

Canadian AIDS  
Society



Société canadienne  
du sida

## **HIV as an Episodic Illness: Revising the CPP(D) Program**

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**A Brief Prepared for the Sub-committee on the Status of  
Persons with Disabilities**

Submitted by

**The Canadian AIDS Society  
and  
The Canadian Working Group on HIV and Rehabilitation**

**February 2003**



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Canadian Working Group on HIV and Rehabilitation  
Groupe de travail canadien sur le VIH et la réinsertion sociale

## **The Canadian AIDS Society**

The Canadian AIDS Society (CAS) is a national coalition of more than 115 community-based AIDS organizations across Canada. CAS is dedicated to increasing the response to HIV/AIDS across all sectors of society, and to enriching the lives of people and communities living with HIV/AIDS. Since 1996, the Canadian AIDS Society has served as the national voice for the community-based AIDS movement. The national office advocates on behalf of people and communities affected by HIV/AIDS, develops programs, services and resources for its member organizations, and provides a national framework for community-based participation in Canada's response to AIDS.

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## **The Canadian Working Group on HIV and Rehabilitation**

CWGHR is a national charitable nonprofit organization that promotes innovation and excellence in rehabilitation in the context of HIV disease. CWGHR develops rehabilitation resources, new knowledge, and awareness in a multi-sector collaboration with partners in the HIV/AIDS sector and with disability groups on issues of common concern. CWGHR members include people living with HIV disease, members of community-based HIV and disability organizations, national associations of health professionals, government agencies, private businesses, and the employment sector.

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## Table of Contents

<b>I.</b>	<b>Introduction.....</b>	<b>1</b>
a.	Definitions of disability.....	1
b.	HIV as an episodic disability.....	1
<b>II.</b>	<b>Broadening Coverage.....</b>	<b>2</b>
a.	Contributions to the CPP.....	2
b.	Expanding the criteria for disability in relation to HIV.....	2
c.	Ability to remain in the workforce.....	2
	<i>Recommendations.....</i>	<i>3</i>
<b>III.</b>	<b>Returning to Work.....</b>	<b>4</b>
a.	Labor market challenges.....	4
b.	Discrimination in the workforce.....	4
c.	Earnings Exemptions.....	5
d.	Trial period and immediate reinstatement.....	5
e.	Part-Time work.....	6
f.	Rehabilitation.....	6
	<i>Recommendations.....</i>	<i>6</i>
<b>IV.</b>	<b>Adequacy of Support.....</b>	<b>7</b>
a.	Universal coverage.....	7
b.	Contributory.....	7
c.	Partial replacement.....	7
d.	The benefit as taxable income.....	8
	<i>Recommendations.....</i>	<i>8</i>
<b>V.</b>	<b>Integration with other programs.....</b>	<b>8</b>
a.	Working with local AIDS service organizations.....	8
	<i>Recommendations.....</i>	<i>8</i>
<b>VI.</b>	<b>Application and Appeals.....</b>	<b>9</b>
a.	Access to information.....	9
	<i>Recommendations.....</i>	<i>9</i>
<b>VII.</b>	<b>A Financial Analysis.....</b>	<b>9</b>
a.	The financial costs of disability and the CPP (D) program.....	9
	<i>Recommendations.....</i>	<i>9</i>
	<b>Appendix 1 – Endnotes.....</b>	<b>10</b>
	<b>Appendix II – Summary of Recommendations.....</b>	<b>11</b>
	<b>Appendix III – Bibliography.....</b>	<b>12</b>

## **I. Introduction**

In the 20 years since HIV was first diagnosed, we have seen a number of significant social, cultural, and scientific changes. The response from the medical and scientific community has transformed HIV from a near immediate death sentence to an illness that can be managed, increasing both life expectancy and quality of life for infected individuals. Despite the changes in treatment options for HIV, there is no cure. Despite two decades of public education campaigns, new infections rise. Despite the fact that HIV touches everybody, HIV continues to be associated with stigma and discrimination. Living with HIV is living with uncertainty, and never knowing when illness will set in, and never knowing when discrimination will be encountered.

