the insurer. The insurance industry made this case before the Parliamentary Subcommittee: most LTD plans are designed and priced on the assumption that such applications will be made. This assumption makes LTD plans significantly more affordable for plan members. Indeed, one estimate indicates that LTD plan costs could increase by as much as 45 per cent if such applications were not assumed. (CLHIA, 2003.)

However, some advocates have argued that CPP-D should augment, not offset, other sources of disability income.

BCPWA’s Bromm notes: “there is a strong argument that, because CPP benefits are fully taxed.... whereas private LTD benefits are not, insurers must be under a duty to specifically warn insureds that, should they become disabled and qualify for CPP as well as private LTD benefits, they will be unable even in theory to collect the full amount for which they have contracted.... In addition, the Canadian Life and Health Insurance Association’s Guidelines state that reductions should be summarized in the disclosure statement that is delivered to the insured with the policy.”

Some private insurers offer LTD recipients an opportunity to enter into an assignment agreement specifying that CPP(D) benefits, including amounts advanced by a private insurer during a beneficiary’s CPP(D) assessment period, would be paid back by the government directly to the private insurer.

2. Reassessments

Periodic reassessments are common for LTD recipients (unlike CPP-D). Reassessments typically occur after the first two years of disability, and annually thereafter. Reassessments typically assess if the client is able to work at any occupation for which he/she is qualified.

“For people living with lifelong and episodic illnesses, and if a claimant’s health status is changing frequently (unwell/very unwell/nor feeling better) ‘new’ forms must be constantly filed to reflect changes in health status. There is a requirement to continually prove (or re-prove) your illness. This becomes unwieldy not only for the individual, but also his/her health

care provider(s), especially the family physician, who often functions as ‘gatekeeper’ for both the public and private sector insurance providers.” (Proctor, 2002.)

Our key informant interviews have not identified this as insurmountable barrier; reassessments are often routine, especially if physicians are familiar with them. However, many recipients and their advocates express significant fears that reassessment could be triggered by earned income, volunteering, returning to and/or completing training, engaging vocational rehabilitation, etc. Reassessments create a great deal of stress for individuals and take time and human resources to complete more forms.

3. Interactions with Insurance Staff

Interactions with insurance staff vary greatly. Most interviews have reported no interactions or largely positive interactions. We did hear some illustrations, however, of very insensitive and/or inflexible interactions with staff.

4. Earned Income

Allowable earning limits and exceptions vary widely. Some LTD recipients fear that any reported earned income will trigger reassessment. We learned of one case where the insurer supported the client to return to work part-time, but deducted all earnings dollar-for-dollar.

5. Access to education, vocational rehabilitation

Policies vary widely on support for education or vocational rehabilitation. Some recipients express concerns that even inquiring about or accessing education/rehab would trigger reassessment or cutoff. In some cases, PHAs expressed concern that vocational rehabilitation services are assigned by the insurance company, not chosen by the client.

4e) Returning to Work

1. Barriers/Inhibitions to Returning to Work

Key informants expressed fears about what would happen if their health failed again. Some also worried about how much the workforce may have changed since they left. Most critically, PHAs we spoke with worried about regaining access to LTD or other insurance should the return to work be unsuccessful. Concerns ranged from:

- (1) becoming eligible for insurance coverage upon return to the workforce with a different employer, given pre-existing condition clauses;
- (2) access to insurance benefits with the same employer should they become sick again;
- (3) returning to work and being fired, and hence, left with no insurance coverage.

2. Part-Time or Contract Work

Key informants expressed concern or confusion about limits to earned income or short-term income, as well as fears of reassessment or cutoff. It appears that PHAs are reluctant to explore any potential flexibility with their insurers for fear of triggering a reassessment.

3. Trial Period

Continued LTD benefits after returning to work, either with the same or a different employer, are rare or non-existent.

4. “Fast-Track” Reinstatement

It appears that access to “fast-track” reinstatement is rare, if someone returns to work but is again unable to work within a certain period. This is particularly concerning for people living with HIV or other episodic disabilities.

Section Five: Conclusions and Areas for Further Research

This environmental scan suggests that barriers for people living with HIV/AIDS to accessing disability insurance and to returning to active living are complex.

