

DISABLED WOMEN'S LIFE SPACES AND EXPERIENCES OF PAID WORK

CHANGES IN DISABLED WOMEN'S EXPERIENCES OF  
THE WORKPLACE, LIFE SPACES AND EMPLOYMENT SUPPORTS  
IN HAMILTON, ONTARIO

By

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## **ABSTRACT**

Little research into the lives of women with arthritic conditions has been conducted by geographers and other social scientists; particularly using qualitative methodologies. We therefore know little about how these women negotiate experiences within Canadian society and space. Further, few researchers to date have viewed people with disabilities as being policy experts, and looked to their lived experiences to inform policy directions. The focus of this feminist geographic study is on explaining the workplace experiences of eighteen women residing in the City of Hamilton, Ontario since acquiring an arthritic condition, and examining how these lived experiences can be used to help assess and improve government employment policies and programs for persons with disabilities.

The experiences of paid employment, the workplace, and changing life spaces investigated include: the types of workplace accommodations these women have sought from their employers; the women's changing views of themselves as being 'productive workers'; how experiences in the workplace are affected by experiences in other spaces of daily life; and the government-funded and community support programs they have used to assist them in remaining in the workplace or with the

transition to unemployment. The overall objectives are to explain why and how these women's experiences of paid work and the workplace have changed in a particular place, namely the City of Hamilton, and to discuss the implications of their experiences and policy recommendations for current and future policy and program directions.

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## TABLE OF CONTENTS

	Page
<b>ABSTRACT</b> .....	iii
<b>ACKNOWLEDGEMENTS</b> .....	v
<b>LIST OF TABLES</b> .....	x
<b>Chapter One: Introduction</b> .....	1
1.1 Background.....	1
1.2 Study Focus.....	2
1.3 Study Themes and Aims.....	3
1.4 Thesis Structure.....	5
<b>Chapter Two: Literature Review</b> .....	8
2.1 Introduction.....	8
2.2 Disability, Geography and Disability & Space.....	8
2.2.1 Defining "disability".....	9
2.2.2 Disability & Space.....	11
2.2.3 Feminist Analyses of Disability.....	15
2.3 Women and Disabling Conditions.....	17
2.3.1 Women with Disabilities in Canada....	17
2.3.2 Changing Life Experiences After Acquiring a Disability.....	19
2.3.3 Women & Musculoskeletal Impairments..	23
2.4 Employing Canadians with Disabilities.....	26
2.4.1 Disability & Employment: The Canadian Context.....	26
2.4.2 Barriers to Finding and Maintaining Employment.....	28
2.4.3 Workplace Accommodations.....	30
2.4.4 Employing Women with Disabilities....	31
2.5 Conclusion.....	33
<b>Chapter Three: Research Methods and Techniques</b> .....	35
3.1 Introduction.....	35
3.2 Conceptual Framework.....	36
3.3 Feminist Research Considerations.....	37
3.4 Historical Policy Analysis.....	38
3.5 Interviewing Techniques.....	39

3.6 Conclusions.....	44
<b>Chapter Four: A Review of Ontario and Canada's Employment Support Policies and Programs for Persons With Disabilities: 1962-2001.....</b>	<b>46</b>
4.1 Introduction.....	46
4.2 Government Assistance in Ontario, Canada....	47
4.3 Determining Eligibility for ODSP and CPP-D Assistance.....	55
4.4 Conclusion.....	64
<b>Chapter Five: Interview Findings: Changing Life and Employment Experiences After Acquiring an Arthritic Condition.....</b>	<b>66</b>
5.1 Introduction.....	66
5.2 Participant Characteristics.....	66
5.3 Changes in Life and Life Spaces After Acquisition of an Arthritic Condition.....	71
5.3.1 Changes in Self-Image and Self-Worth.....	72
5.3.2 Experiences of Depression.....	76
5.3.3 Changing Views of Themselves as Workers.....	78
5.4 Physical and Social Workplace Barriers.....	82
5.4.1 Physical Workplace Barriers.....	82
5.4.2 Social Workplace Barriers.....	85
5.4.2.1 Disbelief & Lack of Understanding from Co-Workers and Employers.....	85
5.4.2.2 Lack of Knowledge about Arthritic Conditions.....	88
5.5 Experiences Outside the Workplace.....	89
5.5.1 Experiences in Spaces of Health Care.....	90
5.5.2 Lack of Medical Credibility or Legitimation.....	94
5.5.3 Lack of Public Awareness about Arthritic Conditions.....	96
5.6 Workplace Accommodations Sought by Interviewees.....	97
5.6.1 Modified Work Duties.....	98
5.6.2 Modified Work Hours.....	101
5.6.3 Physical Workplace Accommodations....	103
5.6.4 Willingness of Employer to Provide Accommodations.....	104
5.7 Conclusions.....	106

<b>Chapter Six: Interview Findings: Employment Supports Used by the Interviewees and their Recommendations for Improvements to Employment and Income Support Programs and Policies.....</b>	<b>110</b>
6.1 Introduction.....	110
6.2 Government-Funded Employment Supports Used by the Women.....	110
6.2.1 Non-Income Assistance Employment Supports.....	111
6.2.1.1 Visits to Employment Centres..	111
6.2.1.2 Vocational Training Courses...	114
6.2.2 Income Assistance Programs: Applying For and Receiving Benefits.....	119
6.2.3 Difficulties in Accessing Policy and Program Information.....	126
6.3 Community-Based Supports Used by the Interviewees.....	133
6.3.1 Support Groups.....	133
6.3.2 Other Community-Based Supports.....	137
6.4 Changes and Improvements to Employment Support and Income Assistance Programs Suggested by the Interviewees.....	139
6.4.1 Flexible Work Hours.....	140
6.4.2 Job-sharing and Work from Home.....	146
6.4.3 Allowing Income Assistance Beneficiaries to Work Part-Time.....	151
6.4.4 Considering the Messages Sent by Programs and Policies.....	156
6.4.5 Increasing Awareness about Arthritic Conditions.....	159
6.4.6 Recognizing non-Western Medical Practitioners in Income Support Application Processes.....	164
6.4.7 Develop Programs for People with Disabilities, Not Employers.....	165
6.4.8 Considering Preventative Measures....	169
6.5 Conclusions.....	171
<b>Chapter Seven: Conclusions.....</b>	<b>184</b>
7.1 Introduction.....	184
7.2 Significant Findings.....	184
7.2.1 Changing Experiences of Employment and Spaces of Daily Life.....	184
7.2.2 Experiences of Government and Local Supports.....	187
7.2.3 Using Experiences to Address Employment Policies and Programs.....	189
7.3 Implications of Findings for Employment and	

Income Assistance Programs in Ontario.....	191
7.3.1 Clarifying ODSP and CPP-D Eligibility Requirements.....	191
7.3.2 Creating New Employment Support Policies and Programs.....	193
7.3.3 Reassessing the Application Process for CPP-D.....	195
7.3.4 Increasing Access to Policy and Program Information.....	197
7.4 Implications for Future Social Scientific And Geographic Research.....	198
<b>Appendix 1:</b> Map of the City of Hamilton.....	203
<b>Appendix 2:</b> Interviewee Release Form.....	204
<b>Appendix 3:</b> Interview Guide.....	206
<b>Appendix 4:</b> Free and Tree Interview Nodes.....	209
<b>Works Cited</b> .....	210



**LIST OF TABLES**

		Page
<b>Table 4.1</b>	Changes in the language used in government employment assistance programs for persons with disabilities.....	55
<b>Table 5.1</b>	Characteristics of the Interviewees...	67

## **Chapter One**

### **Introduction**

#### **1.1 Background**

People living with disabilities in Canadian society are a marginalised population. They often are underpaid, under- or un-employed, living in poverty, and located at the margins of society and space. Disabled women are doubly disadvantaged as they are both female and disabled. These women face many barriers to full participation in Canadian society and space, both physical and social in nature. Such barriers have resulted in disabled women becoming one of the most underemployed and underpaid groups in Canada, even more so than disabled men and able-bodied women. Further, men who acquire an impairment are more likely to remain in the workplace than women. Men and women with disabilities encounter many of the same workplace barriers, such as discrimination and a lack of support from co-workers, but often have different experiences of these barriers and their outcomes.

While the lived experiences of men and women with disabilities are different, the social policies which exist to support them are not. The social policies which assist

persons living with disabilities, such as employment and income assistance programs, do not generally distinguish between types of impairment or gender, there is one set of policies and programs to meet the needs of this very diverse group of citizens. However, experiences of disablement, the workplace, and socio-spatial barriers vary by gender, ability, and impairment.

## **1.2 Study Focus**

The focus of this study is on the workplace experiences of eighteen women residing in the City of Hamilton, Ontario since acquiring an arthritic condition, and how these lived experiences can be used to help assess and improve government employment policies and programs for persons with disabilities. Government policies and programs which fall within strategies developed to assist people with disabilities with employment and income assistance, such as the provincial Ontario Disability Support Program (ODSP) and the federal Canada Pension Plan for persons with disabilities (CPP-D), are discussed at length with particular emphasis on how eligibility is determined. This thesis also investigates the socio-spatial workplace barriers and changes in self-identity experienced by these women after acquiring an impairment. The workplace experiences investigated include the types of workplace

accommodations these women have sought from their employers, the women's changing views of themselves as being 'productive workers', and the government-funded and community support programs they have used to assist them in remaining in the workplace or with the transition to unemployment. The participants' experiences and knowledge of government employment policies and programs is used to identify ways in which policies and programs can be reformed so as to be more supportive of the needs of women who have acquired an arthritic condition. The overall objectives are to explain why and how these women's experiences of paid work and the workplace have changed in a particular place, namely the City of Hamilton, and to discuss the implications of their experiences and policy recommendations for current and future policy and program directions.

### **1.3 Study Themes and Aims**

The main themes being investigated with respect to employment and income assistance in Ontario are: establishing what the main policies and programs are, when they were developed, and how disabled persons' eligibility is determined. A related aim is to understand how women who have acquired arthritic conditions have used such policies and programs, and whether they believe that they meet the needs of this group of

people with disabilities. Furthermore, the main themes being investigated in relation to the women's changing workplace experiences and life spaces include: whether changes in self-worth and self-image in relation to their roles as 'workers' have been experienced, the types of workplace accommodations they have sought, and how experiences in other spaces of daily life, such as the health care system, have impacted on their experiences of paid work. The reasons for these emphases are discussed below.

Little research into the lives of women with arthritic conditions has been conducted by social scientists; particularly using qualitative methodologies. Further, few researchers to date have viewed people with disabilities as being policy experts, and looked to their lived experiences to inform policy directions. This study will address these knowledge gaps through its five main aims:

- to contribute to geographic and social scientific literature on disability and disablement using a feminist perspective
- to gain a better understanding of the lived experiences of women who have acquired arthritic conditions, particularly as they pertain to their involvement in the labour market
- to provide an historical review of Ontario's employment policies and programs for persons with

- disabilities, emphasizing how applicants' eligibility is determined and how current policies and programs differ from those developed previously
- to examine how the policy experiences of the eighteen interviewees can be used to assess employment and income policies and programs for persons with disabilities residing in Ontario
  - to recommend changes to existing employment and income support programs, and suggestions for the development of new programs, based on the opinions of the women interviewed and the findings of other related studies

These aims have been used to guide this study and to select the research methods. The potential contributions of this study and the rationale for these aims are discussed in detail in Chapter Two.

#### **1.4 Thesis Structure**

The remainder of this thesis has been organized into six chapters. Chapter Two reviews the existing literature, produced by both geographic and feminist disability scholars, on the lives of people with disabilities, their experiences of employment, and, more specifically, the experiences of women with disabilities in the Canadian labour market. This

literature review will introduce relevant themes, such as socio-spatial workplace barriers, and define terms which are used throughout the remaining chapters. Further, Chapter Two discusses the potential contributions to knowledge and social relevance of this research study. Chapter Three discusses the methods and techniques used in this study, and why they were chosen. Chapter Four is an historical policy review of the past and present employment and income support policies and programs available for people with disabilities in Ontario. The two programs primarily discussed in this chapter are the Ontario Disability Support Program (ODSP) and Canada Pension Plan for persons with disabilities (CPP-D). The discussion presented in this chapter will provide the background knowledge needed to understand the policy experiences of the women interviewed. Chapter Five, drawing on the results of interviews with eighteen women who have acquired an arthritic condition, examines changes in their life spaces and employment experiences including the socio-economic and socio-spatial 'placelessness' of being unemployed and changes in self-worth and self-esteem. Chapter Six also draws on these interviews, discussing the women's experiences of employment and income support policies and programs in Ontario and their recommendations for creating more supportive policies and programs. Chapter Seven summarizes the significant findings of this study, and discusses its implications for future

research on employment and income assistance policies and programs for persons with disabilities.



## **Chapter Two**

### **Literature Review**

#### **2.1 Introduction**

The purpose of this chapter is to discuss potential contributions of this study to geographic and social scientific knowledge about disabled women's experiences of the workplace, paid work and employment and income assistance programs. It is divided into three main sections: the first introduces concepts used in this study and sets them within the relevant geographic and feminist literature. The second section explores the changing life spaces and lifeworlds, particularly in relation to employment, of disabled Canadian women. Furthermore, the obstacles disabled women face in maintaining employment and changing experiences of employment are discussed. The third section discusses issues related to the employment of disabled Canadians, such as employment rates and workplace accommodations, with a focus on disabled women.

#### **2.2 Disability, Geography and Disability & Space**

The purpose of this subsection is to examine concepts of 'disability' relevant to this study, and how geographers

and feminist researchers have incorporated studies of persons with disabilities and experiences of disablement in the disciplines.

### **2.2.1 Defining "disability"**

There is no single, universally accepted definition of 'disability' or 'impairment.' Disability scholars and activists have identified two distinct concepts of 'disability,' each of which results in drastically different definitions. These are the social and biomedical models of disability. Those who adopt a social model of disability, also sometimes described at times as socio-political or socio-spatial, view disablement a process of exclusion resulting in people experiencing disabling social, attitudinal, and physically inaccessible conditions of life. The World Health Organization (WHO) (1999, p.26) has acknowledged such disabling processes, indicating that "disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment."

Biomedical definitions of 'disability' focus primarily on understanding disability as a medical problem, often pitying those of lesser health or ability. The World Health Organization (1999, p.26) biomedically defines 'disability' as

"...a personal problem directly caused by the disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals," and advocates for an integration of the social and biomedical models; they have termed this model the 'biopsychosocial' approach. Studies which have adopted a biomedical definition of disability are often positivistic in nature, relying heavily on quantitative methods and various types of statistical analyses (Park et al., 1997). The social and biomedical models of disability offer very different understandings of the causes and consequences of disablement.

The social model does not deny the presence of a biomedical condition, rather its advocates assert that the medical condition results in one or more impairments, but that socially constructed experiences such as discrimination and stigma are what disable people. According to Gleeson (1996, p.391):

Impairment is simply a bodily state, characterized by absence [of ability or health] or altered physiology, which defines the physicality of certain people. Importantly, no a priori assumption is made about the social meaning or significance of the impairment.

Hence the distinction between a physical or mental impairment and disabling societal processes is important when using the social model of 'disability'. Gleeson's (1996) definition of impairment will be adopted throughout this study to specifically refer to the "bodily states" of persons with

disabilities.

For the purposes of this study, 'disability' will be defined as (Wendell, 1996, p.23):

any lack of ability to perform activities to an extent or in a way that is either necessary for survival in an environment or necessary to participate in some major aspect of life in a given society...[and that] disability has biological, social, and experiential components.

The advantages of this definition are that it recognizes multiple forces shaping disablement and that experiences of 'disability' differ between people. Further, the term 'disablement' will refer to (Chouinard and Crooks, 2001, p.4):

an embodied process in place through which [disabled] women are situated (by themselves and others) in society and space, and through which their embodiment is inscribed with particular social and spatial meanings.

Therefore, disablement is the process being and becoming a person with a disability in society and space which can, for example, result in socio-economic and socio-spatial exclusion.

### **2.2.2 Disability & Space**

Until the last decade, there had been little focus on disability-based research in geography (Imrie, 1996). An early area of interest for geographers in this field was the relationship between persons with disabilities and access to the built environment. According to Park et al. (1997), geographers who started to study the disabling nature of the built environment were motivated by a belief that a lack of

physical access to a space is an infringement upon human rights. Imrie & Kumar's (1998) study of access to the built environment follows this early tradition of disability-based research in geography: they concluded that persons with disabilities are oppressed by the inaccessibility of certain spaces but also feel powerless in evoking change.

Geographers, however, have started to move beyond studies of access in the built environment and have re-focused, to a certain extent, on issues of daily life facing disabled persons. Gleeson (1998), for example, has offered an historical explanation of disabled peoples' lives and spaces, as far back as the feudal period, and has explored the changing beliefs about people with disabilities and the social value placed on them throughout time. Butler and Bowlby (1997) have explored the experiences disabled people have of public space; illustrating how the "social significance accorded to bodily normality, the fear of bodily impairment, and ignorance of the capabilities of visually impaired people" (ibid, p.430) shape the experiences that visually impaired people have in such spaces. MacKian(2000) has used a traditional geographic tool, the map, to show how the ways in which people with chronic fatigue syndrom (Myalgic Encephalomyelitis) experience spaces of daily life can be represented using mapping techniques. Kitchin (1998) has explored the spatiality of disability, concluding that space

can be used to keep people with disabilities powerless and out of the mainstream by keeping people with disabilities 'in their place', in the margins of society, or 'out of place', away from the mainstream of society. Recent studies of disability within geography such as those discussed above have been quite varied in terms of the subject matter explored, and have shifted the focus away from issues of physical accessibility towards understanding the daily lived experiences and changing life spaces of persons with disabilities. This new focus in geographic studies of disability and disablement has been a positive change, resulting in geographers paying more attention to what causes disablement in society and space, and how disablement has disempowered particular groups.

Gendered differences in experiences of disablement have received increasing attention among geographers. Dyck (1995, p.307) has identified the need for more geographic research into disabled women's lives, saying that "there has been relatively little analysis of the specific social practices and experiences of such women." Her research has focused on the lifeworlds of women who have acquired multiple sclerosis (MS) and other chronic illnesses, and how these women negotiate their changing experience in society and space. For example, she has chronicled how women with MS have changed residential locations in order to search for increased

accessibility in their homes and neighbourhoods as their impairments become more severe and disabling. Chouinard (1999<sub>1</sub>) has also focused on the experiences of disabled women by exploring their exclusion from activism in Canadian society and space. Her research has shown that state restructuring in Ontario has limited the funding of organizations which promote the rights of persons with disabilities, and that the geographic distance between politically active women with disabilities also pose significant barriers to the political organization of disabled women. What Dyck (1995) and Chouinard (1999<sub>1</sub>) have shown is that disabled women encounter barriers to participation in everyday life which are due to their extremely marginalized position in Canadian society and space.