### **a. Definitions of Disability**

When identifying illnesses as disabilities, HIV stands alongside a variety of illnesses which require a specialized description<sup>1</sup>. This description must acknowledge that while the illness itself is permanent, it can, and often does result in recurring and unpredictable periods of good health and poor health. While terms such as “cyclical”, “episodic” and “recurring” have been used in conjunction with these illnesses, there has yet to be developed terminology that adequately reflects the complexity of these illnesses. For the purposes of this brief, the term “episodic illness” is used to describe HIV<sup>2</sup>. Further investigation into disability terminology needs to include discussion of episodic and lifelong illnesses. In addition, disability terminology is not standardized across government departments, in legislation, among medical and rehabilitation providers, and in insurance and government benefit programs.<sup>3</sup> The goal of establishing and standardizing definitions is to ensure that terminology used in policy accurately reflects the realities of people living with HIV. It would also ensure that all policies and programs are informed by a single source, limiting the degree to which it can be interpreted.

### **b. HIV as an Episodic Disability**

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. During this time, a period of ill health usually resulted in the need to withdraw from the workforce permanently. Ill health could include symptoms ranging from mild yet debilitating chronic fatigue and treatment side-effects to more life threatening opportunistic infections, pneumonia and cancer leading to death.

Due to a revolution in treatment research and availability during the 1990s, people living with HIV have a variety of treatment options. A large number of individuals now living with HIV are able to experience extended periods of good health. Furthermore, treatment has enabled many individuals to fully recover from serious and deadly opportunistic infections and reintegrate into an active life. Unfortunately the effectiveness of treatment, the onset of debilitating side effects, psychosocial factors as well as the onset of new HIV related illnesses are unpredictable.

There are three principles factors that define the nature of HIV as an episodic illness that must be taken into consideration when evaluating the CPP (D) plan:

1. Even with a variety of treatment options, people living with HIV are vulnerable to periods of ill health due to physical and psychosocial factors that will require them to withdraw from the workforce, and make reintegration difficult.
2. These periods of ill health for some people are temporary, and many individuals are able to return to the workforce in some capacity for varying periods of time.
3. The nature and progression of HIV, effectiveness of treatment and subsequent vulnerability to illnesses are different for every individual, and can not be predicted.

## **II. Broadening Coverage**

### **a. Contributions to the CPP**

Living with an episodic illness 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.

### **b. Expanding the criteria for disability in relation to HIV**

The current criteria used for evaluating whether a person living with HIV is eligible for disability rests primarily on CD4 cells and viral load. While this information is readily accessible from physicians, it does not reflect the capacity of an individual to participate in the workforce. 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. Disability in relation to HIV should include a wide variety of factors that include an overall physical, emotional and psychological assessment.

While treatment can have an overall positive impact on one's health, failure to take treatment should not be a reason to disqualify an individual from receiving benefits. Many HIV specialists suggest that some individuals should postpone starting treatment, while others are not able to adhere to the restrictive and demanding regimen and/or tolerate the side-effects of medication. An individual's failure to take treatment does not reflect the lack of desire to be healthy or to improve his or her capacity to work. Beginning treatment is an individual decision that is made with the help of a HIV specialist, and the autonomy of this decision must remain with the individual.

### **c. Ability to remain in the workforce**

In addition to discrimination, there are a number of challenges that people with HIV face when maintaining and seeking new employment. The nature of an individual's position or employment environment may not be able to support the requirements of a person living with HIV. For example periods of fatigue, diarrhea and/or nausea or fasting associated with medication may not be able to be accommodated if a position involves high levels of stress, or levels of awareness that affects personal or public safety. If an individual is no longer able to continue in one position or environment, it is not a reasonable assumption that another form of employment will be easily accessible.

There are also a variety of other factors that must be taken into consideration when evaluating an individual's ability to find employment. These include literacy and education, limited work experience, availability of employment, location and access to support networks (these networks include family, friends, social support services), and limited access to specialized HIV treatment and services. While many of these often pre-date infection with HIV, they nonetheless play a large role in determining the likelihood of an individual acquiring meaningful and gainful employment.