To access CPP-D or private insurance LTD benefits, it appears that people living with HIV/AIDS are largely accepted onto the program provided that:

- a) they meet the contribution requirements and
- b) they are assertive or literate enough to complete the application properly – initially or upon reconsideration - or they get the right support in doing so from their doctors, social workers or ASO advocates.

The large percentage of initial refusals, however, suggests that the application process is complex or unclear enough to present a significant barrier to many PHAs who eventually qualify. This barrier is more significant for those who lack access to advocates, who lack assertiveness, or who have language or literacy barriers.

It is unclear how many people living with HIV/AIDS who could benefit from CPP-D do not apply because they do not meet the contribution requirements, are discouraged by the wording (and government communication about the wording) of the “severe and prolonged” eligibility requirement, are discouraged by the application process, or are discouraged by an initial refusal and do not pursue a reconsideration or appeal.

It is also unclear how many PHAs, if any, are discouraged from accessing private insurance LTD benefits because of the application process or because of lack of support from their employers or human resource departments.

Once people living with HIV/AIDS are on CPP-D or private insurance LTD benefits, it appears that many recipients are fearful of the possibility of reassessment or suspension of benefits. This fear precludes many PHAs from exploring the flexibilities that their plans may offer in supporting return to active living. A significant number of the PHAs we spoke with would welcome an opportunity to return to work (at least part-time) if they did not fear for their long-term income security.

The environmental scan adds further weight to the recommendations for action already voiced by many consumer advocacy groups and by the Parliamentary Subcommittee. In particular, the scan suggests that some of the following actions are still highly needed:

- Plain language materials and in-person communication from disability insurance plans to clients about the application process, allowable income levels, access to training and rehabilitation, supports to return to work, and other rights and responsibilities.
- Support, funding, training and on-going communications from disability insurance plans with community-based organizations, social workers and other advocates for PHAs.
- Targeted communications and outreach strategies from disability plans to other potential advocates: health care professionals, vocational rehabilitation specialists, human resource professionals, union representatives, and others.
- Increasing limits on allowable earnings and “substantially gainful” earnings (without clawbacks or fear of reassessment) with CPP-D and LTD plans.
- Increasing trial periods for returning to work, with automatic reinstatement to benefits should the return to work prove unsuccessful.

The scan concludes that further study is required to understand how CPP-D and private insurance disability policies and procedures, and especially the perceptions of them, may inhibit or facilitate return to active living. In particular, further research should explore:

- How do PHAs and their advocates receive and internalize information, misinformation and perceptions about CPP-D and LTD plans?
- What strategies have CPP-D staff, private insurance companies and advocates used to inform PHAs about their rights and responsibilities regarding disability insurance? Which strategies have been successful?

- What information and/or assurances would PHAs on disability insurance need to ease their fears about exploring returning to active living?

Further research should also identify strategies to overcome those real and perceived barriers, and to elaborate on the recommendations already developed by other reports aimed at improving disability policies.

(See also Appendix D: Parliamentary Subcommittee Recommendations).

CWGHR Appendices

Appendix A: Methodology, Consent Form

This project consisted of the following components:

- V. A literature review
- VI. Based on the implications from the literature review, key informant interviews with individuals from the following stakeholder groups:
 - i) Fifteen people living with HIV/AIDS who have had experiences with CPP-D and/or private disability insurance;
 - j) Four policy and program staff within CPP-D and the private insurance industry;
 - k) Five AIDS service organization advocates who assist people with accessing benefits;
 - l) Five health care providers and other professionals who support people living with HIV in accessing benefits.

The literature review focused on articles and briefs specifically related to CPP-D and private disability insurance but also included documents that provide a broader view and analysis of Canadian income security programs. It did not include a detailed analysis of government legislation. A bibliography is provided as Appendix B to this report.

Key informants were recruited based on suggestions from the project advisory committee; some people living with HIV/AIDS were recruited with assistance from AIDS Service Organization advocates; others were recruited directly by the research team. It is important to note that our recruitment strategy would bias towards PHAs who had access to advocates.