This geographic study will contribute to the existing disability and space literature by adding to our understanding of how disabled women negotiate the labour market and workplace after acquiring an impairment, such as their changing relationships with employers and co-workers, and how government policy can help facilitate this negotiation. It differs from the existing body of geographic literature in its examination of the relationship between social policy and the lived experiences of women with arthritic conditions. This study will also build on the feminist disability and space analyses such as those conducted Dyck (1995), Moss and Dyck

(1999) and Chouinard (1999<sub>1</sub>) by describing and explaining the lived and embodied experiences of women with disabilities.

### **2.2.3 Feminist Analyses of Disability**

Traditionally, there has been little feminist analysis within disability studies (Morris, 1996; Sheldon, 1999). Until recently, feminist researchers who did conduct research on disability tended to produce similar types of studies. The aim of such studies was to uncover and record subjective experiences of disabled women, rather than to produce social explanations of disability and disablement (Sheldon, 1999). Hence, early feminist research on disability had a narrow focus, producing accounts of disability rather than theoretical or social understandings. Their studies did, however, lay the foundation for current feminist analyses of disability which has moved beyond producing experiential accounts in an attempt to investigate larger socio-economic and socio-spatial causes of disablement throughout the world. Studies of this sort include: Bailey (1996), Begum (1996), Butler & Bowlby (1997), Chouinard (1999<sub>2</sub>), Frank (1998), Hema (1996), Morris (1996), and Sheldon (1999).

Studies of the double disadvantage of disabled women by early feminist researchers have been over-produced according to Morris (1996) and Sheldon (1999). Double



disadvantage research focuses on how disabled women are doubly-oppressed as they are members of two socio-economically marginalized groups in society: women and persons with disabilities. Such research has tended to lack explanations for the double disadvantage, or explanations of the structural forces that result in this (Sheldon, 1999). Sheldon (1999) and Morris' (1996) argue that feminist researchers within disability studies must move beyond researching double disadvantage, unless such research is accompanied by further social and structural explanations; however, experiential accounts of double disadvantage or disablement must not be discounted as they have made an important contribution to our understandings of the lived experiences of women with disabilities. The work of these earlier researchers has, for example, provided accounts of disabled women's lives which have informed current efforts to explain disabled women occupy such a marginalized position in society and the ways they have resisted ascribed roles. A goal of this study is to understand the lives of women living with arthritic conditions in a particular place, specifically in relation to experiences of paid employment, and how these lived experiences can then be used to inform social policy using a feminist perspective.

## **2.3 Women and Disabling Conditions**

The discussion presented in this subsection will illustrate some of the socio-spatial barriers encountered by women who have disabilities and provide an overview of the nature of arthritic conditions.

### **2.3.1 Women with Disabilities in Canada**

In the Province of Ontario approximately 500,000 women live with mental and physical impairments which create disabling life conditions (Fawcett, 2000). Disabled women are an extremely impoverished and marginalized group both in Ontario and in Canada. In 1995, for example, the rate of poverty for working-age women with disabilities (those aged 15 to 64) in Canada was twice that of working-age women without a disability: 36 per cent compared to 18 per cent (Fawcett, 2000, p.4). Workforce participation has a large impact on the poverty rates experienced by various groups in Canada. In 1996, poverty among women with disabilities in Canada employed full-time was 8% while it was 40% for those who were unemployed (Fawcett, 2000). Thus, women with disabilities in Canadian society and space face high rates of poverty in general, and those who are unemployed, as Fawcett's (2000) findings indicate, are even more likely to be extremely socio-economically marginalized.

Experiences of disability and disablement vary greatly between women who identify as being 'disabled'. Stone (1995) argues that the experiences of women with hidden disabilities, where there is no outward or obvious sign of impairment, are drastically different from those women with visible disabilities. She has found that people are less knowledgeable about the nature of many hidden disabilities, and of the socio-spatial barriers experienced by women who have non-visible impairments. For example, as Dyck (1995) had documented, disabled women may encounter hostility from members of the public over using parking spots reserved for persons with disabilities when there is no visual sign, such as a wheelchair or cane, of impairment. Brassard (1994) has also found that there are drastic differences between the experiences of women who have congenital impairments (those that are present from birth) and women who have acquired impairments. These two groups face different challenges and barriers in their everyday lives which impact their daily experiences. For example, women who have congenital impairments are more likely to experience discrimination based on ability throughout their years of school and when they attempt to enter the labour market, whereas, according to Brassard (1994), those who have acquired impairments while employed are more likely to have difficulty maintaining their jobs after becoming disabled. The everyday life experiences

of disabled Canadian women also vary based on the type of impairment present, whether it is visible or hidden, and whether or not assistive devices, personal attendants and other such supports are needed and available. Hence, women with disabilities are not a homogeneous group as there are many socio-economic and experiential factors which shape their daily experiences, as was suggested by Wendell's (1996) definition of 'disability' presented earlier.

### **2.3.2 Changing Life Experiences After Acquiring a Disability**

As stated previously, the daily experiences of, and barriers faced by, women with congenital and acquired impairments are often quite different. According to Marris (1996, p.25): "if you have an illness from birth or early childhood, it has a very different impact on your life than if you develop it as an adult." Dyck's (1995) research on the changing lifeworlds of women who have acquired MS highlights some of the changes in experiences of life encountered by these women. She defines the lifeworld as being "the taken-for-granted mundane experiences of daily life as carried out in particular spatio temporal settings" (Dyck, 1995, p.307). Dyck (1995) shows that the lifeworlds of women who have acquired MS had been interrupted due to changing physical abilities, such as reduced mobility, and changes in how paid

and unpaid work was done. She has concluded that (Dyck, 1995, p.319):

As the illness experience is given meaning within the constraints and opportunities experiences in home, neighbourhood and work spaces, women also actively seek ways in which to remap their lives in time and spaces.

Hence, the lifeworlds of women who have acquired impairments may change over time and space resulting in the women remapping their everyday lives to accommodate changes in ability and mobility. The frequent changes made to their lifeworlds due to changes in ability level, employment and participation in household chores, show that impairments are not static and that therefore women with chronic illnesses must constantly renegotiate the changing spaces and experiences of their daily lives as a result of the disablement process.

Impairment, illness and disability also have profound influences on the social lives and daily interactions of women who have acquired an impairment. Robinson (1990) has studied the 'social careers' of people who have acquired MS. He defines the social career as the "socially visible operation of a sequence of interactions and their social consequences" (Robinson, 1990, p.1173), and argues that the social career may be impacted by changes in social status as a result of the processes of disablement. Robinson (1990) has concluded that a person's biomedical condition, and the impairments which

develop as a result, can negatively impact a person's social status due to changes in employment status, such as moving from full-time to part-time paid labour, and financial independence (Robinson, 1990). For example, a person with a disability who is currently unemployed and receiving income assistance who previously had participated in full-time paid labour will most likely have experienced a negative change in social status thus impacting his/her social career. Not only may one's lifeworld be interrupted after acquiring a chronic illness, but the social career may too be changed due to alterations in socio-economic status, such as changes in labour force participation, which are the result of changes in the type of employment or a reliance on income support programs which may not equal the salary earned when employed in the paid labour force.

Living with an acquired impairment can be a very isolating experience for many disabled women. According to Marris (1996, p.9): "Illness reminds us that each of us is a solitary unit among other solitary units, and brings home to us the limits of human companionship and sharing." This loneliness and solitude can be experienced in many places of daily life including the workplace. Such solitude can occur when, for example, an employee with an impairment which impacts his or her energy levels must take extra rest breaks during the working day; ones which other employees are not

allowed. It can also occur when employees who experience mobility restrictions use ramps and elevators which are not located in the same spaces used by other co-workers, potentially making them feel alone and 'out of place'. This solitude can also be experienced when a chronically ill woman has to remove herself from the workplace due to worsening symptoms, an inability to perform work duties, and/or an inability to obtain reasonable workplace accommodations, and misses out on daily interactions with her co-workers and other casual acquaintances (Marris, 1996). Living a solitary existence, or perceiving one's existence to be solitary, can unfortunately be a daily reality for disabled women who have to withdraw from the labour market or who are made to feel 'out of place' within their work environments.

Another important life change that can take place after acquiring certain types of impairments, such as arthritic conditions, is that of fluctuating physical and/or mental health. Often women who have acquired an arthritic or musculoskeletal impairment report unpredictable changes in levels of ability, energy and perhaps degrees of pain (Marris, 1996) making it difficult to maintain a daily routine. Such unpredictability can be manifested, for example, in the onset of fatigue experienced by women who have acquired lupus, by the stiffness and inflammation of joints previously unaffected by osteoarthritis, or by the sudden onset of numbness caused

by fibromyalgia. This unpredictability can result in daily changes in levels of ability and energy resulting in changes in abilities to cope with daily life. It is difficult for persons with fluctuating physical abilities to remain actively involved in the paid workforce as physical unpredictability makes it hard to consistently perform work duties. Marris (1996) notes that mental and physical health are closely related, and that fluctuations in one's physical condition can result in increasing mental frustration and anxiety. Such anxiety can be brought on when a person is unsure whether they will be able to maintain their position in the workforce, thus generating concern about a loss of income, due to fluctuating ability levels. Living with, and understanding, such daily changes in ability poses a significant life challenge for many impaired women who have acquired musculoskeletal conditions.

### **2.3.3 Women & Musculoskeletal Impairments**

There are many types of mental and physical impairments that affect Canadian women, some more frequent than others. The chance of acquiring a musculoskeletal impairment, for example, is far greater than that of being born with a congenital physical disability (Baldwin & Johnson, 1998). There are a wide range of musculoskeletal disabilities, including: arthritis, back and spine injuries,



missing extremities and amputated limbs (Baldwin & Johnson, 1998).

Arthritic conditions, including all forms of arthritis, lupus and fibromyalgia, are some of the most commonly occurring musculoskeletal impairments acquired by Canadian women. Rheumatoid arthritis, for example, affects 300,000 Canadians, impairing twice as many women as men and is most likely to be acquired between the ages of 25 and 50 (The Arthritis Society, 2001<sub>1</sub>). Lupus and fibromyalgia are also both more likely to impair women in a range of ages from 15-55+ than men (The Arthritis Society, 2001<sub>2,3</sub>). The exact causes of fibromyalgia, lupus, rheumatoid arthritis and osteoarthritis are unknown. Pain and fatigue are common symptoms of all of these illnesses, while other symptoms vary by type of illness. Further, the range and severity of symptoms experienced varies between women: in some cases short or long-term remission of disease may eliminate symptoms completely while in others symptoms are severe and unrelenting. A common symptom of osteoarthritis is pain and swelling around one or more joints which lasts for a period of no less than two weeks (The Arthritis Society, 2001<sub>4</sub>). Osteoarthritis commonly involves localized joint swelling and pain resulting from damage to specific joints over time. Rheumatoid arthritis is an auto-immune disease which can affect any and potentially all joints in the body causing

inflammation, redness, pain, and swelling which damages cartilage, bones, tendons and ligaments throughout the body (The Arthritis Society, 2001<sub>1</sub>). Symptoms of lupus are extremely varied and can include: low energy and fatigue, skin rashes, sores in the mouth or nose, increased sensitivity to sunlight, hair loss, and sudden weight loss or gain (The Arthritis Society, 2001<sub>2</sub>). The symptoms of fibromyalgia include stiffness and pain in muscles and joints throughout the body, difficulty sleeping, numbness, poor memory, an inability to concentrate and migraine headaches (The Arthritis Society, 2001<sub>3</sub>).

The course of arthritic conditions is unpredictable. Women who have acquired such chronic illnesses generally experience fluctuations in the severity of symptoms such as pain, thus making it difficult for them to cope effectively with demands such as paid employment or performing household tasks. These chronic illnesses can result in severe physical impairment, for example in mobility and energy, and seriously impact the lives of the women who have acquired them. Potential impacts on women's lives can include job loss, reduced income, dependence on income support, and increased isolation in the home.

Little non-biomedical research has been conducted on the lives of women who have acquired arthritic conditions. In general, disability scholars have neglected to study the lives

of this group of individuals. Little is known about how these women attempt to deal with disablement and overcome related challenges such as maintaining paid employment and applying for income assistance. This study looks at the employment experiences of women living in the City of Hamilton who have acquired an arthritic condition, as well as their knowledge and experiences of government employment and income support.

## **2.4 Employing Canadians with Disabilities**

There are many factors which can impact the employment experiences of Canadians with disabilities including gender and geographic location. There are also many barriers which prevent the full participation of persons with disabilities in the Canadian labour market, such as discrimination in hiring processes. These issues will be discussed in this sub-section along with factors which specifically impact disabled women's employment.

### **2.4.1 Disability & Employment: The Canadian Context**

In 1990, 37.5% of disabled women and 59.2% of disabled men were employed (Scott, 1993, p.26). In 1998 it was reported that while 40.3% of working age Canadians with disabilities were employed, only 30.7% of disabled women were actively in the workforce (Runte, 1998, p.102). It is also

important to note that while 18% of all women are disabled, 62% of those of working age (ages 18-65) are unemployed (Ternette, 1993, p.18). These figures illustrate the fact that disabled Canadian men and women typically have very different employment experiences, in that women with disabilities are more likely to be unemployed. Employment experiences do not simply vary between the sexes, there are also regional differences within Canada that affect the employment rates for persons living with an impairment. Within Ontario there are significant regional differences in rates of labour force participation by women with disabilities. Approximately one third, or 33%, of women with disabilities living in Sudbury, Ontario, a city which experiences extremely low rates of employment, in 1995 were employed while 44% of those residing in Kitchener were employed (Fawcett, 2000, p.6). Fawcett (2000, p.6) argues that despite regional differences in (un)employment rates, women with disabilities are "the most likely to be without employment and the least likely to have full-time, full-year employment" regardless of their place of residence. These statistics show that gender, such as the higher unemployment rates experienced by women with disabilities, and geography, in that regional differences in employment rates of women with disabilities vary throughout Ontario, do play a role in the workplace experiences of disabled Canadians.

In 1991, a total of 4.2 million Canadians reported having a disability (HRDC Evaluation and Development, 1999, p.4). A further breakdown of the 1991 figure shows that: 48% of working aged individuals with disabilities were employed in full or part-time paid labour, 44% were not in the workforce (also known as the "hidden unemployed"), and 8% were unemployed (HRDC Evaluation and Development, 1999, p.7). Thus, just under one-half of this group of Canadians was employed. However, not all those who are employed are able to stay above the poverty line. For example, 18.7% of women and 19.1% of men with disabilities who worked in both 1993 and 1994 were not able to stay above the poverty line during those years (Fawcett, 2000). The economic fate of those who were unemployed during these years is far worse: 53.8% of women and 46.6% of men with disabilities unemployed in both 1993 and 1994 were unable to remain above the poverty line, as compared to 30.1% of able-bodied women and 35.8% of able-bodied men (Fawcett,2000). These figures show that many disabled women and men are extremely economically marginalised, many not being able to remain above the poverty line.

#### **2.4.2 Barriers to Finding and Maintaining Employment**

Disabled Canadians face many barriers to employment; not simply physical barriers, but social and attitudinal ones

as well. The Roeher Institute (1992) has classified 6 common types of employment barriers faced by Canadians with disabilities:

1. discrimination when trying to seek training
2. exclusion from "mainstream" jobs
3. lack of access to disability supports
4. barriers to education and training
5. poor service funding and delivery
6. medical/assistive device-related costs

Discrimination in entering the workforce is still a major barrier for disabled Canadians regardless of employment equity legislation existing at the federal level such as the Human Rights Act and the Canadian Charter of Rights and Freedoms. In 1992, 15.8% of Canadians with disabilities actively seeking employment reported being unlawfully discriminated against to a Human Rights Commission due to their impairment (Roeher Institute, 1992); this figure would be much larger if it could account for all those who did not report experiences of discrimination. According to the Ministry of Citizenship, Culture and Recreation (MCZCR) (1998), it was not until 1981 that the federal Government even considered a 'handicap', as it was termed at the time, to be grounds for work-related discrimination.

There are other significant barriers to finding and maintaining employment which have been identified. The Federal Task Force on Disability Issues (1996), set up to identify issues facing Canadians with disabilities, has found

that there are three main types of barriers preventing disabled Canadians from fully participating in society and space: attitudinal, systemic and physical, and argues that the social environment and economic system are more significant barriers than those posed by physically inaccessible environments. Thomason et al. (1998) and MacGregor (1995) support this view, concluding that the attitudes of co-workers are *more important* in making an inclusive workplace than the physical design and layout of a workspace. Thus, there are a variety of socio-spatial workplace barriers faced by Canadians with disabilities which employment and income support programs must be able to effectively address.

#### **2.4.3 Workplace Accommodations**

There are a variety of workplace accommodations needed by disabled Canadians. They vary by types of jobs and impairments. There is a common misconception that providing workplace accommodations is a costly venture. However, according to Ontario's Ministry of Citizenship (1996), two-thirds of all accommodations cost less than \$650, with only 4% of working Canadians who have disabilities needing some type of building modification (ramp, accessible washroom). There are other types of accommodations beyond physical accessibility to be considered. Some disabled employees

require job modifications such as reduced hours, job-sharing contracts and/or flexible work hours in order to fulfill their duties. However, according to the Global Applied Disability Research and Information Network on Employment and Training (GLADNET) (1993), only a minority of individuals require such modifications as 70% of impaired individuals do not require any type of job accommodation or restructuring.

#### **2.4.4 Employing Women with Disabilities**

While both disabled men and women share experiences of discrimination and barriers to employment, such as workspaces designed in ways that make use and access difficult for workers with physical impairments and lack of understanding and support from employers and co-workers, women with disabilities also experience gendered barriers to inclusion and well-being in the workplace. These include such social barriers as judging women with visible impairments as being unacceptable for jobs normally given to 'attractive' female employees, such as receptionist or sales representative. Being disabled and female often means being disadvantaged in hiring processes and in receiving accommodations in the workplace (Fawcett, 2000). Disabled women face many barriers to employment that are not encountered by men, or are experienced to a lesser extent by males. Once in the



workforce, women with disabilities are also less likely to be promoted than other groups in the Canadian labour market including able-bodied women and men with disabilities (Runte, 1998). Physical, social and attitudinal barriers all play a role in the hiring and promotion of disabled Canadian women.