Some people with HIV experience a number of psychosocial factors associated with their illness. While these are not easily physically measured they can play a large role in determining an individual's capacity to work. "Many people with HIV have endured chronic or multiple periods of grief, anticipatory loss, and a host of life changes intrinsic to a degenerative, life-threatening disease."<sup>4</sup> Other psychosocial factors include the changing relationship an individual has with his or her personal identity and body image, a process that can have a serious impact on self-esteem. For many people, setting life goals can be difficult if not impossible. Living with a sense of failure is not uncommon among people facing these challenges.<sup>5</sup> This emotional stress combined with a lack of social supports has been associated with anxiety and depression. All of these factors can lead to fatigue, poor motivation, apathy and anguish.<sup>6</sup> For an individual to return to work with all of their physical and psychological capacity, it is imperative that these conditions be taken into consideration when evaluating the level of disability. Attempts at building any program with the goal of returning to work must include a grounded understanding of the psychosocial issues associated with living with HIV.<sup>7</sup> Effective policies must respect the many aspects of HIV and allow room to tailor programs according to the needs of each individual.

#### **Recommendations:**

- 1. Remove the recency of contributions requirement.**
- 2. Reduce the minimum number of years required to contribute to CPP (D) in order to qualify for benefits.**
- 3. Include contribution to CPP (D) during periods of part-time work.**
- 4. Expand the criteria used to identify disability to include the range of direct and indirect physical and psychosocial factors associated with HIV illness.**
- 5. When evaluating an individual's eligibility for benefits, include factors such as skills, education, and geographical location, and local labor market.**
- 6. Not participating in a HIV treatment regimen must not be considered as a factor when considering eligibility for benefits.**
- 7. Identify a standard definition of disability that corresponds with medical, legal, and private insurance definitions. Ensure that people with disabilities participate in this determination process.**

### **III. Returning to Work**

#### **a. Labor market challenges**

Due to restructuring and downsizing through the 1990s, there has been an increase in temporary, contract, part-time work and self-employment. In fact, 33% of Canadian jobs are comprised of one of these non-permanent types of employment.<sup>8</sup> This has resulted in overall weakened long-term financial security for many people.<sup>9</sup> While the impermanency of the workforce can be attractive to individuals who need the flexibility and freedom that is sometimes associated with non-permanent positions, these arrangements rarely provide the social and health benefits required by people with HIV.<sup>10</sup> It is clear that the current labor market does not reflect job stability, associated social and health benefits and the opportunity for retirement savings that existed during the development of CPP in 1966.

If an individual has left the workforce, they may have a gap in their employment history, and/or will require training for lost skills. They may not have the means to pay for new training, and if the individual is on Long Term Disability, training may not be covered.<sup>11</sup> For many people, the risks associated with seeking new employment outweigh the possible benefits.

Many women experience additional barriers when considering seeking employment. These include family and relationship issues, having children, sexual abuse and poverty. In addition, women living with HIV have a different experience of living with the illness than men do. Treatment is one example: "Women have been slower to take up combination therapy, and in their frequent role as caregivers for children, partners or older family members, often attach less priority to their own needs."<sup>12</sup>

There are a number of cultural factors that must be taken into consideration when examining the ability of people living with HIV to integrate into the workforce. Many people in Canada face language barriers when accessing social support such as benefits counseling, advice and treatment information.<sup>13</sup> Canadian Aboriginals also have differing values, customs and beliefs surrounding health and healing. There needs to be an increased awareness of the variety of cultures of when building social support frameworks for health.<sup>14</sup>

#### **b. Discrimination in the workforce**

It has been suggested that individuals who are required to leave their position due to a disability, must search for employment that can adapt to their needs, either locally or in a new region. This is not a realistic option for many people living with HIV. Despite local and national sensitization campaigns alerting Canadians to the nature of HIV, there exists considerable discrimination in the workforce. Many people living with HIV face not only the challenge of having a disability that limits the range of options available to them in the labor market, but often face the stigma and discrimination unique to HIV. Unfortunately, despite the rights and legal provisions given to persons with disabilities, many employers are successful in intentionally not hiring, or terminating positions held by people living with HIV.