Of the fifteen PHAs we interviewed:

- Three were women and twelve were men.
- Six were from Ontario, four from Quebec, three from B.C., one from the Prairies and one from Nova Scotia.
- Six had been diagnosed with HIV for ten years or less, six for eleven to fifteen years, and three for longer than 15 years.
- Three had been in the workforce prior to going on disability for less than ten years, seven had been in the workforce from eleven to twenty years, and five for greater than twenty years.
- Two have been on disability for five years or less, seven have been on disability for six to nine years, and six for ten years or more.
- Two of our PHA informants had returned to work, and one had returned part-time.

Key informant interviews were semi-structured, based on an interview guide. Key points from the interviews were recorded by hand by the research team. Results were analyzed for consistent and contrasting themes by topic and by stakeholder group.

The Ethical Review process was completed through Russel Ogden from the Community Based Research Centre - Ethics Review Committee based in Vancouver, B.C.

- The ethics review was for all participants, not just people with HIV/AIDS.
- Participants were not asked to sign a consent form, but instead were asked for verbal consent after reviewing an information sheet. As this is a low risk study, it was felt that written consent was not necessary and could be a barrier. Participants also had the option of pulling out of the interview at any time.

A sample of the information sheet and interview guide follows. The interview guide was modified slightly for each stakeholder group.

Consent/Information Sheet: “Current Policies and Practice of the Canada Pension Plan Disability Program and private disability insurance relevant to People Living with HIV/AIDS – Phase 1: Environmental Scan”

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is doing a study about the experiences of people living with HIV/AIDS in accessing Canada Pension Plan-Disability and Private Insurance Industry disability benefits.

We would like to talk with you to try to understand your experiences in accessing benefits. We would like to talk with you to try and understand the policies and practice of CPP-D/private insurance disability benefits. We are particularly interested in understanding how easy or difficult it is for people with HIV/AIDS to access benefits, and maintain benefits, and their ability to earn income while on benefits.

Joan Anderson and Glen Brown are consultants hired by CWGHR and are interviewing people living with HIV/AIDS, people who work on the front-lines with CPP-D/private insurance disability benefits, people who assist people with HIV/AIDS to access CPP-D/private insurance disability benefits to discuss their experiences. The interview will last between half an hour to an hour.

All information that you discuss in the interview is confidential. Your name will not be used to identify your comments. The consultant will take written notes during the interview. The results of the interviews will be made available to CWGHR and presented in group form - that is, no individual will be identified.

You can choose at any time to stop the interview. You can ask for an answer to be changed or removed. If you decide to withdraw from the study, the information you provided will be removed from the study record.

If you have any questions about this interview, or your participation, you may call Glen Brown at XXX or Joan Anderson at XXX in Toronto. If you wish to speak to someone who is not associated with the study, you may call Russel Ogdon with the Community Based Research Centre – Ethics Review Committee in Vancouver at XXX.

The study will take about 3 months to complete. The results will be presented in a public report. If you are interested in receiving the report, please let Glen or Joan know. The report will give a general thank you to the people who helped us. Your name can be on a list of people who helped by speaking about their experiences if you wish. The list won't identify people's titles, just names. Would you like your name to be included or not?

Do you have any questions? Do you understand what will happen to the information you are about to provide?

Do you agree to proceed with the interview questions?

Interview Guide For People Living with HIV/AIDS

First, we'd like to know a bit about your own history: (geography, gender, age, education, years in & out of workforce, years positive, years on disability).

We'd like to hear about your experience with CPP-D and with private insurance disability (if you have it)

What worked well?

What was difficult? Problems, barriers you encountered?

What helped?

How long did it take?

How did you manage for income in the meantime?

Were you given clear information and explanations? Did you understand each step of the process? Did you know how to contact someone at the program for help?

Do you think the workers understood the nature of HIV illness? Why do you think that?

Some specific issues to explore:

- *Definition of disability*
- *Application process including gathering of medical documentation – are there problems getting the information needed from medical personnel? If yes, why do think that is?*
- *Timeliness*
- *Replies from CPP-D or insurance company – were they in person with an explanation?*
- *Appeals, if any - success rate, timing*
- *Re-Assessments*

Have you attempted to earn any income while on disability? If you reported income, did you experience any problems?