As was discussed earlier in this chapter, disabled women typically have yearly earnings lower than those of disabled men and able-bodied women. In 1994, the Canadian Council on Social Development determined that 38% of women with disabilities earned less than \$15,640 per year, placing them in the lowest earnings category (Fawcett, 2000). Low wages can contribute to many other substandard daily living situations such as an inability to pay for bills or a reliance on food banks for daily subsistence. For example, disabled women are more likely to experience food shortages as a result of their poor economic condition than other groups in Canadian society (Fawcett, 2000). This results in greater use of food banks by women with disabilities who are below the poverty line, and potentially poor nutrition which may aggravate or worsen their physical impairments.

Despite the findings presented here regarding the workplace experiences of disabled Canadians and, more specifically, disabled women, we still know little about the workplace experiences of women who have acquired arthritic conditions. Information reported regarding disabled women in

general, for example the workplace barriers reported by Fawcett (2000), may not apply to this group of women as little is known about their workplace needs and experiences. This study will contribute to our knowledge about their employment experiences and the abilities of existing policies and programs to address their employment and income support needs.

## **2.5 Conclusion**

This chapter has established the need for research regarding the lived experiences of women who have acquired arthritic conditions and the implications of these experiences for their access to employment, and for government employment policies and programs. Existing geographic literature relating to disability and space, while increasingly becoming concerned with issues pertaining to the lives of women with disabilities, has yet to specifically examine the employment experiences and support needs of this group. Furthermore, existing literature regarding the workplace barriers faced by, and labour force participation of, women with disabilities has yet to fully explore how different types of impairment and chronic illness affect access to, and experiences within, the workplace. Discussing the relationship between disabled Canadians' experiences in labour markets and the workplace, and of social policy, as is done in this study, enables

researchers to move beyond simply describing the life experiences of persons with disabilities, by explaining how policies and programs can better address the employment needs of this group. The issues discussed in this chapter will provide a knowledge-base for understanding and interpreting the experiences discussed in the interviews. The next chapter, Chapter Three, will discuss the methods and techniques used in this study as well as the conceptual framework guiding this research.

## Chapter Three

### Research Methods and Techniques

#### 3.1 Introduction

Two main qualitative research methods were used in this study: 1) a descriptive account of recent support policies and programs for persons with disabilities in Ontario and 2) a case study of employment and employment support programs as experienced by women who have acquired an arthritic condition residing in the City of Hamilton, Ontario. This study's reliance on qualitative research techniques stems from the acknowledgement that (Mazumdar and Geis, 2001, p.256):

In disability studies, statistical reports can reduce emotions to dry and dreary numerical formulations that fail to convey the most significant elements of the world of persons with disabilities and provide little advanced understanding of that world.

The specific research techniques used were a review of documents pertaining to recent changes in employment policies and programs for persons with disabilities in Ontario, Canada, and in-depth interviews with eighteen women who have acquired an arthritic condition residing in the City of Hamilton, Ontario. The main goal of the historical policy review was to

establish the current employment support programs for Ontarians with disabilities and how they differ, if at all, from previous ones. The main aims of the interviews were to explore the types of employment supports the women interviewed desired, as well as their experiences of current employment support initiatives. A related aim was to identify if there were any employment and/or income assistance programs that had affected these women's abilities to maintain employment, and the barriers that they had faced in the workplace. The research methods and sampling techniques are described in detail throughout the remainder of this chapter. First, however, a discussion of the conceptual framework which underlies both this study and the methods used is presented.

### **3.2 Conceptual Framework**

This study uses a *socialist feminist approach* to conceptualize the lives and life spaces of women who have acquired an arthritic condition. The socialist feminist approach is guided by the acknowledgement that capitalism, the state, and 'traditional' gender roles are all factors which influence women's daily lives (Pratt, 1994). In the case of women with disabilities, this means that societal values around 'health' and 'ability', and the states' regulation of negatively different bodies such as in the development of

eligibility criteria for income assistance programs, both assist in shaping their daily life experiences in a particular place. Furthermore, women with disabilities are 'active agents' in negotiating such experiences through their changing identities and life spaces as an attempt to cope with illness and with being and becoming disabled.

### **3.3 Feminist Research Considerations**

Ethical guidelines for conducting feminist research, as established by the Canadian Research Institute for the Advancement of Women (CRIAOW), were followed as closely as possible (CRIAOW, 1996). Such considerations included: considering the confidentiality needs of the participants, allowing for a variety of interview locations so as to not inconvenience the interviewees, and informing participants about how the findings of this research may be used. The methods and techniques employed are also typically feminist geographic in nature as the interview is considered to be the 'quintessential' feminist method and the use of multiple methods is also characteristic of feminist research (Maynard & Purvis, 1994). Harding (1987) also finds that document analysis, such as historical analysis of policy documents, is a technique often used by feminist researchers. Thus, the ethical considerations and methods used in this study help

shape it as a feminist research project.

### **3.4 Historical Policy Analysis**

In order to understand how women who have acquired arthritic conditions living in the City of Hamilton have used employment support policies and programs, and what the implications of their experiences are for the future of such social policies, an understanding of current and recently discontinued policies must be gained. Such an understanding is needed in order to identify the types of employment supports available for persons with disabilities, their eligibility requirements, and to put the experiences of women with arthritic conditions in a particular place into context. Relevant government documents regarding employment support policies and programs available to persons living with disabilities in Ontario between 1962 and 2001 were reviewed in addition to articles discussing these policies and programs. Information regarding the current programs and policies, as well as those that they replaced, was gathered to establish what supports are available at present and how eligibility criteria have changed over time.

The documents used for the historical policy review were gathered from a variety of sources. Most of the documents were published by the government while some

literature, such as articles by Leeson (1990) and Moorhead (1991), and policy reviews, including those written by Beatty (1998) and Campolieti and Lavis (2000) were also incorporated. Government documents were published by several different Ministry offices at both the federal and provincial levels. These documents were collected from libraries, research institutes, government clearinghouses as well as the Ministry websites on the internet.

### **3.5 Interviewing Techniques**

The interviewees who were recruited for this study had to meet several sampling criteria. First, the interviewees had to reside in the City of Hamilton, see **Appendix 1** for a map of this area. An exception to this criteria was made for three interviewees who do not currently reside in the area but who use services offered within the City. Second, the women interviewed had to have acquired an arthritic condition since first entering the workplace. This is because women who have acquired an impairment or disability after first participating in paid labour have specific employment support needs (MagGregor, 1995) and have not faced additional barriers to employment such as discrimination based on ability in the education system (Baldwin & Johnson, 1998). A total of 18 women who met the study's criteria participated in an



interview; these women's life situations and impairments were quite varied. There are a variety of arthritic conditions; those acquired by the women interviewed were fibromyalgia, lupus, osteoarthritis and rheumatoid arthritis. Two of the women were undergoing diagnosis at the time of the interview. Five of the women interviewed had acquired multiple arthritic conditions, and three had been diagnosed with both fibromyalgia and arthritis. The interviewees ranged in age from late twenties to late sixties. Five were involved in full-time paid employment, five were employed part-time, and the remaining eight interviewees were on short- or long-term leave from paid employment.

The qualitative sampling strategies used in this study were both *snowball* and *opportunistic*. Snowball sampling occurs when one "identifies cases of interest from people who know people who know what cases are information-rich" (Miles & Huberman, 1994, p.28). An opportunistic strategy is similar, it involves "following new leads; taking advantage of the unexpected" (Miles & Huberman, 1994, p.28). Most of the participants were contacted in a snowball-fashion with the assistance of the Arthritis Society's Hamilton office. The office's staff was able to provide a list of approximately 15 potential interviewees and their contact information. From this list a total of 11 interviewees were recruited. The

remaining 7 interviewees were contacted in an opportunistic fashion, as a result of electronic-mail (e-mail) sent to various people and offices based at McMaster University and the contacts made from the responses. The main limitation of these sampling techniques is that they limit the potential pool of interviewees to only those in touch with the Arthritis Society or with the persons contacted by electronic-mail. However, as interviewing a representative sample, in terms of class, gender, race, socio-economic status, was not a goal of this research project, the benefits of using these sampling strategies, in that eighteen women were interviewed in a limited period of time using the contacts provided, outweigh the potential limitations. Using both snowball and opportunistic sampling techniques, several potential interviewees who met the study's criteria were contacted resulting in 18 interviews being conducted.

Prior to the interview each participant was informed of her ethical rights as a study participant. It was essential that participants be informed of such rights, not only because this is required by most university research ethics offices, but also because it is important that they are aware of their role in the project, how the information they provide may be used, and any potential implication of their participation. Upon being informed of these rights they signed a release form, as seen in **Appendix 2**. To ensure

confidentiality, participants were asked to choose a pseudonym. They were informed that no person other than the researcher would have knowledge of their true identities. These pseudonyms appear throughout the remaining chapters.

The interviews varied in length from thirty-five minutes to one and one-half hours, with the average length being one hour. The participants were offered a choice of potential interview locations; this was done to make each interview as comfortable as possible for the participants. Thirteen of the women chose to be interviewed in their homes, one having been conducted over the telephone. Most of these interviewees experienced mobility restrictions due to their impairments, and some were unable to find transportation to a location outside of their home thus impacting their choice of interview location. Those interviews not conducted in participants' homes were held in local coffee houses (2 participants), in private offices at the workplace (2 participants) and in a local library (1 participant). Of these five interviews done out of the home, two were with the women who resided outside of the City of Hamilton, but used the services offered within its boundaries.

Although the interviews varied in length and location the interview guide used was the same for all participants. In-depth questions were asked using an active interviewing style. An active interviewing style is "...guided by the

interviewer and his or her research agenda" (Holstein & Gubrium, 1995, p.76). An interview guide was used because it allows flexibility in the topics covered in each interview as it "can provide the interviewer with a set of predetermined questions that might be used as appropriate to engage the respondent and designate the narrative terrain" (Holstein & Gubrium, 1995, p.76). Having such flexibility was important as the interviewees had varying experiences of the different government policies and programs asked about so that, for example, interviewees who had not used certain program were not questioned about their experiences of them. This flexibility is important when conducting an active interview as the purpose of using an interview guide is to "let the respondent's responses determine whether particular questions are necessary or appropriate as leading frames of reference for the interview conversation" (Holstein & Gubrium, 1995, p.77). A copy of the interview guide is presented in **Appendix 3**. The questions posed were subjective; encouraging each interviewee to share her experiences regarding government-sponsored employment programs.

Each interview was divided into four main sections. First, the women were asked to discuss the nature of the musculoskeletal condition they had acquired and their employment history. Second, they were asked to identify

socio-spatial barriers to employment that they had experienced since acquiring an arthritic condition. Third, the women were asked to discuss government employment programs and local support programs used since acquiring an arthritic condition, and whether or not they were satisfied with current employment policies and support programs and services. Finally, the participants were asked to comment on how government social policies and programs, particularly those related to employment, can better support the needs of women who have acquired arthritic conditions since entering the paid labour force.

The data generated by the interviews were analysed using Nvivo © Revision 1.2 qualitative software. Using Nvivo ©, the transcribed interviews were coded for major themes in the data, this coded information was stored in free nodes and in tree nodes (sets of related nodes). A total of 33 free nodes and 8 tree nodes were created using Nvivo ©, a list of these free and tree nodes can be found in **Appendix 4**. The coded documents were then used to help make sense of the experiences the interviewees reported.

### **3.6 Conclusions**

This chapter has outlined the specific conceptual framework, methods and techniques used for data collection and

analysis in this study. Again, the main purpose of the historical policy review was to determine what the current employment policies and programs for persons with disabilities in Ontario are, how they determine eligibility, and how they have changed over time. Active interviewing, in which the interviewer and interviewee engage in a conversation aided by an interview guide, allowed flexibility in discussing only those employment and employment program experiences relevant to a particular interviewee. Results of this research are discussed in Chapter Four, with a focus on the employment programs and policies reviewed, and Chapters Five and Six, which discuss the employment and government support experiences of the interviewees, and the recommendations they make to create programs and policies which are more supportive of the needs of women with acquired arthritic conditions.

## Chapter Four

### **A Review of Ontario & Canada's Employment Support Policies and Programs for Persons with Disabilities: 1962-2001**

#### **4.1 Introduction**

This chapter will discuss two of the most recently developed federal and provincial employment support programs for persons with disabilities. The first is the Ontarians with Disabilities Support Program (ODSP) which is administered under the federal government's Employability Assistance for Persons with Disabilities (EAPD) Act. The second program is the Canada Pension Plan for persons with disabilities (CPP-D) which is discussed to a lesser extent as it is not considered to be one of the main federal strategies to assist disabled persons, though it is an important source of income support for those eligible for assistance through it.

There are two main subsections in this chapter. The first presents an historical review of how the current Ontarians with Disabilities Support Program (ODSP) and Employability Assistance for Persons with Disabilities (EAPD) came into existence. The second subsection offers a discussion of how the ODSP and CPP-D determine eligibility.

#### 4.2 Government Assistance in Ontario, Canada

Since the early 1960s (1962) the Vocational Rehabilitation for Disabled Persons Program, or VRDP, had been the main employment-support for disabled Canadians provided by the federal government. Between the 1960s and 1990s, 6 main federal strategies had been developed to assist disabled Canadians in the workplace (Roehrer Institute, 1992):

1. Human Rights Legislation
  - This includes the Human Rights Act and the Canadian Charter of Human Rights and Freedoms.
2. Employment Equity Legislation
3. Canada Assistance Plan (CAP)
  - Funds for this Plan are provided by the federal government for provincial initiatives including welfare, rehabilitation and personal assistance.
4. Vocational Rehabilitation of Disabled Persons (VRDP)
  - Both the federal and provincial governments shared the cost for training and employment placement services under this program.
5. Canadian Jobs Strategy (CJS), Labour Force Development Strategy (LFDS)
  - The CJS was implemented in 1985, it funded employment training for persons with disabilities.
  - The LFDS was a framework created for the development of labour market policies, four major programs were created out of it:
    1. Information & Special Initiatives Program
    2. Employability Improvement Program
    3. Labour Market Adjustment Program
    4. Community Development Program
 Each of these four programs ran out of Canada Employment Centres (CECs), they promoted partnerships between business and government.
6. Employability Enhancement Agreements
  - These agreements were started in 1985 and were developed to promote the training of persons with disabilities who were receiving social



assistance.

The VRDP was a funding program which reimbursed the provinces and territories for 50% of the costs of the vocational rehabilitation programs and services offered for people with disabilities (Crawford, 1997). It was thus essentially a mechanism through which funds to assist disabled individuals were transferred from the federal government to the provincial and territorial governments. The services funded with VRDP funds included: skills assessment, counselling, assistive devices, vocational training, books & tools needed for vocational rehabilitation, maintenance or training allowances, goods & services required during periods of "vocational crisis" (such as providing clothing funds for a person returning to work) (Crawford, 1997). The breakdown of VRDP funding at the federal level in the 1993-94 fiscal year was as follows (Crawford, 1997): non-profit workshops and vocational rehabilitation agencies 24%, individualized supports to participate in job training 16%, mental health programs in clinics and psychiatric hospitals 10%, drug and alcohol programs 36%, administration 13%.

In 1996 the VRDP was reformed and in 1997 was replaced by the Employability Assistance for Persons with Disabilities, or EAPD (Social Service Ministries, 1997<sub>1</sub>). The main difference between the VRDP and EAPD Acts were in the way that support was administered to individuals and in how they

determined eligibility; both of these points will be discussed later in this chapter.

"In June 1996, the Prime Minister and Premiers made tackling the needs of people with disabilities a national priority as part of the social policy renewal process" (Social Service Ministries, 1997<sub>2</sub>, p.1). The Employability Assistance for Persons with Disabilities agreement, or EAPD, is a multilateral funding agreement between the federal and provincial governments. The federal government contributes 50% of the costs for eligible provincial and territorial services, those which are designed to assist in the employment and income support of persons with disabilities. Each province and territory develops a 5 year contract with the Canadian government regarding this multilateral funding, with the first five-year contracts having been developed in the 1998-99 fiscal year (Social Services Ministries, 1997<sub>2</sub>). The first set of contractual agreements will be in place between 1998 and 2003 in all provinces and territories but Quebec.

One of the major reasons for the establishment of the EAPD was so that provincial and territorial priorities could be funded "...in a manner consistent with their needs and the requirements of persons with disabilities" (Crawford, 1997, p.15), rather than creating national level policies and programs for *all* persons with disabilities in Canada; this

allows for considerable variation in government responses to the Act's funding at the local and provincial levels.

Many of the EAPD's programs and services are administered by Human Resources Development Canada (HRDC) (Ministers Responsible for Social Services, 1997). The federal government has committed to spending \$168 million annually on this program since its inception in 1998, to be divided between the provinces and territories involved using multilateral agreements between each province or territory and the federal government (Ministers Responsible for Social Services, 1997). The money provided by the EAPD funds a wide variety of programs and services, and it is up to each province and territory to determine how the funds will be used. Examples of how this funding may be used are (HRDC, 1998): employment counselling and assessment programs for persons with disabilities who are unemployed but able to work, skills training workshops for disabled individuals who want to increase their skills base, and wage subsidies for businesses who hire employees with disabilities.

Ontario's provincial government currently has 7 legislative Acts governing the rights of and assistance for persons with disabilities. These are the Ontario Building Code, the Ontario Corporations Tax Act, the Ontario Disability Support Program (ODSP) Act, the Education Act, the Blind Person's Rights Act, the Highway Traffic Act and the Election

Act (Beatty, 1998). Of these Acts, the ODSP is the Act which governs most of the province's employment support policies and programs for disabled citizens. Prior to 1998, under the federal VRDP program, the main employment support program for disabled people in Ontario was administered under the Family Benefits Act. Under the VRDP, individuals with disabilities who were labelled "permanently unemployable" were given income assistance in lieu of seeking and maintaining employment (Beatty, 1998). In 1998, Ontario's Social Assistance Reform Act was created and implemented; the Ontario Disability Support Program, or ODSP, is one of the 2 main components of the Act (Beatty, 1998), the other being the Ontario Works Act (Crawford, 1997). The ODSP replaced the Vocational Rehabilitation Services (VRS) program, Ontario's former counterpart to the national VRDP.