Documented cases of discrimination in the workplace include: breaches of confidentiality; a lack of accommodation for medical appointments, illness and treatment scheduling; as well as harassment and ostracisation. Often small companies and agencies who can provide a supportive and flexible environment can not afford to engage employees living with HIV due to the

financial burden they pose to the company's health insurance plan and human resource requirements of the small business.<sup>15</sup>

Fearing negative reactions from their employers, many people with HIV prefer finding employment in a milieu that can provide more support or where they do not have to disclose their HIV status. What is also essential to understand about discrimination in the workforce is that it may be actual or potential, since perceived negative attitudes can also act as a deterrent in finding employment.<sup>16</sup> 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. Strategies must be put into place to provide awareness and education to the community, and enforce current law and policy that prohibits discrimination against persons with disabilities.

c. Earnings Exemption

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.

d. Trial Period and Immediate Reinstatement

Providing a flexible trial period is an essential component of an effective disability/return to work program. Allowing an extended period of time in the workforce on a trial basis without jeopardizing benefits, provides people living with HIV the opportunity to evaluate their readiness to return-to-work. During this time, the individual has the opportunity to evaluate his or her physical and psychological capacity to adapt to the work environment. An increase in time further enables employers and co-workers to adjust and adapt to a person with individual needs in the work environment. This period will vary depending on the disease and the individual. An effective policy will be flexible and can adjust based on each person's situation.

Despite well planned trial periods, it often occurs that a person is not able to fulfill the requirements of a position. This may be due to the onset of illness, the psychosocial factors associated with living with HIV and returning to work, or the physical demands of the position. It is imperative that, given the episodic nature of HIV, individuals can easily make the decision to stop working and have disability benefits reinstated quickly. 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. It is also unacceptable to force individuals to sell their personal goods, assets and property to sustain themselves during a period of months while they wait for their assessment and reassessment. This is not a reasonable request for any applicant, particularly when assistance and reimbursement is not guaranteed. Individuals who are approved for disability should qualify to have their benefits reinstated quickly, with limited amount of work on his or

her behalf to collect documents. 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.

e. Part-Time Work

Some of the less serious symptoms and treatment side-effects that are experienced by many people living with HIV include chronic fatigue, diarrhea, and nausea. While these are not life-threatening symptoms, they nonetheless impact on the ability of individuals to participate in the workforce. Many people living with these symptoms however are able to manage them so that they can work part-time.

Adherence to treatment regimens for HIV can require significant changes to daily schedules and routines. Treatment regimens often require periods of fasting, extensive nutritional requirements accompanying each dose as well as specific and inflexible time periods between each dose. These regimens impact on the amount and quality of sleep an individual is able to have, as well as how a person schedules his or her meals. Not all work environments are able to support the rigid scheduling of HIV treatment regimens. Furthermore, many individuals experience severe side effects immediately after taking a particular dose, usually in the morning, and are not able to leave their home for a number of hours until the side effect wears off. A policy that provides payments that are supplemented by part-time work can be an excellent compromise, without compromising the health of a person with HIV.

f. Rehabilitation

People living with HIV who are interested in returning to work must have access to relevant vocational rehabilitation programs. As discussed throughout this brief, there are a wide variety of factors that must be taken into consideration when examining a vocational rehabilitation program. However, it is also clear that many individuals will not require or will not have interest in pursuing vocational training. The decision to pursue vocational training as a therapeutic option must rest in the hands of each individual.<sup>17</sup>

A need has also been identified for multi-sectorial partnerships, involving rehabilitation service providers, AIDS Service Organizations, disability organizations, and vocational rehabilitation providers.<sup>18</sup> It is imperative that CPP (D) participate in this partnership as a means of increasing awareness of HIV related issues, and maintaining open lines of communication with all stakeholders.

**Recommendations:**

- 8. Provide Aboriginal communities with the autonomy to develop and implement strategies and programs that are appropriate to their communities.**
- 9. Conduct research into the effectiveness of early intervention of rehabilitation programs and prevention of illnesses related to HIV.**
- 10. Support HIV and discrimination education and awareness strategies that target the workplace.**
- 11. Conduct research into the "loopholes" that employers use to discriminate against and terminate positions held by individuals with HIV and enforce current anti-discrimination law and policy.**

- 12. Once an individual is approved for assistance, he or she should be able to have benefits reinstated immediately, allowing individuals to move in and out of the program as needed.**
- 13. Increase the time reserved for the trial period at the beginning of each return to work process to 18 months for each return to work initiative.**
- 14. Increase the earnings exemption while on benefits as a way of removing work disincentives.**
- 15. Provide benefits to individuals who return to work part-time.**
- 16. Decisions about whether to return to work should be made by the person living with HIV and his/her primary physician, free from coercion.**
- 17. Medical confidentiality in correspondence with employers and CPP (D) administrators must be enforced according to the laws of Canada.**

