Enabling Income:
CPP Disability Benefits and Women with Disabilities

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and
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ABSTRACT

Enabling Income: CPP Disability Benefits and Women with Disabilities

Tanis Doe, MSW, PhD, and Sally Kimpson, BSN, MA

The Canada Pension Plan (CPP) is a contributory insurance program designed to be universal for all working Canadians, originally intended to replace a portion of lost income for workers at retirement or disablement. Currently, women (and men) with disabilities who show the capacity to earn income are generally disallowed CPP disability benefits because of the strict definition of "disability" and administrative inconsistencies. This research uses existing quantitative data and new qualitative data gathered in focus groups of disabled women in four cities across Canada, including qualitative data from a focus group with CPP administrators who were consulted on how the CPP currently works before developing cost-effective recommendations to "enable income." These alternate disability pension policies would distribute resources equitably and respond to circumstances in the lives of women with disabilities, such as fluctuating health and ability to work. Although it is recognized that any policy reforms would affect both women and men with disabilities, this research focuses on women because of the inordinately adverse impact of current official federal definitions of work and disability, and thus policy, on the lives of disabled women. The report contends that, by eliminating the penalty for working, the CPP could empower women, provide incentives for returning to work by removing the threat of losing CPP disability benefits, generate needed income for the CPP and increase taxable dollars for general revenue. The proposed changes extend recent (1995) policy changes focused on creating "work incentives" for people with disabilities and would allow disabled women (and men) to return to work when they are able, without penalty, until such time as they can sustain themselves financially. Suggested policy reforms also address the need to redefine "disability," aligning it more closely with the complex reality of being a woman living with disability. Themes emerging from these women's experiences of the CPP demonstrate the difficulties they experience, including the fear of losing secured CPP disability pension income if they engage in paid employment.

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EXECUTIVE SUMMARY

The Canada Pension Plan (CPP) was originally designed to replace a portion of lost income at retirement or disablement. This research developed alternate pension policies that would distribute resources equitably and respond to changing circumstances such as fluctuating health and ability to work. Women with disabilities were interviewed in groups, and CPP administrators were consulted to develop recommendations to "enable income." Currently, women (and men) with disabilities who earn income through work are often disallowed CPP disability benefits because of the strict definition of "disability" and administrative inconsistencies. During this research we uncovered policy directives which provide opportunities to earn income while still collecting benefits. Yet, all the women we contacted and all the literature we reviewed showed that the public was unaware of this. In addition, it is not clear if administration of this policy has been thwarted by more pressing requirements to cut costs and save future expenditures by re-assessing beneficiaries and collecting overpayments (HRDC 1998b). By eliminating the penalty for working, the CPP could empower women, provide incentives for return to work by removing the threat of losing CPP disability benefits, generate needed income for the CPP and increase taxable dollars for general revenue. This would be a policy-consistent approach given current rehabilitation and three-month, trial working period initiatives.

Administrative staff and resources now being used for surveillance of the CPP disability program could be used to encourage people to return to work rather than penalize them. Some of the people who have been cut off or re-assessed could be brought back to the program under these new policy suggestions. Women receiving CPP disability benefits are usually not eligible for Employment Insurance/Vocational Rehabilitation (EI/VR) employment programs because they are categorized as "unemployable" and would lose the CPP disability income if they returned to work. People who are denied CPP disability benefits inevitably turn to provincial social welfare programs for financial assistance. Within the last few years, thousands of people have been re-assessed as not eligible for CPP benefits and some have been required to return overpayments. Many may seek provincial social assistance unless they can find employment, which is often difficult given the current employment market and lack of support to work flexible hours tailored to accommodate fluctuating disabilities.

Fiscally, it makes better sense to support eligible disabled workers on contributory schemes than to force them onto tax-based (federal/provincial cost-shared) welfare programs. More than $69 million a year could be contributed through CPP premium payments at the rate of six percent if just 25 percent of the women and 30 percent of the men (under 60 years of age) currently receiving disability benefits were enabled to work, according to the statistical model developed (see Appendix B). An estimated additional $190 million in tax revenue could be generated if women and men earned taxable income, even if they were eligible for disability tax credits. We recommend that all people eligible for CPP or provincial disability benefits should automatically be considered eligible for the federal disability tax credits. This calculation draws from the fact that CPP disability benefits are taxable and from our assumption that those receiving benefits and working would earn a salary ranging from low to high income (see Appendix B for calculations of tax contributions). Last, provincial social assistance programs, funded through the Canada Health and Social Transfer (CHST), could potentially save $55 million a year if 30 percent of women who returned to the work

force earned enough income to disqualify them from provincial financial assistance. Another $37 million could be saved if only 20 percent of the men with disabilities who returned to the work force stopped receiving provincial income assistance. These final figures do not represent income for the federal government, per se, but do represent substantial savings on the social cost of disability and disabling policies.

It is important to understand the specific ways that CPP programs affect women differently than men. Primarily, women have a different experience of “work” and, consequently, a different experience of the benefits attached to being workers. Women are often unpaid community volunteers and, more often than men, work part time. Neither part-time work nor volunteering qualifies women for private pension plans. The CPP program does recognize part-time employment but only proportionately, leaving women working part time with far lower pensions than women and men who worked full time during their careers. Women on average still earn less than 75 percent of what men do and are more likely to be single heads of households, divorced or living on their own as compared to men of similar age. As women age, it is assumed that the pension programs will “take care” of women. In fact, inadequate pensions result in women using social welfare programs and supplements to sustain their meagre existence.

These demographic facts are true for most women in Canada but they have a specifically negative effect on women with disabilities. Women tend to be more prone to cyclical and fluctuating illness that creates difficulty in sustaining employment and basic life activities. However, some of these disabilities are “invisible” or at least less visible than the spinal cord injuries and brain injuries that young men sustain in higher proportions than women. Autoimmune conditions, such as systemic lupus, arthritis and multiple sclerosis, although empirically verifiable, affect women disproportionately to men and are not always visible, despite significant fatigue, neurological or organ involvement. In addition, illnesses like chronic fatigue syndrome and unipolar depression are more frequent in women, and are difficult to diagnose or are believed to be primarily “psychological” as opposed to organic. Even with significant medical research verifying the existence and severity of these particular illnesses, women with chronic fatigue syndrome and fibromyalgia have to fight and often appeal for benefits, due to the stigma and ignorance surrounding these conditions.

Compounding these disability-related factors and their effect on women are the differential social expectations for women, and for disabled people. Attitudes that disabled people should not work and that women’s work is discretionary are prevalent and pervasive. That women raise children, contribute to social causes and work mainly for “extra” income are strong societal myths that have negative effects on women with disabilities, who are often not seen as deserving income replacement, or worse, because they can still do housework, not even seen as “disabled.”

While we, as researchers, recognize there are larger, structural inequalities impinging on the economic status of women with disabilities, we believe, at the very least that the CPP, rather than contribute to inequality should support work-force re-integration. Our recommendations provide a step toward systemic change. As women researchers under contract with the Status of Women Canada, our primary responsibility was to consider the situation of women with disabilities. However, we want to ensure that all policy reforms be extended to all eligible Canadians, both men and women. This policy research has particular importance for women but would also support the re-entry of men with disabilities into the paid work force, and subsequently support their dependants. A proper reconceptualization of disability focuses on allowing people to work, without penalty, when they are well enough to do so.

Chapter 6 provides a detailed explanation and rationale for these recommendations in the context of the research conducted. These are only concise proposals for change, which should be considered within the larger context of the socio-economic climate and the lives of women with disabilities in Canada.

Summary of Recommendations for Policy Reform

1. Administer policy guidelines for future policy changes uniformly and especially for existing programs such as work incentives, including the National Vocational Rehabilitation Program (NVRP).

2. Return to work: encourage men and women with severe and prolonged conditions to return to work to their maximum capacity, if and when they are healthy enough to pursue paid employment.

    a. Tax earned income, with provincial social assistance remaining untaxable.

    b. Change CPP contribution rules so beneficiaries contribute to the CPP from their earned income instead of refunding these dollars.

    c. Eliminate penalties for attempting to work part or full time and extend the NVRP to any one interested.

    d. Raise substantially gainful occupation (SGO) limit from 25 percent to 33 percent of the yearly maximum pensionable earnings (YMPE).

    e. Establish work incentives for “high achievers” and reduce CPP disability benefits proportionately for those able to earn between $12,000 and $24,000 annually. Persons earning over $24,000 would no longer be eligible for CPP disability benefits but would be fast-tracked if their earnings drop.

3. Extend permanent disability status to all those who originally qualify for CPP disability benefits so that fast-tracking does not involve re-applying but simply re-activating a claim.

4. Replace the three-month limit with an indefinite trial-of-work period.

5. Streamline intersections with other policies and programs so CPP disability eligibility criteria are recognized by provincial and federal programs. This could include automatic eligibility for provincial medical benefits, Revenue Canada’s disability tax credits and other disability-related support programs. Continue research to create a gender-informed, seamless, national disability resource system in Canada.

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We publicly acknowledge the risk and contribution made by all the women who agreed to be interviewed. They shared with us their stories and struggles, and we hope the results of the project accurately reflect their voices.

We also must thank our project officer, Julie Dompierre at Status of Women Canada, and Zeynep Karman, Director of the Research Policy Fund, who gave us the confidence to pursue this investigation.

I, personally (Tanis), would like to thank Trista Bassett for acting as my ears and mouth, right hand, left brain and taxi driver during the project. Scott Wilson also deserves special thanks for providing child care, technical and emotional support and the occasional Snapple®. Sally was both compassionate and tolerant of my moods and methods, and I appreciated her directness.

Thanks to Barb Ladouceur for helping to edit the final report. Sign language interpreters who provided professional communication assistance included Mary Warner, Kristi Falconer, Judy Settle and Pauline Landry. Francine Mayer helped with French translation. Both Kerry Anderson and Nancy Lawand from the HRDC Income Security Program Direction were invaluable in gaining access to information and people. The CPP staff who participated in the focus groups were wonderful! I also want to recognize Lorraine Cameron and Patty Holmes from the BC/Yukon Regional Office of Status of Women Canada for almost a decade of encouragement, mentoring and disability-friendly feminist discourse.

My own development and ideas as a feminist researcher with disabilities have been dramatically influenced by the community-based work of DAWN Canada, the DisAbled Women's Network and the rigorous and discursive investigations by staff at the Roeher Institute. Keep up the good work!

Sally would like to thank Tanis for being receptive to me and to my ideas, and for inviting me to join her in this project. I have learned so much (and had lots of fun) during this time together. I would also like to acknowledge and thank Greg Mittag, my partner, for his caring support, and especially for cooking while I worked. There are so many things that would be so much more difficult or impossible without his help. A big thanks also goes to my PhD supervisor, Dr. Antoinette Oberg at the University of Victoria, for recognizing the importance of my engagement in this research to my studies of women and disability. Her flexibility and open pedagogical stance are both refreshing and necessary as I negotiate the challenges of disability, and work, and study.

Toward the end of this contract, the project officer responsible for our activities changed. Despite stepping into the role at the last minute, Nora Hammell helped us contend with editing and clarifications required, as well as being supportive of our disability needs. Many thanks to Nora.

LIST OF ACRONYMS

BIA	*Budget Implementation Act*
CFS	chronic fatigue syndrome
CHST	Canada Health and Social Transfer
CPP	Canada Pension Plan
EI	Employment Insurance
EI/VR	Employment Insurance / Vocational Rehabilitation
FM	fibromyalgia
HRDC	Human Resources Development Canada
ISP	Income Security Program
ME	myalgic encephalomyelitis
NVRP	National Vocational Rehabilitation Program
OAS	Old Age Security
SGO	substantially gainful occupation
YBE	year’s basic exemption
YMPE	yearly maximum pensionable earnings

CHAPTER 1: INTRODUCTION AND OVERVIEW OF CPP DISABILITY

Canada is known as the “benevolent state,” one of the best places in the world to live. Our land, resources, people and democratic political system are the envy of many. One of the most important strands in Canada’s social safety net is the public pension program. Along with universal access to health and education, public pensions for retirement and disability provide a sense of security in an increasingly unpredictable world. However, over the last 10 years there has been vigorous debate about the affordability and sustainability of a pension plan (Guest 1997; Townson 1995) that will take from a declining population of working people to support an increasingly large population of retired and disabled people. After consultation and policy research directed towards reforming the plan and preventing impending economic disaster (so the rhetoric goes), the Canada Pension Plan (CPP) was revised in 1998, when Parliament enacted Bill C-2 amending the CPP. This legislation was designed to increase the contribution rate of workers and employers, and reduce expenditures. Our report looks at how additional policy changes could take into account fluctuating health, the social context of women and the desire of disabled people to return to work when they are able. Although we interviewed only women, we want to make it clear from the beginning that proposed policy changes should be extended to men with disabilities. The adverse impact of the current policies financially affect women more significantly than men, but it would benefit all Canadians to encourage a return to work for all.

Overview of the CPP

For readers to understand the significance and relevance of the policy changes we recommend, an accurate picture of the CPP disability benefit is necessary. Most of the information presented here about the CPP and CPP disability benefits was drawn from materials readily available to Canadian citizens, including information from the CPP Web site. Readers should be aware that we began this research with a basic understanding of how the CPP and CPP disability benefits operated from our own experiences and from publicly available information. Our understanding about CPP disability was no different from that of other women with disabilities who receive or read CPP documents, including many of the women we interviewed. This experience is significant in light of information revealed to us as part of this research by plan administrators and via CPP documents sent to us on request.

This information told us that there is a substantial gap between what CPP beneficiaries experience and know about the CPP and what, in fact, is supposed to happen in practice, according to CPP administrators and policy makers. In this overview of the CPP, the “official” information is presented first, then alternate experiences and commentary follow.

The CPP was introduced in 1966 and is “a contributory, earnings-related social insurance program [ensuring] a measure of protection” to contributors and their families “against the loss of income due to retirement, disability and death” (HRDC 1999b). Three kinds of benefits are provided:

1) disability benefits, including pensions for disabled contributors and benefits for their dependent children;

2) retirement pension; and

3) survivor benefits, including the surviving spouse's pension, the children's benefit and the death benefit.

Also offered to people with disabilities are services under the CPP National Vocational Rehabilitation Program (NVRP). The province of Quebec operates the Quebec Pension Plan (QPP), a similar program to the CPP, which works together with the CPP to ensure all contributors are protected. The CPP is self-supporting, financed mainly through mandatory contributions, not through general tax revenues. For the most part, all Canadian citizens over 18 earning an income are required to contribute to the CPP, the contributions being equally shared by workers and employers. Self-employed workers pay both portions of their contributions. As part of the revised legislation (Bill C-2), contribution rates will rise over the next six years (1998 to 2004) from the current 5.85 percent of contributory earnings to 9.9 percent, and then remain steady (HRDC 1998a). Individuals receiving CPP disability benefits (or retirement pension) do not make contributions to the CPP.

The focus of our research is on CPP disability benefits as they apply to women with disabilities, although we recognize that men with disabilities also receive CPP disability benefits and are affected by CPP disability policy. All the women in our study had been previously employed in the work force in either the private or public sector, and forced to leave because of disability. None had been self-employed. None were currently engaged in paid employment. In fact, fewer than 50 percent of women with disabilities (outside Quebec) were in the labour force in 1991, leaving many women with disabilities who are not working to rely on CPP benefits for income support.

In a submission to the Standing Committee on Finance of the House of Commons, the Council of Canadians with Disabilities cited statistics which showed that, for recipients of CPP disability benefits, "CPP benefits were their single most important source of income, accounting for 27.9% of their total income" (Council of Canadians with Disabilities 1997:3). Women have often received pension income as surviving spouses of male CPP contributors, but are increasingly also being pensioned themselves. For women with disabilities who paid into the CPP while working, CPP disability benefits provide a substantial contribution to their overall income. Yet women with disabilities benefit from the CPP substantially less than men due to lower wages and shortened attachment to the work force, because they contributed less, and less frequently, than men. In 1991, 77.2 percent of working men and only 61 percent of working women were contributors to the CPP (Statistics Canada 1995b: 31).

Qualifying for Benefits

Eligible beneficiaries receive a taxable monthly pension, which is adjusted yearly (in January) to increases in the average cost of living as measured by the Consumer Price Index. To qualify for benefits, an individual must have contributed to the CPP for a minimum number of years, be considered disabled according to CPP legislation and be between the ages of 18 and 65 (HRDC 1999b). Contributions are based on a worker's earnings (or on net business income if self-employed) between a minimum yearly income of $3500 and a maximum (in 1998) of $36,900. The former is also known as the Year's Basic Exemption (YBE) and the latter as the Year's

Maximum Pensionable Earnings (YMPE). In 1998, the YBE was frozen at $3500, but the YMPE is adjusted yearly to reflect increases in average Canadian wages.

To meet the minimum number of years requirement, applicants must have contributed to the CPP for four of the previous six years. This is a recent (1998) policy change from that which required individuals to work two of the last three years, or five of the last 10 years. In addition to the minimum number of years requirement, individuals must have earned at least 10 percent of each year's YMPE. To reduce discrimination against women who leave the work force or reduce working hours to raise small children (under age 7), gaps in contribution or low earnings during these years do not disqualify them, and low earning years are dropped from the calculation.

"Disabled according to Canada Pension Plan legislation" refers to a definition of disability created by the CPP to delineate both medical and employment criteria used to establish eligibility for disability benefits. A person can have a condition which is either physical or mental, and which is "severe" and "prolonged." "'Severe' means [the] condition prevents [a person] from working regularly at any job, and 'prolonged' means [the] condition is long term or may result in [the person's] death" (HRDC 1999a).

The report of the Committee on Disability Issues undertaken by the CPP Advisory Board and tabled in Parliament in the spring of 1995, stated that the Board saw "no need to amend the general eligibility provisions for the CPP Disability Benefit at this time" (a minority statement suggested that the definition of disability be reconsidered) (HRDC 1999c). This recommendation was tabled despite the fact that, in 1994, the Council of Canadians with Disabilities had pointed out how the definition used by the CPP to establish eligibility was inappropriate for meeting the self-identified aims of disabled Canadians in their struggles to return to the work force.

People with disabilities have strenuously argued that, under current CPP legislation, the definition of disability used for CPP eligibility is disempowering because it creates a significant barrier to re-entering the labour force (Council of Canadians with Disabilities 1994; Norman and Beatty 1997). Stated another way, a "severe" disability is one that renders an individual incapable of "regularly pursuing any substantially gainful occupation" (Fawcett 1996: 141). Disability activists and scholars argue for definitions of disability which focus on disability as a social construct, that is, created not by a physical or mental impairment, but by societal understandings of "normality," which fail to recognize the situational and experiential components of living with disability (Oliver 1990).

What then becomes disabling are the social arrangements that fail to compensate disabled people for their physical conditions "or accommodate them so they can participate fully, or support their struggles and integrate those struggles into the cultural concept of life as it is ordinarily lived" (Wendell 1996: 42). Thus, the language used for the eligibility criteria becomes important when considering changing policy. These criteria:

> ... appear to be somewhat of an anachronism, given the scientific and technological progress that has been made in recent years in the field of disability. In most cases, the problem is not lack of capacity on the part of the person with a disability. Rather, the problem lies in lack of access to appropriate goods and services which

> allow people with disabilities to live independently and work where possible (Torjman 1996: 83).

Existing criteria, as understood by disabled people, prevent them from seeking part-time or temporary paid employment when or if their disability permits work. For disabled women, this is a disincentive to work because they must demonstrate (and maintain the perception) that they are physically or mentally incompetent in order to continue receiving benefits. Women are disproportionately affected by disabilities arising from fluctuating, degenerative autoimmune conditions (e.g., multiple sclerosis, systemic lupus and arthritis), and women are also more likely to be single parents (Fawcett 1996), two situations which potentially affect their ability to work. A woman with a fluctuating condition may have periods of remission during which time she might be able to engage in some work; caring for a child as a single parent may exhaust any energy gained during a remission, making it impossible for her to work despite being "able" to do so. Without subsidized child care, she again becomes "disabled."

Doctors play a key gatekeeper role in access to benefits, because their accurate assessment and diagnosis of a condition are crucial to determining eligibility. Thus, women's primary social roles as mothers and caregivers are sometimes constructed in unhelpful ways when doctors are considering diagnoses. For example, doctors reason that a woman will be taken care of by her husband, or that she can still do housework, so is not really disabled (McDonough 1997). Women's cyclical and fluctuating illnesses also create difficulty for physicians who diagnose them, especially if the condition appears dormant or is judged to be psychological, as often happens with chronic fatigue (CFS), myalgic encephalomyelitis (ME) and fibromyalgia (FM) (Carruthers 1999). These kinds of errors mean that women with significant disabilities are deemed ineligible for benefits and are forced to endure the appeal process without guarantee, or else turn to provincial social assistance to meet their needs. Provincial assistance is means-tested, often requires dissolution of assets and is not usually available to women with income-earning husbands.

The Roeher Institute points out that people on disability benefits who are using devices and medical supports funded by disability insurance are more likely to consider themselves completely prevented from working compared to people who do not have to qualify as "unemployable" to receive benefits (Roeher Institute 1992: 156). Considering these factors, women often end up in poverty on various income support schemes. Despite their needs for healthy lifestyles and positive identities, women with disabilities are thus trapped in "inactivity" in order to remain eligible for CPP disability benefits.

The amount of benefits a person receives comprises two elements: a flat-rate amount ($336.77 monthly) and a second amount based on contributions and the length of time contributions were made, to a maximum amount. This second element is 75 percent of the expected retirement benefit if the applicant were 65 the day eligibility for disability benefits was established. The expected retirement benefit is calculated at approximately 25 percent of yearly earnings (while taking into account lower earning years because of childbearing or schooling). This means that women with incomes of $36,9000 or more yearly at the time eligibility for disability is established will receive the maximum monthly benefit of $895 and women earning less than $20,000 may be receiving less than $650 monthly.

In 1997, the average CPP disability benefit was $663.74 monthly, with the maximum that year set at $883.10 per month (HRDC 1999a). These figures do not reflect gender differences in average amounts. Women with disabilities receive an average monthly benefit of less than $600 (in March 1998) compared to an average of $727 for men. Benefits are paid to qualified beneficiaries up until age 65, provided they continue to meet the eligibility criteria. At age 65, disability beneficiaries can expect their income to drop because "the conversion to a retirement pension is based on the YMPE at the time the disability began, with adjustments to price increases to retirement" (HRDC 1999a).

Up until 1998, for those receiving CPP disability benefits at the time of retirement, the calculation for the retirement pension was based on the YMPE *at the time of retirement,* hence the reduction in income for CPP disability beneficiaries at age 65. In retirement, the difference between men and women is even greater. Men between the age of 65 and 69 received a monthly average of $517 (in 1996). Women's average for the same age group was $289 per month (National Council of Welfare 1996: 27).

Children's benefits are paid on behalf of the dependent children of a disabled beneficiary provided the children are under 18 years of age, or between 18 and 25 and in full-time attendance at school or university. Benefits for dependent children are fixed. In 1998, the monthly amount was $169.80 per child. Children can receive two benefits if both parents paid into the CPP and each parent is disabled according to CPP legislation.

CPP Disability Initiatives

In response to an unprecedented increase in the number of disability claims in the period between 1991 and 1994, a "comprehensive set of administrative measures [was] developed and implemented to ensure that only those eligible receive benefits and only those who remain disabled continue to receive benefits" (HRDC 1998b). Included in these measures were both programs to re-assess current beneficiaries to determine continuing eligibility for CPP disability benefits and incentives to reduce barriers to employment for CPP disability beneficiaries.

With respect to re-assessment, a successful (from the CPP's point of view) project launched in 1993 and ending in March 1996 reviewed the continuing eligibility of clients who may have regained the capacity to work while receiving disability benefits. Forty percent of those re-assessed during this period showed significant improvement in their condition or enough changes in their circumstances to have their benefits stopped, resulting in substantial savings to the CPP account (HRDC 1999c). The CPP asked for approval from Treasury Board to expand and prolong re-assessment operations until March 1998 following these results. It is not clear whether any of these individuals re-applied for benefits because of a reversal in their condition or circumstances between 1996 and 1998. In the fiscal year 1996-97, nearly 19 percent of those re-assessed showed sufficient improvement in their condition to have benefits stopped (HRDC 1998c).

Work Incentives

In May 1995, the Report of the Committee on Disability Issues (of the CPP Advisory Board) tabled a recommendation that:

> a project be set up to develop rules and legislative amendments to encourage people who have already qualified for a CPP Disability Benefit to participate in rehabilitation or modified work, with the possibility of continuing to receive a partial CPP benefit, or if necessary, to revert to a full benefit more simply than an initial claimant (HRDC 1999c).

Four work incentives were introduced in 1995 “to encourage re-integration of beneficiaries into the work force without exposing them to the automatic loss of benefits” (HRDC 1998b). Before 1995, women and men receiving CPP disability benefits were not allowed to engage in *any* volunteer work or schooling. If they did so their pensions were disallowed based on an assumption that participating in these activities meant they were no longer disabled and should be able to return to work. The first incentive officially allowed disabled people to engage in volunteer activities without penalty, that is, losing their benefit.

Three other new measures included:

- beneficiaries with continuing disabilities could attend school, college, university, retraining or upgrading programs while retaining benefits;
- beneficiaries who return to work would continue receiving benefits during a three-month trial period to ensure they have regained the capacity to work and to help them with the transition; and
- beneficiaries who successfully return to work and who then must later leave the work force because of the same medical condition, would be offered a fast-track re-application process (HRDC 1998b).