Vocational Rehabilitation Services was started in Ontario in the early 1960s as the province's response to the federal VRDP program. The program was based on the belief that people with disabilities were unable to maintain competitive employment and that they therefore must rely on social services, namely income support, in lieu of working in the paid labour force (Waxman, 2000). According to Waxman (2000), a current Director in Ontario's Ministry of Community and Social Services, the program had many deficiencies:

The program was not effective in obtaining employment

outcomes for people with disabilities - only 26% of clients exited the program due to employment. There were long waiting lists (up to 2 years) and poor customer service, a limited scope for client choice and a limited scope for competition among service providers.

VRS funding was used to provide counselling and employment assessment, medical services, assistive devices, training, rehabilitation, and job placement programs (Waxman, 2000). As indicated above, few of the clients who used VRS services were able to find employment. This program was discontinued in 1998 when Ontario's multilateral agreement with the federal government came into effect.

The ODSP program provides supports to assist disabled people in acquiring and maintaining competitive employment. Competitive employment is considered to be full-time, part-time, contract or self-employment which is waged, or: "any remunerative employment which can reasonably be expected to contribute to a person's economic well-being" (MCZCR, 1999, p.2). The ODSP has two main components, the financial assistance program and the employment support program. Services funded under the employment supports program include: employment planning assistance, individualized supports such as counselling and vocational training for job seekers, technological aids and devices for the workplace, pre-employment services such as skills training and employment workshops, and the development of employment strategies including job searching, for individuals who have disabilities

(MCZCR, 1999<sub>2</sub>). In order to be eligible for employment assistance through ODSP, a person *must want, and be judged to have the ability,* to obtain and maintain competitive employment (MCZCR, 1999). The ODSP came into effect June 1, 1998, with approximately \$35 million being spent on employment supports in that year (MCZCR, 1999). Families with the financial resources to do so are encouraged to share in the financial support of family members who are using the ODSP (Beatty, 1998). They can do this by paying for extra administrative costs or additional services not fully funded by the ODSP. There are 3 main funding components to the program. These are the Basic Needs Allowances, the Shelter Allowances, and the Board and Lodging Allowances (Beatty, 1998).

The ODSP has four main goals: integration into the community, interdependence between government agencies and the individual, individualization of services, and quality of life (MCSS, 1998). These goals indicate that the program places a great deal of responsibility on individuals by making them responsible for their own employment and program successes and failures. Individuals are expected to enter into a personal contract with the ODSP administrators in order to utilize the program. This contract, known as the Individual Support Agreement (ISA), is designed to outline the financial support

that will be contributed by the ODSP and that which must be provided by the individual (MCSS, 1998). The use of the ISA reduces the need to create province-wide policies and programs as individuals are responsible for defining their own employment needs and for finding service providers who can fulfill their individual needs, yet they are still expected to negotiate the terms of support and services with the state. The individual is now responsible for creating and finding his/her own employment supports, such as employment and rehabilitation training, using the financial support provided by the ODSP.

Since 1998, the Canadian government has re-vamped its employment support directions for persons with disabilities, culminating in the creation of the EAPD at the federal level and the ODSP in Ontario. The main shift in direction is the new emphasis on employability rather than the old view that persons with disabilities could potentially be labeled as "permanently unemployable." In general, the responsibility for finding and maintaining employment for persons with disabilities is shifting from being a government responsibility to being shared between recipients, now known as participants, and the government; thus requiring more of individuals and their families than before. This change can also be discerned by looking at shifts in how these policies have viewed people with disabilities and how this has changed

over-time, **Table 4.1** outlines some of these changes. The language and definitions used, and conceptualizations of persons with disabilities identified, in policy sources documents the overall shift in policy directions between the older VRDP and its newer version, the EAPD.

**Table 4.1:**

Changes in the language used in government employment assistance programs for persons with disabilities.

<b>VRDP's view of persons with disabilities</b>	<b>EAPD's view of persons with disabilities</b>
people viewed as recipients	people viewed as participants
recipients receive passive income support	participants adopt active measures to seek competitive employment
recipients are dependents on the state	participants are independent from the state
the Government is responsible for recipients	there is a shared responsibility for participants' successes and failures
recipients can be "unemployable"	participants identify their work skills

Source: Ministers Responsible for Social Services, 1997

#### **4.3 Determining Eligibility for ODSP and CPP-D Assistance**

This subsection will focus on who is and is not eligible for receiving employment and income support from the ODSP and other related programs. Introduced in this section is the Canadian Pension Plan for persons with disabilities (CPP-D), it was not discussed in the previous subsection as it



is not one of the 6 federal strategies to assist disabled Canadians. The boundaries between those who are 'eligible' and 'ineligible' will be examined and it will be shown how they create blurry categories and labels for Ontarians with disabilities. As will be shown, the categories of 'eligible' and 'ineligible' are not neatly divided, but, rather, they have inconsistencies in their criteria. It is important to examine such boundaries and inconsistencies as they play a part in establishing who, including women with arthritic conditions, is eligible for support from these programs and on what bases.

The task of categorising who is and who is not 'eligible' to participate in certain government-funded programs may sound simple - either an applicant is eligible or ineligible based on their application; however, it has become an extremely complex process in Ontario and Canada, particularly when income assistance is at stake. As mentioned previously, the ODSP has two main program branches: income support and employment supports. The income support program provides Basic Needs and Shelter Allowances or Board and Lodging Allowances for recipients; these allowances are expected to cover rent or mortgage payments, utility bills and basic subsistence costs. The amount of support varies greatly from person to person and depends on such factors as marital status and whether or not the applicant has children s/he is

supporting (Beatty, 1998). This variation occurs because recipients can receive a larger allowance if they are, for example, supporting children or are married to a spouse who is also disabled and receiving income assistance. People who apply for assistance under the ODSP must meet its definition of a 'person with a disability' which is defined as (Beatty, 1998, p.42):

- a. the person has substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;
- b. the direct and cumulative effect of the impairment on the person's ability to attend to his or her personal care, function in the community or function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and
- c. the impairment and its likely duration and the restrictions in the person's activities of daily living have been verified by a person with the appropriate qualifications.

In order to receive income support through the ODSP one must satisfy these criteria. The old VRDP, as regulated by the Family Benefits Act, had used the category of "permanent unemployability" as the criterion for eligibility for income assistance. This category is no longer used as the ODSP allows someone to qualify on the "basis of a 'substantial' restriction in his or her ability to function in a workplace" (Beatty, 1998, p.42).

Beatty (1998), in his report to the Council of Canadians with Disabilities, views changes in eligibility requirements to be an improvement because more applicants are

better able to demonstrate substantial restrictions than can be considered permanently unemployable. One does not necessarily need to qualify for the program based solely on a lack of function in the workplace. It needs to be demonstrated that an ODSP applicant experiences restrictions or reduced abilities in the workplace, and/or in the community, and/or with personal care; thus, people who have not recently been involved in the paid labour market are also eligible for income assistance under the ODSP Act.

There are many specific evaluation procedures that applications for ODSP financial assistance must successfully pass through. First, two professional assessments must be completed by the applicant's doctor, psychologist and/or optometrist (Beatty, 1998). These reports will establish the applicant's current medical condition and medical history. A second report, the Activities of Daily Living Report, is needed to establish the impact of the applicant's impairment(s) on his/her workplace and community activities as well as personal care. This report can be completed by one of many health care professionals, including: physiotherapists, registered nurse practitioners, occupational therapists, chiropractors, optometrists, psychologists and doctors (Beatty, 1998). Applicants have the choice to complete a third form, the Self Report, which gives them the opportunity to describe how their impairment(s) impact their daily lives.

These completed forms are then turned over to the Disability Assessment Unit, administered by the Ministry of Community and Social Services, where the staff (mostly health professionals) will make a determination as to whether or not the applicant is eligible for assistance under the ODSP Act (Beatty, 1998). It is difficult to assess how many applications are successful as a percent of those submitted as the ODSP is relatively new, having been in existence for little over three years, and has yet to have a program audit.

The Canada Pension Plan disability benefit (CPP-D) is another source of income support for Ontarians who are disabled. It is a contributory benefits plan where only those who have been employed and thus contributed to the CPP are eligible for CPP-D support. The CPP-D is similar to the ODSP as they both offer vocational and employment assistance for those who qualify, and are judged to be able to return to the workplace. CPP-D benefits will not solely support a person, they will simply provide a limited amount of financial assistance for daily food and shelter expenses, so it is recommended that applicants also apply for ODSP and any other benefits they are eligible for in order to assist them in receiving benefits adequate to cover the costs of meeting basic needs (Leeson, 1990). In order to be eligible for CPP-D benefits, one must be of working age (under 65 years old) (HRDC, 2001, p.3):

- a. meet the requirements on earnings level and years of contribution [to the fund while involved in paid labour]; and
- b. have a physical or mental disability which is "severe and prolonged". This means a disability which is long-term and prevents them (the applicant) from doing any type of paid work on a regular basis.

In 2000, 283,581 Canadians received the CPP-D benefit and the average amount of monthly support was \$676.33 (HRDC, 2001). The number of CPP-D beneficiaries has risen steadily over time. In 1970, one out of every four-thousand people in the workforce was receiving CPP-D benefits, this number rose significantly to 91 per four-thousand in 1996 (Campolieti & Lavis, 2000).

The CPP-D application process is similar to ODSP in that there is a great deal of paperwork and several reports, establishing the type and severity of the medical condition and any physical limitations, needed from professionals. In order to receive CPP-D financial assistance one must have contributed to the Canada Pension Plan when actively involved in the paid labour market. An applicant's contributions and past earnings must also satisfy specific criteria, which are (HRDC, 2001, p.2):

If you became disabled after December 31, 1997, you must have contributed to the CPP in four of the last six years. During that period, you must have earned at least 10 per cent of the Years' Maximum Pensionable Earnings (YMPE). In 2001, the YMPE is \$38,300. The YMPE changes each year.

Thus, in order to qualify for CPP-D one must have actively

been involved in the workforce in recent years. The main difference between CPP-D and ODSP is that CPP-D is a contributory benefits plan that can be used by those who have made a contribution and met its eligibility requirements, while the ODSP is a social program that can be used by all those who are eligible regardless of their past labour market involvement. A secondary difference is that CPP-D is a national plan and ODSP is a provincial Act.

Both the ODSP and CPP-D have established criteria to assist them in determining who is "eligible" for their programs; however, there is some uncertainty about which types of disabilities qualify for support. For example, some Doctors have difficulty recognizing and diagnosing fibromyalgia (Moorhead, 1991), which potentially makes it difficult for someone undergoing assessment to get approval for financial support from several health professionals as required by the ODSP and CPP-D. According to one Canadian woman who has acquired fibromyalgia and applied for CPP-D funding: "Because of stringent policies, sceptical insurers, disinterested physicians and administrative hoops, qualifying for disability payments can 'in worst-case scenarios' turn into a veritable circus of horrors" (Moorhead, 1991, p.1). Dr. McCain, a rheumatologist based in London, Ontario, believes that there is a "significant percentage of the family doctors, interns and surgeons who feel that this

[fibromyalgia] is still a psychosomatic disease, because they can't get over their bias" (Moorhead, 1991, p.2). The paperwork used in applications for CPP-D or ODSP can also be viewed as being potentially biased as it fails to take some types of impairments or symptoms that are relevant into account. "Arthritis has a few unique characteristics (namely, remissions and exacerbations), and sometimes, the forms don't have the right categories and space to accurately describe...[one's] condition" (Leeson, 1990, p.3). These biases are also found in the ODSP and CPP-D systems which result in inconsistencies about whether persons with fibromyalgia and other contested conditions belong in the 'eligible' category.

People who are employed either full or part-time in the paid labour force are technically ineligible for ODSP or CPP-D financial support. However, exceptions have been made to this rule as recipients are now allowed to continue receiving financial assistance while re-entering the workforce. This flexibility in funding is a positive development, and is definitely helpful for those who are in the transition back to work, but it also shows how the categories of 'eligible' and 'ineligible' are becoming less distinct. As of January 1, 1998, CPP-D changed the nature of its assistance to allow recipients to volunteer in the community or attend school without losing benefits, where previously this was not

allowed. Furthermore, recipients can now receive benefits for up to three months after returning to the workplace (HRDC, 2001). Previously, recipients were unable to volunteer in the community as it was considered to demonstrate that s/he was able to perform certain work-oriented tasks. Any involvement in the paid labour force is still not allowed unless the recipient is in the process of relinquishing CPP-D financial assistance. The three month return-to-work assessment period is allowed so that people who are unable to maintain their new jobs due to medical or health reasons can continue receiving benefits without needing to reapply (Leeson, 1990). This is similar to ODSP benefit rules which stipulate that recipients who re-enter the workplace temporarily can regain benefits without being reassessed as long as their disability review date, where the nature and extent of their impairment is assessed by administrators, has not passed (Beatty, 1998).

Though provisions have been made to allow CPP-D and ODSP beneficiaries to return to work on a full-time basis temporarily without losing benefits, some recipients are still wary of entering the workforce. "People who are completely disabled for months or even years may find themselves in remission, and want to try to work again, but fear the loss of their benefits" (Leeson, 1990, p.20). These return-to-work and volunteer provisions within such support programs blur the categories of 'eligible' and 'ineligible' as the new



provisions are applied differently in the cases of existing recipients versus new ones. Such inconsistencies in applying eligibility criteria to those who are new 'applicants' and those who are existing 'participants' may confuse applicants who, for example, know recipients who are undergoing the three-month paid transition into the paid workforce which leads them to believe that they can be considered 'eligible' for assistance when working on a paid basis at the time of application. Offering flexibility in funding for existing recipients, namely the three-month return-to-work period while remaining on income assistance, is a positive change in making these programs more supportive of people with disabilities; however, it must be made clear to applicants how eligibility is determined so as to reduce any potential for confusion.

#### **4.4 Conclusion**

This chapter had two main purposes: to chronicle the development of both Canada and Ontario's support programs for persons with disabilities, and to establish how eligibility for these programs is determined. The historical policy review showed that the VRDP and VRS Acts preceded the current ODSP and EAPD Acts. These new programs are quite different from the ones they replaced as they have removed the label of "permanent unemployability" for recipients, or participants,

in favour of a model where recipients are expected to maintain competitive employment whenever health allows. The discussion of program eligibility showed that while the ODSP and CPP-D both have specific definitions of who is and is not eligible for employment support (including income assistance), the criteria used to determine eligibility does not necessarily take into account the ability to work associated with the fluctuating nature of certain chronic illnesses, disabilities and impairments. Another important point about program eligibility is that persons enrolled in these programs may volunteer in the community while receiving assistance, and can even attempt to re-enter the full-time workforce without funding being cut-off in the early stages, but that ODSP and CPP-D do not allow recipients to qualify for full or partial funding while being involved in the part-time paid labour force, which can create confusion among applicants. Issues of eligibility and of ODSP and CPP-D employment and income assistance will be examined in the following two chapters which discuss the employment experiences of the 18 interviewees, their experiences of government employment support programs, and how they believe that such programs can be made more supportive of their needs.

## Chapter 5

### Interview Findings: Changing Life and Employment Experiences After Acquiring an Arthritic Condition

#### 5.1 Introduction

This chapter is the first of two which discusses findings from the eighteen interviews conducted with women who have acquired an arthritic condition. First, basic health, demographic and employment characteristics of the participants, including type of arthritic illness, age and employment history, are discussed. Then the changes in life and life spaces experienced by the participants since acquiring an arthritic condition are discussed, including changes in self-identity. Following this is a discussion of the social and physical barriers to workforce participation faced by the participants both inside and outside of the workplace.

#### 5.2 Participant Characteristics

The participants interviewed varied significantly in age, employment history, impairment and current employment status. **Table 5.1** summarizes these characteristics.

Table 5.1:

Characteristics of the Interviewees

<b>Interviewee</b>	<b>Age</b>	<b>Impairment</b>	<b>Employment History</b>	<b>Current Employment</b>
Ann	30s	lupus	- previously was involved in full time employment and was a graduate student	- unemployed and receiving short term financial assistance for the past 2 years
Anne	54	fibromyalgia osteoarthritis rheumatoid arthritis	- has had various part time jobs over the last 10 years	- part time
Darlene	30	fibromyalgia	- previous 13 years with the same employer	- on leave for the past year
Diana	30s	arthritis	- has been involved in full time employment for several years	- full time

Gloria	56	currently undergoing diagnosis for lupus	- has worked on and off over the past few years - took 3 months off this year due to worsening condition	- full time
Karen	46	osteoarthritis with nodules	- steady history of full time employment prior to acquisition	- unemployed and receiving financial assistance (CPP-D)
Kathryn	48	rheumatoid arthritis fibromyalgia osteoarthritis	- worked 18 years as a full time nurse and 5 as a part time nurse	- unemployed and receiving financial assistance (CPP-D)
Kim	45	rheumatoid arthritis	- has been involved in full time employment since graduating from university	- full time
Margaret	60s	fibromyalgia	- has worked on and off throughout her life	- part time

Marilyn	44	lupus fibromyalgia	- previously involved in both part time and full time employment - currently actively involved in volunteer work	- unemployed and receiving financial assistance (CPP-D)
Nicole	39	currently undergoing diagnosis for arthritis	- was employed part time as a grocery clerk for the past 10 years	- currently on leave
Patricia	69	fibromyalgia	- has worked full time and part time throughout her life	- currently working part time and actively involved in volunteer work
Robyn	28	fibromyalgia	- previously trained as a butcher's assistant	- currently seeking compensation through the Workplace Safety and Insurance Board (WSIB) (her initial claim was denied)
Sadie	43	fibromyalgia osteoarthritis	- previously involved in full time employment	- part time

Sam	30s	fibromyalgia	- has not been involved in paid labour for 6 years - previously involved in part time employment	- currently attending university on a part time basis
Sean	26	fibromyalgia	- involved in part time employment while attending university over the past several years	- full time
Susan	46	osteoarthritis	- previously employed full time until 1986 - currently actively involved in volunteer work	- unemployed and receiving financial assistance (CPP-D)
Vicki	40s	arthritis	- has been involved in contract work for several years	- currently holding several employment contracts

The participants' ages ranged from twenty-six to sixty-nine, with the average age being 44 years. Nine of the women lived alone at the time of the interviews, and the remaining nine lived with partners and/or other family members. Five of the participants were involved in full-time employment at the time of the interview, another five were

involved in part-time employment and the remaining eight were not actively involved in the labour market. Two of the women were undergoing diagnosis at the time of the interview. Of the sixteen participants who had been diagnosed, one had lupus, six had fibromyalgia, five had some form of osteoarthritis or rheumatoid arthritis, and the remaining four had been diagnosed with multiple arthritic conditions. Each woman was involved in the paid labour force at the time of acquiring an arthritic condition.