#### **IV. Adequacy of Support**

##### **a. Universal Coverage**

One of the unique features and strengths of the CPP (D) program is the fact that it provides universal coverage. It is the only disability program that provides coverage regardless of an individual's medical history, unlike the extensive screening that is carried out by private insurance plans. Because of the application procedure for private insurance plans, many people with health-related problems are excluded or are required to pay higher premiums.<sup>19</sup>

##### **b. Contributory**

Unfortunately, the structure of the contributory aspect of the program reduces the degree to which it provides universal coverage. Because part of disability payments are 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.<sup>20</sup>

##### **c. Partial Replacement**

The difficulty in the principle of partial replacement lies in the social and economic changes that have occurred since the eligibility requirements were developed in 1966.

Economic changes have increased the cost of living. A large number of people, primarily women, who had traditionally stayed at home and made themselves available to care for disabled persons are now in the workforce. Populations such as the elderly and the disabled are living away from the family unit in apartments and residences. Accompanying social and financial independence is the disconnection from networks that provided social and financial support. A person living with a disability in 2003 can not expect to remain in the home of parents or siblings, nor can they expect that family members will be able to act as full-time caregivers during periods of poor health. As described earlier, a significant amount of the population is no longer engaged in a permanent, full-time position, have fewer benefits, and fewer opportunities for long-term savings.

Partial replacement of income is no longer a feasible option. For CPP(D) to be an effective plan, it must be able to provide enough financial support for an individual so that he or she will not be required to acquire debt, sell personal possessions, real estate, or other assets, nor rely on family and friends for financial aid.

d. **The Benefit as Taxable Income**

As taxable income, individuals receiving benefits are faced with the possibility of paying tax at the end of the fiscal year. There have been two possible solutions identified as a means of reducing the likelihood of individuals with a limited income of facing financial hardship during tax season. The first option is the provision that allows individuals to request that CPP (D) administrators withhold a portion of each payment, with the actual tax owing to be reconciled at the end of the fiscal year. While this is currently an option, it is not widely known or understood. The second option is for administrators to automatically withhold a standard amount.<sup>21</sup> The issue of benefits as taxable income must be revisited.

**Recommendations:**

- 18. Develop a faster, more efficient process for review for all applicants that are denied and/or disqualified from CPP (D).**
- 19. Index disability benefits to inflation and Consumer Price Index.**
- 20. Conduct a cost analysis of the actual costs of living with a disability and index benefits accordingly.**
- 21. Establish a policy to ensure that women do not receive an overall lower average benefit income than men.**
- 22. Revisit CPP (D) benefits as a taxable income, through a process that involves economic analysis and stakeholder participation.**
- 23. Rely on income assessment rather than asset assessment to determine financial eligibility.**

**V. Integration with Other Programs**

a. **Working with local AIDS Service Organizations**

Working in partnership with local AIDS Service Organizations (ASOs) can be a useful tool. ASOs can provide information to CPP (D) program on the needs and lived experiences of people with HIV, and can provide information about the program directly to their clients, as well as indicate which communication strategies will be effective (i.e. language and design of informational pamphlets and packages aimed at people with HIV). By integrating ASOs in peer consultations, decision making opportunities and overall communication, benefit administrators can ensure that the needs of the community are being integrated, and can ensure that information is disseminated at the community level. Unfortunately many ASOs are underfunded and have limited ability to provide extensive training and education sessions, as well as staff time to contribute to partnerships. Nevertheless, their participation in decision making, the development of training and education sessions, as well as conduits of information to people living with HIV is essential. Efforts at working with ASOs must respect their lack of resources and ensure that services are reimbursed. Funding to develop and provide educational programs for CPP (D) employees and administrators must be secured.

**Recommendations:**

- 24. Develop and implement mandatory and professional training programs on HIV to develop and promote best practices for all CPP (D) employees, including assessors and members of the appeal board.**
- 25. Increase ongoing community participation in decision making about CPP (D) programs through peer consultation and interagency partnerships.**

## **VI. Applications and Appeals**

### **a. Access to Information**

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 the workforce. A need was identified for continued “accurate, independent advice and information”. This was especially important for individuals returning to their former employer.<sup>22</sup> 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.