The National Vocational Rehabilitation Program is another CPP disability initiative designed to provide incentive for people with disabilities to return to work and to assist them through vocational rehabilitation. It was originally initiated as a pilot project in 1993 and became an ongoing part of the CPP disability program in December 1996. Along with the other incentives, for the first time, it recognized that people with disabilities may in fact be able to participate in the work force and still be “disabled.” The CPP NVRP helps identify individuals who might be able to re-enter the work force with retraining, supportive technology or other accommodations.

Services to clients are provided through contracts with private-sector companies across Canada (HRDC 1998c) and are funded by the CPP. This funding hinges on several determinations, including the likelihood that, with vocational rehabilitation, an individual would be able to return to work; the beneficiary’s willingness to undergo vocational rehabilitation; and the stability of the medical condition and physician’s approval to engage in rehabilitation. Once a beneficiary has completed rehabilitation, he or she then would continue receiving benefits for the three-month trial period once work had been established.

The NVRP allows for a transition back to the work force (via the three-month trial period) that was impossible under previous CPP guidelines and provides a much-needed bridge for highly motivated disabled people. However, this bridge is not a guarantee of employment, and suitable CPP disability benefit recipients are sometimes unwilling to attempt re-entry without a stronger guarantee of security and stability for their income and disability status. Many who might be interested in pursuing the NVRP would be unlikely to take advantage of provincial (CHST-funded) vocational rehabilitation services for fear of losing CPP disability benefits. At any rate, in most provinces, people receiving CPP disability benefits are not eligible for employment programs because they are categorized as "unemployable."

Both the re-assessment and rehabilitation initiatives are significant in light of our experiences as disabled women and this research. The re-assessment process has not gone unnoticed. It substantially increases both the fear of losing CPP disability benefits and feelings of being at the mercy of an impersonal and uncaring bureaucracy. With respect to employment incentives, knowledge and understanding of these varies — some women were clear what these are, others knew very little or had partial understanding. One strategic objective for the CPP disability programs in 1997 was "to balance the objective of replacing earnings for as long as clients are unable to return to work with the need to identify those who have regained the capacity to work and to provide services and supports to improve a person's residual earnings capacity" (HRDC 1998c). Clearly, the CPP has identified continued re-assessment and rehabilitation as objectives for the future (HRDC 1998d).

As for the three-month trial of employment, we believe it is patently inappropriate for women with disabilities as it assumes that a person has successfully returned to work within three months of re-entering the work force. For those (mostly women) living with unstable, fluctuating conditions, this is inadequate.

> A large proportion of women suffer from chronic or degenerative health problems. Indeed in 1991 66% of women aged 15 and over reported that they had at least one health problem. Arthritis/rheumatism and allergies are the health problems most frequently reported by women. Women are also more likely than men to report most of these chronic health conditions (Statistics Canada 1995: 36).

In fact, the women we interviewed revealed that the three-month trial actually acts as a barrier to re-employment because few could imagine their conditions being stable enough over that relatively short length of time. If they *could* imagine it, the possibility of exacerbation shortly after the trial period had expired, forcing them back out of the work force (without their CPP benefits), made it too risky even to consider.

The third major policy change in 1995 with a significant impact on women and men with disabilities was that the CPP began to allow people to re-apply for CPP disability benefits under a "fast-track" program (HRDC 1998b) if their disability prevented them from working once they had re-entered the work force. This change is particularly important because many women have cyclical or episodic disabilities, which do in fact get better and then worse. The unpredictability of disabilities combined with the high risk of exacerbation due to stress prevents many women from planning to return to work. Many women told us they are afraid of losing the security of their

CPP benefits and jeopardizing a short-term recovery by returning to work. The concept of returning to work and retaining benefits has been used as a starting place for the scenarios used in our research. Since it is already CPP policy to extend monthly benefits for up to three months for disabled people returning to work, we have hypothesized that this could quite feasibly be extended indefinitely.

However, even after the 1995 policies were implemented, the Council of Canadians with Disabilities received complaints about penalties and re-assessments resulting in termination of benefits. The "CPP continues to penalize those who attempt training, education and rehabilitation or a part-time, or time-limited return to work by finding them 'employable,' in spite of a supposed policy which says this shouldn't happen" (Norman and Beatty 1997: 2).

Determining "Substantially Gainful Occupation"

Clearly, the CPP does seem to "allow" disabled people to return to work (for a limited time), yet this simple reality belies the complexity of administrative decisions, not described in the informational brochures and Web site material. The issue of being allowed to work (and retain benefits) is not as clear cut as the basic information suggests. What we were unaware of at the outset of this research, but discovered after our interviews were completed, is a 1995 Income Security Program (ISP) Policy Interpretation Guideline that focuses on the criterion "severe." This document provides guidelines for CPP officers who must make decisions about eligibility with respect to disabled people who might be working and, presumably, whose medical condition falls into the "severe" category.

The discovery of the Policy Interpretation Guideline became significant for us because we realized that CPP disability has a much broader (and more complex) interpretation of disability. The information about the ISP policy guideline, which we received immediately upon request from the CPP, subsequently provided a basis for two of our recommendations. A detailed description of the guideline follows to orient readers to this aspect of determining eligibility, and to provide background for understanding our recommendations and how they differ from existing policy and practice.

While the guideline consists of a number of components used to determine eligibility and factors within each component that officers need to consider, one component is significant to this research. The component is called Substantially Gainful Occupation (SGO) and addresses two factors, "profitability" and "profitable but not productive" in terms of whether or not a disabled person's earnings (from employment) indicate a "capacity for work" (HRDC 1995: 22). Ranges of earnings with respect to an SGO benchmark are considered in assessing profitability of work. In 1995, the benchmark for earnings that would indicate a capacity for work at a substantially gainful occupation was $8,559 yearly. This amount represents 25 percent of the average YMPE. Individuals earning amounts under this were (in 1995) *normally* considered "disabled." Those earning income between $8,559 and $17,118 (twice the "benchmark") were *normally* considered "not disabled." Those earning more than twice the benchmark were considered "not disabled," *with few exceptions*. Currently in use, the 1995 SGO benchmark ($8,559) is lower than the low-income cutoff and poverty line (Canadian Council on Social Development 1997-98).

Determinations of eligibility are made in part based on an individual's earned income compared to the SGO benchmark. "An individual who is working to *maximum capacity* but whose earnings are less than the SGO benchmark [$8,559] is not likely to have a capacity for work at a SGO level, provided he or she is not 'productive'" (HRDC 1995: 24) (emphasis in original). Some factors considered in this case might include the reasons why a person is working at the particular job, the relationship between these reasons and the medical condition, whether or not the person always earned at this level, whether or not the person is capable of earning any more than the benchmark, and whether or not the person is performing and productive despite low earning levels.

At the next level, between the SGO benchmark and twice the benchmark ($8,559 to $17,118), "very strong evidence must be present to lead to a determination that the individual is eligible for CPP benefits" (HRDC 1995: 25). In this case, other factors are considered, including:

- an indication of work activity on the Record of Earnings (some individuals may have remuneration despite not having worked, as when on sick leave);
- whether work was full or part time;
- relationship between a person's performance and productivity;
- earnings reflecting short-term effort with a strong likelihood of work discontinuing; and
- relationship of earnings to capacity or personal choice, for example, working part time to stay at home with children (HRDC 1995: 25).

Interestingly, the document does not clear up the ambiguity in the example given for the last factor. It is not clear whether working part time and caring for children represent a person's "capacity" or "personal choice." Presumably, a CPP officer could consider that arranging one's life this way might reflect a "personal choice," and thus determine a woman ineligible for benefits: she could be using her capacity by "working" instead of staying at home caring for her children. Regardless of this particular discretionary element, the above factors indicate that "the SGO benchmark is not a pure income threshold. Therefore, individuals earning between $8,559 and $17,118, in 1995, do not necessarily have their benefits ceased" (HRDC 1995: 25).

Those with earnings which are twice the SGO benchmark or more ($17,118 plus) "are presumed to have a capacity for work at a substantially gainful occupation. In other words, the earnings level alone is to be taken as conclusive evidence of capacity for work unless the client can provide strong evidence to the contrary" (HRDC 1995: 24). However, the guideline leaves an opening in this situation for individuals whose "work effort is greatly aided or if the work is irregular" (HRDC 1995: 24). These factors could be treated as grounds for considering a person as disabled according to the CPP legislation.

The second factor is titled "profitable but not productive" (HRDC 1995: 22) and relates to the fact that "remuneration for employment may not always lead to the conclusion that a person has the capacity for work" yet stresses that "[u]nless strong evidence is provided, receipt of remuneration *is* an indication of capacity" (HRDC 1995: 26) (emphasis in the original).

One other factor concerns individuals who are considered “highly motivated,” that is, who are working despite medical advice. These are people who are unable to cope with a complete lack of work activity despite having a terminal medical condition. In this situation, the key element considered is level of earnings according to the basic guideline (above), i.e., earnings at or above the SGO benchmark conclusively indicate a capacity for work.

Previous Research

The intersection of work and disability policy has been researched previously. Using the 1991 Health Activity and Limitation Survey data, an HRDC report (Fawcett 1996) provides significant information about the economic lives of Canadians with disabilities and factors influencing decisions about work. Some people with disabilities who were out of the labour force reported that they were not seeking work for reasons that involved the disability income and support programs available at that time. For example, 21.4 percent reported they were afraid of losing their income support, and 13 percent said they were afraid of losing their disability supports and services, such as subsidized medication, special transportation, assistive devices and medical services not covered by basic provincial health care plans as well as other disability-related services (Fawcett 1996: 119).

The Health Activity and Limitation Survey (1991) revealed that 31 percent of the 1,004,630 people with disabilities not in the labour force listed the possibility of losing income or benefits as a barrier to employment (Statistics Canada 1993a: 52). This means that one in four or five disabled people not currently in the labour force could potentially consider returning to work if the penalties, risks and disincentives were removed or substantially reduced.

Advantages of the Research

As the rate of disability increases with the ageing of the population and the nature of work constantly changes with economic and technological shifts, disabled people will increasingly be a part of the work force. This report looks at how pension policy at the federal level could respond to fluctuating health and abilities to earn income. The policy changes we recommend might also be used to consider reform to provincial disability benefit legislation as well as programs operated by insurance companies and Workers’ Compensation Boards (WCBs).

The policy reforms suggested as part of this research (see Chapter 6) address the problems for women (and men) with disabilities in three ways. By eliminating the penalty for earning income, the CPP could:

- provide incentives for return to work by removing the threat of losing CPP benefits;
- generate needed income for the CPP; and
- increase taxable dollars for general revenue.

Assuming that administrative costs to operate the suggested policies could be covered through reallocating existing administrative staff and resources, the financial cost to the federal government would be minimal. Over $26 million could be contributed through CPP premium payments at the rate of six percent if just 25 percent of the women (under 60 years of age) currently receiving disability benefits were enabled to work. An additional $57 million in tax revenue could be generated if the women earned taxable income, even if they were eligible for disability tax credits.

Lastly, provincial social assistance programs, which are funded through the Canada Health and Social Transfer (CHST), could potentially save approximately $55 million a year if 30 percent of the women who returned to the work force earned enough income to disqualify them for provincial financial assistance. Even if each province were to provide medical coverage to those women who were working and receiving CPP disability benefits (at an average cost of $250 monthly), the total expenditure would be $19.8 million annually, leaving a net surplus of $35.6 million for the provinces. These savings would be distributed among provincial governments based on the number of women in each province who were working and had previously been receiving social assistance. In addition, provincial taxation would generate additional funds proportionate to the population of women and men with disabilities working in each province (see Appendix B for calculation and sources of data).

The potential savings could also motivate the provinces to encourage retraining and return-to-work incentives among those receiving both CPP and provincial disability benefits. A change in policy to allow for some work would mean that those CPP beneficiaries formerly considered “unemployable,” and therefore ineligible for provincial employment programs, would become eligible for provincial retraining initiatives. In addition, people denied CPP disability benefits, or who are re-assessed and then disallowed, inevitably turn to provincial social welfare programs for financial assistance. Given these factors, it makes better fiscal sense to support disabled people who could work on contributory schemes than to create conditions which force them onto tax-based (federal-provincial cost-shared) welfare programs.

Situating the Study

As researchers conducting this investigation, our report and analyses also reflect our personal experiences as feminists and as women with disabilities. We found it useful to ask ourselves, and each other, gender and disability questions as a way of guiding our thinking about this research and the differing situation of women. Some of the questions we posed were:

- How is the experience of disability different for women from that for men?
- Do the types of disabilities women experience differ from men’s?
- Is living on disability pension or welfare different for women than men?
- How does raising children, as a single adult or in a relationship, have an impact on women and men with disabilities?
- What are the experiences of culture, race and class for women with disabilities compared to men with disabilities and women without disabilities?

- Do disabled women have more in common with other women than with disabled men?
- Are there administrative decisions that have a different impact on men and women with disabilities?
- What are the influences of the kind and type of work that women with disabilities do, including part-time, home-based and short-term contract work?
- How do other social issues — such as housing, safety, violence, transportation, medical care, family, child care and sexuality — intersect with income?

Both of us have extensive experience dealing with income security programs. Quantitative and qualitative methods were used in this research, which take into account not just statistics about women with disabilities, but the meanings of those numbers in their lives. The report attempts to be as true as possible to the words and expressed concerns of the women interviewed. Our recommendations reflect the concerns of these women, the fiscal importance of ensuring cost-effective changes and our beliefs and attitudes about the need for change that will more closely meet the needs of women with disabilities.

Although our project specifically looks at the experiences of women with disabilities and the intersection between their gendered lives and the CPP disability benefit system, we strongly believe that men experience similar disincentives to employment and would benefit greatly from policy changes. In addition, dependents of men with disabilities — spouses, partners and family members — would also benefit. We also acknowledge that many women are not part of the paid labour force and are often dependent on men for economic security. When a woman with a disability is being supported by a man with a disability, the costs of living are higher and the need for income security even greater. Non-disabled women and women with disabilities who perform homemaking duties or care for children should also have an income. Under the current legislation, the CPP disability, dependent child and survivor benefits are the only way for family members to receive support. Women will directly and indirectly benefit if men with disabilities are enabled to return to work and secure higher amounts for future pension income. It is our opinion that women’s experience should be explored using a gender lens, but that the recommendations be applied to all workers in Canada.

In its submission on CPP reform, the Roeher Institute discussed the problem of reducing CPP entitlements by all or part of WCB benefits so that CPP costs are reduced. They pointed out this “stacking” of CPP and Workers’ Compensation would “likely result in increased demand by injured women for income from WCB and other provincial schemes such as welfare” (Crawford 1996:10). This points to the importance of looking at the CPP in the larger context of support systems for people with disabilities in Canada. Tables 1 and 2 provide details of the complex system of supports for people with disabilities.

Table 1: Income Support Programs in Canada for People with Disabilities*

CPP Disability Benefits	Eligibility based on matched employer-employee contributions to the CPP over a minimum number of years. Medical determination of eligibility based on not being able to do *any job* because of severe and prolonged disability. Indexed to cost of living. Not means-tested. Universal. Self-employed contribute both employer and employee portions. Calculated at approximately 25 percent of what would have been the retirement pension at time of disablement (about 75 percent of average earnings after low earning years are factored out). Three-month trial of employment period follows completion of CPP vocational rehabilitation program offered to eligible beneficiaries.
EI Sick Benefits	Eligibility based on contributions to EI over 700 insurable hours and letter from doctor. Up to 32 days' benefits provided with the possibility of extension. Employee required to use up employer's sick leave provisions first, which replaces two-week waiting period if up to or more than two weeks. Not means-tested. Not universal — only people contributing to EI are included (excludes self-employed or contract workers). Very short term.
Employer-Sponsored Long-Term Disability Benefits	Eligibility based on contributions (usually employer-paid). Medical determination based on inability to do *previous job* or occupation. Benefit amount tied to percentage of former earnings (sometimes up to 60 percent). Usually not indexed and not means-tested**.** Individuals are often required to apply for CPP disability benefits at the same time. Most LTD programs then top up to the calculated benefit amount. Generally include some form of rehabilitation but penalize people for working for income.
Private Insurance (Disability Related)	Some workers purchase private insurance which replaces lost income, pays credit card balances or provides extended medical when workers become disabled. Generally, these are not available to homemakers and are not means-tested. Definitions of disability are narrow and restrictive. Programs offer only a small monthly payment proportionate to previous earnings. It is unclear how much of the population uses this type of insurance.
Provincial Welfare	Cost-shared between provincial and federal governments. Means-tested. Eligibility based on poverty and lack of resources. Not allowed to have more than $500 liquid assets, although a vehicle and house may be kept if both are used by the applicant and not leased or rented out. Open to any one who meets provincial requirements. Generally single mothers and youth are supported more often than adult employable males. Some disabled people apply for this benefit because they are not considered disabled enough for CPP disability pension or provincial disability benefits.
Provincial Disability Benefits	Varying levels of support providing additional financial resources above standard welfare benefits for people with disabilities medically unable to work, or medically determined to have a disability which affects their daily lives, especially those requiring extensive medication or supervision (often for developmentally disabled or mentally ill persons). Eligibility not based on prior employment. Means-tested. Most provinces require those who have made CPP contributions while working first to apply to the CPP, then provide only the difference between the CPP benefit and eligible provincial amount.

Workers' Compensation Programs	Employer-based contributions to cover employees. Does not include those self-employed, working on contract or some home-based workers. Payment of partial earnings based on severity of disability determined medically. Cause of the injury must be determined to be related to employment. Many claims are for back injuries, repetitive stress injuries and respiratory disease related to work environments. Most workers' compensation programs require rehabilitation and are time-limited.
Vocational Rehabilitation Services	Some provinces administer programs that provide income support and disability-related services to assist disabled people to enter the work force. Most consumers of these programs are young people disabled before graduating from a college or university. The CPP NVRP is modelled partially on these provincial programs. Recently, the programs have stopped paying tuition and education-related costs and instead, expect students to take out student loans or seek grants much as other students do. Eligibility medically/vocationally assessed.
Overpayments and Clawbacks	It is common for one program to determine that another program was overpaying or that a person was ineligible for benefits for a specific month or period of time. The disabled person is then asked to repay the benefit amount received, or overpayments are calculated and deducted from income tax refunds. Workers' compensation works closely with welfare to prevent "double-dipping" and often both require paybacks or deductions if overpayment is detected.
Work Incentives and Work Disincentives and Deductions	Generally, each program that allows for some employment deducts dollar-for-dollar on declared earned income. Sometimes a percentage of former earnings is allowed before direct deductions are made. Or some programs allow a monthly $100 to $200 earnings exemption. The B.C. welfare program allows adult males to keep 25 percent of earned income up to the benefit amount normally received. They are also allowed to maintain assets of $500 with no penalty. This allowable amount changes to $800 for adults with children and is different for disabled people. The basic principle is that earned income is deducted from entitlement payments above a specific amount.

*Missing from the above table are the non-financial benefits which are a part of the disability support system. For example, medical benefits that pay for prescription medication or durable medical equipment like wheelchairs and bath seats are an important part of the disability support system in Canada. Disability tax credits, rental subsidies, home renovation grants and home care services are other pieces which do not directly provide income to a disabled person but relieve some of the financial pressures of having to pay for disability-related supports.

This research looked primarily at the CPP disability benefits as they affected women with disabilities, but clearly there is a significant need to look at the intersecting and complicating programs and services in Canada to understand the larger picture. Table 2 demonstrates the complicated process of securing income support, depending on cause of disability and qualification for various programs mentioned above.

Table 2: The Process of Securing Income Support or Replacement in Canada

Situation	First step or eligibility issue	Process until benefits assigned or regulations for application	If and when benefits assigned, or denied, next step...
A. Work-related disability	Person becomes disabled because of a job related injury: goes to WCB (if covered).	While waiting for WCB, apply for EI sick benefits and see doctor.	Await WCB medical decision. If approved, benefits partially replace work income. Rehabilitation commences when appropriate.
B. Non-work-related disability	If a non-job-related disability begins or worsens: apply for EI sick benefits based on doctor's recommendation.	See doctor, exhaust employer and EI sick benefits: if injury or illness has not improved, consider employer-based LTD benefits, if available, CPP as next step.	LTD benefits provide income replacement up to 60 percent if disability is prolonged.
C. Eligible for CPP disability benefits	Exhaust EI and employer sick leave: LTD plans require application to the CPP first, then top up benefits to allowable amount based on former earnings, if eligible for the CPP.	If worked four out of the last six years, contributed to the CPP and condition is severe and prolonged, apply for CPP disability, using medical documentation and possibly an independent medical examination to decide eligibility.	Once receiving LTD and CPP benefits these continue depending on ongoing inability to work due to disability. Some people are offered vocational rehabilitation, either through LTD or CPP.
D. Not eligible or denied CPP disability benefits	If disability unrelated to work and there is no work history, or if denied CPP disability benefits: individuals must apply to provincial disability benefit program (unless they have parental, spousal or independent means of economic support).	Provincial benefits are means-tested: person must be considered medically disabled and in need of support for daily living. If determined eligible, individuals get equipment, prescription medication and home support paid by province.	If ineligible for disability benefits, can apply for regular welfare benefits, based on need. Dietary supplements are sometimes covered. Crisis grants are considered and medical costs often covered. Many programs require training, volunteering or rehabilitation.

This report is structured as follows: Chapter 2 reviews the methods used in the research, and Chapter 3 provides a narrative of the themes from the focus group interviews and the literature. Chapter 4 looks at the statistics and the context of women's inequality, and Chapter 5 offers a discussion and analysis of the data, including our own perspectives and those drawn from the current literature. Chapter 6 brings forward our recommendations in detail, potential strategies for empowering women with disabilities, and Chapter 7 concludes the research by refocusing attention on the political and economic context of this research and suggesting directions for future research into the lives of women with disabilities.

CHAPTER 2: PARTICIPATORY RESEARCH METHODOLOGY

In this section, we describe how the research was conducted. The methodology is described to communicate as clearly as possible how we thought about and approached the research, and how we arrived at our recommendations. We consider this most important for women with disabilities who may be reading this report. We have drawn from participatory action research methodology (Maguire 1987) because it reflects the fact that the research is not just focused on the concerns of women with disabilities, but engages them in all aspects of the research process. The idea for the research was generated from the experience and knowledge of both researchers, who are also women with disabilities. Together we discussed and decided how to proceed, who to involve, how to understand the findings and what kind of recommendations to make. As Park (1993: 1) suggests: “Participatory research is a means of putting research capabilities in the hands of the deprived and disadvantaged people so that they can transform their lives for themselves.” Maguire (1993: 157) adds: “Participatory research is a process of collective, community-based investigation, education, and action for structural and personal transformation.”

This research was conducted in community settings nationally, with the exception of one focus group interview that engaged the CPP administrators in discussion. Our purpose was to use other women with disabilities in focus groups to discuss their experiences of CPP disability benefits and disability, and whenever appropriate, to take up opportunities to educate women by sharing information they might need. Education in this context is not a one-way street; other women with disabilities taught us so much about their lives. It is the problematic aspects of their lives (in relation to CPP disability) we seek to change through our recommendations. Many of the women expressed support for the work we were doing as part of this research and viewed the changes it may foster as long overdue.

As both researchers are women with disabilities, our chosen methodology was an important factor in our ability to pursue answers to difficult questions. As women with advanced degrees, we are located differently from many of the women in our study, yet have experienced, and continue to experience, some of the same circumstances as the women we interviewed. This parallel experience provides a lens through which we interpreted the data and grasped the potential effect of our recommendations not just in the lives of women (and men) with disabilities, but our own. Recommendations for policy change could be considered the “action” part of this research, but by collaborating with us as part of this research, women in the focus groups have taken action on their own behalf and that of all other women who might be affected by their participation. We cannot predict what effect or influence this may have in women’s lives, but believe a feeling of hope for a better future was sparked among the women in the focus groups.

Combining quantitative (statistical) data with a qualitative method (participatory method) ensures that a more comprehensive picture of the lives of women with disabilities is created. Statistics also provided an important data base from which to develop the scenarios and do federal revenue and cost projections on our recommendations.

Describing how we proceeded is also done in the spirit of encouraging other women (and women with disabilities) to think about conducting their own research, and to critique our data and findings. Eleven activities conducted over the eight-month project to complete this research are described below.

1. Reading the literature to review various policy options

We drew from various literature sources to examine existing perspectives and understandings of recent CPP reform. In addition to theoretical literature focused on women and public policy, we reviewed consumer perspectives on economic and social justice issues, especially those written by people with disabilities and by women. By and large, these documents were informed and created by those whose lives are directly affected by public policy. Some of these sources include the Council of Canadians with Disabilities, the Roeher Institute, the Caledon Institute, the B.C. Coalition of People with Disabilities, the Gerontology Center at Simon Fraser University and Status of Women Canada research reports.

2. Searching data bases and statistics available through the Internet and books

Useful information is publicly available (and accessible) through the Internet. Statistical and demographic data was sought out via Web sites of the Canadian Council on Social Development, Statistics Canada, Human Resources Development Canada (HRDC), Income Security Programs (ISP), CPP and Health Canada. Being able to access material via the Internet was crucial for us as women with disabilities. It meant that we did not have to expend limited energy searching data banks at the local university or having to look for, and carry around, books from the university and local libraries. Other examples of published sources for statistical data on women's lives and people with disabilities include these Statistics Canada publications, *Women in Canada* (1995b), *Adults with Disabilities: Their Employment and Education Characteristics* (1993a), Canadian *Social Trends* (Manette 1996), *Perspectives* (Clark 1995) and *Living with Disability in Canada: An Economic Portrait* (Fawcett 1996).