If you have tried Vocational Rehabilitation or entering the workforce, how was the experience? Did you encounter problems with CPP-D or private insurance?

If you have not pursued Vocational Rehabilitation or entering the workforce: Would you be interested if your health permitted? If not, why not?

Do you have any other observations you wish to make about the process?

Appendix B: Literature Review Bibliography

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 - o *The Link Between Poverty and HIV*
 - o *Living With the Cost of a Disability*
 - o *The Economics of Risk and Vulnerability*
 - o *How is Poverty Identified in Canada?*
 - o *What is the Impact of Poverty on the Life of Someone with HIV?*
 - o *HIV and the Downward Drift Into Poverty*

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Appendix C: Advisory Committee Members

The Project Advisory Committee members for this environmental scan are:

Glenn Betteridge - Policy Analyst, Canadian HIV/AIDS Legal Network, Toronto
Pamela Bowes - Program Director, Ontario AIDS Network, Toronto
Jacqueline Gahagan, Ph.D. - Dalhousie University, Halifax
Francisco Ibáñez-Carrasco, Ph D. – Canadian Working Group on HIV and Rehabilitation Co-Chair and CWGHR Research Committee member, Vancouver
Irene Klatt - Canadian Life and Health Insurance Association, Toronto
Marcel Lariviere - Senior Manager, Policy, CPP Disability Benefits & Appeals Directorate, Social Development Canada, Ottawa
Glyn Townson, British Columbia Persons With AIDS Society, Vancouver
[Ex Officio] Elisse Zack, Executive Director, Canadian Working Group on HIV and Rehabilitation (CWGHR)

Appendix D: Parliamentary Committee Recommendations

Recommendations from *Listening to Canadians – A First View of the Future of the Canada Pension Plan Disability Program - Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities*, 2003.

CHAPTER 1: ONLINE CONSULTATIONS: THE NEXT STEP IN PARLIAMENTARY DEMOCRACY

Recommendation 1.1

Given the success of the pilot project on e-consultation in complementing its regular committee study of the Canada Pension Plan Disability and providing Canadians with information as well as involving them, the committee recommends that:

- a. Each committee of the House of Commons consider putting in place an information-based Website. Such a site could include common elements (e.g. information about how Parliament works, how committees operate and how to contact the committee) as well as information specifically related to an individual committee's mandate, activities and background information related to its specific studies.
- b. The House of Commons and Library of Parliament be given appropriate additional resources to put in place information-based committee Websites with the capacity to facilitate e-consultations.
- c. The House of Commons and the Library of Parliament should put in place an overall framework or suggested course of action to guide any future e-consultations.
- d. Where circumstances warrant, other committees of Parliament consider including e-consultations with Canadians as one of the options in carrying out a study.

CHAPTER 2: CANADA PENSION PLAN DISABILITY AND THE GAP BETWEEN VALUES AND PRACTICES

Recommendation 2.1

The Committee recommends that the current Federal/Provincial/Territorial Review of the Canada Pension Plan Disability take into account the fact that the current operations of the plan do not fully reflect the values that underlie the current legislation and regulations. One of these relates to equal access and we recommend that the Year's Basic Exemption (YBE) for the purposes of disability be returned to \$3,500 the same as that for retirement benefits.

Recommendation 2.2

The Committee recommends that the Government of Canada establish a permanent joint government and stakeholder advisory group (the CPP Disability advisory committee) with an ongoing mandate and resources to monitor and appraise the performance of the CPP disability program to ensure that it meets its stated purpose and objectives. Representation on the advisory group should include federal officials (Human Resources Development and Finance), health care providers, various disability organizations, patient advocacy groups, return to work and rehabilitation professionals. This advisory group should review performance and recommend changes to the CPP(D) on an ongoing basis and as part of the three-year federal/provincial/territorial review. The advisory committee should submit an annual report on its activities to the Standing Committee on Human Resources Development and the Status of Persons with Disabilities.