### **5.3 Changes in Life and Life Spaces After Acquisition of an Arthritic Condition**

Many of the women interviewed indicated that their identities, including other's images of them, their own self-images, and their views of themselves as workers, had changed after acquiring an arthritic condition. It is important to discuss these changes as many of them relate to and affect experiences in the workplace and of paid employment, and they also reveal how several of the interviewees gauge their self-worth in terms of employment status and financial independence; both of which can change dramatically when receiving income support from the government through CPP-D or ODSP due to being unemployed and financially dependent on income assistance.



### 5.3.1 Changes in Self-Image and Self-Worth

Sixteen of the women, including Marilyn, Karen and Sam, indicated that other's perceptions of them as being workers and productive people had changed, while Darlene indicated that it was her perceptions of others such as co-workers that had been altered. When Darlene continued working after having being diagnosed with fibromyalgia, for example, she found herself constantly comparing her abilities and needs to those of her co-workers:

Darlene: My co-workers had young children who they were having to shuffle off to day care before they were commuting in and some of them commuted in from further away than I did. So I would find myself comparing myself to them and saying, "well they've got even more on their plate and if they can do it then of course I can do it". And I just kept pushing myself harder and harder instead of maybe stepping back and looking at myself and what I really needed. In doing that, I found that I really started looking down at myself and my abilities and I was feeling really frustrated by the impatience that I was experiencing. I was younger than these women and other things.

Darlene's comments show that her image of herself as an unproductive or dis-abled worker was generated by her own comparisons of her abilities to those of her co-workers.

Karen and Marilyn found the opinions of the general public to be upsetting due to how they were viewed in public spaces, especially in relation to their use of mobility aids:

Karen: That's awful too because then they [the public] think it's [your disability affects] your intelligence. It's not your intelligence, its physical but it makes you

feel - it [your disability] affects your self-esteem definitely, and the way people look at you. It took me quite a while just to use the cane because when I walk up the street, people look at me different and, for me psychologically it was hard. And I still don't use it all the time because I don't want people staring at me. Self-pity or the pity of thinking I can't [walk] - or they just walk right by you and don't even look. They're running and I'm crawling.

Marilyn: I make sure I paint a face [by wearing make-up, painting nails and wearing presentable clothing at all times]. My hair's done. I'm always dressed. I don't walk around in my slippers and my pajamas, even if I'm having the most terrible day. It's very, very rare that you will see me looking the way I feel. So most people say to me, but you look great, I say yes. And I've painted a good picture and I'm a good artist. The people who know me know. When you're out there, people expect if you look good... if you look like you're put together, people expect you to be together. Even if they know, even if they see the walker - [they think] "what does she need that for"?

Karen and Marilyn's comments indicate that they were aware of how the public viewed them and how their dependence on the use of mobility aids made their impairments more visible to others, allowing them to be viewed as 'negatively other' in public spaces. Not surprisingly, they have let other's opinions of them influence how they live in their life spaces, such as Marilyn choosing to 'paint a picture' of health and Karen consciously deciding not to use her cane, regardless of the fact that she needs it to assist her in her spaces of daily living, in order to be less-visibly disabled in public places and spaces such as sidewalks and shopping malls. These two women have engaged in what Frank (1988) refers to as conscious management of their appearances. Marilyn's

conscious management came in the form of accentuating the non-impaired parts of her body such as her face, with make-up, and her hands, with nail polish, which is typical of many disabled women (Frank, 1988). Frank's (1998) case study of a woman with congenital limb deficiency, named Diane, has found that she too partakes in wearing make-up as a way of managing her appearance. Karen's conscious management was choosing to present her body in a way which is more socially acceptable by not using her cane. Karen and Marilyn's desire for social acceptance of their disabled bodies have made them extremely aware of how they present their differently-abled bodies to the public. These strategies have affected Marilyn and Karen in both positive and negative ways. On the positive side, by engaging in the conscious management of their appearances, they are able to meet their desired goals of appearing less-visibly disabled, or of being less conspicuous, in public spaces. However, Marilyn's comments also suggest that her outward appearance disguises her feelings of chronic pain and fatigue, thus presenting a false image, and Karen is negatively comparing her abilities to those of other people when she says that "they're running and I'm crawling," therefore creating some negative outcomes from the conscious management of their appearances.

Sam noticed that her self-esteem and self-image changed dramatically after ceasing to do paid work. So much

of her self esteem was connected to her role as a worker and productive person that the transition to unemployment and financial dependence on government income support initially left her with a poorer self-image:

Sam: A lot of my self esteem came from my work, and my self-worth. It wasn't quite going from paid work to volunteer work, there was [sic] a number of years in there where I spent totally focussed on getting healthy, and that was about three years. And saying that, it really doesn't end up in [being] three years. You're constantly reinforcing your coping techniques in order to stay as [mentally and physically] stable as you are, or as stable as I am. I have to practice everything that I learn. In order to build self-esteem back up, where I got a lot of it from was work. When that was taken away from me, I knew I had to replace it with something.

Sam explained that the positive sense of self-worth that she experienced as a paid employee was lost after she stopped doing paid work, and she has struggled since then to fill the 'void' created by participating in volunteer work.

Darlene, Marilyn and Karen's experiences of a changing self-image, as discussed previously, and Sam's changing sense of self-worth and identity after acquiring an arthritic condition, are typical of those noted by all the participants. The examples shown here indicate that what differs are their responses to these changes: Karen choosing not to use her cane in order to be less 'visible', Marilyn 'painting a face' to draw attention away from her walker and Sam volunteering to fill the 'void' left by unemployment. They, like the other interviewees, have accepted these changes and have developed

'coping' mechanisms in order to adjust to their changing lives and lifeworlds. It was not surprising to find such changes in self-image and self-worth as Marris (1996) has reported that they are common to most chronically ill women. In fact, Marris (1996, p.19) interviewed a woman who had such a poor, or negative, self-image after acquiring arthritis that she said she'd prefer to be "invisible," so that others wouldn't be able to see her or her impairments, rather than go out into the public eye.

### **5.3.2 Experiences of Depression**

In addition to changing self-worth and self-image, seven of the participants experienced periods of depression and anxiety after being diagnosed. Anne noted how her depression was tied to her shifting sense of self-worth:

Anne: I had a lot of depression which didn't help. Your self-worth goes down [after acquiring an arthritic condition]. You suddenly find that you can't do things that you used to do. When your self-worth goes down, it affects other people. Your work [productivity] goes down and you are no longer [seen by yourself or others to be] as valuable [an employee] as you once were.

Sadie and Sean also found that depression and anxiety were associated with concerns about their value as an employee, and their prospects for future involvement in the labour market:

Sadie: I started to get very depressed also [after acquiring fibromyalgia and osteoarthritis], feeling that way [like a less-productive employee]. Who's going want

to hire me, I'm an injured worker?

Sean: I've suffered a really, really nasty period of depression and anxiety, going, "Oh my God, what am I going to do with my life, I'm only 26!"

Anne, Sadie and Sean's periods of depression are all linked to their beliefs that they are now devalued as employees due to their acquired disabilities and actual experiences of being devalued by others. The experiences of depression shared by these three women are similar to those experiences reported by the other four interviewees who had become depressed after acquisition. It can be said that the high value society places on 'healthy, productive workers' has negatively affected these seven participant's images of themselves, contributing to depression.

According to Marris (1996), society places value on people who are active and who "do", such as those actively involved in the labour force, rather than those who "don't", such as disabled women who are unable to work. Society also values youth and health, which can leave disabled women who are unemployed "roleless" as they cannot earn an income, and may be able to perform only limited household tasks (Meyerowitz et al., 1988). Such "rolelessness" takes place when they are no longer able to perform the societal roles ascribed to them as women, such as those of worker and caretaker. Conceptualizing themselves as potentially "roleless" women who "don't" do certain tasks may have led

seven of the participants to experience periods of depression after acquiring an arthritic condition.

### **5.3.3 Changing Views of Themselves as Workers**

It has been shown through the seven cases discussed above that some of the participants' self-worth and self-image were tied to their roles in the workplace and their value as employees as assessed by themselves as well as others. It is also important to explore how their views of themselves as a worker, or employee, changed after acquisition, if at all, and to examine how they were able to negotiate this transition inside and outside spaces of employment. By understanding the importance of being a paid employee, or worker, in these women's lives, particularly in relation to the value that society places on 'healthy' and 'productive' workers, we can begin to see why it is important to have effective employment and income support policies and programs which place value on what these women are able to contribute, including part-time and volunteer labour.

Ann's response to her changing image of herself as a worker was to redefine her understanding of "work" based on what she *is* able to do, such as light housework, rather than focus on what she can no longer do, including being actively involved in the paid labour force. According to Ann:

Ann: I struggled with those sort of internalized, societal values around work within the home. Initially I couldn't even read. I would be lying in bed , so exhausted, just so frustrated and so sick. I mean, I had no idea how I was functioning as I was, but certainly my views of the role of work in our lives has changed. I've done readings in the areas of what's called the simplicity movement -- how your job isn't necessarily what your life's work is, they could be two different things. Come to value what it is that I do in the home [light housework and meal preparation], because it allows my partner to work and make lots of money now. And the only way that can happen is for me to be taking care of the animals.

Ann's re-definition of work, now viewing unpaid housework and caring for animals as important forms of labour, has allowed her to see such work as a significant contribution to a household where her partner is the primary breadwinner.

Karen's change from being employed and financially independent to being financially dependent on government income support radically changed her daughter's view of her:

Karen: They were used to seeing me go to work all the time, paying for everything and it had a major [impact] on my daughter. She couldn't accept the fact that I was ill and she was used to more money. Eventually she stopped coming home as often, eventually moved out, [and] my son left. Yea it's like I'm a totally different person now [after acquiring osteoarthritis] and it's very hard for me [to deal with].

Changes in Karen's financial and workplace roles, in response to her osteoarthritis, and her dependence on CPP-D financial support, has negatively impacted the relationship she has with her children. That is, limiting her ability to support her children financially, causing her children to see her as a



more negatively different person, and, in her view, encouraging them to leave home and visit less often.

Kim is aware of the shifting views that she's had of herself as a worker over time, in relation to her productivity, and continues to struggle, as she notes, with conflicting pressure between being a 'productive worker' and preserving her health:

Kim: I tried to see myself as not being different from other people and I also though, was very concerned, as I've said, to prove myself. So I worked, I think, a lot harder and placed greater pressure on myself to succeed and excel, and to work harder and better than other people. Now I feel, somewhat guilty, because I come in late and I'm always justifying it to myself that for all of those years, I've worked extra hours and long hours and so it's alright, I'm entitled to this. I have to keep reminding myself, so I probably feel less productive, less energetic.

Ann, Karen and Kim's experiences show that their images of themselves as 'productive employees' have changed over time. Kim and Ann have both attempted to develop strategies to deal with their new roles, Ann finding value in what she is able to do, and Kim reminding herself that her impairment does require accommodations and that she should try not to feel guilty about those that she's made. Karen has struggled with her changing role because, with becoming unemployed and dependent on CPP-D income assistance, she is no longer the breadwinner of the family, thus altering her relationships with her children.

The shifts that Ann, Kim and Karen experienced in

relation to their working lives and images of themselves as workers are not surprising. Marris' (1996) research indicates that society views employment as being a sign of normality, and that if a person is not able to be employed and financially independent, or even to perform certain workplace duties while being employed, then they are not normal. The experiences of these three interviewees reflect this notion as they were all struggling with being perceived 'less-normal' by others, including children, co-workers and partners, and by themselves, as a result of unemployment or a change in workplace ability. Furthermore, Marris (1996), based on the findings of her research which investigates the lives of chronically ill women, argues that unemployed disabled women are placeless, as they have no recognized, socially-valued place in the world. As Marris (1996) argues: "workers may often be exploited, but they have a recognized place in the world" (p.48). Her research shows that society places people who do not work in a position of little value. Further, her research demonstrates that unemployed chronically ill women do not have a physical place in which to make social contacts with co-workers and other casual acquaintances as they lack a recognized workspace. These women lack both the social contact that comes from co-workers and the income generated from working, thus rendering them placeless in a world that values productivity and employment status over health and

well-being.

#### **5.4 Physical and Social Workplace Barriers**

The participants were asked to comment on what they experienced as the most disabling barriers facing them in the workplace. Two of the interviewees, Diana and Vicki, said that physical workplace barriers affected them more so than social barriers. The remaining sixteen women found social barriers, or a combination of physical and social workplace barriers, *more* oppressive and prevalent than the physical ones.

##### **5.4.1 Physical Workplace Barriers**

Diana and Vicki were the only two interviewees who believed that physical workplace barriers, such as climbing stairs or moving between buildings, were the biggest obstacles to their abilities to participate in the labour market.

Vicki: Well, what I'm most dealing with right now, which is what I can speak to, it the physicality of it [the arthritis]. How far I can walk, how long I can be at a place, how long I can teach standing? Yeah, it's more the physicality right now. There is another component to it in terms of just preparation. If I am teaching and it really whacks me out and I'm really tired, really sore, then the chances are I don't sleep well. No matter what I do that night [physically], it impacts on the next day. So I'm finding that it's not just strategizing for that day, I have to really look at [my energy reserves] in a longer picture. It's not something in terms of my physical reserves [of energy], I guess, and I'm not used doing that. It's [conserving energy] a real pain in the

butt. (Laughter) I'm just not used to doing that [conserving energy for later use]...

Diana: Physical access to get to the workplace is a problem. The social environment of the job is really not a problem. I think it's better to build accessible environments right from the start. Because when the [physical accessibility] needs come on, or when the person is living with the physical changes themselves at the time, they really don't want to deal with the political lobbying necessary to get the workplace changed.

Diana, a security officer, and Vicki, a sessional lecturer, also said that they have become more aware of the physical demands of their jobs, both minimize trips between buildings and on stairways. Vicki has actively worked with her Department to ensure that she can teach courses in the same area in which her office is located so that she does not need to expend much-needed energy in moving between buildings. They have developed a variety of coping mechanisms, including conserving energy and planning daily routes, in order to deal with the physical demands of their jobs while conserving energy for later tasks. The development of such mechanisms is not surprising. As Dyck (1995, p.319), for example, reports in her research on the lifeworlds of women who have acquired Multiple Sclerosis: "as the illness experiences is given meaning within the constraints and opportunities experienced in ...work spaces, women also actively seek ways in which to remap their lives in time and space." Diana and Vicki are remapping their work spaces in order to maximize their energy

levels and abilities during the working day.

Physical barriers in spaces of volunteer labour were also a concern. Marilyn found that physical barriers at a local community centre had detracted from her ability to run a recreational program. She is angry about the lack of physical access at a local recreation centre, including its physical inaccessibility for people who use mobility aids, and questions the abilities of those who are operating such centres to ensure accessibility:

Marilyn: I think whoever is making the laws, whoever is implementing change, I think we are using the wrong people, first of all. I could talk about... [a local recreation centre], for one. This is supposed to be the flagship rec centre in Hamilton because it is totally accessible. No, it's not. On paper it is. They didn't use anybody with any handicaps to say, oh this is what you should have done here and this is what you should do there. It's the most accessible rec centre in the city. Fully accessible, no. The government, whether it be municipal, provincial or federal, have the wrong people helping them out in this area. There isn't enough input from the people who are immediately involved. Okay? Also when, when the government makes laws, laws are meant to be broken and everybody will find a way around it.

The lack of full access at this site has made it difficult for Marilyn to run her pool support program for persons with disabilities at the centre because some potential participants cannot gain access to the site. This means that women with arthritic conditions are not necessarily able to gain access to local programs which are designed for their support.

#### **5.4.2 Social Workplace Barriers**

Although physical workplace barriers are somewhat of a concern for a majority of the interviewees, sixteen of women felt that social barriers created by co-workers and other staff members were *more* disabling than inaccessible physical environments. Three types of social workplace barriers were discussed by the interviewees: disbelief about the nature and severity of arthritic conditions, a lack of understanding about their needs, and a lack of knowledge about arthritic conditions.

##### **5.4.2.1 Disbelief & Lack of Understanding from Co-Workers and Employers**

Marris (1996), Ware (1992) and Wendell (1996) have all shown that the friends, family members and co-workers of women who have become impaired often react with disbelief in regard to their illness and the symptoms they report. Karen felt that the disbelief expressed by co-workers posed a significant social workplace barrier as she was looked down upon for taking breaks during the working day which were needed to improve her productivity. As she explains:

Karen: No, as matter of fact when I did take days off they would reprimand me and wouldn't believe me. I would tell them I was sick ... a lot of people take days off for nothing, so they just thought I was skipping out. That didn't make it easier...especially [since] I was working under a supervisor who was [a] very ladder-

climbing type and I seemed to be in his way I guess... What was funny is that I take two breaks [during the work day other than lunch] and then they [co-workers] would complain that I was taking [extra] breaks. And I said it actually makes people work better. I'd only take ten minutes, once in the morning and once in the afternoon. I was there till 9:00 at night. After 5:00, I was there till 9:00 and didn't go anywhere except work. And they thought that [taking two breaks rather than one during the work day] was a problem back then.

Karen's co-workers thought that she was abusing the 'system' by taking extra breaks rather than believing her about the severity of her impairment, how it affects her ability to perform work duties by reducing energy, and how taking rest breaks can help her regain energy needed for the work day.

Five of the participants, including Karen, indicated that there was a lack of understanding from co-workers about their impairments and the disabling conditions they encountered in the workplace. Marilyn discussed a friend's experiences with an employer's lack of understanding of arthritic impairment, including being told to 'hide' her symptoms to appear 'healthy', and explained that this is why she chooses to volunteer rather than doing paid work:

Marilyn: I know a friend of mine who works full-time who does have arthritis. She's been told by her employer if she's not feeling well, not to show it as much as she does. She's been told, as well, that the other employees don't want to know when she's not feeling good. They've made all the concessions for her to be comfortable at her desk - she's got a special chair, she's got a special stool, she's got everything she needs - but no one is supposed to know that she's sick. It doesn't sound right, because if you have a cold and you go to work and you're sniffing everyone knows you have a cold but you're not supposed to let them know that there is something else

wrong with you [as it is discouraged]. It's a catch 22 situation. They make concessions and they say they are understanding, but when push comes to shove, everybody wants their money's worth [out of an employee]. If you can't give your moneys worth, you're really not, you know, not fulfilling your bargain, and so you have to be really careful [about the commitments you take on]. That's why for me, as a volunteer, they're getting more than their money's worth [because there's no salary required] and nobody complains.