3. Constructing scenarios and calculating costs

Once we had compiled numerical data and developed a fairly clear statistical picture of the lives of women with disabilities in Canada, we were able to begin constructing scenarios that would represent hypothetical changes in CPP disability policy (see Appendix A for scenarios). Our plan was to suggest these scenarios to women with disabilities in focus group settings, to generate discussion about their lives currently and how these might be altered by policy change. Taking into consideration the current costs, size of population and existing regulations, we developed a few different scenarios. Three different scenarios were ultimately projected and refined: one that allowed almost limitless earnings, one that allowed earnings to a maximum and a third that provided for increased disability or pension amounts if earned income after disability was higher than previous earnings. Using these scenarios, we calculated projected costs, in both savings and revenue, if women with disabilities returned to work and retained eligibility for the CPP. The calculations and sources for the data are available in Appendix B.

4. Preparing the scripts and recruiting focus group participants

Scripts were prepared as a guide to discussion in the focus groups. These provided a basic outline of what we would say to the women in the focus groups and were also designed to elicit details about particular aspects of the lives of women with disabilities. These scripts outlined our intentions, described confidentiality measures of the research and suggested basic rules for communication in the group setting. Questions were created to guide discussion. Our knowledge of women's lives and of fluctuating illness was used to create situations that would be easily identified by women in focus groups. The scripts used are in Appendix A.

Women were recruited nationally through non-profit organizations. Most of these were consumer groups associated with particular conditions, such as Canadian Mental Health Association, the Multiple Sclerosis Society, chronic fatigue and fibromyalgia support groups, and the Arthritis Society. Women who were blind or deaf and women with other chronic disabilities were recruited either through other disability-related organizations such as Independent Living Centres or by word-of-mouth. The Internet was also useful in publicizing the project and communicating with interested women. The recruitment process was difficult due both to unwillingness to share names and information about individual women at the organizational level and to a climate of cynicism and lack of trust among women asked to participate in policy research. We designed this research to be conducted nationally so some of our recruitment difficulties, not unexpectedly, resulted from not being located in the same cities or provinces as the women we were seeking.

5. Conducting a pilot focus group followed by formal focus groups

The criteria for participation in the focus groups (including the pilot group) were that the women had to be currently receiving CPP disability benefits, had previously received CPP disability benefits or were engaged in the appeal process to receive CPP disability benefits. Demographic data was optional in our study. We asked the women if they would like to answer a few questions focused on demographics (e.g., age, type of disability/illness, length of time working, CPP disability pension monthly amount). Only 75 percent of the women completed these questions. Of those who answered, the average CPP benefit was $635 per month. The occupations ranged from managerial and public service work to health care and sales. Women ranged in age from 20 to 62, and all but four said that if their conditions improved and penalties were removed they would be interested in working again at least part time. The average number of years for receiving CPP benefits was 6.8.

Being researchers *and* women with disabilities allowed us to establish trust with the women we interviewed and to demonstrate enhanced empathy toward the women in the focus groups. We believe participants were as candid and honest as they were, in part, because of this shared reality. Five women attended the pilot focus group, strongly urging us to take into consideration the issue of age and its impact on any consideration of returning to work, since the average age in this group was much older than we had anticipated. All our groups revealed a serious gap in knowledge about the rules and specific details of CPP disability benefits or of the changes introduced in 1995 and, more recently, in 1997. A total of 29 women were interviewed in the formal focus groups conducted in Nova Scotia, Ontario and British Columbia. All the focus groups except one were conducted in English, the exception being in French. None of the women's names have been included in this report, and we have endeavoured to protect the anonymity of the women involved. Verbatim comments have been stripped of any details which might reveal a woman's identity. Many of the women made it clear that they would not participate without a guarantee of anonymity.

It has been pointed out to us that the women recruited for this study seem to be among the most active and able of CPP beneficiaries. In our opinion, the women we interviewed represented a range of ability. Some belonged to disability organizations, others were not even aware that disability organizations which supported women existed, and still others were volunteering to help others. It is also not up to us to judge by some objective standard who are the most able or active; that is really up to the individual woman. Some of the women might have been having a good day when we saw them and then spent the rest of the week in bed because of the activity or exertion. In addition, it is important to note that quotations taken from transcripts may represent the most astute or illustrative comments of the hour, or session, while other women may have been silent or not able to articulate their thoughts as well.

We also had women participants who found the focus group difficult because of cognitive impairment and impairment in concentration. As researchers, we made every effort to make materials accessible and easily understood, and to accommodate needs in the focus group, but it was impossible to anticipate every need. We think it is important that we do not assume too much about women's lives based on objective standards and one-off meetings. Unfortunately this is exactly what happens when women are forced to meet with independent medical examiners to "verify" how disabled they are.

6. Understanding the themes

After the first three focus groups (including the pilot), and before the last three, we reviewed the transcripts to decipher tentative emerging themes and to develop better our understanding of the key problems these women were facing. Each researcher did this individually and then we compared our impressions. Tentative themes emerged along two lines: experiences that were repeatedly mentioned, and those experiences which were most strongly felt by the women. Developing tentative themes helped to focus the questions for the final focus groups. Saturation of the themes was achieved, supporting the rigour of the qualitative analysis. We repeatedly heard similar problems, from different perspectives, from women living quite different lives. In addition, this information allowed us to reframe the scenarios and understand the responses from CPP administrators.

7. Developing a model and questions for administrators

The scenarios and suggestions received from the women in the focus groups were used to develop a composite model which was presented as an alternate scenario to CPP disability administrators. From this model, an interview format was developed for the administrators' focus group in Ottawa. With the co-operation of Income Security Program Direction, several key staff provided important input which helped immensely to develop feasible and appropriate recommendations. In fact, without the information received from plan administrators, the research results would have been significantly different.

8. Transcribing and interpreting the data

All the focus groups were audio-taped and transcribed. One focus group in French also required translation, and American Sign Language (ASL) interpreters were used when needed. Following transcription, both researchers independently coded the data and compared notes. Discussions about quality, quantity and strength of comments helped in identifying and developing key themes. This process was repeated with the administrators' focus group, whose data were integrated with that of the other participants. Once the themes were identified and developed, the researchers also consulted existing literature to aid with interpretation and analysis of the data and development of recommendations.

Interpretation of the quantitative data was also important because it involved considering the women's comments in the context of fiscal realities. The scenarios were based on statistical modelling, and the women's suggestions drove us back to the computer to rethink and understand how to make the CPP more flexible and responsive to women with disabilities as they entered and left the work force.

9. Thinking through the meaning of the experiences

Before the analysis was conducted, a considerable effort was made to understand the meaning of the experiences and which policies would be most useful to the women. In particular, an effort was made to create recommendations which would not have any adverse impact on women. We had concerns about inadvertently appearing to support the neo-liberal agenda of economic restructuring undertaken by the Canadian government and tinkering with a problem without addressing macro-level inequalities. We referred back to the women's comments about what a big difference in their lives it would make simply to be able to work without fear of losing benefits, as a way of supporting our commitment toward change in the lives of women with disabilities. Recommendations that were grounded both in what women said themselves and in our own understandings of social policy and inequality were developed over time, as we continued to reflect on the themes and the experiences shared by the women in the focus groups. Both researchers had strong feelings about how difficult the lives of many of the women are and how even small changes could make big differences for them.

10. Consultation of literature and available options

Before finalizing the report, the literature was reviewed again for both structural suggestions and recent data or information not previously available. It was very useful to read other reports by women contracted through the Status of Women Policy Research and to access Internet documents such as the *Annual Report of the Canada Pension Plan* (1995/96 and 1996/97) (HRDC 1997b, 1997c) and census data from 1996. This information was useful in developing the analysis and getting a clearer picture of the necessity of change in the lives of the women who receive CPP disability benefits. Literature on the effect of economic structuring in women's lives was also very helpful at this stage. It helped us understand the political context in which this research is being conducted, and the urgency and necessity of economic security for those who receive pensions. In addition, slightly before the final report was due, a special edition of the British Columbia newsmagazine *Transition* (February 1999) came out focusing on chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and benefits. This edition solidified our finding that the reality of policies and benefit administration and the reality of women's experiences were virtually kilometres apart.

11. Construction of recommendations

Finally, after completing the analysis, interpreting the qualitative data and constructing a narrative analysis (see Chapter 3), the recommendations were created. They reflect the perspectives of the women who participated in the focus groups, current literature and statistics, and the feminist scholarship of both researchers. Recommendations are also made in light of our discussion with the CPP administrators and of recent changes to CPP policy that introduced work incentives to encourage re-integration of beneficiaries into the work force without exposing them to loss of benefits.

12. Revisions and late additions

There are always more sources of data to be added after the final draft. Based on reviewers' suggestions, clarification of program guidelines and recommendations were added which we felt supported the project findings. Calculations were redone and errors corrected, and contexts and comments clarified when necessary. This is an important step in all research, the last review.

CHAPTER 3: THE PERSPECTIVES OF WOMEN WITH DISABILITIES

Introduction

The focus group interviews provided us with a unique glimpse into the complex reality of the lives of women with disabilities, in the context of their relationships with the Canadian Pension Plan and paid work. In response to the scenarios we provided (see Appendix A), women in the focus groups spoke candidly about their experiences of living on CPP disability benefits. Although individual lives, circumstances and experiences varied, commonalities also surfaced, and we were able to identify themes emerging from subjects discussed repeatedly or with intensity. What follows is an elaboration of 10 themes interspersed with excerpts from the transcripts to sharpen the picture of these women's lives. The themes were a consensus of fear, enforced uselessness, responding to fluctuating health, barriers to employment, complicating bureaucratic relations, age and family, volunteering, retirement, hope and information gaps. Central to all our discussions was a sense of the value of work.

All the women in the focus groups had been employed in the paid work force at some time or another; a clear sense of the importance and value of paid work in their lives threaded through our discussions. We heard of their largely unequal (with men) participation and remuneration during the time they were engaged in the paid work force. Women's unpaid work, in the domestic sphere and as community volunteers, is not pensionable. Thus women often do not qualify for private pension plans if they do not work full time. The gendered division of unpaid caring labour means women participate in paid work less frequently than men and so receive fewer of the work-related economic and social benefits which accrue to employed males. This results in substantially lower pension benefits when they leave the work force because of retirement or disability. Indeed, women's participation in the labour force is largely viewed as discretionary in nature (McDonough 1997).

Disproportionately, women engage in paid work at lower paying and service sector jobs. Women tend to be employed in part-time work more often than men, especially with the increasing prevalence of part-time and temporary positions, and limited-term contracts in both private and public sectors (Jenson 1996). Yet the economic need, especially for women who are living on their own, divorced or single-parenting (or both), forces them into paid work that rewards them at 72 percent of men's wages on average in comparable jobs on a full-time, full-year basis (Day and Brodsky 1998). The work lives of women interviewed in the focus groups reflected many of these discriminatory circumstances.

For these women, work is not just about earning an income. It is a valuable source of meaningful connection with others, potentially minimizing their isolation and the depression and boredom that arise from reduced participation in the paid work force. Working increases personal motivation and the ability to make a contribution to society, a society which values paid work differently from the contributions these women may provide as homemakers, mothers and volunteers. (We did not interview any women who were primarily homemakers and mothers before their disablement.) In general they spoke of having well-developed work identities and clearly talked about the centrality of work in their lives. The issue of unpaid work surfaced primarily in discussions concerning volunteer work. Unpaid work in the domestic sphere did not surface as a prominent topic for discussion.

Contributing to society through paid work was viewed as crucial to the women's sense of usefulness, worth and value. With the onset of disability, this important source of motivation, social connection and worthiness was lost. For some, the loss of paid work also meant losing an important part of their identities. By making a contribution and receiving an income, women with disabilities feel useful and worthy. Thus, working was seen to be closely related to their health and sense of well-being. All the participants were keenly interested in changes to CPP disability policy that would allow them to work. Their consent to be interviewed and share their views demonstrated willingness to contribute to changes they hope will reduce the frustrating and demeaning experience of receiving CPP disability benefits and of being restricted from working. Along with us as researchers, they too, sought policy that would enable income.

A Consensus of Fear

Fear is ubiquitous in the lives of women with disabilities who are connected to CPP disability benefits. A veil of fear surrounded the whole topic of returning to work. Women in the focus groups spoke of fears of losing pensions because of review or re-assessment by doctors contracted by the CPP who may not have the whole picture of their health, or may see them on an unusually good day; fears of the re-assessment process itself (having to prove disability by writing letters describing daily activities); and fears of talking on the phone not knowing if someone from the government is listening. One woman mentioned "the fear to succeed," which arose when she thought about returning to work and the threat of losing benefits.

An important note is that *all* the women we interviewed believed strongly that if they earned "one cent," or worked for one hour a day it would result in the loss of benefit entitlement. This belief comes from a variety of sources, (e.g., CPP brochures, discussions with officers, correspondence) which they are interpreting in a particular way and which differ from what might be intended by the CPP. What they understand to be true conflicts with actual policy around earned income (as described in the Overview of the CPP in Chapter 1) revealing how discrepant their understanding is from what actually happens in practice. We, as researchers, also believed work was prohibited until shortly before our research was finished.

This chapter is written from the women's point of view. Thus this belief is reflected as "true" in our writing about the women's experiences, despite the fact that it might not reflect the current reality of policy interpretation. Any reference to CPP rules and regulations or policy in this chapter reflects the women's understanding of that policy, whether or not it mirrors actual CPP policy.

Fear of losing pension benefits is not only ubiquitous, it also has the potential to immobilize women with disabilities, leaving them with little or no trust in decisions made by authorities.

The actuality of policy and comments from a CPP medical doctor were not enough to convince one CPP recipient that she should not be afraid to work even for a few days. Her reality was fear, and this was common to all the women we talked to. This woman, who had been a teacher, filled in for her daughter, a primary school teacher, for a few days. Her story points not just to the morale-boosting effect of doing some suitable work, but also the cumulative effect of living with the fear of losing benefits. She illustrates the role of surveillance and the capricious nature of the review process, which itself engenders fear.

> I did go back to work a few days. My older girl was teaching; I used to go to her classroom — so she called me up in the morning and said, "Mom, will you take the classroom?" I was a bit hesitant, but I did. I forget exactly how many hundreds of dollars I earned — but when I filled in my income tax — then I got a letter from the CPP. I wrote them a letter and explained everything — that it was good for my morale, and why it was easy for me to go into the classroom, but I also told them — I would like to speak to someone. So this doctor called me. It depends on who you happen to talk to, but he was very understanding, and I got a good scare — and he told me — yes, you can earn a few dollars, and I won't change anything. But I really didn't take his word for granted. So I never did go back in the classroom, because I was too afraid to lose my pension.

Similarly, one woman turned down paid employment that was suitable to her energy and mobility needs, choosing instead to remain in a volunteer capacity for fear of losing benefits. Having to comply with CPP rules and regulations (as understood by women we interviewed), combined with the fear of losing benefits, erases any gratitude a woman might feel for receiving these benefits, or even a feeling of entitlement. Some participants mentioned able-bodied friends who were shocked to learn that women receiving CPP disability benefits are not allowed to work. For these women it seemed antithetical and anti-intuitive in an "enlightened," developed nation such as Canada.

One of the specific fears mentioned by women receiving CPP disability benefits is being denied benefits after re-applying. There are discrepancies in how the CPP policy is administered from place to place, but the reality is that women have been cut off, re-assessed or denied benefits. This fear arises in part from their experience in trying to establish eligibility at the time of disablement. It had been so difficult for them to become eligible, and the money was so desperately needed, they would not risk losing it.

> The biggest factor is the fact that anybody that goes off on disability — and it's a big thing when you're younger to do that — to technically try to go back to work. You're so afraid of losing what benefits you've got, because it was so hard to get them in the first place.

Others take the risk and suffer the consequences:

> . . . I could go back maybe an afternoon per week. But I would not take the risk at all now. Because it already happened to me. I was disabled in 1991 and I returned to work in 1994 part time and then eventually I turned full time. But I was obliged to give up my disability pension and now I that I have re-applied [for disability benefits] I have been denied, and I am in process of appeal [translated from French].

What became clear in our interviews is that all the women felt strongly that any revised policy allowing them to return to work should also ensure that they would not have to go through the application process to re-establish eligibility if they could no longer work. We learned that some women had avoided opportunities to develop skills and abilities that might lead to work because of the potential threat of losing benefits, as this woman indicates.

> You mentioned something . . . about even if I didn't go back to work, would it change how I felt, if I could? And it certainly would. Because I know that I've turned down lots of opportunities that would expand my interests, my abilities and skills since I've been on CPP, because I don't even want to get tempted by those things because I know that they won't lead anywhere. . . . So just knowing that I could, would make a big difference to just that. I would do some training, I would do some things that might be more interesting because they might lead to work, but I won't even trust them now because I'm afraid that they might lead to work and I can't do it.

Significantly, some women even felt that participation in the focus group might put them at risk. Others "couldn't even imagine" what it would be like to return to work, in part because they had internalized so well the message conveyed by the CPP prohibiting work while receiving disability benefits. Thus, fear generated by this message made it very difficult for some to imagine that they might even want to return to work or retrain. Some women put it out of their minds, with troubling consequences, as this woman illustrates.

> It's very frustrating. Because you just don't focus on it, on any type of training or career development, because it's not in your future. You know what your future is if you earn one cent then it's gone. It's all gone. So you don't even think of it. You don't want to. So then you have that feeling of non-accomplishment, adding to just not feeling good about yourself. Because you can't contribute to your community, society you just give up. You're discouraged.

The threat of losing benefits was also mentioned as the cause of an increased need to hide from the public, or avoid any volunteer or part-time work that might enhance their quality of life, for fear that someone would expose them (with subsequent loss of benefits). All of the women, except three, had been on disability benefits before the work incentive program of 1995 started encouraging people to volunteer or go to school. These women were still convinced it would put them at risk. Women who were so ill or chronically disabled that work was an impossibility, said that even with one "good" day the uncertainty of their illnesses would prevent them from attempting to work, including part time.

Secure CPP disability benefits could free women with disabilities from abject dependence on men, but this is far from saying it makes women with disabilities free (Young 1990). For many of the women, their disability pension is not enough to live on. Several women had other long-term disability insurance or welfare payments because the CPP disability pension was inadequate. Subject to formalized administrative procedures and restrictions against paid work, the autonomy of women with disabilities and their ability to define their own needs is seriously compromised. The fears that arise from this situation in part confine women to the domestic sphere, a space primarily occupied by women, and thus devalued, their economic, social and political power, and consequently their social well-being, is reduced.

Enforced Uselessness: Issues of Worth and Well-Being

> It's not really living, it's an existence.
>
> [Woman from one of the focus groups]

Women in our focus groups were greatly concerned about the drop in their sense of worth and linked it directly to being prevented from making a contribution to society through paid employment. Although all the women were clear that there are many factors affecting a decision to return to work, comments about identity and self-worth were also high on their agenda. Women noted that losing a job was paramount to losing the "self."

Self-definition as being useless and non-contributing shows how pervasive societal values and attitudes around productivity and self-sufficiency are as the mark of a "good" citizen. Underlying these attitudes are well-established ideas that economic productivity and self-reliance are traditionally appropriate for men, not for women, who are more appropriately dependent and nurturing (Fine and Asch 1981). For women with disabilities, the possibility of attaining the status of good citizen is doubly compromised as women, and again as women with disabilities. The dramatic effect of becoming disabled, and of leaving the public sphere of the workplace must be taken into consideration. It is particularly important to note that almost all the women we interviewed were not disabled as children, students or as young adults. Most became disabled long after their identities, including career paths, were in place. Implicit in the lives of women receiving CPP disability benefits are the boundaries around work drawn by the rules of the CPP and, again, the role of fear in keeping women with disabilities at home.

What is particularly noteworthy is women's awareness of how their lives are narrowly constructed by the CPP definition of disability (which is tied to their ability to perform paid work) as useless and non-contributing.

> When you've worked all your life, and then all of a sudden you're told no, you have to sit at home and stare at walls.
>
> Interviewer: It's very hard.
>
> It's very hard, but also it affects you mentally.
>
> Interviewer: Can you say more about that?
>
> Because you're a very, I know myself, and I know [names another participant] we're very, very active. Extremely active people. Into everything. I went to university at night, and all the rest of it. Now all of a sudden I'm told, "You're useless. Just sit at home, and we'll give you enough that *maybe* you can buy enough food."

Women with disabilities whom we interviewed were quick to tell us how they were being put in their place and kept there by CPP rules. Repeatedly, we heard how this had a profoundly negative effect on who they believe they are and on their intrinsic value. Some women told us how their independence had been "stripped away" by the economic and social restrictions engendered by CPP policy. Paid work contributed to a sense of accomplishment and belonging to society, but was also seen as an asset in terms of enhancing their self-esteem and assertiveness. A woman's sense of control in dealing with the outside world could potentially be enhanced by returning to work, as indicated in this response to a question about possible changes one woman might imagine if she were allowed to do some work.

> I think also you would have to add power to that list. Self-empowerment. In terms of dealing with the outside world and having to go in to deal with people in the CPP offices and social services or whatever. I think that would give a little bit of a lift with respect to your own self-esteem, that you may be able to handle those situations a little bit better as well. Because when it's really, really bleak it's um, you just don't function as well. You don't ask the right questions, you forget what you said, you never say no — so I think having the opportunity to get out and do some real work when you're feeling well would be just a tremendous thing.

In fact, enhancing self-worth was viewed by some as a primary reason to return to the work force.

The effort of having to prove one's worth is not just something directed at others who may label you as your illness (e.g., "the arthritic") but is also something that women with disabilities have to do within themselves. In a discussion focused on the difficulty several women in one group have had with stereotypical women's roles (i.e., staying home and doing housework), this woman clearly illustrates the additional burden women with disabilities carry with respect to their worth.

> It seems like we're always having to prove ourselves that we're worthy. We're worth something. Even more so with your disability than if you were fine. It seems like even to yourself you have to prove that you're not just a person with a disability.

The difficulty of doing this in the context of lives constructed by the CPP's narrow definition of disability is apparent. What also became apparent is the contradiction at the heart of current definitions, which does not escape these women with disabilities. Many of the women believe that they are not completely useless, but are made to feel this way, uselessness being the "appropriate" role for them as women with disabilities.

> So that you were hung up and classified as being totally useless, and you *better* be totally useless, and that there's lots of [disabled] people out there that are not useless but they cannot maintain a job. It's that simple, they cannot do that.

Women with disabilities in our focus groups were also aware of the effect on their well-being of staying home, and many were able to describe ways their disabilities are socially constricted by the poverty of living on CPP disability benefits. One woman spoke about not having enough money to put gas in her car so she could go to a free dinner.

> I can only afford so much gas. If I use up gas to go to that, I can't go. I can't do it. That's going to cut me off on something else. So it totally, totally strips you of everything, and they're making you more of an invalid.
>
> Interviewer: Tell me a little bit about that. What do you mean by that, becoming more of an invalid?
>
> Well, psychologically you become more of an invalid because the doctors are going around and saying "depression." And looking and saying, "it's all psychological." When you sit at home and you have nothing to do, there's only so much cleaning you can do in a house. That's it. So you sit and stare at a television, and look and say, "Oh my god, I know I could be doing something. I know I can be contributing." It is totally demoralizing. They're putting you as almost prisoners in your own house.

For women with invisible disabilities, such as depression or fibromyalgia, who are receiving CPP disability benefits, the experience of being disabled often includes trying to maintain self-worth and educate others while having to prove they are disabled, yet feeling pressured to minimize or deny the fact that they are receiving benefits.

> I know from my own experiences just having to prove that you're disabled — one of the things about being on disability is if you are brave enough to share it with someone you don't know very well they really do wonder, if your disability is invisible what the heck are you doing using up our tax dollars? So it's something that you would like to be able to keep under your hat, but yet you need to educate people that there's another kind of disability.

Significant in this excerpt is the perception that, even though women receiving CPP disability benefits made contributions while they were working, they are using valuable and scarce tax dollars. This was also true when discussing possible options for policy reform: women were convinced the public would see any expanded benefits as undeserving and ineffective use of public funds. This perception surfaced in the focus groups and mirrors similar perceptions in the general public, further stigmatizing women (and men) with disabilities. There was much agreement among the women we interviewed about having to explain to others that they are disabled and "not working" to people who don't understand. The women clearly did not like to do this and avoided it as much as possible. This was especially true of women with invisible or fluctuating disabilities, who, because of the nature of their illnesses, have to do it more often.

For example, one month a woman may use an electric scooter for mobility and the next month be walking with a cane, and those around her question the severity of the disability. Some described pretending, that is, telling people they were working to avoid the discomfort of having to explain. The benefits of returning to work are evident in the following discussion prompted by a question about how their lives might be different if they were allowed to do some work.

> Interviewer: How would your life be different?
>
> A: It would make me feel better because I have a lot of problems when people ask me “What do you do?” because I am quite young looking. When I tell them I’m not working they just think I’m lazy or unemployable and stuff, and they don’t really believe that I cannot work. So it would be nice if I was able to work, to have some money and feel good. And I think it would improve my self-esteem, too. People judge people on what they do, as their work, if you don’t work, there’s bad connotations.
>
> B: I get the same thing when people ask, “What do you do?” And I say, “I don’t work,” and they say, “Well, why not?” And then you have to explain.
>
> C: Especially I go back to see people I used to work with and they say, “Well you look so good.” It’s hard for them to understand, yeah sure I look good, but I’m just not capable. And it would make you feel a lot better if you were able to work a little bit that way, just to get out there with other people.