Recommendation 2.3

So that future policy decisions pertaining to CPP(D) will be based on higher quality information, the Committee recommends that the Government of Canada make improvements to the analytical base of information about CPP(D) by encouraging research and establishing:

- a. partnerships between Human Resources Development Canada and the Social Sciences and Humanities Research Council of Canada;
- b. financial support for academic research on disability income and supports to improve quality of life for Canadians with disabilities;
- c. fellowships to lever money for research on the disability income system; and
- d. public sources of data pertaining to the operations of the federal disability income system, at Statistics Canada data centres across Canada.

CHAPTER 3: MODERNIZING CPP(D) DEFINITIONS AND ELIGIBILITY

Recommendation 3.1

Given the ongoing problems with definitions of disability, the Committee recommends that the Privy Council Office establish a taskforce, modelled on the Voluntary Sector Taskforce, to work with relevant partners from the community to address these problems (particularly those associated with CPP(D) and the Disability Tax Credit). The Committee further recommends that the federal government initiate discussions with the provincial and territorial governments to bring some consistency and coherence to the definitions of disability used by programs in all jurisdictions.

Recommendation 3.2

The Committee recommends that a comprehensive information package be developed to provide a description of each federal disability program which requires medical assessments, its eligibility criteria, the full range of benefits available, copies of sample forms, and any other relevant material.

Recommendation 3.3

The Committee recommends that the terms “severe and prolonged” in section 42 of the Canada Pension Plan be amended to take into account cyclical and degenerative mental and physical conditions.

Recommendation 3.4

Whether Recommendation 3.3 is implemented or not, the Committee recommends that Human Resources Development Canada (HRDC) immediately amend its CPP regulations, administrative guidelines, and manuals to ensure that the interpretation of the term “severe and prolonged” disability properly considers degenerative diseases, as well as mental, episodic and invisible illnesses (e.g. chronic pain, chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivities). In addition, HRDC should develop, in consultation with the community and health care professionals, specific evaluation tools for these particular disabilities to be used in assessing eligibility for CPP(D).

Recommendation 3.5

The Committee recommends that the mandate of the taskforce to clarify the definition of disability (see Recommendation 3.1) include, as a priority, consideration of specific ways to reduce the administrative burden placed on health care providers and applicants for federal disability benefits by using a common application form (or by consolidating application procedures) and common assessment procedures (e.g. using CPP(D)’s nurse practitioners also to determine eligibility for the Disability Tax Credit).

Recommendation 3.6

The Committee recommends that Human Resources Development Canada provide the comprehensive information package (see Recommendation 3.2) to all health care professionals and put in place an outreach program to provide them with information and education.

Recommendation 3.7

The Committee recommends that HRDC immediately commission an independent evaluation of how the “severe and prolonged” eligibility criteria for CPP(D) are applied by CPP personnel in making decisions about eligibility. The Committee further recommends that the results of this evaluation be submitted to the CPP Disability advisory committee (see Recommendation 2.2) for discussion and recommendations no later than June 2004.

Recommendation 3.8

The Committee recommends that the Government of Canada amend the Canada Pension Plan to define “prolonged” for the purposes of establishing eligibility for CPP(D) benefits as any period of 12 months or longer regardless of whether an individual has returned to work prior to the approval of his/her application or appeal.

Recommendation 3.9

The Committee recommends that qualified health care professionals in addition to physicians be allowed to provide medical assessments for the purposes of determining eligibility for the CPP(D) and to complete application forms.

Recommendation 3.10

Given the inconsistency in CPP(D)’s program administrators’ understanding of “socio-economic” factors, the Committee recommends that CPP(D)’s definition of disability be revised to explicitly include the decision of the Federal Court of Appeal in the Villani case. All CPP policies, manuals, administrative procedures, medical evaluations, and information to the medical professions and to the public should consistently and explicitly incorporate the spirit of the Villani decision.

Recommendation 3.11

The Committee recommends that HRDC amend its administrative practices so that no application for CPP(D) shall be deemed completed and assessed for eligibility until it contains a full and complete functional assessment of the applicant that specifically discusses non-medical factors that affect the individual’s employability.

Recommendation 3.12

The Committee recommends that HRDC conduct a detailed evaluation of how the CPP(D) program administrators are applying CPP(D) legislative guidelines in light of recent Review Tribunal and Federal Court decisions. The results of this evaluation should be submitted to the CPP Disability advisory committee (see Recommendation 2.2) for discussion and recommendations by June 2004.