Kim found that because the symptoms of her rheumatoid arthritis were hidden in the workplace, it was more difficult for co-workers to comprehend the nature of her impairments, such as a lack of energy and chronic pain, and the health-related struggles she was dealing with, including leaving work early for medical appointments. As she explains:

Kim: In terms of my work experience, I'm quite certain in many ways my colleagues, in particular people I report to, have very little idea -- would have very little idea of my disability unless I were to tell them. When I do tell them, they're quite surprised. There is also no real understanding of it [the rheumatoid arthritis] because I seem to be a functioning person. But they look at me, they can tell. They use their eyes, they look at my hands and immediately know something's going on or in the way I walk. I don't limp like I used to. Sometimes I would be limping about and so people would know. For a period of time I wore splints, so that was like a sign, and emblem so people would clue in and know that I had a problem and ask what they were for.

The lack of understanding from co-workers and employers experienced by Kim and Karen is typical of those reported by other chronically ill women (see Marris (1996) and Wendell (1996)). Marris (1996) has found that an inability on behalf of co-workers and employers to accept a colleague's



illness in a supportive way may stem from the fact that they feel that they too face burdens such as tiredness, exhaustion and too much work on a regular basis. Ware (1992) concurs with this finding, arguing that co-workers often trivialize the severity of symptoms identified by chronically ill co-workers due to their commonness, particularly in relation to expressions of tiredness and aches. The reaction of Karen's co-workers to her 'extra' daily break may reflect this notion as they too may have believed that they deserved an extra break due to their own tiredness and lack of energy.

#### **5.4.2.2 Lack of Knowledge about Arthritic Conditions**

Another workplace barrier identified by participants, in addition to disbelief about their conditions and a lack of understanding of their needs, is that of a lack of accurate knowledge about arthritic conditions. Twelve of the interviewees found that their co-workers and supervisors, and other people they interacted with on a daily basis, were uninformed about the nature and severity of arthritic conditions. There was also a lack of knowledge about the types of appropriate accommodations that should be made for people with arthritic conditions in the workplace. Kim's experiences of the ways in which co-workers and colleagues

'deal' with her impairments, have convinced her that many people she interacts with in the workplace are completely uneducated about rheumatoid arthritis. She recounted a recent experience when a potential job candidate she was interviewing said "it must be awful to have little aches and pains" after she disclosed that she had rheumatoid arthritis. Kim explained that this was a typical reaction, and that often people completely misunderstand the nature of rheumatoid arthritis and underestimate the severity of the illness, believing that it is reducible to minor aches and pains. Such lack of knowledge about arthritic conditions can encourage the disbelief and lack of understanding that was reported by many of the participants in that a lack of understanding can potentially be rooted in mis-education, mis-information, or a lack of information about arthritic conditions.

### **5.5 Experiences Outside the Workplace**

In addition to facing many socio-spatial barriers in the workplace, all of the participants identified experiences in spaces other than the workplace which impacted on their daily lives and abilities to maintain paid employment. Three different types of experiences were discussed by the women, these were their experiences in spaces of health care, the search for medical legitimation, and the lack of public

awareness about arthritic conditions.

### **5.5.1 Experiences in Spaces of Health Care**

Although the women were never asked to comment specifically about their experiences within the health care system, it seemed to become an unavoidable subject; having been raised by twelve of the interviewees. A majority of the participants found that the health care system is a significant imposition on their everyday lives; for example, the frequent appointments and the difficulties with diagnosis, which can impact their involvement in the labour market. Ann has found it difficult to negotiate experiences with health care practitioners, particularly when applying for income assistance:

Ann: It has certainly been difficult for me when it comes to getting my doctors all 'on side' around LTD and CPP stuff. If it's my Lupus specialist, it's one thing, but if I'm going to a different specialist -- I have 10 different doctors. They'll see me and then they say presents well, looks very blah-blah-blah, appears la-la-la, you know! (Laughter) That's all hopeful. You say, "My kidney is not functioning!" Never mind she looks fine!

Ann is concerned that her outward appearance, one of being healthy and put-together, is not consistent with others' images of a person who has an arthritic condition. She is extremely aware of her appearance even more so now than prior to acquiring an arthritic condition as she is now considered

to be chronically ill, particularly in the Doctors' offices she visits. She believes that looking good is a form of resistance against peoples' perceptions of how chronically ill women should look, as she explains:

Ann: I won't go in to the doctor's office looking like crap! I just won't do that because I demand certain respect from them, and I want them to hear what I'm saying. I think if you go in and present as a sick, feeble person, they don't always hear you. But the problem is when you present the other way [looking healthy], then they don't always see the illness. So I think similarly, that's true [that people think you're healthy if you look well] for people in work, for friends, for family.

Ann's form of resistance against looking 'ill' is similar to Marilyn's, as discussed earlier, where they both 'paint a face' to demand a certain respect and portray what health and illness is in their view. According to Frank (1988), disabled women constantly struggle to be viewed as people and not only patients in the eyes of others, including the medical community. Ann's comments embody this struggle, one of the desire to be recognized as a person and not solely as a chronically ill woman.

Darlene has found the health care system to be a place of extreme struggle for a consistent diagnosis, a place where her medical condition is sometimes not legitimated by doctors who have evaluated her work potential. She believes that her experiences reflect a lack of accountability within the health care system:

Darlene: I think also there's a fine line I guess as well between finding a doctor who's going to tell you what you want to hear versus finding a doctor who is going to give you an actual, appropriate, accurate, objective diagnosis and recovery plan. I have seen more than a dozen doctors and each doctor tells me something different. Each doctor puts me on a medication and another doctor says, 'Oh I can't believe you're on that!' And takes me off of it... I have had to struggle with my own family doctor for over a year to get a referral to somebody who may have some kind of knowledge or qualification in Fibromyalgia who may be able to help me with some accurate diagnosis and intervention. I think that the state that health care in general is in - you're in, you're out, you're in, you're out, you're a number, you're a file - you've got a cold, it's something that a pill can fix [meaning that the quick services has made it difficult to effectively treat patients who are dealing with chronic illness and long-term health issues]. Then great. If you go beyond that, then you're sort of left out there by yourself. It's been very frustrating and very eye opening for me to have experienced what I have in the medical community. I am somebody who at least has the faculties about me to be able to advocate for myself, to be able to do research and do that kind of thing. I think about people who maybe are less able than me to do that and it really scares me. How you go about doing that [the speed and delivery of services, it's unclear], but I think it all comes down to accountability [of health care practitioners].

The fact that fibromyalgia is a contested medical condition, in that it is difficult to diagnose and not recognized by all health care practitioners as being legitimate, has left her with little legitimation from the health care community. This has forced Darlene to develop a coping strategy whereby she advocates for herself and her own best interests, and conducts research regarding the issues she faces, within a system that she is not overly familiar with. Self-advocating within the

health care system is a potential burden for someone like Darlene, further taxing her limited energy supply.

The types of experiences discussed above have left twelve of the interviewees feeling that spaces of health care are difficult to negotiate. Such experiences have left them in a position where they are not empowered with knowledge about their impairments; thus making it difficult for the women to, for example, articulate their impairments, physical limitations, and possible workplace accommodations to their employers. Also, as Chouinard and Crooks (2001) have shown, experiences within spaces of health care, for women who have acquired arthritic conditions, are not neatly bounded and impact on other aspects of women's lives and spaces of daily life such as the workplace. They note that, for example (Chouinard and Crooks, 2001, p.12):

Lack of a medically legitimate diagnosis of illness is likely to disadvantage her [a chronically ill woman] in struggles with employers and co-workers for accommodation of her changing mental and physical needs, and with insurers and government agencies for entitlement to disability benefits.

Furthermore, Doctors play a pivotal role in determining eligibility for CPP-D and ODSP programs and income support, as discussed in Chapter Four, determining whether or not a chronically ill woman is 'able enough' to work or 'dis-abled enough' to receive income assistance. This means that the negative experiences in spaces of health care discussed by

twelve interviewees may potentially have had implications for their participation in the labour market.

### **5.5.2 Lack of Medical Credibility or Legitimation**

Another non-workplace issue raised by four interviewees is the lack of validity given to fibromyalgia as a legitimate medical condition by some members of the medical community. Sean explained this legitimation issue best when she said:

Sean: Some of the solutions to it [problems in the health care system] is awareness [about fibromyalgia]. It's increased medical validation that these conditions are real, they're systemic and although they happen in a preponderance of women, it's not because women are the weaker sex, etc. etc. It's balance and social awareness [about fibromyalgia] and those kinds of things [that will bring increased validation of fibromyalgia].

Sean's comments suggest that if fibromyalgia was given more medical validation, if the causes and symptoms of this illness were better understood, that the perceptions of it being a psychosomatic women's illness would be challenged.

This desire for credibility within the medical system has left Margaret searching out books that legitimate fibromyalgia and lend credibility to her symptoms in the eyes of others. Here she tells of a book she's found helpful in convincing others that fibromyalgia is a legitimate biomedical illness:

Margaret: Anything - we're desperate for any education, verification, not that it helps in what we're coping with, but at least if we know that somebody else has the same thing going on, we can say, "Ooh it's part of that", and move on [to being concerned with how to live with fibromyalgia]. Like now, every little twinge you think, is this something new? I haven't read about that. I found a God-send in an inexpensive, large book about 8½ x 11, and its really written by an American doctor. I don't know if you've heard of it, the Fibromyalgia Advocate [1998]. Fibromyalgia Advocate. By Devin J. Starlanyl [M.D.]. She has this condition, she's a research physician. Thank God for the woman, because I've gone to that book so many times, and I've bought them [several copies]. My niece has got one of them, my friend has got one. It's so nice to have this "no you're not going crazy, no you're not getting paranoid, this happens". To have some kind of authority there that says "no, you're not dreaming it. We understand that other people have this as a symptom."

Margaret's search for credibility with respect to fibromyalgia is unique amongst interviewees as only two of the other participants reported seeking resources in order to find validation; that is, evidence that could be used to convince other that their condition is 'real' and legitimate. However, Margaret's search for legitimation is still not surprising. As Wendell (1996) argues, Western society places value on the opinions of health care practitioners and does not legitimate disabled women's experiences of their own bodies as a source of knowledge. Thus, in order for someone like Margaret to feel legitimated in the eyes of others, including her family, she must seek validation of her symptoms within the medical system, such as the Doctor's book that she purchased, and not simply from her own bodily experiences.



### 5.5.3 Lack of Public Awareness about Arthritic Conditions

Insufficient public education and awareness about arthritic conditions has also posed a social barrier for twelve of the participants. They have found the public not to be knowledgeable about arthritic conditions, their symptoms, and their seriousness. Patricia, Marilyn and Gloria's comments regarding the issue typify the concerns of the twelve women who identified this as a barrier:

Patricia: I think education is wonderful. I think people have to realize that just because you look great, maybe that day you can't hardly move.

Marilyn: The government is simply people down the street in the same village or city. They [policy-makers] have to be educated as people, just not legislators. I shy away from a lot, too much legislation [because when that happens] everything bogs down in mud. Education [about arthritic conditions is needed] first [in order to reduce barriers], definitely.

Gloria: It [arthritis] should be more publicised and the public made more aware of the people who have it. Wear a bracelet or something to make them aware that you have this condition... I think people should be made aware of this situation. Honest to God, I'd never even heard of it [lupus]. I would never even have imagined. Some people told me about it, and I'm going Huh?

This need for public education and awareness about arthritic conditions influences workplace experiences, as was indicated previously, where co-workers and administrators had not previously been aware of the conditions and symptoms these women are living with.

The women's call for increased public awareness about the nature and severity of arthritic conditions is not surprising. Kitchin et al. (1998), in their study of disabled people's experiences of employment programs in Donegal, Ireland, concluded that raising awareness about all types of disabilities was the primary concern of the study's sixteen participants. They argued that "at present, both the general public and employers remain ignorant of disability issues and this needs to be rectified" (Kitchin et al., 1998, p.800). Thus, a desire to increase public awareness about disabilities is not limited to the women involved in this study, having been raised as a major concern, and potential barrier to finding and maintaining employment, by persons with disabilities residing in rural Ireland.

### **5.6 Workplace Accommodations Sought by Interviewees**

Of the eighteen women interviewed in this study, fifteen had requested that some type of workplace accommodation be made after acquiring an arthritic condition. Three types of workplace accommodations were requested by the interviewees: modified work duties, modified work hours and physical accommodations.

### 5.6.1 Modified Work Duties

Two of the women requested that their employers modify their duties, so that they wouldn't have to perform tasks that were physically difficult. Employees who request modified duties, however, may be given tasks to complete that are no easier for them to accomplish than prior tasks when they are not consulted about their abilities; this is what Robyn experienced after requesting modified duties. She requested lighter duties, to be determined by her employer, when she was no longer able to fulfill her duties as a butcher. The company agreed to alter her duties and provided her with a letter that read:

To Whom it May Concern,  
The Barn Fruit Markets believes in providing their Associates with little or no interruption to earning an income, therefore you should be aware that we provide modified duties in cases of injury preventing them to perform [sic] their regular duties.

MODIFIED DUTIES AVAILABLE ARE:

- operation of fresh squeeze juice machine
- packaging and labeling of juice
- dispensing, packaging and labeling of frozen yogurt
- prepackage salads and fruit
- perform shelf price audit in grocery aisles
- light cleaning in the store
- answer phones
- facing, presenting grocery aisles [displaying products at the end of grocery aisles]
- packaging up strawberries in quarts
- bagging up grapes
- demonstrating products
- watering plants
- bag groceries at front end [bagging purchases at the cash registers]
- retrieve shopping carts and carry baskets
- sell promotional tickets to customers

- make price signs (produce, grocery, etc...)

Robyn was able to systematically read down the list, during the interview, and explain why she was unable to complete the "modified duties" listed due to the lifting and repetitive physical movements involved. Further, she had been training to be a skilled butcher in the store, and the duties she was asked to perform after acquiring fibromyalgia were unskilled: meaning that she would receive less pay. Robyn ended up leaving her position as an apprentice butcher due to her employer's unwillingness to provide suitable modified duties.

Nicole experienced a similar situation to Robyn's when requesting modified workplace duties of her employer. She too was employed in a grocery store and was moved by department managers between four or five "modified" duty jobs. After performing several "modified" tasks she came to the realization that the accommodations she had been offered were not adequate for her physical needs as they involved sitting for long periods of time which was difficult for her. Nicole eventually left her position as a grocery clerk when she came to the conclusion that her employer was not willing to consult with her about the types of modified duties she was able to, and wanted to, perform. Sam was an employee at a large retail store before acquiring fibromyalgia after being involved in a car accident. She said: "I was trained in all the

departments, I thought that would be to my benefit, but it made no difference to them [the managers]." She explained that her employer was not willing to find suitable accommodations and modified duties as they believed it was too difficult a task, which resulted in her leaving her position.

Sam, Nicole and Robyn all expressed a sense of frustration when explaining how little input they'd had in their modified work plans as they weren't able to work with their employers in assigning modified duties. These women's experiences show how employees who acquire an arthritic condition may not adequately be consulted with as to the modified duties they can perform when seeking a job accommodation which involves a change in duties. Adequate consultation should ideally involve the employer and employee discussing issues of accommodation and modified duties together to find a resolution that is satisfactory for all parties involved. In workplace situations such as the ones these women encountered, where adequate accommodations were not given due to their employers' refusal to properly address their requests, legal recourse is available through the duty to accommodate case law. As Lynk (2000, p.2) has found:

The accommodation duty in Canada has changed to focus from a singular requirement that the employee with a disability fit the demands of the workplace (through medical services and vocational rehabilitation), to also determining how employment requirements can be adapted to the particular needs of an employee's disability (through modifying the workplace and the tools of production)

However, in all three cases discussed above, the women chose to leave the workplace rather than pursue their right to be given reasonable job modifications.

### **5.6.2 Modified Work Hours**

Modified work hours was a type of accommodation requested by two of the women interviewed. Both Ann and Kim requested that their full-time hours be reduced as they were no longer able to work full work days five days a week. Ann reduced her work week from five to four days, and reduced the number of clients she made appointments with each day to allow her to take longer breaks. Her existing flexible work schedule allowed her to modify her work-week as she was in a position where she could set her own meetings and appointments to accommodate her desired work hours. Ann explains how she also modified her work day to allow for a longer lunch break:

Ann: There was too much [work] and I started going through the day and crossing off, so instead of seeing 5 or 6 students a day I just couldn't do that. I would put it down to 4 and arranged with the team [to have co-workers see other clients]. I mean Human Resources wouldn't have supported this, but I used to take an hour and a half lunch 'cause they said strictly speaking, you get a 15 minute lunch break, or coffee break in the morning and the afternoon. So I would come home at lunch and it was an hour and half, I would come home, 15 minutes home and then I would lay down for an hour, then 15 minutes back [driving to work after the break] and then I would try to do my afternoon [appointments]. So that was how I handled it and the team [of co-workers] was more supportive that way.

Like Ann, Kim also modified her working hours to accommodate her medical condition. Kim's schedule is now more flexible in that she is able to arrive later and leave earlier wherever her schedule allows rather than her former practice of arriving at a set time in the morning and leaving late in the evening. She has also modified her duties so that she is no longer required to do some of the more physically demanding aspects of her job such as hanging paintings and preparing rooms for art displays. Kim has found that these modifications in both hours and duties have made it easier for her to visit her doctors more frequently. Modifying work hours and days is a potential accommodation for women who have acquired arthritic conditions, but it is only appropriate in certain work environments where such flexibility is allowed. Kim and Ann both had jobs where they were able to schedule their days to allow for breaks; however, women who do not have such control over their schedules may find it much more difficult to seek modified hours as an accommodation while remaining a full-time employee as Kim and Ann were able to do. This may explain why so few of the interviewees cited modified work hours as a workplace accommodation they had sought from their employers.