For women in the focus groups, to work even part time or at self-employed business activities would give them a sense of purpose as well as replenishing depleted financial resources due to living on a fixed income. Some women had sold their cars and houses in order to qualify for provincial financial assistance because some provinces require liquidation of assets.

Many spoke of the difficulty dealing with boredom, which itself was considered a stressor affecting their well-being, and with problems keeping themselves motivated while staying at home. Being connected to others in the social realm of paid work was closely tied to feeling useful, and having a sense of worth and well-being. Contact with others in the workplace was mentioned frequently as an important source of morale. Conversely, the loss of that contact contributed to depression, loneliness and uselessness, all of which were frequently mentioned as constant threats to the emotional and physical health of the women we interviewed.

One woman spoke of the positive relationship between working and her health and well-being, saying that work forces a woman with a disability to make an honest appraisal of her ability, while taking into consideration her health. In this regard, working would necessitate learning other ways of achieving the delicate balance needed to live with her fluctuating illness, allowing her to manage her health better in the long term. Women with disabilities are more likely to benefit from this kind of healthy effect of working, as they suffer disproportionately from chronic, fluctuating conditions.

Responding to Fluctuating Conditions

Chronic, unpredictable illnesses that fluctuate are more likely to be found among women with disabilities than among men, making it more difficult for women to satisfy medical criteria for CPP disability benefits. According to one study in the United States, women meet vocational eligibility requirements less often than men mostly because of intermittent work patterns or non-participation in the work force due to domestic responsibilities (Baldwin 1997).

Most of the women in the focus groups have disabilities that are unpredictable or unstable, and most, but not all, were able to satisfy both medical and vocational criteria for CPP benefit eligibility. For many of these women, their day-to-day health varies, making it difficult for them to imagine returning to work, even part time. The issue of fluctuating conditions permeated all our discussions, and most of the women talked about responding to unpredictable health as a central element in any decision to return to work. No one said that she could return to her former position. Repeatedly, the women in the groups told us that going back to work (or training for new or different work) was only possible if they were physically and emotionally well enough.

> Just in terms of having to look at, really take a close look at what you can and can't do. What you think you may be able to do or would like to do turns out to be something that you can't do . . . so it would have to be a bit of trial and error period in there too. And then again having to learn how to balance out your health care energy because you're not always capable of doing the same things every week, or every day for that matter.

The women in the focus groups repeatedly stressed the importance of finding suitable work that takes the unpredictability into account and is responsive to fluctuating energy levels. A related concern mentioned by some (many knew little or nothing of it) is the new CPP work incentive providing for education and retraining followed by a three-month "rehabilitative employment" phase (the National Vocational Rehabilitation Program). As previously noted, women in our study clearly stated that a three-month trial-of-employment period would be grossly inadequate for their needs. Built-in flexibility allowing for the possibility of numerous exits and entries over time is one thing women with fluctuating conditions thought should be in place in order to accommodate their particular health- and work-related needs.

> I know, like, you don't know how much you can do until you try. Right? And this is the thing, right? With my long-term disability, and CPP, you're not even really allowed to try. Like I know with CPP now there's a three-month grace period where you see what you can do, but that means that you have to have everything in place and do it in order to be able to tell. But if you can only teach like one night a week or work whatever, out of home, a couple hours a week, or whatever, then you want to build it up, because I know for myself, and I know for a lot of people, you can't just go bang, you have to slowly go into it to see how much you can do.

Several women also spoke of how, by engaging in some work, their stamina and ability to do more work may be enhanced, but remained clear about the necessity for built-in flexibility.

> Because I don't know if you can do the work, or whatever, and if you could work for a month or whatever, and show that you could do it, then maybe you would be able to go back to work full-time and not need your CPP. You might be able to go back to work and find out that you could actually continue working if you were given the option and not pressured to make a formal commitment.

One woman told us that, if the first scenario (see Appendix A) had been in place at the time of her disablement, enabling her to move in and out of the work force as her disability permitted, she would have retained her health and, thus, worked longer because she would have been able to take time off as needed. For many, home-based employment seemed the most suitable to the unpredictability of symptoms and fluctuating energy levels. It was also seen as a means to retain independence stripped away by living on CPP disability benefits. Working at home also has the potential to offset disabling aspects of work outside. Most employment outside the home requires transportation, challenging those who may be mobility-impaired. For those who experience fatigue, the pace of work and travel to and from the workplace make participation extremely difficult, if not impossible. For most women, previous employment is unsuitable, even if done part time, and discriminatory attitudes toward those with disabilities continue to pervade workplaces, requiring additional effort to combat. (See the next section, Barriers to Employment, for further discussion.)

There was considerable concern that returning to work could actually worsen an existing condition, particularly for women with immune-mediated conditions that are particularly susceptible to stress. Some women thought that fatigue and pain or altered cognitive function would make it difficult for them to go back to school or even hold a part-time job, but that it should be an option if they were well enough. It might even contribute toward getting well, because the lack of activity and the inability to foster a work identity often leads to increased isolation and depression. One woman said that trying out her limits was necessary for her to know how far she could take herself, but because she feared losing her benefits, she dared not even try to work or go to school. But she wanted to be able to try.

Interestingly, education for work was often seen as more demanding than a return to work because of the perceived impossibility of sitting long hours to study or the stress and demands of meeting assignment deadlines. Implicitly, these women assume inflexibility on the part of educational institutions in terms of accommodating their disability-related needs. There was also concern that career choices made by the women might not be acceptable to CPP administrators. Of equal concern to women in our focus groups was the attitude, and power, of employers to make it difficult, and for some, impossible to find suitable employment. They argued that employers would not want to hire women who might come to work one day and not the next, as this woman, referring to the first scenario indicates.

> Because I think that it values (the scenario) that a person could go back to work. But it understands also that when a person becomes disabled we have a lot of limits or restrictions so that if an employer wants to accept me... that I’ll have some days that I can not go to work. That would be very good. But it’s necessary also to be realistic, and think what the employers would want. They wouldn’t want you if every two days you had to rest at home.

Barriers to Employment and Disabling Demands of Work

Intersecting with the experience of fluctuating conditions, discussions about returning to work brought forward crucial concerns about employment equity and serious reservations about the ability to compete with able-bodied others for scarce jobs. Although all the participants were keenly interested in changes to CPP policy which would allow them to work, most had serious concerns about returning to work as disabled women. As they voiced their experiences and thoughts about employers' (and employees') attitudes, women in the focus groups revealed an acute awareness of normative expectations for performance held by employers and society that markedly discriminate against them. The gendered nature of these difficulties does not escape the women we interviewed.

> A: There are men with degrees who cannot find jobs so imagine how hard it is with a disability where it costs thousands of dollars for the employer to give you a position. Who would offer a job on a silver platter?
>
> B: Also, again the employer has to choose between a candidate who is pretty and who is not disabled. It's not just about being disabled.
>
> C: Yes, but I said that already. All the women are less than — you know, they can go to school and study more than the men, but they are still at the bottom I have found [Translated from French].

While some women had experienced the emotional cost of trying, often unsuccessfully, to manage discriminatory work practices, others had suffered at the hands of unsupportive co-workers who saw them as not performing to "normal" standards. All the women strongly advocated the importance of having not just suitable equity policies in the workplace, but also that these be enforced by governing bodies.

> We need to go back to the idea of employment equity, and that policy, and force employers to become more understanding and suit to our needs. We have no control, no law now to protect us, so it's harder. There are even more barriers for us. If we had some sort of law there, then some barriers might come down. The barriers are outside of me [Translated from American Sign Language].

Included in these barriers are the disabling demands of work, which create problems for women with fluctuating energy. Equity does not just include affirmative action. For these women, it includes measures to structure work flexibly, enabling them to meet deadlines at their own pace. One woman spoke of the impossibility of returning to her former occupation as a nurse because it was unlikely that the unpredictability of her condition would be accommodated.

> In my position if I did not inform them 12 hours in advance, they need to replace me at time and a half [paid to a replacement worker]. I am sure that they would not want to take me back [Translated from French].

Concerns about competing in a tight job market infused all our discussions, and the women we interviewed are aware of how disadvantaged they would be in any return to work. This disadvantage is heightened by the gendered effects of Canadian restructuring for a global economy, in which men compete successfully against women to acquire traditionally female-dominated jobs (Armstrong 1996). Gender differences in type of work, stability of work, unionization, benefits and income are additional factors that construct how men and women are affected differently by socio-economic changes. The deficit crisis has been invoked to legitimize the reduction of government-subsidized services, such as employment subsidies for people with disabilities, job readiness for women and career counselling for youth. By not spending money on these kinds of programs, the equality of women with disabilities is compromised (Day and Brodsky 1998). The discussion excerpted below reveals some of the complex issues confronted by women with disabilities when thinking about returning to work.

> A: . . . the only jobs that I have had have been the jobs that have been reserved for disabled people, in special programs. It was nice but it's over now.
>
> B: . . . when it's finished they don't renew it any more.
>
> C: You have to think that there are people who are not disabled who are also searching for jobs and so employers are going to start by picking those who cost them less.
>
> B: Yes. Also often the reason that some employers hire a disabled person as you just said is because they got a subsidy [money incentives]. Like I always say all the translation departments have a need for disabled people as long as they get them subsidized.
>
> A: In the hospitals I worked in . . . it makes them look good to hire a disabled person. And they look for them, and they have a subsidy that pays a part of my salary or a part of my expenses [Translated from French].

The issue of working part time is also complicated for women with disabilities. In many cases part-time work is more suited to the fluctuating nature of their conditions and reduced activity levels. However, engaging in part-time or casual employment often means less income, no benefits or seniority, further eroding the economic security of women with disabilities. For some of the women, medical benefits were tied to their former employers who would subsidize medical and other premiums only if the women were employed full time.

Class differences surfaced in discussions around returning to work, as women who had previously been professionals would be unlikely to take lower paying or less-skilled work. One highly educated woman told us she would find it difficult to change her profession "overnight." To some degree, middle-class women seemed more attuned to the idea of developing some kind of home-based employment. In general, discussions about home-based employment revealed that this type of work is well-suited to women who have fluctuating conditions. It would allow them to tailor work to their health needs.

> But again there is a lot of federal government jobs that the disabled can do. . . But give us the damn material to work at home, at our speed. If we could only work — let's say I can't work till 12:00 [noon], but at 2:00 in the morning 'cause I can't sleep I could get up and do a bunch of things. Hey, what difference does it make as long as it's done? Because most disabled cannot handle nine-to-five. But I believe they can handle various other kinds.

Complicating Bureaucratic Relations

The convergence of different support plans and programs in the lives of these women with disabilities is complicated and complicating (see tables 1 and 2, Chapter 1). This is especially true for the intersection of federal and provincial programs. Women spoke of how CPP intersected with other benefit plans in ways that are inflexible and reduce their income. For instance, one woman received, in addition to her own CPP disability benefit, a CPP dependent child benefit of approximately $170 monthly (given to dependent children of pensioners with disabilities). The woman applied for this benefit when the child was under 18 and not eligible for any form of social assistance. This is a taxable benefit that recipients cannot seem to stop when they no longer want to receive it. In this woman's case, her daughter began receiving provincial social assistance benefits (which are not taxable) because the daughter also had a disability and was eligible, but which was reduced monthly by the child benefit amount ($170) she received from the CPP. In essence, she does not receive any additional income, yet is forced to pay income tax on the "extra" benefits from the CPP, which has the effect of reducing her yearly benefit income substantially.

In this case, the mother is actually penalized for having a child with disabilities because the CPP doesn't make a distinction (in administering the child benefit) between disabled mothers with non-disabled children and those with disabled children. And, if you have a child who receives provincial disability benefits, the child's provincial benefit is reduced by the CPP amount, whereas disabled women (and men) who do not have disabled children (who thus are not eligible for the provincial benefit) get to keep the entire CPP amount for dependents.

We also heard of women who had worked in the public sector for the federal government, which forces women to choose either the federal government employee pension benefits or the CPP, but not both. There were several stories about women who were not fully informed of their rights, their choices or the consequences of their decisions when they became disabled.

The intersection of publicly funded and private sector plans, known as long-term disability insurance (LTD), is particularly troubling for women with disabilities. For many, even a part-time return to work would make them ineligible for LTD benefits. Many find the frequent reports and medical assessments upsetting, and insurance companies difficult to deal with. Yet some of the eligibility criteria are more liberal, in that disability is defined as not being able to do the original job, or something similar, not *any* job at all.

Some combinations of the CPP and the LTD result in more (or less) income than others, as this woman illustrates.

> I decided to drop the LTD because the LTD in my case was not giving me that much money because I had been teaching half-time, ever since I was married, just half days. So this would only give me about $15,000 a year, and your Long-Term Disability is calculated on 70 percent of that. . . . I had accumulated 25 years [of service], because before I got married I worked for 12 complete years, and then I worked about 20-some years about half time. I let go of the Long-Term Disability, and now I'm getting my teacher's pension. I got that 25 years without penalty, so

> it gave me $17,000, $16,000 a year, something like that. Which was more than the $500 a month that I was getting from Long-Term Disability. And it did not affect my CPP. Well, it did in a way, right? Because they took $2000 less from my teacher's pension, because I was getting disability, but still I'm getting — I said $750 a month, so that would be $9000 a year. Of course, I have a drop of $2000. That's it anyways. It's complicated.

In this situation she relinquished her LTD and received her teacher's pension and her CPP. However, becoming eligible for the CPP meant she had a substantial drop in income. What her story also demonstrates is the effect for women of their different engagement with work from men, in which intermittent work patterns and interrupted careers become necessary to assume responsibilities for unpaid caring work in the domestic sphere. Simply, it means women with disabilities are penalized by receiving lower benefits, forcing them to bear greater economic losses than men because of disability (Baldwin 1997).

Any consideration of returning to work becomes complicated for women receiving privately funded LTD benefits. Most of these women spoke of LTD rules that prevent them from returning to work, at least not without permanently losing their benefits. For those whose LTD income was larger than CPP disability benefits, even if the CPP made it possible for them to return to work, the potential to jeopardize LTD benefits would rule out their doing so. Women in the focus groups agreed strongly on this point. Responding to our question about the possibility of returning to work while continuing to receive CPP benefits this woman said:

> The only time it would be an advantage is if you only earned the CPP. If it was your only income. Then the policy change would be useful. But as soon as you receive other pensions with it, whether it be the long-term one, or [provincial social assistance], it would be you would get the punishment on the other end. Give in one end, out the other.

There are other equally compelling reasons for retaining LTD benefits. For some women with disabilities, medical benefits which cover disability-related medical costs are part of their LTD benefit packages, and they can ill afford to lose these. Medical benefits are particularly important to women who have disabilities that are managed with medication and equipment. Most of these things are not covered by basic provincial health plans.

We heard of the additional costs of living with disability and of how the basic CPP benefit amount often doesn't even meet the most basic requirements for some women. The need to have disability-related medical costs funded was mentioned frequently by women in the focus groups. Crutches, wheelchairs, scooters, supplies for incontinence and even non-steroidal anti-inflammatory pain medication were among the basic needs not covered without additional medical insurance. We asked if the possibility of receiving an extra $100 monthly at retirement might be an incentive to returning to work. One woman replied:

> Definitely. Because there's lot of times . . . that extra $100 a month would mean that I can afford to buy the medicine I need. Which — there's been months that

> I’ve had to look and say, “Wait a minute, I’ve got this to pay, I’ve got that to pay, I can’t afford my medicine.”

One of the expenses crucial to receipt of benefits and seen as a “pricey penalty” by women we interviewed, was the exorbitant cost of having medical reports completed by doctors to maintain LTD eligibility. Some women pay up to $134 (the fee recommended by the B.C. Medical Association for completing LTD reports, for example) for each report, which may be required as often as every two months, depending on insurance company policy.

Different disability benefit plans have different criteria for eligibility, something which leaves women with disabilities frustrated and in economic limbo. The disability tax credits offered by Revenue Canada have a more narrowly defined, stringent standard for eligibility, seen by some women with disabilities to be impossible to meet. One woman, who had met the eligibility requirements for the CPP but not the disability tax credits said, “I’m not entitled to it because I’m not disabled enough.” There is a tone of frustration and, to some degree, resignation in women’s experiences with different pension plans. As one woman’s story reveals:

> These laws are awkward because — what happened to me, I had to re-apply for CPP. They would question it [CPP reviewed her file], and it took a while to sift through the papers and everything. But in the meantime, I didn’t have an answer yet from CPP, and LTD wrote me a letter saying they were cutting me off. And then a few weeks after, I get a letter from CPP accepting me as having a disability. So then I went back to LTD and said, “Now make up your mind. Am I disabled or not?” I am disabled for CPP, but I’m not disabled for LTD. So as I said, then they put me back on it, but it’s such a mess that I’d rather take the teacher’s pension and not argue about it anymore.

Embedded in her experience is the actual effort of dealing with different benefit plans, a prime example of a struggle that wears women down. Women in our focus groups, faced with the prospect of ever-increasing medical costs and general cost-of-living increases, were left wondering how they would make ends meet, given their present difficulties.

Age and Family

The impact of age, and to a lesser degree, family, were also threads running through each focus group interview. Generally, women close to age 60 were not really considering a return to the work force and found it extremely difficult to imagine what their lives might have been like 10 years ago if the policies had been different. Many older women did suggest that for a 30-year-old, retraining and going back to work, even part time, would be a wonderful opportunity. Younger women, thinking about spending the next 30 years unable to work, expressed defeat at facing the possibility of poverty in older adulthood. One woman with a chronic degenerative condition expressed her need for extra income now in the following way.

> A lot of your scenarios are based on the pension when you’re 65, and I think a lot of people who are disabled don’t really plan that far ahead, don’t know if their health is going to make it so they can get to 65. Like in my mind, I don’t think I’m going to live to 65.

Women who were recently disabled told us how their lives are focused on coping with the physical and emotional changes of their disabilities. Older women thought that the policy changes suggested in the scenarios would be of benefit to younger women, but might not apply to women nearing retirement. They also thought it might be too hard to return to school or to learn a new skill at an older age. Statistics demonstrate that the incidence of disability and risk of disabling chronic health conditions increase with age, an important factor to consider when designing a return-to-work scheme.

Several of the women noted that age and family situation interacted differently, depending on whether a woman had a husband or children. Some women had only worked a few years before leaving the work force to raise children, while others worked while raising children, and still others were not married nor living with partners. Women who were married were grateful that their CPP disability benefit was combined with a wage earning (or retired) husband. They could not imagine subsisting on the CPP disability pension alone. There is the possibility that women receiving CPP disability benefits may be staying in unstable marriages or unsafe living situations because of the advantage of another source of income. Another factor to consider is that marriages don’t always last, and worry about the transition from marriage to separation was expressed by one woman as follows:

> I try not to even think about it; it’s a scary time for me because my husband and I are just separating, and he’s not going to give me too much. At this point I’m just on my CPP, and ’um . . . it’s pretty tight.

Eligibility for medical benefits provided by her husband’s employer is linked to her marital status: she can receive benefits only so long as she isn’t divorced from him. Another woman found her income went up when her husband retired and they became eligible for the Old Age Security benefit. The additional costs of supporting children or a dependent spouse, or being a single person are other circumstances we heard about that make it extremely difficult to live on a fixed pension. Even though pensions are indexed, the cost of living does not restrict itself to indexed increases — inflation affects women on a fixed pension disproportionately.

We heard how women had to give up so much because of living on CPP benefits. The harsh reality of parenting a child in poverty ruled out motherhood for some women, and expectations of a certain standard of living and attendant material possessions, such as owning a comfortable home or repairing an old vehicle, are gone. One woman expressed concern about paying for veterinary bills for her dog. These women have markedly limited access to the role of consumer (typically a female role) and are unable even to consider treating themselves to new clothes, a gift for a friend or relative, or a concert or movie.

A particularly troubling example of the effect of poverty and economic insecurity on not just women with disabilities, but also on family members, was one woman’s comment that, in considering the prospect of a future of economic hardship, she would rather commit suicide and leave the death benefit to her family, than be a burden to them.

In another situation, a mother and adult daughter, both living with disabilities and receiving the CPP, told us they live together to make ends meet because individual benefits do not meet each woman's basic costs of living. Because they share the cost of rent, their incomes are pooled and, together, they earn too much to qualify for welfare. This living arrangement jeopardizes any provincial social assistance benefits they might be entitled to if living singly, despite the fact that medications for the daughter can exceed $1,000 monthly. Her brother lives in a room in the basement, so because of their shared residence she can subscribe to his Blue Cross insurance, which meets some of her medication expenses. However, this arrangement may not be permanent, leaving her vulnerable to any decision he might make to change his residence. An application for a grant to adapt the house to the mobility needs of both women was denied because their combined income exceeded what was allowed for eligibility.

> A: That's the thing with her and I. We live together, but we make too much money, even though we are both disabled.
>
> Interviewer: Too much money for what?
>
> A: To get the grant to fix the house. We can't do it. We can't move out on our own, we have to live together. But we make too much money between the two of us to get a grant [from CMHC].
>
> Interviewer: So that you can modify the house for your disability?
>
> B: Yes. So it's getting to a point where we have to sell this house, because of our disabilities. We can't be out on our own. That's something that's unacceptable to both of us. And it's not fair. We're both disabled and we can't get that money.
>
> A: The government puts both of our money together and says, "Okay, if you two are stupid enough to live together to try and make ends meet and maybe have hamburg[er] twice a week instead of once a week, you're cut off."

Both women know that without renovations they will be forced in the near future to sell their home and move. This is an example of how means-tested programs such as the Canadian Mortgage and Housing Corporation (CMHC) Homeowner's Grant to modify homes, exclude those living on CPP disability benefits who, by necessity, economize by sharing residences. This choice to live together was not without emotional cost. Both had concerns (for self and other) about future care as their conditions worsened. In addition, both mother and daughter had concerns about not having a choice to be (emotionally) independent from each other. This experience also illustrates how intersecting benefit plans construct economic and emotional relationships with intimates and other close family members in complex and, perhaps less-than-healthy ways.

Volunteering: A Double-Edged Sword

Most of the women we interviewed were engaged in some kind of volunteer activities. For many, volunteering offset the loss of work as a motivator and a source of connection with others, which contributes greatly to their sense of well-being. Being a volunteer contradicts the pervasive sense of uselessness felt by women who have left paid work because of disability. One woman saw volunteering as a necessary choice: it was either be a volunteer or “go nuts.” With the onset of disability and the loss of attachment to the work force, volunteering plays a key role in these women’s lives in terms of maintaining (and sometimes restoring) this attachment. Volunteer work fits well with women’s fluctuating disabilities because it allows them choices in when to volunteer and how much. The structure and pace of paid work is often disabling for women.

The women in the focus groups spoke of the other side of volunteering. One woman referred to it as a “ghetto of unpaid work” and that being restricted by the CPP to volunteering was “a handicap.” We also heard of the tension between volunteering (and appearing to be well) and the importance of demonstrating that one is “appropriately” disabled. Some women view volunteering as a potential threat to benefits, especially if they are seen as able to “work.” This is part of the double-edged sword.

Paid work was always named as preferable over volunteer activities; but even when paid work was offered to women who were volunteers, it was refused because of CPP rules. Volunteering was also a way to gain training, often for free, and some women felt unable to accept formal training if it led to employment because of the restrictions on earned income. For some, the kind of social contact experienced as part of paid employment made it preferable to volunteering. Being limited to volunteering has costs, as this woman describes.

> . . . volunteering has been a very important part of my life, but you get to the point after a while where you’re losing a lot of your energy, a lot of your skills; you begin to feel used. You’re doing a big job, but you’re not getting paid for it. And it begins to feel — there should be a paid position.

Her sentiments regarding receiving income for work done as a volunteer were echoed throughout the focus groups, and point to the irony of allowing women with disabilities to work — after all volunteer work is work — but limiting it to unpaid work. Women are all too familiar with the “double ghetto” (Armstrong and Armstrong 1984) of unpaid work in their lives as mothers, homemakers and caregivers. In addition, many of the women in focus groups were contacted through non-profit organizations run for people with disabilities. Their involvement in support groups and self-help organizations was part of how they became aware of the research project. Some women were not only volunteering but often volunteering with other women who had similar disabilities, so they had quite a well-informed perspective on the situation of others. One woman spoke eloquently about the informal economy of volunteer work and its relationship to women with disabilities, and what should be done differently.

> Just to make another comment on the volunteering. I think there’s a whole economy out there that runs on the efforts of women with disabilities. I don’t know one woman with a disability who does not do volunteer work. And I think

> that if we were getting paid for that, it would make a big difference. I think there are a lot of agencies, non-profit organizations, all kinds of organizations that are running based on women with disabilities who volunteer their time. And there's nothing like getting a pay cheque for what you do. Because certainly we're also using up our time with volunteer work, we could be filling up our time with paid work. We should be paid for it.

Retirement

Nowhere was the concern about the widening gap between income and expenses more urgent than with women facing retirement in the near future. Many women put it out of their minds because it was too bleak a prospect to think about for any length of time. When we asked women their thoughts about retirement, all too frequently we heard comments like these.

> A: . . . as far as pension and retirement is concerned, I don't personally. . . . I don't think about it. I've got no money to put towards retirement, that's a fact. There's nothing I can do to change that right now. So my choice is to sit around and worry about it, or to hope I win the lottery, you know. Retirement is a non-issue for me. My pension is just going to go down. So how I can support myself at that stage of the game is beyond me.
>
> B: My imaginary retirement would be scary because if I can't live on my disability pension now, how would I live with something less than it? So I can't even think about it. It's just too overwhelming, too depressing.