Recommendation 3.13

In keeping with the Government of Canada's commitments in the Skills and Learning Agenda and in its promotion of family-friendly workplaces, the Committee recommends that HRDC incorporate dropout provisions in CPP(D) for attending school or training, and for caregiving of family members. These new dropout provisions should be the same as the child-care dropout provisions.

Recommendation 3.14

The Committee recommends that all CPP(D) dropout provisions include identical provisions for allowing partial years in determining the duration of the dropout.

Recommendation 3.15

The Committee recommends that CPP(D) applicants 60 years of age and over be entitled to CPP(D) benefits if they meet the eligibility criteria instead of being encouraged or forced to apply for CPP retirement benefits. CPP(D) administrators should be instructed accordingly.

Recommendation 3.16

The Committee recommends that the Government of Canada amend the Canada Pension Plan after paragraph 44(2)(a) so that it reads:

- (i) for at least four of the last six calendar years included either wholly or partly in the contributor's contributory period or, where there are fewer than six calendar years included either wholly or partly in the contributor's contributory period, for at least four years; or
- (ii) for at least one-third of the total number of years included either wholly or partly within an applicant's contributory period but in no case for less than three years, or
- (iii) for at least ten years; or
- (iv) for each year after the month of cessation of the contributor's previous disability benefit.

CHAPTER 4: IMPROVING THE CPP(D) APPLICATION AND APPEAL PROCESSES

Recommendation 4.1

The Committee recommends that Human Resources Development Canada (HRDC) establish, as a priority, client-friendly policies and practices in the application, assessment and approval processes for CPP(D).

Recommendation 4.2

The Committee recommends that HRDC process and approve all applications from clients who are terminally ill within 30 days of receipt and that the Government of Canada amend the Canada Pension Plan to eliminate for them the retroactivity provisions.

Recommendation 4.3

The Committee recommends that CPP(D) prepare and implement a comprehensive communications plan for CPP(D), that includes strategies to provide information to clients or potential clients of the program.

People with disabilities, or their representatives, should be consulted during the development of this plan.

This communications plan should include:

- a. training for frontline HRDC staff to provide appropriate responses to questions about CPP(D) and to assist people in filling out application forms;
- b. a targeted campaign to raise awareness of the program among organizations and community groups in contact with large numbers of possible applicants;
- c. better utilization of the resources of other government departments (particularly the Canada Customs and Revenue Agency); and
- d. formation of partnerships with other federal departments, provincial governments, income support programs, non-governmental organizations, support groups and qualified health care professionals to provide information about CPP(D).

Recommendation 4.4

The Committee recommends that the application forms and the accompanying guide be reviewed and revised to ensure that they are written in plain language, are as short as possible and provide clear information on how to submit the application. All information should be made available in alternate formats. Persons with disabilities, advocacy organizations representing them and the health care community should be consulted in this review process.

Recommendation 4.5

The Committee recommends that CPP(D) launch a targeted outreach program for organizations, support groups and individuals who provide information and assistance to applicants for CPP(D). This outreach program should have dedicated resources to answer their questions and provide them with up-to-date information about application procedures.

Recommendation 4.6

The Committee recommends that HRDC, at its own expense, make greater use of independent medical examinations, functional capacity examinations and/or vocational assessments to provide more information about an individual's inability to work.

Recommendation 4.7

The Committee recommends that when an individual's application for CPP(D) is approved, the applicant should be reimbursed for the cost (upon submission of a receipt) of additional assessments (medical or functional) in addition to the physician's report currently paid for by CPP(D).

Recommendation 4.8

The Committee recommends that HRDC:

- a. include in the CPP(D) application form a question asking all applicants to identify any third party that required them, for whatever reason, to submit an application for benefits to CPP(D); and
- b. charge the third party the cost of processing any such unsuccessful application.

Recommendation 4.9

The Committee recommends that HRDC explore ways of speeding up the flow of information required to complete an application. The department, for example, could encourage the electronic transmission of medical information from physicians provided this can be done in a manner that ensures confidentiality.