### 5.6.3 Physical Workplace Accommodations

Physical types of workplace accommodations were requested by three of the women interviewed. Ann requested that a dictation-based word processing program be added to her computer to make administrative duties easier as her lupus makes typing difficult. Patricia requested that a supportive mat be placed on the floor where she was required to stand for long periods to allow more joint support as standing aggravates her fibromyalgia. Sean had an ergonomically correct keyboard placed at her workstation to assist her in typing without aggravating inflammation in her joints. As mentioned in Chapter Two, according to Ontario's Ministry of Citizenship (1996), most physical modifications to the work environment are low cost and the ones requested by Ann, Patricia and Sean are consistent with this finding. It is not surprising that only three of the eighteen women had sought physical modifications to their work spaces. Kathryn, felt that there weren't any physical accommodations that could be of help to her in her job as a Registered Nurse (RN) due to its extremely physical nature, while Vicki works on contract and thus has no direct supervisor to request accommodations from, and Susan, a former RN, worked in an environment where such job modifications were discouraged and looked down upon.



#### **5.6.4 Willingness of Employer to Provide Accommodations**

Six of the women had found their employers to be unwilling to provide any type of accommodation. Susan and Kathryn, both former RNs, said that although they would've liked to modify their duties by reducing the lifting required, it was impossible as those involved in the nursing profession all had to "pull their weight" by completing all assigned duties. Their comments about the nursing profession suggested that RNs were expected to fulfill all their workplace duties without modification or withdraw from the profession. Kathryn reduced her hours to part-time, taking cuts in her salary and benefits, to allow her more time to rest, but found that the part-time nurses were often given extra duties and hours in order to help out the "full-timers." Kathryn helped out with these extra duties, citing that it was what she and other part-time nurses were expected to do. Susan indicated that the nursing profession is not designed to allow modified duties, as she said: "If I couldn't do everything then I shouldn't have been there." Susan and Kathryn were unwilling to discuss their needs with their employers because modifying duties was not looked highly upon by their employers or colleagues, they both left the nursing profession after deciding not to fight for their legal rights to be

accommodated at work due to chronic pain and fatigue. While their employers are legally required to accommodate their needs, known in Canadian law as the duty to accommodate, neither sought legal action against their employers because, based on their experiences in the nursing profession, they felt that nurses performing modified job duties were not generally treated with respect by colleagues and administrators.

Darlene found that her employer was unwilling to accommodate her requests to be moved to a workplace closer to her residence within the same corporation. She felt that she got lost within an "administrative system", where she was continually having to fill-out paperwork regarding her medical condition and missed work, once she was no longer able to commute to her workplace and therefore was no longer able to work. Darlene believed that if she could work closer to her home, more of her energy could be spent while at work rather than on her one-hour commute to her workplace. She explains:

Darlene: My experience with my employer has been less than favourable. They've done very little to support me. They basically put me in the hands of the insurance company. The insurance company has basically shuffled me into their paper work and declined my application for benefits [due to conflicting medical reports by different Doctors]. I've asked my employer for assistance in that regard and they basically tell me that I have to follow the process of the insurance company. So I would say no, they've done very little. I was working in Toronto for about a year and it just got to the point where it was too unbearable and I was really sick last year. I literally collapsed one day and I couldn't get up and I

couldn't get up out of bed, the pain was so excruciating and I was just so weak and so exhausted. At that time, I told them that I needed to start to look for work closer to home and that the commute was seriously affecting my health and my ability to work. They told me that it wasn't an adequate reason to relocate me so that I would have to resign and reapply for a position locally. I was willing to do that and I told them that, and once I told them that, they refused to let me resign because they felt there was too much exposure on their part because I did have a medical diagnosis. They knew it wasn't right that I should have to resign and reapply. So I've really been stuck in limbo and fighting between them and the insurance company to try and get an appropriate balance or assistance.

Sadie had a similar experience to Darlene. Her requests for modified work hours were denied and she was told that her inability to complete her work was making the employer look bad: "They really didn't care [to make accommodations] that much... And they were angry at me, I made them look bad [due to a lack of productivity]." The lack of appropriate accommodations afforded Susan, Kathryn, Sadie, Darlene and the other two participants was related to the fact that they were working with employers and co-workers who were not understanding of their physical and social needs.

## **5.7 Conclusions**

The experiences discussed in this chapter have shown that women who have acquired arthritic conditions face many workplace and social barriers which alter daily life spaces and lifeworlds, generally in a negative fashion. It was shown

that interviewees' self-identities and other's views of them in many roles, including that of a 'worker', had changed dramatically since acquiring an arthritic condition. Many of the unemployed women struggled with a diminished sense of self-worth compared to when they were a full-time employee, and with how to re-conceptualize and re-value themselves based on their fluctuating or decreased levels of ability. Those women who were no longer able to work struggled with their new sense of having "roleless" existences, trying to find value in what they are able to do rather than on what they once were able to accomplish as an active member of the labour force. Not surprisingly, seven of the women underwent periods of depression after acquiring an arthritic condition at least in part due to the changing roles they played in the workplace, at home and in society at-large. Their changing experiences of self and work after acquiring an arthritic condition show how complex the factors causing these changes are and that the changes were generally unsettling for the women involved.

The experiences discussed above also showed that these women faced many physical and social barriers to participation in the workforce. Three significant workplace barriers were identified by the participants: physical barriers, a general lack of knowledge about arthritic conditions, and a lack of understanding from co-workers about the nature and severity of these illnesses. Most of women found the social workplace

barriers to be more concerning and prevalent, and potentially more oppressive, than physical ones. Three significant experiences outside the workplace were discussed by the interviewees which affected their capacities to be involved in the labour market. These included: 1) experiences within spaces of health care, such as having one's work-potential evaluated, 2) the lack of medical legitimation afforded to fibromyalgia which can result in employers and co-workers minimizing the seriousness of these biomedical conditions, and 3) the lack of public knowledge and awareness about arthritic conditions which can lead employers to make inappropriate workplace accommodation arrangements.

Just as there were a variety of socio-spatial workplace barriers identified by the women, there were also several different types of workplace accommodations sought out after they had acquired an arthritic condition. Two of the women unsuccessfully tried to modify their workplace duties, an additional two modified their work hours and three of the interviewees sought physical accommodations such as floor mats and specialty computer keyboards. It was also demonstrated that six of the women believed they had been working for employers who were unwilling to provide the types of accommodations they would benefit from. Although employers are legally bound to accommodate full-time disabled employees through the duty to accommodate, it was shown that some of the

women, including Susan and Kathryn, opted to leave the workplace without exercising their rights to seek and obtain accommodations due to chronic pain and fatigue, and the fact that they believed that RNs with modified duties were looked at in a negative fashion by co-workers and employers.

The experiences discussed in this chapter, both those which relate to the workplace, such as social and physical barriers, and those which impact workplace experiences, including a lack of medical legitimation and public knowledge about certain arthritic conditions thus impacting employers' and co-workers' perceptions of these chronic illnesses, lay the foundation for the discussion presented in the next chapter. Chapter Six will outline the types of employment supports the interviewees have used and their views on how government income and employment support programs for disabled people can better meet the needs of women who have acquired arthritic conditions.

## **Chapter Six**

### **Interview Findings: Employment Supports Used by the Interviewees and their Recommendations for Improvement to Employment and Income Support Programs and Policies**

#### **6.1 Introduction**

This chapter examines the use of various government employment supports by the women interviewed. Their experiences of employment and income support programs will be discussed in addition to their views about how policies and programs can change to become more supportive of the needs of women who have acquired an arthritic condition. As Schriener et al. (1997) have shown, we know little about how women with disabilities are impacted by social policies. The goal of this chapter is to address this lack of knowledge by examining the relationship between employment policies and the experiences of the women who have acquired arthritic conditions interviewed for this study.

#### **6.2 Government-Funded Employment Supports Used by the Women**

Of the eighteen participants in this study, ten had used some form of government-funded employment support. There were two main types of supports used, those for income

support, such as CPP-D and ODSP, and those designed to assist in finding and maintaining employment, such as Canada Employment Centres. Further, fourteen of the eighteen women felt that they had limited access, or no access at all, to policy and program information, thus limiting their knowledge about the types of supports available to assist them.

### **6.2.1 Non-Income Assistance Employment Supports**

Two types of non-income government-funded employment supports were used by the participants. Visits to employment support centres, also known as Canada Employment Centres, is one type and vocational training programs is the second type of non-income assistance employment support used by the women.

#### **6.2.1.1 Visits to Employment Support Centres**

Three of the women had visited employment support centres funded by Human Resources Development Canada (HRDC) in order to have assistance in finding employment, and another woman visited an employment support centre run by the Salvation Army. Darlene visited her local HRDC centre, also known as a Canada Employment Centre (CEC), in order to find out about government support programs that she was eligible for. As was mentioned briefly in Chapter Four, programs designed to assist disabled Canadians in finding and



maintaining employment can be administered through CECs, and those that are generally fall under one of the six federal strategies to assist persons with disabilities in the workplace. She was disappointed at how little she was eligible for, as she said:

Darlene: I went to Human Resources Canada to inquire about what was available or what assistance I could get and they basically said that there was nothing. Because I had the independent medical exam from the insurance company doctor that said she didn't think her diagnosis would be Fibromyalgia, I don't qualify for employment benefits - that's employment insurance. From people that I've talked to in the support groups, they say that it's next to impossible to get anyway [because most applicants are denied income support].

Anne and Sadie both visited a unique CEC designed specifically to meet the needs of people with disabilities. PATH Employment, located in downtown Hamilton, met and exceeded the expectations that they had of this type of government support:

Anne: I am starting on Monday at Path employment, which helps people with disabilities find jobs. It's the best place that I have ever found to help people get work. I start Monday on a 3 week course to learn how to go through job searches. I have a much more positive attitude this time because I know they will advocate for me with an employer, where in the past, well, we'll teach you how to do to, but go do it yourself and you're on your own. Right? But they're saying, okay, we'll show how to do it and you do it yourself, but if you feel you need help, we'll help you. And you sell yourself to the employer. The whole group there in that office are very supportive, very kind, they're willing to help and they don't talk down to you, which is nice.

Sadie: I found that I went to Path Employment, which were [sic] really very good. I found them the only place who that [sic] can understand that you have a disability, and help you towards your goal. Not only that, [the staff] help you feel you can accomplish something. You're not

totally a goner, I don't know what word to use.

CEC's have been designed to offer employment support services and provide information about government programs as they are multi-purpose employment support centres. Anne and Sadie's positive experiences of PATH's services show that CECs are able to meet the employment support needs of some women who have acquired arthritic conditions by referring them to specialized services.

It is not surprising that more of the women interviewed had not used CECs for employment assistance; thirteen of the interviewees didn't feel that they were well informed about the local employment supports available to assist them, and most likely weren't even aware of the existence of such Centres in and around the City of Hamilton because they were discussed by only three of the interviewees. Fawcett's (2000, p.32) research into the labour market experiences of women with disabilities in Ontario has found that women with disabilities are frequently unaware about "opportunities for training, the availability of various employment-related programs, and job opportunities." Based on her findings, and the experiences of the women interviewed in this study, it is likely that many persons with disabilities in Canada are unaware of, or poorly informed about, the programs and services available at CECs.

### 6.2.1.2 Vocational Training Courses

A second type of non-income employment support used by three of the participants was educational and vocational training provided by government agencies. Anne, Karen and Sadie had all participated in different government-funded educational training programs. Each of these three women participated in programs funded by the Workplace Safety and Insurance Board (WSIB). The WSIB offers income support and vocational rehabilitation, such as the ones used by Anne, Karen and Sadie, when an employee becomes injured or disabled during the course of employment or while at work (Campolieti & Lavis, 2000). These three women were eligible for vocational programs funded by the WSIB as they had acquired their arthritic conditions while being employed and also because their employers had paid a premium to the WSIB for each person employed in their companies. The WSIB, like CPP-D, does not fall under Canada's employment support strategy for persons with disabilities as it is based on a contributory fund and only those who have been actively involved in the labour market are eligible.

Anne participated in a Challenges and Changes course and a Building Management course taught at Mohawk College, a local Hamilton College, which was offered by the WSIB. Karen had also received training through the WSIB in Management.

Sadie had participated in a Business Administration training program sponsored by the WSIB. Anne entered her training program with the goal of getting a job in bookkeeping, but, as she explains, the WSIB suggested she take a new direction:

Anne: I'll tell you exactly what programs I took. Okay, let me see. This is the pack. I've got one of my resumes in there. There's ... I did the computer program up at Mohawk to see what I am designed to do. Then I did Myer's Briggs, which said I should be a supervisor in the forestry service. I took a small business program went into [a handmade crafts] business and went bust within a year, and that's a lot of money I'm still paying out. Basically, I had wanted to do bookkeeping and at the suggestion of the counsellors from the government [who work for the WSIB] , etc., because they felt a bookkeeping business wasn't viable, that ... and I had a talent for crafts ... so I went into the craft business. Of course, you have to buy a lot of supplies for that before you start. So, I ended up with an \$11,000 loan and I still owe \$4,000.00. So that went bust and I went back to finding a job. I took Changes and Challenges up at Mohawk which helps you figure out who and what you are [which was funded by the WSIB]. I took a course in Building Management and I spoke with the people [who ran the course] about taking it and they said, "oh yea, you will have no problem getting a job." They [the WSIB employment counsellors] weren't able to find me one within a year because all the places want couples [to manage buildings], they don't want one person.

Anne's courses have all been sponsored by the WSIB and she has taken them while receiving CPP income support. She is no longer eligible for educational and vocational training courses through the WSIB as she has exhausted her training limit. She has a great deal of frustration about being "encouraged" to start her own craft business that was not successful since she now must pay back her small business loan

with the little monthly financial support she receives through CPP. Anne explained that she often has to use local food banks because she pays out almost all of her monthly CPP income in rent, phone bills and loan expenses. Additional frustration stems from the fact that she has participated in several government-sponsored employment training courses through the WSIB and still has had great difficulty in finding a job. As she explains, "So, you know I should be employable [after receiving so much training], but I don't seem to be. I just have a big problem there."

After leaving the workforce Karen enrolled herself in a Microcomputers program that she paid for herself. After her arthritis became more severe and rapid and she was no longer able to pursue a career in microcomputers, she signed up to take a Management course funded by the WSIB, but found the course to be extremely inaccessible:

Karen: I was also on employment insurance [WSIB income assistance], and I did get my program [the Management training course funded by the WSIB] through employment insurance. I really found there was no assistance in gaining employment - it wasn't in their [the WSIB's] interest [as their concern is with training and not with employment outcomes]. We [she and her partner] tried the management program and we lasted two days because of [the winter] weather conditions and [walking to and from public] transportation. Plus I will probably end up in a wheelchair and even my doctor's office isn't accessible - she has stairs.

Participating in the Management course, funded by the WSIB, did Karen more harm than good as travelling to and from the

course aggravated her joint inflammation and painful nodules on her feet. Her experience shows that there are many factors which impact on the experiences and accessibility of educational and vocational programs; including the season in which it is offered and the distance to the program location from participants' residences. These factors aggravated Karen's arthritis and made it physically impossible for her to continue the Management course she had signed up for through the WSIB.

Karen and Anne's experiences of vocational training programs show that the specific physical accessibility and employment needs of participants need to be taken into account when developing such programs. These needs can include the physical accessibility of program locations and the likelihood of positive employment outcomes for women living with chronic illnesses such as arthritis. It has been shown that in developing countries, for example, chronically ill women who participate in vocational training programs are frequently encouraged to make handicrafts, like Anne was, rather being offered training which addresses the needs of those sectors of the labour market in which employment opportunities are located (Groce, 1997). While vocational programs in developed and developing countries cannot be directly compared, as they have drastically different fiscal resources, the experiences of women in less developed countries have shown that

vocational programs, regardless of location, should be developed based on the demand for specific types of labour in local labour markets. Furthermore, Kitchin et al. (1998) have found that being a participant in a vocational training program designed for persons with disabilities in Britain does not generally increase the likelihood of securing long-term well-paying employment. In their study of the employment training experiences of people with disabilities in Donegal, Ireland, they also argue that the sixteen participants "...received little in the way of careers advice, and what advice they had been given pushed them towards a range of training schemes that they might be 'eligible for', rather than schemes they might want to do or lead to a career" (Kitchin et al., 1998, p.792). This finding is similar to Anne's training experience where she had wanted to learn bookkeeping but instead was encouraged by WSIB administrators to open her own craft business. By considering labour market needs in making, or enrolling for, vocational programs, chronically ill women would most likely not be put in Anne's situation where she has taken multiple job-specific courses and still has not been able to successfully find employment. Although this study did not investigate whether or not local labour market considerations and demands were considered in the development of vocational programs in Ontario, it is important that steps are taken to ensure that women with

disabilities aren't encouraged to be trained for jobs that aren't available locally.

### **6.2.2 Income Assistance Programs: Applying For and Receiving Benefits**

Four of the women were receiving CPP-D income assistance at the time of the interview, an additional three were in the process of applying for CPP-D benefits, and another two were on short-term income assistance through the WSIB and considering applying for CPP-D. Kathryn was initially turned down for the CPP-D income assistance she had applied for and successfully appealed the decision through a tribunal. When looking back on the period during which she was applying for the funding, and appealing the decision, she said:

Kathryn: If I had to do it over again, I should have gone downtown and have them [the government CPP employees] fill it [the CPP-D paperwork] out. I was really feeling sick. Not only were the joints hurting, but I would read - like even for me to read this all over now, its hard for me. It was really very hard for me to answer the questions and they want specifics... If I had to do it over again, I would go downtown. It didn't hit me [that she wouldn't be able to complete the paperwork on her own]. I thought, well I can answer these. At the time, I asked my husband to help me but he just wasn't into reading all the questions and helping me out and my daughter was a little bit too young to help. Actually, I felt so sick at the time, I didn't even feel like going out or downtown because I knew for sure that I wouldn't be good at driving or I'd have to take a bus and that would be...and it was Winter and I was just feeling very, very ill.



Her frustration over the administrative practices and amount of paperwork increased when her initial application was denied and she realized that she would have to start the process over again in order to receive CPP-D income assistance.

The three women who were in the process of applying for CPP-D income support at the time of the interview found the application process to be time consuming and exclusionary. Sam was aware of the difficulties in meeting the criteria for CCP-D income assistance after being diagnosed with fibromyalgia, as was discussed in Chapter Four, she said:

Sam: They [the government] are very unsupportive...there are benefits available to people that they don't let you know about. I think they should be up front and say this is what your entitled to by our policies and laws. They don't, and I think that things like CPP mention that volunteer work [is not allowed]. They seem to think that if you could volunteer for two hours a week that you're capable of going to work. Which is bizarre in my opinion... They don't accommodate the "grey area" people. I found that with my injury as well. They didn't know what to do with me because I kept trying to go back to work. Where if I had just stayed at home and said, "Okay I'm ill and I can't do this".