From those who do think about it, we heard descriptions of lifestyle changes that would range from not being able to consider a vacation to the reality of living in poverty. When asked what she meant by "living very poorly" in retirement, one woman replied:

> Not being able to afford things.
>
> Interviewer: Like what?
>
> Like my medications, proper housing, like places in . . . like living in low rental housing and stuff like this. Not being able to live where I want to and going out when I want to because I know I don't have the money.

One woman viewed retirement quite differently. She saw the move to retirement as one that meant freedom in that she wouldn't have the CPP work restriction. The constant worry (which she likened to the pre-menopausal worry of getting pregnant) about being disallowed benefits would be gone. She admitted that working may not improve her income substantially, but she could finally relax in knowing she could do some work without penalty.

Hope: Light at the End of the Tunnel

Discussion about the future always brought out how difficult it was for women with disabilities to feel hopeful, especially about their economic futures. Some expressed feeling downright hopeless.

Our scenarios and the possibility of recommendations for change (made as part of this research) raised hope for a plausible change to women's current circumstances and their imagined futures. Opportunity was a key word in discussions of the possibility of working while retaining benefits or upgrading education.

> Who wants to be disabled? So if you're in your 30s and you have the opportunity to retrain . . . we're always planning and wishing and hoping, and looking ahead, you know what the past has held . . . and if you could make the future hold so much better for yourself than being on CPP, which once you're on there and you know there's nothing more you can do, just sit there and vegetate and dream. But if you could make your dreams become reality — I think it would be great.

Retraining, working or even changing careers are opportunities the women believe are currently unavailable to them, at least not without the threat of losing benefits. Doors to opportunity are closed at present, and our discussions helped women to imagine and hope that they might open someday.

There was a sense for some that our scenarios were unrealistic and idealistic, implying that they do not reflect reality as the participants experience it now, or even in the future. The opinion that our scenarios were unrealistic appeared related to three factors: their belief that the government would be highly unlikely to allow them to work and retain their benefits, that the severity and unpredictability of their illnesses would prevent them from returning to work and that women who were older could not envision either returning to work or engaging in education to prepare them to do so.

All the women were able to name targets for any increased income resulting from working and retaining benefits. Usually these focused on basics — repairing vehicles, paying for medications and even buying groceries more frequently. One woman was asked what she meant by having a better life.

> Having more — more to do with, being able to go out and enjoy an evening out, and not have to worry how I'm going to get home. For example, like I have a "do" tomorrow night, a 15th anniversary "do" and I'm not even sure I've got transportation to get home. So I wouldn't have that worry if I was getting better money.
>
> Interviewer: What would you do? If you had better money, what would you do?
>
> I wouldn't have to worry about how I'm going to get the next month's drugs. Not me so much as my husband because he has a heavy dose of medication. How am I going to get his drugs? How am I going to feed us? I wouldn't have the worry of having to buy groceries a month at a time. I could get afford to get what I wanted whenever. It would be a whole different ball game. A whole different life.

Occasionally we heard of a hoped-for luxury item, like travelling, but these were rare. Some women spoke of the possibility of being able to afford alternative medical services, such as acupuncture, and these were tied to increased wellness and well-being. With current CPP disability pension benefits, this wellness is often inaccessible to women with disabilities. One woman told us she had “always lived in a style that is pretty frugal.” Again, this is an example in which class differences became more apparent. For “working-class” women their incomes were never very high, so their ability to cope, and their access to provincial benefits, may have helped them deal with the loss of earned income. Middle-class and professional women were quite concerned with the drop in their income but felt even a slight increase in income by being allowed to work would make a difference in their lives.

Information Gaps

Having, and being able to get, clear specific information was expressed by all the women we interviewed. Some, but not all, were unaware of changes to their benefit at the age of retirement and appeared concerned when we outlined the changes for them. Quite a few were unaware of recent changes in CPP policy which provide training, despite the fact that the program has been in place for almost three years. Many women were unaware of the intersection between provincial income supports, medical benefits and long-term disability carriers.

As researchers, and active women with disabilities, we believed we had accurate information about the CPP to share with the women in the focus groups. Through research into CPP policy, we discovered that even we were unaware of the whole story. Our knowledge deficit, and the fact that many women have tried and failed to get answers to legitimate questions, demonstrate the severity of information gaps about CPP programs, rules and regulations. These also point to an important direction for income support programs in terms of developing clearer and more accessible guidelines, more consistently administered, across Canada.

We also heard concerns about difficulties getting straight answers from CPP workers, and questions about what appear to be secrecy and even intentional withholding of information about CPP rules and programs for the disabled.

> There’s just so many rules, and they’re so secretive, it’s frustrating. And it adds on to the anxiety. You don’t know, you’re waiting to know if you’re going to be accepted, you don’t know what the rules are.

In the context of lives bound by rules which limit them in complex ways, knowing these rules can make the difference between survival and ruin. Even well-intended doctors had written reports resulting in adverse decisions because these physicians were not privy to the exact criteria for eligibility. Non-profit advocacy groups, active in assisting with appeals, had only been used by a small number of women. For a majority of the women, the focus group and research project was the first time they had learned about some of the regulations and processes of income support programs. If knowledge is power, most of these women are particularly disempowered by the lack of information.

CHAPTER 4: THE RELATIONSHIP OF WOMEN'S SUBSTANTIVE INEQUALITY TO CPP DISABILITY BENEFITS

Current trends such as globalization, devolution of powers to the provinces, economic restructuring and post-deficit Canadian public policies have raised considerable discussion around the future of the CPP. Serious proposals have been made regarding abolishment of the federal CPP in favour of a compulsory private plan, and changes in contribution rates have already been instituted (see discussion in Guest 1997). Alterations to the CPP are not simple, especially now that two thirds of the provinces need to agree to any changes. Loosening the strands of the social safety net is certain to unravel important supports which sustain many of Canada's most vulnerable people. Changes to the CPP must be seen in relation to other social security and welfare efforts. Economic issues must be considered within the social context, and it all needs to be viewed through a gender lens.

> The concentration of poverty among older women in western societies is sometimes viewed as a temporary problem arising from a past era when most women were homemakers. According to this view, gender inequality of income in later life will largely disappear due to younger women's greater employment participation and to various forms of "career credits" in state pensions. Gender convergence in pension income may be more elusive than has been assumed. Gender differences in hourly pay, in types and levels of occupations, in hours of work and in continuity of employment persist (Ginn and Arber, 1998:1).

While employment and income inequalities between women and men have been well documented, there are wide-ranging, less tangible issues surrounding the treatment of women under social policy. Federal and provincial governments have to recognize that women, more often than not, bear the responsibility of child rearing, home care, care of older people and contribution to social organizations through volunteer work (National Council of Welfare 1996). The CPP is one of the few federal programs providing direct payments to people with disabilities. Despite its exclusion of women in the unpaid work force (volunteers, homemakers and mothers), the CPP does cover self-employed and part-time workers and, for some women, is their only safety net. Workers' Compensation and Employment Insurance are not available to self-employed people. Most part-time employment does not include extended benefits or pension plans. Feminists have flagged the danger of economic restructuring, specifically that federal authority is being relegated to the provinces and national standards are being eroded (Bakker 1996; Day and Brodsky 1998; Townson 1996).

According to Day and Brodsky (1998: 5), the *Budget Implementation Act* (BIA) "has implications for Canada's ability to maintain coherent and equitable standards for social programs, for the distribution of power and responsibility between federal and provincial governments and consequently for the shape of the Canadian State."

Political decisions, appropriation of funds and court cases inevitably have an impact on the people most susceptible to economic influences. To understand the effect of any policy or policy proposal on the lives of women with disabilities, the bigger picture must be understood. The following statistics will give a sense of the size of the population, the problems and the ramifications of possible changes.

Women made up 46 percent of the work force in 1993, and in 1994 women earned only 69.8 percent of men’s average salary (Manette 1996: 10). The average income for women in Canada in 1995 was $20,162 and for men it was $42,488. The average income changes dramatically when it is broken down between full- and part-time work status. In 1995, women working full time had an average salary of $30,130, but women working anything except full time had average earnings of $12,586 (Statistics Canada 1998c). Women who did not work full time earned 78 percent of men’s earnings in 1996 (men who also did not work full time).

Not only is there a difference between men and women in earning levels, and between full-time and part-time work (which directly affects pension levels), but there is a significant portion of women who would rather be working full time. In 1993, 40 percent of female part-time workers between the ages of 25 and 44 wanted but could not find full-time work. Only 11 percent of women in all age categories were working part time because of personal or family responsibility (Statistics Canada 1994a: 13).

While more women enter the work force, both full and part time, their rate of disability is close to 16 percent. The number of people with work disability in Canada is growing and is expected to reach 2 million by 2016. By the same year, 60 percent of people who have a work disability will be between the ages of 45 and 64 (Statistics Canada 1996b: 2). This is partly because of the ageing population and partly because medical and health conditions which used to result in death now often cause disability. It is also true that in today’s more accessible and technology-based society, some physical disabilities are less “handicapping” than they were 20 years ago. However, systemic barriers in transportation, architectural design and support services still create limitations in the kind and amount of work that women with disabilities can do. Hidden disabilities, particularly those affecting cognition and stamina, have also emerged as substantial problems facing women. Women often face these disabilities without recognition from “the authorities.”

Being disabled, or becoming more disabled, may require a woman to leave the work force, but she may also be disabled in her retirement. Retirement often has different meanings for women than for men, particularly for those women who have not had a strong attachment to the labour force. Some women consider themselves to be retired when their spouses retire or when they are eligible for a pension. For this reason, lowering the retirement age will have a significantly negative impact on women because their spouses tend to be older, and thus, retirement will result in even fewer work years (Torjman 1996). Thirteen percent of women claimed to have retired to care for a sick spouse or relative, and a large number retire due to health or family reasons. This is particularly significant because women outlive men and tend to have higher rates of poverty in older adulthood. However, because they are less attached to the work force during wage-earning years, they are more likely to be dependent on pension and supplements for income during retirement (Statistics Canada 1996a).

According to an analysis of pension income by Statistics Canada (1994b), persons over 65 with less than $20,000 of income per year were heavily dependent on Old Age Security (OAS) and the

CPP. These income sources represented nearly 75 percent of their income, whereas people with incomes over $60,000 a year used the CPP or OAS for only five percent of their income, demonstrating the urgency of ensuring that CPP pensions do not impose poverty on women with disabilities in their later years. Because the CPP is a contributory program, it rewards high-wage earners more than low-wage earners, even though high-wage earners most often have access to higher income in their retirement than low-wage earners. Because there is a basic exemption of $3,500, the first third or quarter of some working-class incomes is not pensionable. People earning over $40,000 per year will get the maximum pension upon retirement, whether or not they need it.

Women who became disabled before they were able to earn a significant salary, in part because of child-rearing responsibilities and in part because of lower wages, benefit least from the CPP pension. In 1993, 51.7 percent (the largest portion) of people over 65 had incomes between $10,000 and $20,000. Seniors earning $20,000 to $30,000 a year comprised 16.7 percent of people over 65; 13.8 percent earned less than $10,000 per year. For almost two thirds of seniors, the CPP constitutes a significant factor in their income. For those earning between $10,000 and $20,000, the CPP makes up 26 percent of their income. For those earning $20,000 to $30,000, it makes up 22.5 percent. Finally, for those who receive less than $10,000, the CPP provides only 16.4 percent of income. The OAS is a means-tested income support program for low-income seniors. Wealthy retirees do not qualify for this benefit but a large portion of seniors depend on it to supplement low pension earnings. The reason the low earners have a lower percentage of CPP is that the rate of benefit is so low that these people are eligible for the OAS, which makes up 67 percent of their income. In contrast, people earning between $20,000 and $30,000 have other income sources so that the OAS only constitutes 18 percent of their income. The majority of people over 65, however, with incomes of $10,000 to $20,000, still use the OAS for 47 percent of their retirement income (Statistics Canada 1994a).

Women represent a larger portion of OAS recipients in part because their CPP is low enough that they have to be supplemented more often with the OAS and Guaranteed Income Supplement (GIS). In 1993, 53.8 percent of total OAS recipients and 64.6 percent of GIS recipients in the federal program were women (Statistics Canada 1994a: 116). Managers, professionals and unionized workers often have modest to generous insurance and pension plans. For workers eligible for additional privately funded income on retirement, the CPP is not as urgently needed. For self-employed, part-time and contract workers, the CPP may be the only pension they contribute to. Only 33.5 percent of women in the labour force are covered by private retirement plans (long-term disability may also be included in these plans, but these disability benefits generally end at age 65). Men fare only slightly better, with 36.4 percent being covered (Statistics Canada 1994c: 47). These data exclude those who are self-employed, unpaid family members and all unpaid work.

Disabled people, and in particular women with disabilities, are among the poorest in Canada. These poverty rates can be reduced by half if people live with others. As we found in our research, many people live together because of economic necessity, and sometimes, people with disabilities share inadequate housing or stay in unsafe relations because living alone would be economically unfeasible.

Table 3: People with Disabilities Living below Poverty Line, 1995

	Lived Alone (%)	Lived with Others (%)
Women	0.482	0.18
Men	0.397	0.151
Both	0.455	0.165

(Source: Fawcett 1996: 119.)

Statistics Canada does not define “poverty” but rather sets lines commonly known as “low-income cutoffs” which are then referred to by most researchers as the “poverty line” (Ross, Shillington and Lochhead 1994). The low-income cutoff is determined by expenditures compared to income. When a household spends 70 percent of its income on basic necessities leaving only 30 percent for disposable income, this is considered to be low income. There are newer calculations that take into consideration before and after tax and transfers, which may reflect a truer picture of poverty. One of the best predictors of poverty in old age is low income in working years (Canadian Council on Social Development 1996). Because of low income between the ages of 15 and 65, retirement income is even lower.

Table 3 compares the percentage of men and women with disabilities living below the poverty line. Almost 10 percent more women than men are living below the poverty line when they live alone. And one in five or six men and women with disabilities, living with others, is living below the poverty line, even with the help of social programs such as welfare, the CPP and Workers’ Compensation. Many of these people do not earn income through work. People with disabilities who did earn income often earned proportionately less then those without disabilities in the same age brackets (Fawcett 1996).

The majority of women attached to the work force and eligible for disability pensions are not high-income earners. Because their incomes are relatively low, and because many are single parents, the scenarios we developed focused on ways to increase their benefit income. These scenarios were created to suggest the possibility of moving in and out of the work force while retaining the income support of CPP disability benefits.

Earnings from employment foster a stronger likelihood of emerging from poverty, yet women receiving CPP disability pensions are discouraged from even trying to work. Through the use of different scenarios, this research presented women with options for working. We proposed that women who wanted to retrain or start a home-based business or become employed part time in a career that suited their disability needs, would be able to do this without fear of losing their income. In addition, the possibility of increasing their retirement and disability benefits if they did earn additional income was introduced as an incentive. The scenarios were also calculated on the basis that all disability pension income is taxable and that women who went back to paid work, even part time, would also be taxed on new earnings and would make CPP contributions proportionate to earned income.

Women in the focus groups were told only about the hypothetical scenarios rather than the income or savings generated for the government. The focus group with CPP administrators considered the costs of administering the scenarios along with the income generated and cost savings. Administrators made it clear that only policy changes that saved money would be considered by the federal government.

In 1997, 283,585 people received CPP disability benefits, including 124,832 women and 158,735 men. The average CPP disability benefit was $663.74 per month for all, and $596.98 for women and $716.23 for men (HRDC 1998d). To calculate the possible savings arising from encouraging women to return to work, we calculated the number of women with disabilities under age 60 and multiplied by 25 percent. We divided these women into four income categories proportionately spread from low earners to high earners. The amount earned above the basic exemption ($3,500) and below the maximum ($36,900) was calculated and multiplied by six percent. This is the combined contribution of both employers (three percent) and employees (three percent). Potentially, income from women with disabilities working and receiving the CPP (including the taxable CPP disability pension) could result in $25,940,640 of additional CPP contributions per year. Currently, people receiving disability pensions from the CPP are refunded any contributions they make on earned income. Taking the same portion of women (about one out of four women under 60) and the same incomes, we calculated the tax revenue, assuming that these people would qualify for disability tax credits. We also gave them the basic personal exemption, equivalent to married status and averaged CPP contributions to $600. If they do not qualify for disability tax credits, the tax revenue would be even higher. Using this calculation, $57,074,679 could be generated in one year (if women were returning to the work force at the estimated rate). Not surprisingly, some women would not pay tax at all because their federal contribution would be reduced to zero (or below) by the non-refundable tax credits (see Appendix B for calculations).

In addition, if a portion of the women who had been using welfare payments no longer needed them (and could no longer qualify due to higher incomes), the return to work policy could result in $55,440,000 in generated savings (federal-provincial cost-shared). We calculated this on an average monthly welfare payment of $700 dollars (many provinces are higher or lower) for 30 percent of the original 25 percent. Approximately eight percent of women who returned to work *and* retained their disability benefits would stop receiving provincial welfare payments. This would, of course, be subject to the earning power of women and the current welfare requirements which vary from province to province.

Just for the sake of argument, we also calculated the income if men with disabilities were able to return to work. For both men and women, we left out the numbers of disability benefit recipients between ages 60 and 65 and took 25 percent of the remaining women and 30 percent of the remaining men as a sample. If these people had varying degrees of success finding part-time or temporary employment, the total revenue in one year could be $176,113,662, including both tax and CPP contributions. If men were also not receiving welfare, at a low rate (20 percent of people previously receiving income), the savings would be $37,440,000. Table 4 combines men and women under the age of 60 to calculate the savings for the hypothesized CPP policy.

Table 4: Calculations of Savings for Hypothesized Policy

30% of Men and 25% of Women under 60	Totals
CPP contributions in one year	$69,352,320
Tax collected in one year	$189,776,661
Provincial welfare savings in one year	$92,880,000
Provincial medical ***costs***	$38,520,000
Net economic benefit of return to work	**$313,488,981**

(Source: See Appendix B for calculations.)

Even if all these people continued to receive medical benefits at an estimated cost of $250 per month per person (about $38,520,000 per year), the net savings would still be $54,360,000. (Medical benefits would include the cost of premiums, prescription medication and some equipment to assist with safe living and working.) These financial benefits add to another expected benefit — the ability of people with disabilities to feel good about the contributions they are making, however small, to society.

In addition, welfare rates vary from province to province, so we have factored in the assumption that eligible women should retain all medical benefits even if they stop being eligible for the provincial income supplement. The importance of medical benefits should not be underestimated. While all Canadians have access to a good universal health insurance program, people with disabilities have extraordinary costs associated with treatment of, and living with, a disability. These costs cannot usually be recovered using the tax system because most people with disabilities are too poor to spend the cash and do not have enough income to benefit from the credits. People with disabilities on provincial welfare schemes often have these additional costs paid for by the province. Despite the fact that the consumer never sees the money, this in-kind support is one of the reasons people with disabilities dare not risk employment. The labour market does not take into account disability-related needs when it sets wages.

> The overwhelming disincentive for most participants was the loss of medical in-kind benefits when transferring from social assistance of disability benefits to earned or training income. While this is an issue for all income security recipients, it is particularly onerous and significant for those with a disability, because there are often medical costs related to their disability, whether for drugs, assistive devices or specialized medical care (Echenberg 1990: 9).

In March 1997, women under 25 years of age received the lowest average monthly CPP disability benefit ($445.95) and the highest benefit category was women ages 40 to 44 ($610.58). In Table 5, categories of age and benefits have been collapsed from five-year increments in the original to 10-year increments, in order to get a better sense of differences. The sample is based on one month’s calculations because CPP indexing results in constant fluctuation of rates month to month.

Table 5: Sample of March 1998 Rates of CPP Benefits for Women with Disabilities

Age	Mean Number	Monthly Mean $	Percentage of Whole (%)
Under 25	99	445.95	.08
25-29	827	483.44	.66
30-39	1,0975	555.68	8.79
40-49	2,7706	606.84	22.19
50-59	4,8584	601.71	38.92
60-64	3,6639	596.04	29.35
Totals	12,4832	596.98	100

(Source: HRDC 1998f: 14.)

Using this data set it becomes obvious that women earning less than $600 per month without a second income earner in the house would rely on social assistance and other sources of income. Women with disabilities often qualify for additional support under provincial legislation if they have children, are single parents or are deemed to be unemployable. The women with the most severe disabilities who meet the eligibility requirements of the CPP disability program are also most likely to remain in poverty. Women with less severe disabilities may be able to earn some wages and retain provincial benefits through work incentive programs.

For example, a woman who became disabled as a student in university and did not meet the minimum contribution requirements for the CPP may be eligible for provincial income assistance for disabled adults. The monthly allowance might be $700 and would include medical insurance, durable medical equipment and, sometimes, dental and optical services at no or low cost. Under many, but not all, provincial programs, when income is earned and declared, a portion of it is deducted from the assistance. So a woman with a moderate disability who could earn $200 to $300 per month would get to keep the earned income and also receive $600 from the province. This is usually calculated with a basic exemption of $100 to $200 dollars of income allowed. For women on welfare, the incentive is that earning income (low amounts) does not terminate their benefits. We are suggesting that the CPP disability benefit program use this approach to encourage people to return to work without fear of losing much-needed income security. Women with insufficient incomes, who are no longer eligible for CPP disability benefits, will eventually turn to provincial sources.

Even with supplementary welfare dollars, women with disabilities still do not have enough funds to cover disability-related and basic living costs. In Ontario and British Columbia, severe cutbacks and “workfare” programs have put income assistance recipients at a further disadvantage. Torjman (1988: 27) reported that:

> . . . even with maximum rates of basic assistance and with the inclusion of federal and relevant provincial tax credits, the annual income of social assistance recipients who are disabled falls below poverty line standards, in no province do rates even match the low income cutoffs, ranging from only 51 percent to 75 percent of the poverty line.

Women with disabilities who are receiving disability benefits and could work, if their health improved, would be able to raise their own standard of living through earned income and secure CPP support. We interviewed fewer than 30 women with disabilities across Canada but found significant consensus about the problems and about the potential solutions. One way of verifying our findings is to look at independent sources of similar research. At the final editing phase of this project, the B.C. Coalition of People with Disabilities produced a special edition of their newsmagazine *Transition*, which focused on the experiences of people with ME. One British Columbian's story supports the findings of this research and triangulates the qualitative and quantitative experiences of the women interviewed.

> Why does the Canada Pension Plan penalize me for showing initiative by going back to work part-time? After nine years on disability benefits, I have taken a big risk, both in terms of income and health by returning to part-time work. My work income is less than half what it was when I fell ill with fibromyalgia. Should I fall ill again, my CPP disability benefits will be very small. In addition, due to recent changes to CPP eligibility, I will need to work longer to quality than when I fell ill in May 1989. Changes made by CPP several years ago allowed recipients to undertake volunteer work and get back onto benefits again should the recipient's rehabilitation attempt "fail" . . . within a three-month time period. After three months, good luck getting back on benefits. Since many people with conditions like fibromyalgia and ME are only able to work part-time, if at all, why does CPP not encourage recipients to rehabilitate through part-time work and let us keep part of our benefits? Wouldn't that save CPP money in the long run, as well as affording us the dignity of work? One has to wonder why CPP makes rehabilitation so difficult for us (Murray 1999: 9).

CHAPTER 5: DISCUSSION AND ANALYSIS

Providing a Context for the Research

Our purpose in doing this research was to describe what income and pension policies would look like if disability, gender and family had been factored in, and to recommend development and implementation of policies which reflect this. The specific focus has been on CPP disability policy. We were interested in discovering how the lives of women with disabilities, and those who might become disabled, could be improved through pension policies that distribute resources equitably and respond to changing circumstances such as fluctuating health and ability to work.

The focus groups of women with disabilities generated important insights about their experiences of living with and receiving CPP disability benefits. Our interviews with CPP plan administrators and policy makers also provided unique data about current policy (described in detail in Chapter 6) and how it is administered. Both these sets of data, and our own knowledge as feminist researchers with disabilities, inform recommendations for policy which recognizes and incorporates a more flexible construction of disability, the effect of gender in the lives of women with disabilities and relationships with family. We also draw from recent literature in this chapter, which provides a theoretical understanding of disability policy, women and work, and a feminist critique of public policy and the influence of restructuring on social programs.

Both authors are aware of, have respect for and support, the substantial efforts of members of the Canadian disability community in terms of lobbying for change to disability definitions that limit work in the lives of people with disabilities who receive publicly funded income support. We also acknowledge and support continued efforts to secure benefits for those with less visible disabilities, and to overhaul the administration of disability benefits. Disability advocates are correct in their premise that “disability” is socially constructed but individually experienced, and almost all the existing policies reflect an outdated, medical model of impairment. Changes that reflect the reality of disabled Canadians are continually being sought by advocates.

Women in the focus groups were keenly aware of the current economic and political climate. As researchers, we too, are greatly concerned with the erosion of the rights of women with disabilities, especially their right to economic equality, as a result of a reduction in government services, deregulation of markets, privatization of services and cutbacks in social programs (Day and Brodsky 1998: 5). We also have concerns about devolution of responsibility for social programs to the provinces, and urge that the CPP administration seriously consider concrete ways to ensure the continuance of CPP disability benefits for eligible recipients.

Currently, feminists have raised concerns about economic restructuring and the increasing casualization of work, which results in fewer opportunities for women to gain economic equality with men as labour becomes increasingly part time and temporary. Specifically, women are competing more often with men for casual work. Our recommendations may appear on the surface to align with this neo-liberal economic agenda. Given that we support work for women with disabilities that is appropriate to their medical condition, and that for many, this work could only be undertaken on a part-time basis, it could be argued that we support erosion of their economic equality. But the fact that women receiving CPP disability benefits have generally been prevented from working is a deeper assault on their economic equality than being allowed to work part time.