While many AIDS Service Organizations provide information to clients on issues surrounding benefits, many smaller organizations lack the resources to develop programs and address return-to-work issues comprehensively.<sup>23</sup> The responsibility of access to CPP (D) services should not lie solely in the community where access is not guaranteed to all individuals.

### **Recommendations:**

**26. All application processes for CPP (D) must be made accessible by addressing language and cultural adaptation, education and literacy, cognitive and learning capacities.**

## **VII. A Financial Analysis**

### **a. The financial costs of disability and the CPP (D) program**

It is important to note that while there have been analyses conducted of the financial cost of HIV, more research needs to be done on the overall picture of the costs of disability<sup>24</sup>. It can be suggested that by increasing eligibility and benefits, the CPP (D) program will not be able to sustain itself or will result in extraordinary increases in contributions. A more efficient system that responds to the needs of people with HIV and allow them to return to work, has the potential to be a long-term economic investment. By reducing overall poverty, the program will be contributing to the overall health of the population and in the reduction of reliance on other support services, both government and community based. By increasing the opportunity for people with disabilities to participate in the workforce, CPP (D) allows individuals to contribute back into the program through their earnings. In short, there is not enough evidence to demonstrate that a model that includes the aforementioned recommendations will be cost inducing or cost effective. It is imperative that financial research be conducted that can provide short-term and long-term projections on both the immediate costs to the program and the larger, indirect costs to society.

### **Recommendations:**

**27. Conduct research on the economic costs of a flexible return-to-work program. This analysis should include the direct costs/savings to the program, as well as long term, indirect costs/savings to society.**

## Appendix 1 - Endnotes

<sup>1</sup> Other illnesses which can be considered as “episodic disabilities” include Multiple Sclerosis, cancer, mental illness, Crohn’s and Colitis, arthritis, diabetes, fibromyalgia. For more information on how these illnesses are similar, please see P. Proctor. *Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Illnesses*. Toronto: The Canadian Working Group on HIV and Rehabilitation, 2002

<sup>2</sup> The terms “lifelong and episodic” were identified as more accurate descriptors than “chronic, episodic and cyclical” by an Advisory Group participating in the Cross Disability Project in 2001-2002. For more information regarding this group and this discussion, see P. Proctor. *Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Illnesses*. Toronto: The Canadian Working Group on HIV and Rehabilitation, 2002

<sup>3</sup> P. Proctor. *Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Illnesses*. Toronto: The Canadian Working Group on HIV and Rehabilitation, 2002.

<sup>4</sup> *Force for Change* Ottawa: The Canadian AIDS Society, 1998

<sup>5</sup> P. Proctor. *Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Illnesses*. Toronto: The Canadian Working Group on HIV and Rehabilitation, 2002

<sup>6</sup> *A Comprehensive Guide or the Care of Persons with HIV Disease*. Toronto: Wellesley Central Hospital 1998

<sup>7</sup> *Force for Change* Ottawa: The Canadian AIDS Society, 1998

<sup>8</sup> Ibid.

<sup>9</sup> For more details on the percentage of Canadians in full-time, permanent employment, as well as average annual contributions to RRSPs, see S. Torjman. *The Canada Pension Plan Disability Benefit*. Caledon Institute of Social Policy, 2002

<sup>10</sup> *Force for Change* Ottawa: The Canadian AIDS Society, 1998

<sup>11</sup> *HIV/AIDS and Discrimination: A Discussion Paper*. Montreal: Canadian HIV/AIDS Legal Network. 1998

<sup>12</sup> I. Grubb and C. McClure. *Back to the Future: A Feasibility Study on Return-to-Work Programming for People Living with HIV/AIDS*. Toronto: AIDS Committee of Toronto, 1997

<sup>13</sup> Ibid.

<sup>14</sup> *Force for Change* Ottawa: The Canadian AIDS Society, 1998

<sup>15</sup> *HIV/AIDS and Discrimination: A Discussion Paper*. Montreal: Canadian HIV/AIDS Legal Network. 1998

<sup>16</sup> *Force for Change* Ottawa: The Canadian AIDS Society, 1998

<sup>17</sup> *A Comprehensive Guide or the Care of Persons with HIV Disease*. Toronto: Wellesley Central Hospital 1998

<sup>18</sup> Ibid.