Recommendation 4.10

The Committee recommends that HRDC eliminate the use of form letters to deny an individual a CPP(D) benefit. HRDC should provide each client whose application is denied with a personal letter written in plain language (and in alternate formats if requested) that sets out all specific information related to the individual's circumstances, explains the reasons for the denial of benefits and includes all information needed to appeal the decision. The Committee further recommends that similar procedures be followed for all reassessments.

Recommendation 4.11

The Committee recommends that HRDC allocate more resources to the initial consideration of applications in order to lower the number of unjustified denials and resulting appeals. In light of the important contribution of personalized contact in determining the eligibility of an applicant, the Committee further recommends that there be person-to-person contact between an applicant and the person adjudicating the application before a decision is reached on the application.

Recommendation 4.12

The Committee recommends that following an initial denial of an application for CPP(D) benefits, HRDC should automatically put in place a reconsideration procedure. This reconsideration should be conducted by a panel consisting of two health care practitioners — one of whom should be a physician. This panel should have person-to-person contact with the applicant.

Recommendation 4.13

The Committee recommends that HRDC offer and provide translation services to all applicants who speak neither English nor French to assist them with their CPP(D) application.

Recommendation 4.14

The Committee recommends that the Office of the Commissioner of Review Tribunals (OCRT):

- a. include in the request for appeal form a question asking all appellants to identify any third party that required them, for whatever reason, to appeal a denial of benefits to the OCRT; and
- b. charge such third party the cost of processing each unsuccessful appeal.

Recommendation 4.15

The Committee recommends that the Office of the Commissioner of Review Tribunals appoint outreach officers who will personally contact every appellant to explain the appeal process, the resources that might be available to assist them in their appeal, and their right to use representatives in the appeal process. This would also provide an opportunity to explain a decision respecting the applicant's eligibility for disability benefits under the CPP.

Recommendation 4.16

The Committee strongly recommends that HRDC fund disability organizations (e.g. independent living centres) to help them provide advocacy and service delivery supports to individual CPP(D) applicants and appellants.

Recommendation 4.17

The Committee recommends that HRDC work with the federal Department of Justice to determine to what extent automatic legal assistance can be provided to all those who appeal CPP(D) denials at the Office of the Commissioner of Review Tribunals or the Pension Appeal Board in order to ensure that appropriate representation is available for appellants.

CHAPTER 5: THE ADEQUACY OF CANADA PENSION PLAN DISABILITY BENEFITS

Recommendation 5.1

The Committee recommends that Human Resources Development Canada return to the pre-1998 method for calculating CPP(D) benefits and retirement benefits for CPP(D) recipients.

Recommendation 5.2

The Committee recommends that Canada Pension Plan Disability payments commence on the day that Human Resources Development Canada qualifies a person to be eligible for CPP(D) benefits.

Recommendation 5.3

The Committee recommends that the Technical Advisory Committee on Tax Measures for Persons with Disabilities established by the Minister of Finance examine how best to adjust CPP contributions deducted for tax purposes in order to remove amounts paid in respect of disability benefits and thereby eliminate the taxation of Canada Pension Plan Disability benefits. This measure should be fully anticipated in the next federal budget and be in place by the beginning of the fiscal year 2004-2005. Once in place, similar treatment should be afforded to all Canada Pension Plan Disability benefits in pay.

CHAPTER 6: THE CANADA PENSION PLAN AND OTHER DISABILITY INCOME SUPPORT PAYMENTS: THE NEED FOR BETTER INTEGRATION

Recommendation 6.1

The Committee recommends that Human Resources Development Canada, in conjunction with the Canada Customs and Revenue Agency, prepare a plain language brochure that outlines the tax treatment afforded long-term disability earnings replacement plans. This brochure should also indicate how these plans operate vis-à-vis the CPP(D) with, and without, an assignment of benefits agreement between Human Resources Development Canada and private insurers.

Recommendation 6.2

The Committee recommends that:

- a. Human Resources Development Canada work vigorously with private insurers, Workers' Compensation Boards and other providers of disability income support program to ensure that integration improves the economic welfare of CPP(D) recipients, especially in instances where the level of disability income support payments to these individuals is low;
- b. HRDC broaden the membership of its working group with provincial/territorial social assistance providers to include all disability income providers; and
- c. This working group report annually to the advisory group we recommended be created (see Recommendation 2.2).