Perhaps concerns about erosion of equality more closely reflect the experiences of able-bodied, middle-class women who fail to recognize and acknowledge the very different experiences of women with disabilities. For those women with disabilities who experience fluctuating conditions, part-time employment may be the most suitable. Women who view casualization of the labour force as a slide backwards, lack the awareness that women with disabilities in general have not had access to what men (and non-disabled women) have had. Women with disabilities may view this construction of disadvantage very differently.

In this chapter, we discuss and analyze our findings in ways that point to recommendations for policy change. Specifically, we draw on the aforementioned data, existing policy, disability and feminist literature and our personal knowledge as researchers with disabilities, to understand what is helpful and empowering for women with disabilities who are receiving CPP disability benefits, and what is not. We seek to re-affirm that which is helpful and change that which is not.

Reflecting Women's Concerns

Throughout our interviews, women either told us about or demonstrated a lack of knowledge concerning important CPP rules. By and large, these women were well-informed individuals, so this lack of knowledge to some degree surprised us. Our own lack of awareness at the outset that women (and men) with disabilities receiving CPP disability benefits could engage in some work and yet retain benefits aligned with the women's. The research proposal emerged from our belief that this situation should be changed. Women's experiences of trying to extract pertinent information from CPP workers also reveal crucial gaps in services, recent CPP efforts to improve communications nationally aside. Despite the initiation of an ongoing communications strategy in 1993-94, reaching just over 1.5 million clients in 1995-96 (HRDC 1997c), most of the women knew little about the work incentives, and we heard differing understandings as a result of conflicting information proffered by CPP workers. Especially instructive was the lack of uniformity in knowledge and understanding of policy surrounding work incentives (e.g., fast-track and trial of work) and the National Vocational Rehabilitation Program. Our first recommendation, focused on administering policy guidelines uniformly, emerges from these particular findings. Women in the focus groups also expressed considerable concern about a particular element of our first two scenarios, which assumed that women returning to work could earn unlimited income without fear of losing benefits. (Other elements of these scenarios were altered to prompt responses focused on specific issues, such as retirement and re-education.) Before the third scenario was even presented — it suggested a policy model that incorporated a scale of allowable earnings — women were making their own suggestions about setting a limit on what a person might be allowed to earn before CPP disability benefits were reduced or disallowed. These concerns were based in their knowledge and understanding of the current economic climate of cutbacks, and also on what they believed would be negative perceptions of non-disabled Canadians if women (and men) with disabilities were to return to work, earn a substantial income *and* retain their CPP disability benefits.

Even the importance of an income that accounted for the additional costs of living with disability did not supersede the above concerns. Women in the focus groups differed as to what an adequate, allowable earned income might be, and to some degree this reflected class differences and perhaps differences in marital status. Some women felt $15,000 would be adequate, while others wanted a $36,000 limit. Women also rejected the idea that the limit should vary depending on past earning history. Suggestions responding to our third scenario reflected some women's concerns that earned income should be reduced proportionately when in excess of an allowable amount, rather than having benefits disallowed on earning a specific income. Simply put, the women wanted any policy that allows them to work and retain benefits to be flexible. Recommendations focusing on allowable earnings (see recommendations 2d and e) reflect the importance of flexibility and of having an adequate income in terms of current costs of living, that is, an income beyond survival or subsistence.

What our research did not reveal were the differences and disadvantages among women with disabilities who were also members of ethnic minorities or First Nations, or who were lesbians. Available statistics and literature do not adequately address these intersections, nor were they raised by women in our focus groups. We believe there is a need for future research on how disability intersects with these issues for women.

Economic Inequity: The Gendered Nature of Disability and Work

The particular barrier we examined was the inability of women with disabilities (designated as "unemployable") to earn income without losing their CPP disability benefits. A few discussion papers and reports have developed arguments about the disincentives to employment inherent in income security regulations and the impact these have on employment and productivity. Until our research, the impact on women was notably absent. In *Canada Pension Plan Reforms: Issues for Women* (Zimmerman 1997), the author described the impact on women of proposed changes to the CPP. There was no mention that the disability rate for women is over 15 percent nationally or that women have a higher incidence of disability and lower pensions comparatively, based on the gender gap in wages for working women (Statistics Canada 1996b). Research on the impact of the CPP on women as they age and on discrimination against women who have stayed home to raise families has excluded the issue of disability. These gaps point to the importance of including disability and gender in research on CPP policy.

Again, it is important to recognize that we are not interested in seeing just women benefit from our research. We believe our recommendations may also benefit men who receive disability benefits, as well as their partners. However, women with disabilities are particularly disadvantaged. Throughout their life span, women with disabilities have lower incomes than non-disabled women and men with disabilities (Day and Brodsky 1998; National Council of Welfare 1997; Statistics Canada 1995b). This fact has ramifications not only for women with disabilities, but for others in their lives, such as partners, children, adult parents, extended family members and roommates. Our focus groups revealed that women are being forced to depend on others because of inadequate benefits. Improved income through a policy that allowed women to return to work and retain benefits would, for some, ensure that any decision to live with family would be by choice, not by necessity.

As the Canadian population ages, changes to CPP disability benefits, such as we recommend, could have a dramatic influence on income and standards of living for women and their families. The current situation forces women with disabilities to live at, or below, the poverty level if they receive benefits early in their work life or if CPP disability benefits are their sole source of income. Women in our focus groups were explicit about how their lives are financially restricted because of pension income, and how this might be different if they were allowed to do some work and retain benefits. Women (and men) living in poverty also have poor children. Women, especially, are also more likely to be single parents. If women with disabilities had the opportunity to work and retain their CPP benefits, the lives and futures of their children might also be substantially altered.

> At all ages, women with disabilities have lower average incomes than women without disabilities. The average incomes of women with disabilities are also well below those of men with disabilities in all age groups. In fact, the 1990 incomes of women with disabilities in both the 35-54 and 55-64 age ranges were only about 55% of their male counterparts, while for 15-34 year olds and seniors the figures were 70%. (Statistics Canada 1995b: 166)

Women with disabilities are among Canada’s poorest citizens. Inequity in their lives is not merely a rationale for the research, but provides a compelling context for it. Inequity broadly informs all our policy recommendations, as existing CPP policy fails to account for the different experiences and material conditions of women with disabilities. Systemic inequities in women’s lives in Canadian society provide ground for even deeper inequities in the lives of women with disabilities. The material inequality of women in Canada is well-documented (National Council of Welfare 1995).

> Women in Canada are poorer than men and face a higher risk of poverty. In 1995, 18.2 percent of women compared to 14.3 percent of men were living in poverty, with the differences between the sexes most pronounced in the youngest and oldest groups (Day and Brodsky 1998: 6).

While there are many factors contributing to women’s material inequality, several also play a specific role in the economic disadvantage of women with disabilities. Interrupted careers as a result of childbearing and a preponderance of work in service and sales occupations comprise women’s gendered experience of the workplace, with resulting negative financial implications (Moss and Dyck 1996: 745). Women, while working, receive lower wages than men, partially because of unequal access to such higher paying employment as professional and managerial positions. Women also work more often than men at non-unionized, temporary or part-time employment, which frequently fail to provide benefits or access to pensions (Day and Brodsky 1998).

What these work patterns mean for women receiving CPP pensions is that they get only 58.8 percent of the benefits men receive. This figure represents differences across all CPP pension benefits (Canadian Advisory Council on the Status of Women 1994). Gender differences in the amount of CPP disability benefits received are significant: men on average receive $716.23 monthly, and women, $596.98 (CPP 1998). Pension award rates for women and men reflect gender differences in eligibility decisions; fewer women than men who are work-disabled successfully meet eligibility requirements. In Canada, 67 percent of men who apply for CPP disability benefits are successful, as compared to 52 percent of women applicants (McDonough 1997). U.S. research reporting parallel gender differences in success rates suggests gender differences in occupational distributions and work patterns place women at a disadvantage (Baldwin 1997).

Defining Disability, Creating Barriers to Work

Historically, the CPP disability program was developed to provide income replacement support to workers who were no longer able to work, primarily male household heads. Pension policies were formulated in the 1960s when women and people with disabilities were not expected to be active participants in the work force. In addition, the context of society at the time made it difficult for workers who became disabled to remain active or re-enter the work force. Physical barriers, inaccessible transportation and inadequate rehabilitation made it unlikely that disabled men or women would return to former employment or even new careers. Recent accessibility requirements, medical progress in the treatment of disease or injury and enabling technology have made it increasingly possible for disabled people to join community activities, including seeking education and employment.

Under the current definition, a person is only considered disabled for pension purposes if she or he has “a physical or mental disability which is ‘severe and prolonged’” (HRDC 1998b), meaning one which is long term and prevents her or him from doing any type of paid work on a regular basis. Officially, this is known as substantially gainful occupation (SGO). These vocational eligibility criteria were formulated on the labour market experience of men, which is very different from that of women. This eligibility is also quite different from many provincial Workers’ Compensation and private insurance programs which base eligibility on disability preventing a person from doing his or her “own” job rather than any job (Torjman 1996: 83).

The requirement that CPP applicants have worked four out of six years prior to disablement does discriminate against women, who are more likely to be employed temporarily or part time. Exclusion of child-rearing years, while useful in terms of eliminating low income years, prevents women from ever reaching parity with men who did not use those years to care for small children. Because women’s occupations tend to be more sedentary than men’s and women suffer less often from injury-related disabilities, they are less frequently judged to be unable to perform their former work. Hence, as U.S. researcher Marjorie Baldwin (1997) concludes, fewer women are eligible for disability benefits, of those who are eligible fewer apply, and of those who apply, fewer are successful applicants. The term “work disabled,” implicit in the CPP definition of disability, reflects its connections to (men’s) work in the public sphere, in which women are unevenly represented. Embedded in this definition is the implication that, if you are engaged in domestic or volunteer work, you cannot be disabled. In fact, the gendered division of household labour, including “the presence of adults needing special care, and the nature and quality of child-care arrangements . . . may have a major impact on work disability among women” (McDonough 1997: 91).

We spoke both with women who had had considerable difficulty applying for CPP disability benefits, and with those who were successful only after lengthy and exhausting appeals. The problems associated with successfully filing a CPP disability claim are so well known that disability and advocacy groups have set up services to assist consumers with the process. Many women have given up applying because of the stress involved. Fear of going through the application process again was strong enough to prevent many women we interviewed from even considering re-entering the work force if they were to become well enough.

The way disability is defined for CPP purposes makes it impossible for a person to be both disabled and working. Susan Wendell (1996: 20) suggests that:

> Disability . . . and insurance schemes frequently make the assumption that workers are either fully disabled from working or able to work full-time, leaving people with chronic illnesses, or people with progressive life-threatening conditions in impossible positions. Either they must push themselves beyond endurance to appear to be capable of working full-time or . . . declare themselves unable to work at all, often when they want very much to continue working.

We believe the current definition handicaps women, and the women in the focus groups believe this as well, as revealed in their comments about feeling useless and trapped. The concept of returning to work and retaining CPP disability benefits was a starting place for our scenarios, and strongly informs our recommendations. It includes the option of moving in and out of the work force, full or part time, and earning income while continuing to receive CPP disability benefits. Our discussions with the women in the focus groups revealed a desire among most of them to return to work, if they were able and if it could happen without threat of losing benefits. This desire to work reflects the well-known fact that despite disability, discrimination and economic disincentives, people with disabilities want to work, and they want to be supported in their efforts to earn an income that provides independence for them and their families.

One system that might reduce the economic expense of working is Revenue Canada. Being able to claim work-related disability expenses may, for some women with disabilities, mean the difference between staying home to take care of children and to engage in other domestic responsibilities and working at paid employment. Currently, Revenue Canada has different (and more stringent) eligibility criteria than the CPP regarding receipt of benefits because of disability. Also, many eligible people cannot use the disability tax credits because their annual income is so low. Aligning the disability eligibility criteria with that of the CPP may allow more women with disabilities to benefit from the disability tax credit, thereby creating expanded opportunities without actually increasing the amount of money spent federally to support them. Current eligibility criteria for CPP disability benefits are sufficiently strict to require women with disabilities, their doctors and administrators to engage in a rigorous process, which we believe could also be suitable for Revenue Canada’s purposes.

It is important to note that, despite this suggestion to have Revenue Canada adopt CPP criteria for eligibility (see Recommendation 5), the authors continue to have concerns about the current definition of disability. As feminist researchers and women with disabilities, we recognize how the current definition limits women with disabilities notwithstanding our apparent support for the adequacy of the definition in recommending its adoption by Revenue Canada. Defining disability by its relation to work creates an impossible situation for women with disabilities; it prevents them from being *both* disabled *and* employed, and assumes all employed people are without disabilities. In other words, to be eligible for CPP disability benefits under current legislation, women have to be incapable of substantially gainful employment. Conversely, if you are capable of employment you are not disabled. We would like to reconceptualize this from a question of disability to one of eligibility. Doing so would ensure that those who were at one time considered incapable of substantially gainful employment could retain their CPP disability benefits while working. Such coverage would continue until their earned income level precludes eligibility ($24,000 and above), despite the fact that a medical condition may exist, although not so severe as to limit earnings (see Recommendation 2e).

Accommodating Fluctuating Conditions

Another recent policy change with a significant impact on women and people with disabilities is that the CPP now allows people to re-apply for disability pensions through a fast-track method. This option provides a quicker return to CPP disability benefits if their health again prevents them from working after rejoining the work force. This is particularly important because many women have fluctuating or episodic disabilities, which, if they were to return to work in any capacity, would require flexibility on the part of benefit administrators and employers. Women with fluctuating conditions in our focus groups repeatedly revealed their fear of losing the security of benefits and risking a short-term recovery by returning to work. One woman also said that, on returning to work, the treatment she received from co-workers and employers relating to her absence and disability led to so much stress she had to leave work again.

However, fast-tracking is designed for those who have received CPP disability benefits within the previous five years and whose disability, or the effect of the disability, prevents them from working. This five-year restriction makes it difficult for those who may have been well enough to work for longer periods (say five years), but who, because of exacerbation of a chronic illness, cannot continue and require reinstatement of CPP disability benefits. These individuals are forced to re-apply using the initial application process, which is lengthy and may compromise them economically. Fast-tracking does provide some of the flexibility women with fluctuating conditions require, and women in the focus groups indicated that it would be an essential element in considering a return to work. Our recommendation (see Recommendation 3) takes this issue into account as well as suggesting a modification which would simplify the process and eliminate the five-year restriction.

Another element connected to returning to work is the availability of, and support for, suitable re-education or training for women with disabilities. Both the 1995 changes in CPP policy with respect to schooling and the institution of the National Vocational Rehabilitation Program are steps toward helping women with disabilities return to work. Before this change, women and men receiving CPP disability benefits were not allowed to attend school (nor engage in any volunteer work, see below). If they did so, their pensions were disallowed, based on the assumption that participating in these activities meant a person was no longer disabled and should be able to return to work. The new policy allows beneficiaries to attend school (and volunteer) without fear of losing benefits as long as they have a continuing disability.

Added to the new CPP policy around schooling and rehabilitation is a "cushion" of three months following completion of education or training, during which time women (and men) with disabilities continue to receive benefits after returning to work. This three-month period is similar to that provided by many private LTD plans on returning to work. It allows for a trial of employment, a period during which people with disabilities could theoretically adjust to a return to work without threat of losing benefits. The three-month trial period is a measure introduced for *all* CPP disability beneficiaries who return to work, not just those who have upgraded their education, and its purpose is to ensure that they have regained the capacity to work and to help them with the transitions (HRDC 1997a).

Although it is a significant improvement over previous policy that completely restricted work, this three-month period is inadequate for women, especially those with chronic, fluctuating conditions. For the women interviewed as part of this research, it is simply not long enough for most to establish themselves in any kind of work and adjust to the resulting lifestyle changes, while at the same time learning how to balance all this with ongoing and often fluctuating conditions. "The scarce data that exist on gender breakdown by cause of disability show that women have a much higher incidence of claims for mental disorders and stress-related conditions" (CPP 1998: tables 4 and 5). The women in the focus groups expressed concerns about the difficulty of finding suitable work, paced accordingly, and with accessible, accommodating environments, which only strengthens the argument that three months is too short.

Women are more likely to experience episodic difficulties such as debilitating fatigue, pain, depression and allergic asthma. These are, for the most part, less visible problems than the more obvious mobility and sensory impairments. Not only do women experience these types of disabilities more often, but also they are more likely to be refused because of the "ill-defined" nature of some conditions. From January to December 1997, there were just over 28,000 new beneficiaries of the CPP disability pension. Of these 15,325 were men and 12,731 were women. The breakdown of diagnostic category revealed a gender trend in disability type. Twenty-five percent of the new women claimants had psychiatric or mental disorders, while just under 18 percent of the men were receiving benefits for these types of disorders. The other significant difference was for diseases of the musculoskeletal system and connective tissue, which include lupus, arthritis and osteoporosis. Women have substantially higher rates of these conditions, as is evident in the claimant rates: more than 23 percent of the new female beneficiaries had disorders in this category compared to 17.5 percent for males (HRDC 1997b: 196-7).

Women with disabilities who are in or entering the work force are discriminated against on the basis of both gender and disability.

> Research shows . . . that women with disabilities are underrepresented in the labour force, and receive lower wages and have fewer job opportunities than either able-bodied women or men with disabilities (Moss and Dyck 1996: 741).

For women with chronic fluctuating conditions, this underrepresentation is partially indicative of the disabling structure and pace of work. Together, these factors point to the inadequacy of the three-month period instituted in the 1995 policy changes. Interestingly, some of the women we interviewed were unaware of the National Vocational Rehabilitation Program — pointing to a critical lack of information — but when we outlined it, they responded negatively to the suggestion that, in three months, they could be established well enough in the work force to relinquish their benefits. What this short period also fails to account for is the unequal remuneration women receive for the work they do. Returning to work may not substantially improve the income of women with disabilities, given women's historical employment patterns and economic disadvantages.

Several women also spoke of the health-related benefits they believed would accrue during a return to work. They believed a slow, measured return to work may actually develop stamina, which would ensure that they would be more likely to retain their jobs. All of our scenarios assumed a model that would allow women to return to work without a fixed trial period, that is they could work and receive benefits indefinitely. This would be more equitable with respect to women's different experiences of work and being disabled. Our recommendations 3 and 4 combine this element and a simplified fast-tracking process which we believe would treat women more equitably.

Complicated Intersections with Other Income Support Programs

Women in the focus groups raised two closely connected concerns: the additional medical costs of disability and the complicated intersection of federal and provincial benefit programs (see tables 1 and 2, Chapter 1). CPP disability benefits are calculated at a flat rate ($336.77 monthly) plus 75 percent of the expected retirement benefit as if the applicant were 65 on the day eligibility for disability benefits was established. The retirement benefit is approximately 25 percent of yearly earnings (while taking into account lower earning years because of childbearing or schooling to age 7). This means that women with incomes of $37,000 yearly or more at the time eligibility is established, will receive the maximum monthly benefit of $895 and women earning less than $20,000 may receive less than $650 monthly.

A single woman receiving the monthly maximum would likely not qualify for provincial government social assistance, but a woman who has a dependent and receives $650 monthly might be eligible. If this woman is eligible for $700 monthly in provincial assistance (plus medical benefits that include dental and optical benefits, in some provinces), the province will deduct the CPP money from the provincial benefit. The first $100 to $200 of the CPP amount ($650) could be kept, and the remainder ($450 to $550) would be deducted from the provincial benefit dollar for dollar, leaving the woman with between $150 and $250 monthly from the province to supplement the $650 received monthly from CPP disability. The possible monthly total would be about $800 or $900, for which only a small part (the provincial benefit) is non-taxable.

This illustrates one of the primary differences between provincial income support for people with disabilities and CPP disability benefits: the latter are taxable and based on a percentage of former income, while the former is means-tested and not taxable. An example of how this combination resulted in less income for one woman with a dependent child was provided in the qualitative findings (Chapter 2). This was not an unusual example. Not all provinces subsidize medical costs for people with disabilities, so many women are left without adequate supplies and care, thus jeopardizing their health further. We argue this is more costly to provincial health care systems.

One of our policy recommendations focuses on alleviating some of the financial burden of disability-related costs and is designed to benefit women without an existing subsidy for medical expenses. Having appropriate and well-functioning equipment, and services, are absolutely essential to any return to work, and our recommendation, designed to reduce the medical costs associated with disability, supports these essential needs (see Recommendation 5).

Another difference between provincial and federal benefit plans is that a return to work doesn’t necessarily mean a loss of provincial benefit. Similar to the Employment Insurance program, each dollar of earned income is calculated against allowed benefits. In this way, fluctuation in income allows benefit administrators to deduct specific amounts while the claim/case remains open. For most provinces, eligibility is not an “all or nothing” deal. Provincial programs encourage return to work for single mothers, youth, disabled people and employable men in part by using this titrated deduction system so there is some incentive to seek employment. Many of the people currently using the provincial social assistance programs resort to them because they are unable to qualify for CPP disability or other insurance due to early onset of disability (pre-employment) or lack of contributions.

Tied to these complicated relationships is the experience of having to rely on and deal with private insurance companies for a portion of income and, for some, to subsidize costly medical expenses. For those women in the focus groups who receive medical benefits from private plans, the idea of returning to work and possibly jeopardizing these benefits was rejected. They simply couldn’t afford to pay for the additional medical costs of being disabled without subsidy. Approximately 32 percent of the total number of women (40,000) receiving CPP disability benefits outside Quebec also receive income from LTD or other plans. We estimate that about half of those — about 20,000 — receive most of their disability benefits from private insurance plans, with a lesser part from CPP. These would most likely be middle-class professional women, exemplified on several occasions in the focus groups.

Although we make no policy recommendations regarding private insurance LTD benefit plans, many concerns were voiced by women in the focus groups about these plans, especially for those whose benefits were close to the monthly CPP disability amount and included medical benefits. A return to work might mean relinquishing benefits necessary to cover medical costs that may not be offset by earned income. In other words, these women saw little economic incentive to return to work if they became able, despite qualitative benefits. We are also aware that most of the recommended policy changes, if instituted, might not directly benefit these women or those who receive more of their disability income from private insurance plans, but we believe the recommendations wouldn’t harm them either. Perhaps, more openness on the part of the federal government with respect to allowing work for those who have disabilities may also, over time, be seen as possible and even economically feasible by private insurance companies.

The fact that only a third of women in the work force are covered by private insurance also leads us to believe some of these women are among the most privileged women with disabilities in Canada and may not be in desperate need of the income women without insurance are. Women who have insurance plans paying an average of 60 percent of their previous salary may not be suffering the same economic deprivation as women who live exclusively on the CPP or welfare. For example, a nurse or teacher formerly earning $36,000 might receive $21,600 per year in disability pension. Most plans deduct the CPP amount from this benefit so even with $6,750 yearly from the CPP a woman still receives $21,600. However, compared to women living on a yearly income of $5,000, these privately pensioned women are economically secure. Women in the focus groups with good private pensions felt it would not be worth losing their private pension to return to part-time work even if they could retain CPP benefits. The women who received only CPP benefits or CPP and welfare were more enthusiastic about the prospect of earning additional income.

Issues of Unpaid Labour: Volunteer and Domestic Work

Most women in the focus groups indicated that they were engaged in some kind of volunteer activities, often associated with local branches of societies formed around their illnesses (e.g., Multiple Sclerosis Society). In several instances, engagement in these activities provided opportunities for paid work which these women were forced to decline because of the threat of losing benefits. In many instances, we heard how volunteering played a key role in these women's lives in terms of maintaining (and sometimes restoring) their attachment to the work force. Yet many women were engaged in activities in volunteer settings that they pointed out might be paid work elsewhere, for instance, counselling or advising others via telephone. We believe that volunteering could be a stepping stone to paid work for women with disabilities, if the proper supports were in place. The experience of some women in our focus groups, including running out of energy and feeling “used” by agencies for which they volunteer, points to the “unpaid ghetto” aspects of volunteering for these women. It also calls attention to the importance of reconsidering the resources and skills of women with disabilities and their role in the informal economy of unpaid volunteer work. Valuing the time and skills of women with disabilities for the work done as volunteers by remunerating them would go a long way to fostering a firmer attachment to the work force.

Valuing volunteer work in different ways is a trend in Canadian society, bolstering an economy which is increasingly reliant on the volunteer efforts of citizens to provide much needed social services. Applicants for education and jobs are often asked about their community activities as evidence that they are socially responsible individuals. Women with disabilities receiving CPP disability benefits should have an equal opportunity to profit from volunteer activities in this way as able-bodied Canadians do.

Volunteering is not the only unpaid work done by women with disabilities. With respect to unpaid work, what women in the focus groups did not say is as revealing as what they did. As we noted before, the issue of unpaid work surfaced primarily in focus group discussions about involvement with volunteer work, but unpaid work in the domestic sphere was not a prominent topic for discussion. It went largely unacknowledged as part of their lives as women, despite the fact that all performed some unpaid domestic labour.

One woman noted that prior to the onset of her disability, she could afford to pay someone to help clean and maintain her home, but that currently she was not able to do that and subsequently had lowered her standards of homemaking to meet her available energy level. This also raised the issue of class since professional women were much more likely to be able to pay for work that many “working-class” women do without pay in their own homes. Even shopping and laundry were not considered to be domestic work, or at least not identified as such by participants.