<sup>19</sup> S. Torjman. *The Canada Pension Plan Disability Benefit*. Caledon Institute of Social Policy, 2002

<sup>20</sup> Ibid.

<sup>21</sup> Ibid.

<sup>22</sup> I. Grubb and C. McClure. *Back to the Future: A Feasibility Study on Return-to-Work Programming for People Living with HIV/AIDS*. Toronto: AIDS Committee of Toronto, 1997

<sup>23</sup> Ibid.

<sup>24</sup> For information on the financial cost of HIV please see T. Albert and G. Williams. *The Economic Burden of HIV/AIDS in Canada*. Canadian Policy Research Networks, 1997.

## Appendix 2 – Summary of Recommendations

1. Remove the recency of contributions requirement.
2. Reduce the minimum number of years required to contribute to CPP (D) in order to qualify for benefits.
3. Include contribution to CPP (D) during periods of part-time work.
4. Expand the criteria used to identify disability to include the range of direct and indirect physical and psychosocial factors associated with HIV illness.
5. When evaluating an individual's eligibility for benefits, include factors such as skills, education, and geographical location, and local labor market.
6. Not participating in a HIV treatment regimen must not be considered as a factor when considering eligibility for benefits.
7. Identify a standard definition of disability that corresponds with medical, legal, and private insurance definitions. Ensure that people with disabilities participate in this determination process.
8. Provide Aboriginal communities with the autonomy to develop and implement strategies and programs that are appropriate to their communities.
9. Conduct research into the effectiveness of early intervention of rehabilitation programs and prevention of illnesses related to HIV.
10. Support HIV and discrimination education and awareness strategies that target the workplace.
11. Conduct research into the "loopholes" that employers use to discriminate against and terminate positions held by individuals with HIV and enforce current anti-discrimination law and policy.
12. Once an individual is approved for assistance, he or she should be able to have benefits reinstated immediately, allowing individuals to move in and out of the program as needed.
13. Increase the time reserved for the trial period to 18 months for each return to work initiative.
14. Increase the earnings exemption while on benefits as a way of removing work disincentives.
15. Provide benefits to individuals who return to work part-time.
16. Decisions about whether to return to work should be made by the person living with HIV and his/her primary physician, free from coercion.
17. Medical confidentiality in correspondence with employers and CPP (D) administrators must be enforced according to the laws of Canada.
18. Develop a faster, more efficient process for review for all applicants that are denied and/or disqualified from CPP (D).
19. Index disability benefits to inflation and Consumer Price Index.
20. Conduct a cost analysis of the actual costs of living with a disability and index benefits accordingly.
21. Establish a policy to ensure that women do not receive an overall lower average benefit income than men.
22. Revisit CPP (D) benefits as a taxable income, through a process that involves economic analysis and stakeholder participation.
23. Rely on income assessment rather than asset assessment to determine financial eligibility.
24. Develop and implement mandatory and professional training programs on HIV to develop and promote best practices for all CPP (D) employees, including assessors and members of the appeal board.
25. Increase ongoing community participation in decision making about CPP (D) programs through peer consultation and interagency partnerships.
26. All application processes for CPP (D) must be made accessible by addressing language and cultural adaptation, education and literacy, cognitive and learning capacities.
27. Conduct research on the economic costs of a flexible return-to-work program. This analysis should include the direct costs/savings to the program, as well as long term, indirect costs/savings to society.

### Appendix 3 – Bibliography

*A Comprehensive Guide or the Care of Persons with HIV Disease.* Toronto: Wellesley Central Hospital 1998

*Force for Change* Ottawa: The Canadian AIDS Society, 1998

Grubb, I. and C. McClure. *Back to the Future: A Feasibility Study on Return-to-Work Programming for People Living with HIV/AIDS.* Toronto: AIDS Committee of Toronto, 1997

*HIV/AIDS and Discrimination: A Discussion Paper.* Montreal and Ottawa: Canadian HIV/AIDS Legal Network and the Canadian AIDS Society. 1998

P. Proctor. *Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Illnesses.* Toronto: The Canadian Working Group on HIV and Rehabilitation, 2002.

Torjman, S. *The Canada Pension Plan Disability Benefit.* Caledon Institute of Social Policy, 2002