Recommendation 6.3

Until such time that CPP(D) benefits are non-taxable, (see Recommendation 5.3), the Committee recommends that all payments made under any assignment of benefits agreement, particularly those pertaining to re-imbursalment payments, be paid in after tax funds using a standard deduction.

Recommendation 6.4

The Committee recommends that Human Resources Development Canada examine comprehensively the impact of cost of living adjustments made to CPP(D) benefits that are integrated with other disability income support plans. If it is determined that the benefit of indexation on CPP(D) benefits is not being realized fully by CPP(D) beneficiaries, the Government of Canada must ensure that the full impact of cost of living adjustments flows directly to CPP(D) beneficiaries.

Recommendation 6.5

The Committee recommends that the Government of Canada enact the necessary legislative amendments to render illegal the offsetting of CPP(D) benefits paid to dependent children of a CPP(D) recipient.

Recommendation 6.6

The Committee recommends that the necessary amendments be made to the Employment Insurance Act and Regulations to ensure that CPP(D) benefits are not treated as earnings in instances where CPP(D) beneficiaries are entitled to Employment Insurance compassionate care benefits.

CHAPTER 7: RETURNING TO WORK UNDER CANADA PENSION PLAN DISABILITY

Recommendation 7.1

The Committee recommends that Human Resources Development Canada double its budget of \$4.6 million (2002-2003) for the Vocational Rehabilitation Program and begin to measure the long-term impact of this program on the success of clients' return to work and the total economic benefits associated with these outcomes.

Recommendation 7.2

The Committee recommends that Human Resources Development Canada undertake a pilot project to measure the impact of increasing the amount associated with substantially gainful occupation (SGO) to 125% of annual maximum CPP(D) benefits. In addition to measuring the impact of this measure on program costs, this pilot project should study the benefits and work incentive effects of a gradual reduction in CPP(D) benefits as the earnings of project participants exceed the experimental SGO threshold following the return-to-work trial period.

Recommendation 7.3

The Committee recommends that Human Resources Development Canada extend the three-month work trial period to six months and provide an immediate and automatic reinstatement of benefits for two years following a successful return to work.

Recommendation 7.4

The Committee recommends that the federal government create the necessary conditions to permit Human Resources Development Canada to implement pilot projects that test various approaches for integrating CPP(D) with other disability income and supports, including the medical community, to strengthen incentives for beneficiaries to return to work.

Recommendation 7.5

The Committee recommends that the federal government increase expenditures under Part II of the Employment Insurance Act as well as extend eligibility for these benefits to a much broader population than is currently captured under the definition of "insured participant." Moreover, Part II benefits should be treated as pensionable earnings for the purpose of determining CPP(D) eligibility.

CHAPTER 8: NEXT STEPS

Recommendation 8.1

The Committee recommends that the Department of Finance and the Department of Human Resources Development collaborate in the preparation of background documents that can be provided to the Subcommittee on the Status of Persons with Disabilities by 1 November 2003. Officials from the two departments will be asked to appear as witnesses to present the results of their research. The background documents should :

- a. outline the issues, options and costs to disaggregate CPP(D) contributions into two components: one for retirement benefits and the other for disability benefits;
- b. discuss the possibilities and costs for a single point of entry for federal/provincial disability income programs; and
- c. examine various options and costs for alternative income programs. These options should include:
 - applying the national child benefit model to a disability income program;
 - examining the applicability of programs in other countries such as the Netherlands where non-categorical income programs integrate disability into a broader set of programs based on overall criteria regarding employability; and
 - incorporating partial benefits into the Canada Pension Plan Disability program.
- d. Examining the options to establish a case-management system of addressing problems that arise because of the lack of integration between CPP(D) and other disability income support programs (e.g. workers' compensation, social assistance and long term disability).

Recommendation 8.2

In order to monitor the implementation of the recommendations in this report, the Committee recommends that for the next five years, the Departmental Performance Report of the Department of Human Resources Development Canada contain a section setting out progress in addressing our recommendations.