Women who have disabilities are often “degendered” in others’ minds, which contributes to a loss of their domestic identity. We are considered unfit for motherhood and unable to parent children adequately. In addition, our disabilities may make it either difficult or impossible for women with disabilities to do housework without assistance. Yet women with disabilities are mothers, homemakers, partners and roommates and they assume responsibility for these unpaid domestic activities as do their able-bodied counterparts. Many do this without substantial assistance, either formally through home support, or informally through relatives or friends. It is important to remember that many women with disabilities are unable to return to work because of their inability to afford working in terms of time, energy or money as this suggests:

> . . . for women with disabilities, being part of a double ghetto, working a second shift, and performing work related to familial relationships . . . poses an enormous, if not impossible task, as defined by dominant cultural and social norms (Moss and Dyck 1996: 741).

In a review of the literature on women with disabilities and employment, Moss and Dyck use Deegan and Brooks’ (1985) term to describe women with disabilities as “doubly handicapped” by underrepresentation in the work force, lower wages and fewer job opportunities than either men with disabilities or able-bodied women. They add that:

> In addition to this “double handicap” . . . women who are engaged in paid employment and in maintaining a household face further problems. It is likely that women with chronic illness will have minimal assistance in the home — unless they have daughters (Moss and Dyck 1996: 741).

We suggest that what Moss and Dyck omitted is that these daughters would likely have to be able-bodied to assist their disabled mothers with domestic responsibilities if they were to return to work. Quite simply, this underlines the gendered nature of domestic labour.

It is important to bring to the foreground the issue of unpaid domestic labour in the lives of women with disabilities because it presents a significant barrier to returning to the work force. Although our recommendations do not focus explicitly on this, we want to ensure that any change in policy recognizes that not all women with disabilities will be able to return to work, not just because they are not well enough, but because of the structure of unpaid work in the domestic sphere. Yet for those who potentially may earn enough to afford domestic help or child care on returning to work, policy changes will reduce the effects of this *double handicap.*

CHAPTER 6: FEASIBLE SOLUTIONS: STRATEGIES FOR ENABLING INCOME

In this chapter we describe the recommendations formulated as part of this research (and outlined in the Executive Summary). All these initiatives, if successful, will substantially benefit women with disabilities who depend on either provincial or federal disability programs for support. Our intention with this research is to work toward change in a different way and, perhaps, for a different kind of change. Although we recommend significant changes in CPP disability policy, we are aware of the importance of feasibility, so prefer to suggest changes demonstrated through research to be cost-effective, rather than a sweeping overhaul of disability-related policy. We make these recommendations for changed policy based, in part, on information about the lives of other women with disabilities obtained through our contact with them in the focus group interviews. We also draw from our own experience and knowledge of both the lives of women with disabilities and disability benefit programs.

Recommendation 1. Uniformly Administer Policy Guidelines: Existing and New

Perhaps most important as an overall recommendation is that there be a widespread re-education campaign for administrators, CPP beneficiaries and contributors, and physicians to ensure all parties clearly understand the policies and regulations. This is essential. Our research indicates that even current guidelines are not being consistently interpreted across the country. CPP documents telling beneficiaries how the disability benefits work are also obscure and misleading. The definition of “regular work” is not clear, leading people with disabilities to understand that not only are they not allowed to do any work, but also their benefits will be threatened if they “**can** or **are** doing some type of paid work on a regular basis” (bold in original, see HRDC 1998a). This contradicts what CPP plan administrators told us about beneficiaries who are engaged in return to work. Women repeatedly told us they were not allowed to earn even a few dollars without risking their entire pensions. Women receiving benefits were surprisingly unaware of changes to policy instituted three years ago. As previously outlined, administrators assured the researchers that in fact there is a substantially gainful occupation level (currently $8,900) at which maximum allowable earnings are set.

In the focus group with CPP administrators in Ottawa, one person reported:

> The legislation says that to be on the pension you have to be incapable of work, and I am wondering where would we put the line, where would it stop? What would we allow for work, would it be one day a week? Would it be once a month, I am just wondering about the legislation.

If any of the recommended policy changes are followed there must be thorough education of all parties to ensure there would not be any adverse impact of the revised policies due to miscommunication or misunderstanding. A woman returning to work for one day a week might be told by a CPP staff person that once a week is regular enough to disqualify her from eligibility even if the legislation allows it. Often the interpretation of guidelines becomes subjective and, hence, unfair to beneficiaries who believe one policy to be in place while staff practise another. A person receiving CPP disability benefits might start a home-based business believing he or she could earn extra money only to be re-assessed as employable and no longer eligible for benefits despite policy guidelines.

Recommendation 2. Return to Work for Women (and Men)

Although this research looks at the situation of women with disabilities with respect to CPP disability benefits, our recommendations include extending any of the suggested changes to men. We are fully aware that many women partners of men will benefit or suffer from policies that directly affect men with disabilities. It is our hope that policy encouraging return to work will particularly benefit those experiencing fluctuating conditions, and that men and women who have severe and prolonged conditions should be encouraged to return to work to their maximum capacity, if and when they are healthy enough to pursue paid employment.

It is essential that this return to work be voluntary and in no way tied to eligibility for benefits. Women and men who have contributed to the CPP are eligible for benefits if they meet the requirements for disability pensions. Returning to work should be an individual choice, in consultation with a beneficiary's physician. Support should be provided both as vocational assistance, including training, material support for adaptive equipment, career counselling, and as information to enable women and men to make this decision.

This would not require huge changes to the policies because there are, apparently, already precedents for paying benefits while people work. As one CPP administrator described:

> I just want to mention that first of all when someone is on [CPP] disability now, such as people with multiple sclerosis, people who are blind, what we have in place right now is that there is someone on disability and they return to work. There is a work incentive there, they get benefits while they're employed for three months.

Administrators were asked to consider the costs of continuing benefits on returning to work and how this might take place. The administrators assured us that no changes would be possible which cost money, but that anything that saved money might be worth considering.

> Benefits are continued for three months full time and you could take this three months and make it six months part time or 10 months quarter time. I don't disagree that you could push the interpretation of the legislation that way. Because part of what we are trying to deal with in the policy area is defining what is "regularly capable of working" for somebody with MS and some other conditions. Regularly capable is quite different from someone who had a traumatic car accident and is slowly recovering and at some point their limbs are going to work, their hands are going to work and they are going to be able to work.

Specific changes in policy required to enable return to work follow.

a. Tax Income Earned by CPP Disability Beneficiaries

Earned income should be taxable, as are current CPP disability pensions. Provincial social assistance payments should remain non-taxable, and women should be able to request deductions from their CPP disability pensions to avoid inappropriate clawbacks and deductions. As in the example from the focus groups, the disabled mother with a disabled daughter should be able to request that the CPP apply the child's benefit to the mother's tax contribution instead of providing it in cash. There are two reasons for this. First, most people with disabilities are not earning enough money to take advantage of the disability tax credit. Second, taxing the income of workers receiving benefits will reduce the public backlash by demonstrating tax revenue from the productivity of individuals previously not in the labour force.

b. Allow CPP Disability Beneficiaries To Contribute to the CPP from Earned Income

The current basic exemption for contributions on earnings is frozen at $3,500. CPP disability beneficiaries should be allowed to contribute to the CPP on any earnings above $3,500 and below the maximum (YMPE). Although it might be rare, this would create an opportunity to increase retirement earnings if individuals could generate a higher income during disablement than they received before their disablement. This might be the case for working-class women who retrain in technology or scientific careers, or become home-based consultants.

Again, it is important to ensure that working pensioners are contributing to the CPP and that Revenue Canada is not refunding these contributions. Currently, any CPP contributions are given back to the pensioner. This must be altered so that each dollar above the basic exemption allows for a contribution. In addition to contributing to CPP coffers, this will also reduce potential backlash about unfair benefits to working disabled people.

c. Eliminate Penalties and Extend Return-to-Work Policies

CPP administrators should enforce any new policy in ways that ensure persons earning income are not unnecessarily penalized, or reviewed and subsequently cut off. Existing rules around medical determination could remain in place but individuals with stable health conditions should be encouraged to seek employment appropriate to their capacity.

d. Raise the Substantially Gainful Occupation (SGO) Limit

To address the significant poverty of women (and men) with disabilities, we recommend that the base of the SGO be raised to approximately $12,000 per year. The current SGO level of $8,900 a year is lower than the low-income cutoff and poverty line (Canadian Council on Social Development 1997-98). The current SGO level is 25 percent of the YMPE, and our recommendation is to calculate it based on 33 percent. In 1998, the YMPE was $36,900 so the benchmark would be $12,177 per year. This would allow people receiving a CPP disability pension (current monthly maximum of $895.36) to earn up to $1,000 per month in wages without losing benefits. Both income and CPP benefits would be taxable, and CPP contributions would be made on earnings exceeding the $3,500 base. It is important to recognize that, under current estimates, fewer than 25 percent of women on disability pensions would be healthy enough to pursue employment and very few would earn more than $500 monthly. To return to work and maintain benefits, each person would have to inform the CPP administration of any decision to return to work, and ensure that the disability continues to be "severe and prolonged." Under this policy, women and men would not have to prove that they are incapable of doing any work; they would simply declare their earnings to the CPP for potential adjustments.

e. Establish Work Incentive for "High Achievers"

Although we recognize that only a fraction of the women (and men) on CPP disability benefits will be able to be high wage earners, we believe it is important that recipients are not automatically cut off if they earn above the first benchmark of $12,000. We recommend that a second level of work incentives be implemented for people with ongoing disabilities earning between $12,000 and $24,000 per year.

The second benchmark would be calculated at 66 percent of the YMPE or twice the benchmark. In 1998, the second level was $24,354 per year. High earners or productive people would be able to retain a portion of their CPP disability benefit which would be the baseline rate (currently set at $336.77) and a pro-rated portion connected to earnings. That is, for every dollar over $12,000 (the first benchmark) a percentage (50 percent) would be taken from the monthly pension.

A woman with a $700 monthly pension who earns $1,300 per month would have 50 percent of $300 ($150) removed from her monthly pension. She would then receive $550 monthly from the CPP in addition to the $1,300 earned income. Both amounts are taxable. A person earning $2,000 a month would have $500 deducted. Each person earning less than $24,000 a year would be eligible to keep the flat-rate amount. This would serve as an earnings incentive and would also increase incomes for those workers/beneficiaries paying tax and making CPP contributions on earned income.

In order to calculate this type of pension adjustment, two options have been suggested. Further discussion with plan administration and beneficiaries is needed to determine which would work best for all concerned. One option is to use annual income tax filing as a means for determining the amount owed by the plan based on income declared. This would make all pension adjustments one year behind, but would reduce any additional paper work and bureaucratic expense for civil servants. It would also reduce the time and energy beneficiaries would have to spend filing income reports. The other option is to use a system similar to Employment Insurance and most welfare programs, which require a monthly declaration of earnings so that amounts can be adjusted within the next month's payment. Obviously this option allows for greater fluctuation, in both income and health, but also requires more work, both for administrators and people with disabilities.

Recommendation 3. Create Permanent Disability Status

People with disabilities who earn above the second benchmark (approximately $24,000 per year) would no longer be eligible for the CPP disability benefit income, but would retain eligibility for any benefits and reinstatement, if necessary. This recognizes that a person with a disability earning more than 66 percent of the YMPE is being both productive and substantially employed. If people with a high earning ability relapsed and needed to return to CPP disability income support, they would be fast-tracked due to their permanent disability status. However, if the person had worked for four out of the last six years, the calculation of benefits would be re-assessed, based on the higher earning period, pre- or post-disablement. This would allow for a potential increase in disability benefit amount in the case where someone originally had very low earnings and subsequently had higher earnings but then experienced health problems that forced her or him again to leave paid employment. This would also benefit younger people with early onset of disease, who become retrained or find new jobs to suit their physical and mental health needs.

CPP administrators are well aware that fluctuating health could affect a person's ability to engage in paid work. Administrators interviewed in the focus group gave us examples of some people with significant disabilities who do work and receive a good income. In these cases, the work is irregular and individuals are working to their maximum potential but continue to be limited in what, and how much, they can do. These few individuals are generally considered to be highly motivated people, and the CPP has been able to respond to their individual needs. One administrator explained:

> [The] CPP is only meant to replace lost earnings or a portion of lost earnings. If you have the potential to earn income, why would you want to be on the CPP? I understand as you said, certain conditions you go into remission and you become worse and you do see clients like that and that is why I think this whole concept is interesting because it's something we have to consider for people who may be well for a year and do work profitably and then all of a sudden suffer a setback which makes you think they should never have been discharged from the Plan.

Fast-tracking currently provides a quick re-assessment for those who have received CPP disability benefits in the last five years. We believe that five years is an arbitrary length of time and recommend that this should be extended indefinitely. Individuals who, at one time, were deemed eligible for disability benefits should be allowed to re-open their claim without going through the entire re-assessment process. A form could be developed for doctors to complete in most circumstances, without the usual long and extensive medical histories and activity descriptions.

Recommendation 4. Replace Three-Month Limit with Indefinite Trial-of-Work Period

Our contention is that the three-month limit is arbitrary and makes it difficult for those with fluctuating conditions even to consider returning to work. Fear of losing benefits because of a return to work, however long, informs this recommendation. The three-month trial of employment is also attached to the National Vocational Rehabilitation Program. One administrator in the focus group explained how the NVRP works.

> Currently, if you are in the vocational rehabilitation program you get an assessment of your skills now, and what additional training would help you raise your skill level and your benefits are covered while you are in vocational rehabilitation.

Another acknowledged that the primary disincentive is fear.

> It has been very hard to convince people who are on CPP and who appear to be very good candidates who are returning to work to come into the training program because of the fear you are expressing [what the women reported]. So I would say my reasoning would lead me to say in fact more people would come on VR if there was no fear.

NVRP services should be promoted for all those interested, emphasizing that those who seek schooling or employment will not be penalized by loss of CPP disability benefits. If policy changes are implemented and income can be earned, the trial period of work would become moot. However, even without this proposed policy, there should be an indefinite trial period during which people who have retrained or upgraded their skills should be allowed to pursue employment until they and their doctor believe their health is stable enough to maintain substantially gainful occupation. This indefinite period would replace the current three-month limit. In addition, current standards provide a gatekeeping function for establishing eligibility and should remain, eliminating the need for extensive re-application.

Recommendation 5. Streamline Intersections with Other Policies and Programs

This recommendation contains several important elements.

a. Establish Provincial Provision of Resident Medical Benefits

Any person who qualifies for the CPP disability benefit (which has very strict eligibility requirements) should be automatically eligible for medical benefits provided by the province of residence under the Canada Health and Social Transfer. This is not the means-tested income assistance benefit, but the extended medical coverage that reimburses prescription drugs and many types of required durable medical equipment. We recommend this because many people who want to work are afraid of losing medical benefits. In addition, some do not need the income assistance benefit nor are they eligible for it because their income exceeds the allowed amount, or they have assets in excess of the allowable limit. Those receiving CPP disability benefits who do not necessarily require additional provincial income assistance but could use help with the cost of prescription medication and support services (covered by provincial medical plans for people with disabilities) should have access to medical benefits. Considerable negotiation and discussion with the provinces will be required to institute this important policy recommendation. However, there are mechanisms currently in place in Ontario and British Columbia for provincial disability benefit programs to recognize assessments made with respect to CPP disability benefits. These mechanisms could provide cost-effective ways to apply for provincial medical benefits. This is particularly important because, recently, applicants for provincial benefits have increasingly been required first to apply for CPP disability benefits before being considered for provincial support (Crawford 1996).

CPP eligibility currently does not provide medical benefits, and often women with part-time or self-employment histories have no access to employer-sponsored medical insurance plans. If Canada develops a national drug plan or national medical insurance plan that includes these additional costs, the need for this type of arrangement may be removed but, until such time, we strongly urge consideration of this recommendation. Other broad policy initiatives, such as a national disability insurance or benefit scheme, have been suggested by both the Roeher Institute and the Council of Canadians with Disabilities. Our recommendation takes one step toward a more universal approach to providing disability-related supports.

b. Consult with Revenue Canada To Adjust Eligibility for Disability Tax Credits

We believe that Revenue Canada could also make an adjustment regarding disability tax credits, which would mean adopting CPP definitions of disability for eligibility. Currently, many disabled people are not eligible for disability tax credits offered by Revenue Canada because of how disability is defined for income tax purposes. It seems particularly ironic that those people most likely to benefit from the credit, who qualify for it due to wage-based income when working, are often not eligible because they do not meet the criteria for being disabled, based on Revenue Canada’s definition. Yet, those too poor to benefit from it are often eligible for it because of the severity of their disabilities.

c. Investigate Overlaps with Other Existing Programs, Especially with Regard to Eligibility Issues

Other programs that support people with disabilities in various ways could also be partnered with the CPP in ways that reduce costly overlap, both for clients and the programs themselves. Streamlining eligibility using the CPP definition of disability would ensure standardization, reduce confusion for clients and alleviate the effort needed to establish eligibility for different plans. Examples of programs which could be targeted for this investigation (and possible change) include Canada Mortgage and Housing Corporation grants, Workers’ Compensation, Public Service Alliance of Canada long-term disability policies, Human Resources Development Canada training programs, and provincial (cost-shared) vocational rehabilitation services.

CHAPTER 7: CONCLUSION

This chapter refocuses attention on the political and economic context of this research into the lives of women with disabilities, and on important related issues not directly addressed in our research. We provide strong rationale for removing barriers against returning to work so that the economic equality and autonomy of women with disabilities can be enhanced. We also suggest directions for future research into the lives of women with disabilities and consultation with these women.

The treasured social safety net is sagging. The weight of globalization, economic restructuring and the speed of technological change is taking its toll. The feminization of poverty and the cultural bias against women, in particular discrimination against women with disabilities, marginalize and stigmatize women with disabilities, who are among the poorest Canadians. Despite the constitutional mandate to provide equality under the law and equal benefit from the law, struggles for substantive equality continue. Canadian courts are reluctant to make decisions around economic inequality because they argue it is up to government to set socio-economic policy. Day and Brodsky (1998: 94) point out, however:

> The purported distinction between social and economic policy on one hand, and real law on the other, is not sustainable. At the heart of this categorical distinction is a problematic view of what rights are supposed to do and not supposed to do. The view is that rights are supposed to protect the individual's liberty from incursions by the state. Rights are not supposed to address disparities between groups.

Poverty among women with disabilities is "crippling." Because women earn less than men, have shortened attachments to the work force, raise children and perform part-time and contract work, their entitlement to pension income is lower than for men. This lack of economic equality is central to the experience of women as disempowered, marginalized and isolated. Having to leave work as a result of disability directly affects personal self-esteem; loss of work identity occurs and social networks disappear, and reduced income and increasing debt push women with disabilities further down the economic ladder. Lacking information, political power, social status and financial resources, most women with disabilities are hardly positioned to advocate for improvements in policy.

When women (and men) work for pay and contribute two to three percent of their wages to a national scheme that is designed to guarantee a portion of income upon retirement or disability, the eventual benefit should be an entitlement.

> Individuals contribute based on their own earnings, giving them a right to a benefit when they reach retirement or become disabled. . . . Analysts have noted that in a climate of economic restructuring caused by globalization, and the increasing emphasis on the marketplace as the arbiter of change, the need for social protection is growing, not diminishing (Townson 1995: 14).

We want members of the public and policy makers in Canada to have the foresight to consider the full cost–benefit implications of providing support for the most vulnerable in our society instead of counting the expenditures in dollars alone. While our research limited itself to the Canadian situation, other ambitious researchers have compared other countries' pension schemes with a view to understanding the differential impact on women and men.

In a comparative, computer-simulated analysis of the pension schemes in Australia, Chile, Italy, Poland, Sweden and Britain, authors concluded that pension systems:

> . . . dominated by private defined contribution pension schemes perpetuate and widen income inequality in retirement, disadvantage women whose employment was restricted by raising children and will lead to pressure for expansion of means-tested assistance. In contrast, minimum pensions, if these are above the level of assistance safety nets, both protect the vulnerable and provide an incentive for additional voluntary provision (Evans and Falkingham 1997).

The Government of Canada, the governments of the provinces and the workers of Canada need to understand the value of providing incentives to work and continue contributing to the CPP, if and when health permits. Existing definitions of disability make it impossible to be both productive, working and "disabled." Recent conservative predictions, bolstered by the media, that the CPP fund will soon be bankrupt have stirred up discussions of eligibility and cost cutting. Decisions were made to create even more difficulty in applying for, or retaining, entitled benefits under the CPP disability benefit program.

People with disabilities were targeted to reduce the costs, although the CPP denies this, arguing that "these measures are part of a balanced package of changes to ensure that Canada Pension Plan is affordable and sustainable for future generations" and to enable them "to continue to provide disability benefits in a fair, consistent and responsible manner while controlling costs" (HRDC 1998a).

Reviews, re-assessments and tightening of eligibility criteria reduced the number of active cases. The National Vocational Rehabilitation Program, implemented in 1995, encouraged people to return to work after suitable retraining. The idea of economic autonomy as a goal is an honourable one, but neo-liberal rhetoric of individualism and self-reliance informing this concept ignores the material reality of living as a woman with a disability. Although social assistance is often seen as aid for the deserving poor, pensions should be seen as a return on investments.

> Intertwined in these trends is a discourse of dependency that builds on the opposition between two types of exchanges: a contractual exchange among equivalents ("independence") versus the unreciprocal and unilateral charitable relationship ("dependence"). Thus, an ever-tightening boundary is drawn around "the deserving," the notion of interdependence fades, and the possibility of an "honorable" entitlement disappears (Evans 1997: 106).

Contributory programs such as the CPP and EI should be seen by all Canadians as entitlements rather than solely as expenditures. The cost of living with a disability is not adequately offset through tax credits or welfare. People previously living on steady incomes now depend on less than a quarter of their average earnings to meet expenses. In the light of such limited incomes, coupled with the additional expenses of having a disability, it is increasingly important to remove the barriers to returning to work. Both for economic and social reasons, working should be rewarded, not penalized by the state. The Council of Canadians with Disabilities (1996: 2) promotes the idea of both training and returning to work because:

> [m]any people whose disabilities could reasonably be described as "severe" have proven themselves able to work very successfully, particularly with suitable education and training. Many more persons with disabilities would be working successfully, but have not been given a fair opportunity to do so because of the barriers they face.

People with disabilities, and non-disabled women, face systemic barriers to employment. In addition, discrimination in hiring, negative attitudes and stereotypes about women with disabilities make it less likely they will have successful and enduring attachments to the work force. While we, as researchers, recognize there are larger, structural inequalities impinging on the economic status of women with disabilities, we feel, at the very least, the CPP should not contribute to inequality but support re-integration into the work force.

Changes to CPP disability policy that encourage a trial work period, retraining and volunteer work are progressive, yet continue to place emphasis on individuals and their disability without equal emphasis on the structural barriers to working.

> It is well known however, that systemic problems seriously hamper even well-qualified women with disabilities from obtaining suitable employment. Some of these systemic barriers involve employer hiring practices; others involve barriers embedded in programs that were once cost-shared by federal and provincial governments and that provide essential goods and services only on the condition that individuals be identified as unable to work or as having a low employment potential (Crawford 1996: 117).

Bringing the point closer to home, both researchers on this project have been designated as "unemployable" in order to receive benefits. Both of us have substantial training and education, yet we also have disabilities which limit the amount and type of work we do. Additionally, we require significant accommodation in the workplace. It is important to recognize the material disadvantages faced by women with disabilities so that both a gender lens and a *disability* lens are used to analyze policies.

We also wish to point out that while the CPP disability benefit program is a significant income source for eligible women with disabilities, a larger number of women do not qualify for benefits because of inadequate work history and contributions. To address issues of concern to women with disabilities who are *not* eligible for CPP disability benefits, the necessity of providing benefits and pensions for homemakers and others doing unpaid work also must be raised. Even though the issue of providing pensions to women who do not earn a salary is controversial and "is fraught with numerous conceptual and practical problems" (Gunderson, Muszynski and Keck 1990: 171),

> it does merit serious attention. Either by credit-splitting, by having partners contribute on behalf of a spouse who stays home or by pooling taxes collected from employed persons to support the unpaid caregiving of (mostly) women, some mechanism needs to be developed to benefit those without attachment to the paid labour market.

Our strategies for addressing policy problems were outlined in the previous chapter (and condensed in the Executive Summary) to offer a starting place for reaching social and economic justice. We are not suggesting that any of our recommendations, if instituted, would replace or reduce the need for significant restructuring and integration of social welfare and labour market policies. We are, however, suggesting that, until such time as an efficient and effective redefinition of disability and a gender-sensitive political and economic climate exists, these recommendations will directly assist women with disabilities toward enhancing their economic equality and autonomy.

The social safety net in Canada desperately needs to be restrung. The net must not only catch people when they fall and but also be taut enough to enable people to re-establish their socio-economic grip and tightl woven enough to prevent them from falling through the gaps.

Emergent Issues Around Disability and Women's Work.

As this research effort was specifically designed to look at the CPP disability pension, we have not conducted in-depth research on related issues. We recognize that there is a patchwork of programs, which leads to significant difficulties for people with disabilities. We would like to suggest that research and consultation on the following topics be pursued to address some of the problems we identified but which were beyond the scope of this research. Any research focused on these issues would ideally be conducted in consultation with women's organizations, disability rights organizations, labour and business, and full consultation is essential before changes are implemented. We suggest specific recommendations for future research.

Consider Unresolved Issues around Unpaid Work

Domestic caregiving, volunteer work, work in the home and in non-profit organizations are all unpaid labour contributing to the socio-economic life of Canadians by people with disabilities. It is important to consider seriously the socio-economic consequences of not providing credit, income and security for unpaid workers. This includes the issue of pensions for homemakers, credit splitting and innovative ways to share costs and benefits among those in the work force and those who sustain the infrastructure of both work and social life. As the Canadian population ages, there will also be more women between ages 45 and 55 who are taking care of ageing parents (65 to 80) but who are also experiencing disability themselves. In our focus groups, there were two sets of mothers and daughters where both women in each pair were disabled and receiving CPP disability benefits. The caregiving work of assisting a person with a disability is often done by a female family member. This work is almost never paid, and although some social service programs provide respite care or emergency services, people with significant disabilities will end up in nursing homes or hospitals if there is not adequate home care and attendant support.

Consider the Necessity of Redefining "Disability"

Existing CPP policy, which makes it almost impossible to be both employable and disabled, is outdated. Although all our recommendations retain the original definition of "disability," we do this by revealing the hidden benchmark of what is "substantially gainful." We recommend increasing the benchmarks as an interim measure, but further research focused on alternatives is essential. The concept of disability should not be tied to employability but to functional limitation and need. Accommodation in employment situations and the need to remove barriers can be seen as defining feature of disability rather than specific medical or biological measures. A national disability benefits program separate from the CPP is one option, but whichever system is considered, there must be ways for women to be covered commensurate with their work. The Council of Canadians with Disabilities (1994: 25) has suggested that a base level of income, regardless of the cause of disability, be paid directly to individuals with disabilities to offset the cost and "the system must be, and be perceived to be, an insurance system and not a welfare or charity system."

This suggestion is important because it would eliminate the distinction between disabled people who once worked, who never worked and became disabled, who were born disabled and people with partial disabilities. In addition, the benefits would be tied to the individual and, therefore, be both portable and self-directed, so that dependence on a particular service, system or eligibility process would not interfere with the purchase of needed services and goods.

Conduct Research into the Social and Economical Cost to Beneficiaries of Past and Current Re-Assessment Initiatives

Since 1993, 8,435 men and women have been disallowed CPP disability benefits, either through completion of the NVRP and subsequently becoming gainfully employed, or by being re-assessed as ineligible because of no longer being disabled or other changed circumstances (through re-assessment initiatives)(HRDC 1998c). Many men and women are in the process of appealing these decisions. If any of our policy recommendations are implemented, there must be a concerted effort to include those who have undergone, or are currently undergoing, the appeal process, have been deemed ineligible or have had benefits disallowed due to working. These people, under our proposed policy changes, would be allowed to retain their benefits while working. Because CPP disability benefits are taxable, they would pay taxes and contribute to the CPP on earned income.

When we considered the policy implications of our recommendations, we reviewed both the fiscal and qualitative impact on the lives of women. Women in our study tied the ability to work to their identities and sense of self-worth. Even those who were too sick to consider returning to work believed their inability to work led to a sense of despair and difficulty considering the future. Disabled women, such as the ones we interviewed, dependent on a small monthly pension, are literally afraid of receiving any additional income lest they jeopardize the security of their pensions. The cost of not allowing women to work is clearly both emotional and financial.

Re-assessment initiatives (1993-1997), although lucrative for the CPP, especially given the numbers of people who were disallowed benefits and the substantial sum of overpayments to be repaid, substantially increased the fear of losing benefits, as the women in our study clearly stated.

More important, women determined ineligible as part of the re-assessment initiatives did not volunteer for our study. Thus, we have not been able to calculate the social and economical cost to beneficiaries of past and current re-assessment initiatives, although we suspect that many have now joined the ranks of those receiving provincial social assistance. Nonetheless, we believe research into these costs needs to be done.

Conduct Research Focused on Barriers Created by Long-Term Disability Plans Administered by Private Insurance Corporations in Canada

The threat of privatization of health and social services in Canada comes closer to reality each year. In the United States, most people with disabilities are excluded by “pre-existing condition” clauses. Coverage of medical and dental costs, and retirement and income replacement associated with insurance plans are tied to previous employment, so reforms to the CPP will assist only those women (and men) who have inadequate private insurance or none at all. Until federal and provincial governments co-ordinate existing programs with private insurers, significant barriers to employment for people with disabilities will remain.

As with feminists in the women’s movement, the disability rights movement resists looking at social problems through individual policies. We prefer to address problems as a whole, looking at a person’s entire needs and at how these intersect with the societal context, to effect desired changes. Using the argument that disability is socially constructed, we can surmise that the disadvantages of disability would be eliminated if all supports were in place, and attitudes and structures were improved. “An ideal society is one in which needs are acknowledged without shame or condemnation and then support is provided...society must be willing to provide those supports” (Watson 1993: 758). We encourage all Canadians to strive toward this ideal.

Together, our research and recommendations represent a model of policy change that is economically cost-effective, more responsive to the experiences of women with disabilities and, something that is important, more equitable for these women who are eligible for CPP disability benefits. Policies are always in flux, frequently responding to competing demands of citizen rights, political ideology and fiscal responsibility.

The inevitability of change requires that we recommend policy changes that are the most helpful in the present, or at least in the near future. We also want to ensure that our suggestions do not have an unintended adverse impact on women with specific disabilities (or on men). Any changes considered by programs, organizations and governments must look at the implications beyond the immediate cost saving and revenue generation that has been demonstrated. While not every single person will benefit from our proposed changes, it is our intention that any policy be inclusive rather than exclusive and capture as many as possible of those disabled people who want to, and are well enough to, re-enter the work force, without penalty.

Older women in the focus groups were adamant about the importance of helping those women with disabilities who are younger than themselves. Women with disabilities know the wisdom of living day-to-day and how it is not always wise to depend on a possible future. Our recommendations have been developed with hope that change can happen sooner rather than later. For some women it may be too late. For us as researchers, and as women with disabilities, the stories the women shared have made a difference to how we envision disability policy. We hope this research empowers policy makers to draw from this vision in policy-making decisions. We also hope these decisions reflect the realities of women (and men) with disabilities.

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APPENDIX A: SCENARIOS USED IN FOCUS GROUPS WITH WOMEN

Three different scenarios were presented in turn to women in the focus groups, followed by a group discussion of each scenario. We told the focus group members that we wanted to find out how they thought their lives might be different if CPP disability policy were to be altered in ways that made it possible for them to move in and out of the work force as their disabilities allowed, while retaining benefits. They were informed that this was policy research, and that what we recommended from this research might go forward to the federal government and, possibly, be developed into new policies for how CPP disability benefits are administered to women with disabilities. The scenarios were also presented to the focus group of CPP administrators and policymakers.

We also reminded the women that each would have her own point of view about this issue based on her own experience and what was important in her life. We said that we were interested in as many different points of view as possible as well as what may be similar or shared among the women. We suggested they might want to make notes, if able, as we presented the scenarios. We offered to send copies of the transcript of the interview and the final report to each woman, if she wanted.

The pilot focus group was structured differently from the rest because it was designed to determine which questions were useful and appropriate to ask, given the women's experience of being asked and answering the questions. We gave pilot group members two options: use the pilot to tell us which questions worked and did not, and then make suggestions for a final version to use with other focus groups, or engage in this activity *and* use the audio-taped discussion as part of the research data. We allowed pilot focus group members to make their decision once we had completed the focus group interview. Focus group members unanimously chose the latter option.

We began with this statement: "Currently, if you are receiving CPP disability benefits you are technically classified as unemployable because your disability makes it unlikely for you to work. However, we would like to propose changes to CPP disability policy which would allow women to work if/when they can without fear of losing benefits. We have imagined three different types of changes to policy." The three types of changes we imagined are described in each scenario. All the scenarios shared one common feature — women (and men) with disabilities receiving CPP disability benefits would be able to work when able, and move in and out of the work force without jeopardizing benefits. Once the scenario was presented, we opened discussion using guiding questions. (See examples following each scenario.) We did not rigidly adhere to these questions, but rather kept them in mind as the discussion proceeded, with some questions being asked for each scenario. Our focus was on the women's experiences, which also provided structure to the discussions.

The questions used to guide the administrators' focus group were different from those we asked the women with disabilities. In this case, questions focused on the policy changes suggested in a composite scenario (using elements of the first three) and the likelihood these might be considered by the CPP as feasible, given current thinking about CPP disability benefits. The scenarios as presented to the focus groups are described below, followed by questions for guiding discussion. Several general questions are then listed.

Scenario 1

In this scenario, we assumed that CPP disability policy allows women to return to the work force whenever they are able to (when the disability was in remission, for example) and remove themselves from it when they were not able to work (during a flare up). Beneficiaries would still retain their CPP disability benefit as they moved in and out of the work force. Nothing would change in the monthly benefit amount until the woman retires.

At retirement, the retirement benefit is calculated against new earnings rather than earnings at the time of initial disablement (as it is currently). Similar to current policy, there would be a maximum level of earnings against which retirement benefits would be calculated ($39,000). No earnings above this amount would be considered insurable and nothing under $3,500 would be considered insurable.

Guiding Questions

- What does keeping your benefit mean for you with respect to returning to work? Or engaging in other activities designed to enhance your ability to find work, such as, volunteering part time with view to getting a job?
- How do you imagine your life to be on your currently estimated retirement income?
- Even if the actual amount per month at retirement were increased minimally (say $100), what kind of difference would that make to you (at retirement)? Would this change, in any way, how you feel about retirement?
- If you knew you would be allowed to keep your benefits, would you consider re-educating yourself for a new career that might be more suitable to your needs as a woman with your disability?
- What other changes in your circumstances come to mind with respect to this proposed difference in your benefits?
- What do you imagine might be the same?

Scenario 2

Note that scenario 2 was presented as a more complicated change in the policy. The focus group was instructed to suggest ways to make it more understandable or realistic.

For this scenario, we created a case study that describes a hypothetical situation, in which elements might possibly resemble some women’s experiences.

Jenny is a waitress who unexpectedly developed lupus at age 24. She eventually leaves her job, applies for and begins receiving CPP benefits. After four years of living with her disability, she decides to return to school to finish her education degree and, shortly after completing it, finds part-time employment as a teacher. While she is working as a teacher she receives CPP benefits. She also contributes to the CPP at a rate based on her teaching earnings. She often worries whether teaching is suitable for her because of her susceptibility to flare-ups, especially when she is under a lot of stress. She continues working for about three and a half years, but she can't sustain the long hours and hard work and eventually leaves work again. This time though, because she has been paying into CPP at a higher rate than she was at the time of her initial disablement, her benefits are calculated against her most recent earnings, and are increased accordingly. When Jenny retires, her retirement benefit will be adjusted to reflect her additional earnings.

We added a reminder that, in this scenario, if a worker doesn't go back into the work force nothing changes. It's only if she returns to work, and earns more (and therefore contributes more to the CPP) then her benefit will be altered. We also assumed in this scenario that returning to work wouldn't penalize women with respect to benefits. They would keep all their income, both earned and CPP disability benefits. With this scenario, it is also important to remember that if a woman had returned to work at a salary much lower than her previous salary, this would benefit neither her disability nor retirement income.

Guiding Questions

- Is returning to work (even part time) or school, or both, something that could potentially happen to you?

- If not, what would be a likely scenario which could potentially alter the calculation of your benefit to increase it once you were unable to work again?

- Would you be more likely to consider going back into the work force if you knew it might potentially increase your benefits if you had to leave work again? (That is to say, there is no penalty and a possible reward for returning to work.)

- If you could return to work only part time and knew that your earnings would always be less than your previous earnings, would you still do it (for the personal and professional benefits rather than the financial ones)?

- What other ways might this possible situation affect your life (now and later)? Your potential to return to work?

Scenario 3

In this situation, a woman decides that she is able to return to work (at least part time). She keeps receiving her CPP disability benefit at the original rate while she is working. There would be no change in her monthly benefit unless, and until, she earns a certain percentage of her former earnings (at the time of initial disablement) as follows. (These figures were written on a flip chart or overhead, and repeated for blind participants.)

Former earnings	**Percentage of former earnings allowed**
$16,000-$25, 999	150%
$26,000-$35,999	125%

$36,900 and up	100%

Once new earnings exceeded 150 percent of former earnings of $17,500, for example ($26,250), for six consecutive months, CPP disability benefits would then be disallowed while the woman continued working. If or when she left the work force again because of disability, her original claim would be reinstated according to current eligibility criteria of four years out of the last six. If she worked more than four years, she would be re-assessed according to her new earning level (if she has contributed to the CPP). While working, she would submit a report of earnings every six months so that CPP administrators could compare her earnings with what is allowable in her earning percentage bracket.

Guiding Questions

- What would being allowed to earn more than your former wages without penalty mean to you?
- What would be different about your life if this scenario were applied to your situation?
- How might this situation possibly influence your thoughts or intentions to return to the work force?
- What would keeping your benefit while earning wages mean to you?
- Is a six-month reporting period for income too long? Too short? What would be ideal in terms of reporting income? Why?
- Are our allowable earning percentages too high? Too low? Why?

General Guiding Questions

- What do you think would be the major advantages and disadvantages to these proposed changes?
- Now that you have heard all three scenarios, how would each one make your life easier or harder? Which one seems the most appropriate given your experience?
- What other ways would you suggest the CPP could be changed to reduce poverty for women with disabilities?
- Do you have any recommendations for how CPP disability policy (the focus of our research) might be changed to improve how income is determined by provincial sources of funding (welfare)?

APPENDIX B: CALCULATIONS FOR CPP SCENARIOS INCOME AND SAVINGS

CPP Contributions on Earned Income

Women (with Disabilities) Returning to Work

1.1 Approximate number of women on disability benefits in 1998 based on CPP tables for March 1998[1] was 125,000.[2]

1.2 Women between age 60 and 64 numbered 37,000 in 1998 in the same table. Women in our focus groups and women seeking work who are not disabled have told us older women face constant barriers to re-entry and that re-employment at this age is unlikely. It is possible some women would be able to work and they should be encouraged to, but the statistics calculated are based on a conservative estimate using comments from research participants.

1.3 Of this number, 88,000 women remain who could re-enter the work force at some point. This does not take into consideration their previous occupation or illness.

1.4 Based on our discussions with women about the definition of disability and their fear of losing income, a larger proportion of women would take advantage of work opportunities and rehabilitation if they would not face the penalties they currently believe exist. Thirty-one percent of the people with disabilities who were not in the labour force, as recorded in the 1991 Health and Activity Limitation Survey, noted that it was due to the possibility of losing income or benefits. This number was not divided by gender. In the analysis of men, we took the higher number of 30 percent while we decided to use 25 percent for women.

It is also the case that a number of women would be interested in retraining although they would not be able to return to their former positions due to the nature of their disabilities. Even some older women (50 and older) were interested in learning computer skills and working from their home. Twenty-five percent of 88,000 is 22,000 women.[3] Calculation:

1.1 Approximate number of women	125,000	
1.2 Number between 60 and 64	37,000	Subtraction
1.3 Remainder available to re-enter work force	88,000	
1.4 Women likely to earn income (25 percent) estimate	22,000	Product

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[1] "Distribution of Disability Pensions by Age and Sex, March 1998," Table 9, http://www.hrdc-drhc.gc.ca/isp/studies/trends/cpp/9803/cppt9e.htm (Accessed May 21, 1998).

[2] This number does not include those women currently in appeal, or who were re-assessed during the last few years. In total there may be significantly more women eligible for the "proposed" policy change, but this number is taken as an indicator of the impact based on current caseload.

[3] Previous estimates of how many women on the CPP could, in fact, work have been based in part on the medical model of being "recovered" and in part on the employability test, but both would have resulted in losing benefits. This leads us to conclude that many more women would have been willing to try re-entry and rehabilitation if there had been no penalty for trying, succeeding or failing. Between 1993 and 1995, 40 percent of the re-assessed clients showed enough change in circumstances to have benefits stopped, and although HRDC does not indicate how many of these are women, it does support our estimate of 25 percent as feasible.

1.5 In 1996, Statistics Canada poverty rates described in a table of the Canadian Council on Social Development reported that 16.2 percent of women were living below the low-income cutoff. Only four percent of women were earning more than $30,000 annually. Women with disabilities have a record of earning even less than women without disabilities.

Using the economic portrait of people with disabilities, painted by Gail Fawcett,[4] which used Statistics Canada figures, the following division was determined. Eight percent of the women (two percent of 22,000) would potentially be able to earn what they did before disablement or more, that is be high-income earners (more than $36,900 annually). Another 20 percent (the second largest block) would earn modest incomes, below the cutoff, but still enough to sustain themselves. This is only five percent of the 22,000. The largest single group could be the 40 percent who would be able to earn only average incomes if they returned, less than $29,999 but more than $20,000 a year. This would be 10 percent of the 88,000 or 8,800 women. The last group of income earners would be 32 percent of the group returning to work or eight percent of the 22,000. This number was lower than the actual poverty rates of women with disabilities, because we were taking into consideration the fact that more severely disabled women would remain in poverty and that the women most likely to take part in rehabilitation and re-entry would have higher earned incomes than the welfare rates and pension earnings which are reported to Statistics Canada by the lowest earning women. Still, this group of women would earn less than $20,000 per year.

Calculations:
The contribution rate has risen to six percent (three percent from employers and three percent from employees) and is calculated only on earnings above $3,500 and below $36,900.[5]

Table B-1: Calculation of Women's CPP Contributions

Women earning income (%)	Number of women earning	Range of income ($)	Median income ($)	Rate of CPP contribution (%)	Women's contribution ($)[6]
2	1,760	>39,999	40,000[7]	6	3,527,040
5	4,400	30 – 39,999	35,000	6	8,316,000
10	8,800	20 – 29,999	25,000	6	11,352,000
8	7,040	<20,000	10,000	6	2,745,600
25	22,000	Possible	Contribution	Total	25,940,640

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[4] Fawcett 1996.

[5] HRDC CPP calculations for CPP benefits.

[6] Based on one year of collection at this rate (six percent). When the rate rises or when women earn more, the totals will also increase proportionately.

[7] It does not matter for CPP calculations how much over $36,900 is earned, as CPP contributions are only made on the allowable amount, so the figure of $40,000 is used as a placeholder in this case.

Men (with Disabilities) Returning to Work

A calculation for men’s contribution rates was made based on the same principles.

2.1 The exclusion of persons aged 60 to 64.

2.2 The number of men who might be able to work was increased to 30 percent, which takes into account men’s higher employment rate.

2.3 In addition, the proportion of men earning higher incomes was raised to three percent of the available 104,000 men with disabilities. Only nine percent of the men were considered to be able to earn over $30,000 and less than $39,999. Additionally, a full 13 percent of the men would earn less than $29,999 but more than $20,000. Again, this is based on findings that men with disabilities would earn less than men without disabilities. Five percent or 5,200 men would be earning less than $20,000 a year.

Using these calculations a similar estimate of contributions to the CPP was made.

Table B-2: Calculation of CPP Contribution for Men with Disabilities

Men working (%)	Number of men earning	Range of income	Median income	Rate of CPP contribution (%)	Men’s CPP contribution ($)[8]
3	3,120	>39,999	40,000[9]	6	6,252,480
9	9,360	30-39,999	35,000	6	17,690,400
13	13,520	20-29,999	25,000	6	17,440,800
5	5,200	<20,000	10,000	6	2,028,000
30	31,200	Possible Contribution Total			43,411,680

Combined Income from Men and Women Returning to Work and Making CPP Contributions on their Income

Possible combined contributions annually of **$69,352,320.**

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[8] Based on one year of collection at this rate. When the rate rises or when men earn more the totals will also increase proportionately.

[9] It does not matter for CPP calculation purposes how much over $36,900 is earned as CPP contributions are only made on the allowable amount. So for the amount of $40,000, the figure used in calculation is $33,400. Currently the base amount and maximum amount are frozen at $3,500 and $36,900 respectively (which disadvantages low-income earners without penalizing high-income earners).

Tax Revenue on Earned and CPP Income

Federal Tax Contribution on Income by Women with Disabilities

1.1 The same number of women was used as a base (22,000), which is 25 percent of the women, aged 60 and under, currently receiving CPP disability benefits (average).

1.2 The same division among income levels was used, and mean income from the CPP was divided by income level and a total generated using averages.

Table B-3: Calculation of Women's Tax Contribution

Women earning income (%)	1.1 Number of women earning	Range of income ($)	1.2 MEAN INCOME FROM CPP ($)	1.2 MEAN income work and CPP ($)	Possible total income from taxes per female ($)	Women's total estimated federal tax contribution ($)
2	1,760	>39,999	620/m	45,440	6,317.27	11,118,395
5	4,400	30-39,999	550/m	41,600	5,318.87	23,403,028
10	8,800	20-29,999	500/m	31,000	2,562.87	22,553,256
8	7,040	<20,000	480/m	15,760	-154.53[10]	0
25	22,000	Possible Taxation Total				**57,074,679**

1.3. Calculation of tax payable was based on T1 General 1997 tax return, using the following:

Total earned income was the mean income for each income bracket (Line 101)
Added to it was CPP Disability income (currently taxable) (Line 114)
No deductions were made Net income line 236 was totalled

Where line 236 was less than $29,590 the federal tax rate was 17 percent. Where it was more than $29,590 it was $5,030 on the first $29,590 and 26 percent on the amount between $29,590 and $59,180.

To produce a standardized income tax calculation, the same non-refundable credits were used for all — men and women:

$6,456 Basic Personal Exemption
$5,380 Equivalent to Married
$ 600 CPP contributions (averaged — some would be higher, some lower)
$4,233 Disability amount for self (some would also claim for child or spouse)

$16,669 — This amount is multiplied by 17 percent, which results in $2,833.73 in credits.

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[10] Non-refundable credits do not result in a payment to individuals. Women earning in this income bracket will be able to reduce their tax payable to zero.

This amount is applied to federal tax *owing* and is neither refunded nor paid but reduces the amount payable by the individual. It benefits those who have to pay more tax. Often people receiving less than $12,000 per year do not need the disability credit to reduce tax payable to zero. However, not all CPP beneficiaries are currently eligible for the disability tax credits, and if they went back to work, they could take advantage of it as a reduction in their tax burden.

Federal Tax Contribution on Income by Men with Disabilities

2.1 The same number of men was used as a base (31,200) which is 30 percent of the men age 60 and under, currently on disability benefits (average).

2.2 The same division among income levels was used, and mean income from CPP was divided by income level and a total generated using averages.

Table B-4: Calculation of Men's Tax Contribution

Men earning income (%)	**2.1 Number of men earning**	**Range of income ($)**	**2.2 MEAN INCOME FROM CPP ($)**	**2.2 MEAN income work and CPP ($)**	**Possible total income from taxes per male ($)**	**Men's total estimated federal tax contribution ($)**
3	3,120	>39,999	750/m	47,000	6,722.87	20,975,354
9	9,360	30-39,999	700/m	43,400	5,786.87	54,165,103
13	13,520	20-29,999	680/m	33,160	3,124.47	42,242,834
5	5,200	<20,000	580/m	16,960	2,945.90	15,318,690
30	31,200	Possible Taxation Total				**132,701,982**

Possible tax revenue from both working men and women would equal **$189,776,661.**

Social Assistance Savings (CHST Cost-Shared Programs)

The average disability pension for women is $600 per month and average for men is $720. Only a small number receive the maximum benefit of over $880 per month. Some women (and men) receiving only $400 or $500 per month from the CPP would fall under the poverty line and be eligible for at least some provincial assistance.

Each province has different welfare rates and regulations depending on disability or family status. To estimate savings, a flat rate of $700 per month top up was used for women and $500 per month for men. The cost per year to support one woman with a child could be $8,400 (not including her CPP) and for a male, unattached, would be $6,000 per year (not including his CPP). If women or men earned more than $13,000 per year they would no longer be eligible for assistance under the cost-shared means-tested welfare programs.

It is estimated that 30 percent of the 25 percent of women who return to work, or 6,600 women who previously were eligible for assistance, would stop receiving social assistance because of earned income: 6,600 x $8,400 = $55,440,000.

It is estimated that only 20 percent of the 30 percent of men returning to work would stop being eligible, and the rate is lower because fewer would have been eligible in the first place since fewer had low enough income: 6,240 x $6,000 = $37,440,000.

Since our scenarios proposed that health insurance premiums and disability costs be continued for those returning to work, a calculation of health costs is also necessary. A flat rate of $250 per month per person is assessed, assuming that the costs of medication fluctuate and that some costs are one-time only, which can be averaged throughout the year. No difference was used in calculating the costs for men and women as no statistical information was found on differential costs:
6,600 + 6,240 = 12,840 x $250/month ($3,000/year) = $38,520,000.

Since both welfare (social assistance) and health care are cost-shared programs under the *Budget Implementation Act* (CHST) the benefit will be divided between the provinces and the federal government. The cost savings could total $92,880,000 per year, and the cost spending (for those leaving welfare but maintained on health benefits) could total $38,520,000 for a net benefit of $54,360,000 per year in savings.

Table B-5: Calculations of Welfare Savings and Health Costs

Number of persons	**Savings/ year/person ($)**	**Sub-total ($)**	**Totals ($)**	**Costs/ year/person ($)**	**Sub-total ($)**
1.2 6,600	8,400	55,440,000			
1.3 6,240	6,000	37,440,000	92,880,000		
1.4 12,840				3,000	38,520,000
		1.5 NET SAVINGS	54,360,000		

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- **Urban Policy Options for Meeting the Housing Needs of Women Living in Poverty in Four Canadian Cities**
  Marge Reitsma-Street, Josie Schofield, Brishkai Lund
  Community Social Planning Council of Greater Victoria

*Some of these papers are still in progress and not all titles are finalized.