Sam raised some interesting points in relation to CPP-D income assistance eligibility, and demonstrates that there is confusion over the current eligibility requirements, as was discussed in Chapter Four, because recipients currently are allowed to volunteer while receiving income assistance. She refers to arthritic conditions as falling into a policy "grey area." People in this grey area can be well enough work at times, while at others they may not be well enough to

participate in any form of labour. She feels that programs such as CPP-D unfairly categorize recipients as being fully disabled and in need of full income support or fully able to work. Those in the grey area fall between the black and white categories of CPP-D income assistance eligibility due to fluctuations in ability to work over time.

Although Darlene has yet to apply for CPP-D income assistance, she has read about its eligibility requirements and has become frustrated with its inflexible and rigid categories of eligibility, as she relates:

Darlene: There's supposed to be CPP that you can get but again, it's the same thing. The guidelines are so strict and so stringent, and with it being the subjective type of disorder [due to its fluctuating ability levels] that it is. You can't match the criteria. There are many cases where people have gone to court and are fighting it with lawyers [when they have been turned down for income assistance]. I've considered doing that myself, but I just don't have the money or the strength to do that sort of thing. Certainly, policy or social assistance or something in that regard would definitely be very helpful, if it [CPP-D] would be properly administered and not abused. I know that in my case, it would help me tremendously.

Darlene's awareness of the inflexibility in eligibility requirements for CPP-D income support has made her hesitant to apply for this form of assistance because she is unsure if she would be considered eligible. Anne, while currently applying for CPP-D is also concerned about this inflexibility and is aware of the different standards applied to those already receiving assistance and those applying, as was discussed in

Chapter Four, as she comments:

Anne: In Ontario, if I'm on disability [CPP-D income assistance], I could go get a full-time job and they'd continue paying my disability [benefit for three months]. If I'm not on disability and I want to get on disability, I can't have a job. It's like, I've cut my throat by starting to work again and looking for a job. I won't get my disability [CPP-D income assistance]. I know I won't. Because I'm capable of doing something. So there's this catch 22 thing.

Darlene, Anne and Sam's comments indicate that these women are extremely aware of the faults contained within the CPP-D categories of 'eligible' and 'ineligible', such as the differences in work participation allowed by those applying for and those receiving income assistance, as well as within the application process in general, including the time involved in completing the forms, as discussed in detail in Chapter Four.

In addition to difficulties in qualifying for CPP-D income assistance, eight of the women found the administrative processes to be difficult to negotiate and overwhelming. Ann indicated that the forms seemed to be written in language that was inaccessible to most applicants:

Ann: My GP [general practitioner] helped me with a lot of it. She's been really, really supportive and my partner... I had trouble filling this out and I have 2 undergraduate degrees, I have a Masters Degree and all but, I have 6 years of a doctorate. *What the heck is somebody who doesn't have the [same] education level, who is ill going to do with this thing? The only thing you could do is have somebody who's advocating on your behalf fill it out for you. Because it's otherwise impossible.* (emphasis added)

Ann's comments are telling as they indicate that the language used on application forms may force applicants to depend on others, such as Doctors and partners, to assist them. Robyn also said that she believed the massive amounts of difficult paperwork were created to "weed out" those applicants who are determined enough to put the effort into applying from those who are not. Although there is no evidence to support her opinion in the literature reviewed for this study, it is interesting to hypothesize that the paperwork alone might be a mechanism used to reduce the number of applicants for CPP-D income assistance applicants.

Hyde (2000), in his research on the state of income assistance restructuring in Britain and the impacts it has had on persons with disabilities in the 1990s, has termed such inaccessible and lengthy application processes as being a form of "intensified social control." Such social control has been expressed in an increased reliance on strict eligibility testing which has exposed applicants to "higher levels of bureaucratic and medical regulation" (Hyde, 2000, p.332). While his research pertains to income assistance programs in Britain, the women's comments above seem to indicate that this is happening with Canadian policies as well due to their concerns about the administrative processes involved in applying for CPP-D. Although eligibility requirements for CPP-D have been relaxed over time, the administrative work, by

applicants and program administrators, involved in applying for and receiving CPP-D income assistance has increased (Campolieti and Lavis, 2000). For example, Campolieti and Lavis (2000, p.252) have chronicled recent changes to CPP-D administrative processes, which include:

a) mandating the reporting of improvements to health and, if significant, mandating return to work; b) instituting a program of reassessments to determine which individuals have sufficiently improved to make them no longer eligible for benefits...; d) having QPP [Quebec Pension Plan] medical adjudicators review a sample of CPP files to identify differences in decision-making and administration of claims

The changes listed above exemplify the types of increased social control discussed by Hyde (2000). Based on the policy changes Hyde (2000) has discussed in the British context, it is not surprising that the same type of social control would be happening in Canada. The types of overall policy changes he has chronicled in Britain reflect those made by the Canadian government when adopting the new EAPD act in lieu of the former VRDP act, as was discussed in Chapter Four, and changes to CPP-D mentioned above. These similarities include: the emphasis on applicants and recipients abilities to maintain competitive employment whenever possible, and the shifting of responsibility for finding and maintaining employment away from the state and onto the individual (Hyde, 2000).

Sam's concern about the administrative forms is not

their length, or the amount of detail required, but the cost involved with having Doctors fill out the application forms, as she notes:

Sam: But honestly, I don't find - I honestly don't find the forms for CPP or Family Benefits to be too much [in terms of their length or requirements]. What I do find difficult is that fiscally, they expect you to pay for all these doctors reports [as most family doctors charge a fee to complete paperwork because the Ontario Health Insurance Plan no longer covers these types of expenses] and all of these things, when you wouldn't be applying the benefit if you didn't need the money! That doesn't make sense either. The government does a lot of things that don't make any sense.

Sam's concerns are indeed legitimate, since family Doctors in Ontario generally charge between ten and fifty dollars per form for CPP-D income assistance applications (Burgel, 2001). Doctors may choose to waive this fee when applicants are in financial need, and the costs of future medical forms are covered by CPP-D if an applicant is accepted for income support (Burgel, 2001).

Those who administer CPP-D may not realize the financial hardships experienced by applicants due to the costs of transportation to and from Doctors offices and form fees as they, the policy-makers, do not generally live within the same socio-economic or socio-spatial lifeworlds as applicants. Fair (2001) has found that flaws in public policy creation "occur when there is an extreme socio-economic and socio-spatial distance between the policy-makers and lower-income people" (p.29). All CPP-D applicants are unemployed and many,

including Sam, experience financial hardship at the time of application. Policy-makers may not realize the significance of the expenses associated with applying for income support as there is a socio-economic distance between their lifeworlds and those of the applicants. For example, a fifty-dollar Doctor fee may not be a financial burden on a policy maker who has a steady income, and thus such an expense may not be viewed by him/her as having the potential to be a financial burden on, and potential barrier for, those applying for CPP-D or ODSP income assistance. Furthermore, places such as food banks and community service agencies are more likely to be visited by support recipients than policy-makers, resulting in socio-spatial differences in the lifeworlds. This distance may also help to explain the linguistic barrier commented on by Ann as policy-makers often have the privilege of knowing the specialized language used by those developing and administering government programs, and may not realize how inaccessible the language used on application forms may be.

### **6.2.3 Difficulties in Accessing Policy and Program Information**

Fourteen of the eighteen participants think that information regarding government policies and programs is not readily available or easy to access for those who are disabled. Anne said that she primarily found out about

government programs "by accident," by speaking with friends and looking at pamphlets available at her church and the food banks she frequently visited. Margaret and Robyn both feel that information about government employment support programs is not made readily available. They are frustrated with the fact that there is no single location, to their knowledge, where information regarding disability support programs for residents of Ontario is available due to the time they have used in seeking out such programs and services on their own.

Susan believes that the lack of access to information regarding assistive programs and policies is a deliberate government strategy to reduce the number of applicants for income assistance. While there is no evidence to support Susan's claim that inadequate access to information is deliberate, one reason why better access to information regarding support programs may be lacking is that government Ministries and offices have poor co-ordination. Fair's (2001) recent study of Canadian social policies found that the different levels of government (municipal, provincial and federal) do not interact well, and even within governments, different Ministries and offices lack co-ordination. She has shown that, for example, poor co-ordination between Ministries and government offices has resulted in the benefits of some financial assistance and income assistance programs being cancelled out by the policies and programs created by other



offices, generally resulting in negative impacts for individuals with low incomes. Information may be offered by one provincial Ministry regarding an income support program, such as the ODSP, at a particular location while information about CPP-D may be distributed by at a different location meaning that people with disabilities must travel between several locations to get the information they desire. Fair's (2001) findings suggest that better co-ordination in the development and distribution of information about disability programs between various levels of government could potentially improve access to information.

Marilyn says that it took her several years after acquiring lupus to find about the different types support programs, including income assistance and tax rebate programs, available to her as an Ontarian with a disability:

Marilyn: ...I had to go looking for help [in terms of finding out about support programs], I had to search [in order to get program information]. I had to search [sic]. It was only a couple of years ago that I found out that anybody who is disabled can get a rebate off the amount of gasoline that they used on their vehicle to transport them. Who told me that? I found out purely by mistake [in that she didn't know that type of assistance was available]. I'm not sure if I read it or whatever, and I had to go searching it out. There isn't a booklet [from the municipal, provincial and federal governments] that says okay, you're disabled here's what's available to you [in terms of support programs and income assistance]. There's no such booklet, there's [sic] no guidelines [for finding out about government programs], there's no, there's no follow these steps [to searching for assistance], there's no directions [to gaining support], you have to go looking for everything... There's also a disability deduction you can get on your

income tax. Does anybody tell you that that's out there? No. Even if you're working, there is a disability deduction on your income tax. Nobody tells you this unless you find it out by mistake or by chance [based on her experience]. There has [sic] [have] to be guidelines - there has to be an instruction booklet on being disabled.

Marilyn's frustration about the lack of access to information about programs for persons with disabilities typifies those made by the thirteen other women who were discouraged by the lack of access to information about government employment, and income support, programs.

Sam believes that there are ample government and community supports available for women who have acquired arthritic conditions, but that there is a lack of knowledge on the part of these women about their availability. Sam's view that there are ample government programs is based on her own experiences of searching out information on employment support programs for her own use and the support groups she has run in the past. Sean, unlike Sam, thinks that there is a great deal of information regarding support policies and programs available through government websites. However, she is also aware that this form of advertising is exclusionary because women who cannot afford computers, or who are not able to easily transport themselves to public computers, such as those located in public libraries, are not able to access this information.

Sam and Sean's experiences of searching for

information about government policies and programs for persons with disabilities show that it's not simply those women who have not sought out policy and program information who believe it is difficult to access. They both actively sought out, and were able to find, policy and program information and yet they also believe that it is provided in a form, via the internet, for example, which is difficult for many chronically ill women to access. Sean was particularly well-informed about income assistance programs and was the only interviewee to discuss, or even acknowledge the existence, of the ODSP and the income assistance available through it for Ontarians with disabilities. However, it is also important to note that Ann, Sam, Sean and Margaret, four of the best-informed women about government policies and programs, have all been involved in some form of post-secondary education and have more training. These four women were better able to access information than at least ten of the other participants, which supports Marris' (1996) finding, based on her research on the lives of chronically ill women, that one's ability to access information, both health and policy-relevant in nature, is "intertwined" with one's level of education and position in society. This access gap is also based on socio-economic status, according to Marris (1996), which can affect access to educational resources and post-secondary education in addition to one's ability to afford tools such as a computer and

internet access. Thus, measures made to improve access to information about income assistance programs, such as CPP-D and ODSP, and vocational programs, including WSIB courses and CEC services, must take these educational and socio-economic gaps into consideration with particular emphasis on getting information to people who do not have the tools or training to acquire the information on their own.

Five of the participants argued that one way to improve access to information about government-funded policies and programs is to have information packages available, regarding income assistance programs and local community supports, at Doctors' offices. Their suggestion was not to have Doctors' develop the package, simply to have them distribute it. The package should be geographically specific so that information on local supports, such as support groups, can be included as well so that people with disabilities are informed about local, provincial and federal supports all within one package. This package should ideally be created by government agencies working in consultation with local service providers and program users, and should provide information on local contacts, including CECs and Ministry offices, where further information can be gathered. These women suggested that Doctors' offices are one place where people with disabilities visit on a fairly frequent basis, for both diagnostic and treatment procedures, and that they should be

a starting point for the distribution of information about government and support programs. Furthermore, as Sam indicated, it is essential for women recently diagnosed with arthritic conditions to receive information regarding government policies and programs so that they can be well informed about which income assistance programs they are eligible for and can benefit from. She believes that because of the lengthy application procedures for income support, people should be informed of such programs at the point of diagnosis so that they can begin the application process immediately. Diana believes that having a central resource point, such as a Doctor's office, from which further information can be obtained is the best way to inform women about the government supports available. The onus is not placed on the Doctor's office, or its staff members, to provide additional information regarding programs and their eligibility as further contact information could be contained within the information packages.

Marris (1996) has shown that chronically ill women *expect* that their Doctors will be able to provide them with information that pertains to their health and well-being. Given her findings, it is not surprising that five of the women interviewed suggested that Doctors' offices should be a starting point disseminating of information about government

and local support programs. The suggestion of handing out resources at Doctors' offices is only viable if doing so does not detract from the existing duties of these health care practitioners; therefore, having packages prepared by government agencies and local support offices, and then sent to Doctors' offices for distribution, is essential to making this suggestion for information dissemination practical.

### **6.3 Community-Based Supports Used by the Interviewees**

In addition to the government-funded employment and income supports discussed above, eleven of the interviewees had participated in local support groups for persons with arthritic conditions. Further, five of the women discussed utilizing other forms of support such as internet chat groups, personal support networks and community-based recreational programs. Although these programs are not the main focus of this study, it is important to examine the local supports used by the participants in addition to government employment supports as they can be spaces in which important information can be gained, and support can be provided, in relation to employment and income needs.

#### **6.3.1 Support Groups**

The support groups used by the interviewees were most

often those established by the Arthritis Society's Hamilton chapter. They were spaces in which the women were able to obtain advice regarding employment situations and the processes involved in applying for CPP-D and other income assistance programs. There are many formal and informal support groups running in the City of Hamilton that assist people who have acquired an arthritic condition: the actual number of groups varies greatly between years as new groups are established and old ones fold due to a lack of funding or participation, making it difficult to gauge the number of active groups running at any particular time. Therefore, it was not possible to ascertain the number of support groups running at the time of the interviews.

Four of the participants, Sam, Kathryn, Marilyn and Nicole, had positive experiences in local support groups funded by the Arthritis Society. Sam said that the support group was "helpful because each person in the support group brings in their own experiences. Some were still working part-time, [while] some were experiencing a lot of discrimination." Sam, a former support group leader, made a point of discussing local supports, such as community service agencies and their services, and government employment and income assistance programs during support group meetings as she believes that this kind of information should be openly talked about during meetings. Kathryn, a former nurse

diagnosed with fibromyalgia, explained that the social worker who led the support group she belonged to, based in her workplace and funded by her employer, instilled in her that pacing her activities was essential to managing her illness in the workplace, "It was helpful, the support group," she said, "we just basically shared our feelings...cried on each others' shoulders." Kathryn also participated in another support group outside of her workplace. Sam and Kathryn's comments suggest that support groups can offer a nurturing and supportive space where participants can speak openly with others experiencing similar situations as well as learn coping strategies for dealing with changing life experiences, such as unemployment or reduced mobility, from other participants who experience a variety of physical, social and workplace barriers. These women's experiences of support groups are not surprising. Barlow & Harrison (1996) have shown that the most positive aspect of arthritis support groups is their ability to allow "similar others", those who have similar impairments, to connect with each other in a supportive and safe space in which they can speak candidly about their experiences and problems. The four women who commented on their positive support group experiences all had benefited from their exposure to "similar others" as facilitated by support groups throughout the City of Hamilton.

Four of the women who participated in support groups,



Ann, Darlene, Karen, Anne and found their experiences to be more negative than positive. Anne said "I was a member of the fibromyalgia support group for a while but I found it rather depressing. They were always taking about what was wrong [with participants] instead of what was right." Karen brought up the issue of commitment, saying that "A support group is okay if you can commit yourself." Her experiences of support groups had not been good, and she was able to recount being involved in a support group which held its meetings in an inaccessible location:

Karen: I found it difficult, it was 2 hours where you had to sit and only a 10 minute break. The chairs weren't appropriate and also the washroom wasn't accessible. I have trouble with my hands and you can't even open the door knob [to the washroom]. I didn't understand that.

Darlene and Ann both found that constant pleas for support group volunteers at meetings were inappropriate as the participants were chronically ill and most, like them, were in no position to volunteer their time and energy to leading a group. The comments offered about support groups in the Hamilton-Wentworth area indicated that some support group participants were satisfied with their experience while others were not. Those who foremost desired and appreciated contact with, and support of, similar others, such as Sam and Kathryn, generally expressed positive experiences of support group participation. Meanwhile, those women who were more concerned about the types of information conveyed during meetings,

including Darlene and Ann, generally discussed negative experiences of support groups as they felt that such groups had not effectively addressed the issues of most concern to them such as the types of assistive policies and programs available for their support and strategies for remaining in the paid workforce.

### **6.3.2 Other Community-Based Supports**

The use of local supports other than support groups, such as internet support groups and personal support networks was reported by three of the women interviewed. Anne had created an informal personal support network consisting of a phone list of friends and family members who she could call when she needed support, as she said:

Anne: I formed my own support group through my friends and in the church. I literally sat down and put it together. People I could call when things were bad and I was getting depressed about it. If my hands are really bad and I need to go to the store shopping or something or to the food banks, there are two people I could call who could take me.

Diana explained how she had joined an internet support group for people who had acquired Arthritis; however she eventually left the group because "there were so many people with either overwhelming problems or overwhelming [self-] pity." While most of the interviewees participated in local support groups, Anne's use of a personal support network and Diana's use of a

virtual community show that there is diversity in the types of support available and used by women who have acquired an arthritic condition. It is not surprising that a variety of local supports were used by the women interviewed as the discussion presented in Chapter Five established that the women interviewed had had extremely different experiences of the workplace and of changes in self-esteem and self-worth and therefore would most likely benefit from a variety of community-based supports being offered.

Marilyn founded an exercise-based pool support program at a community recreation facility in the City of Hamilton; a program which is promoted by the Arthritis Society. On average she has 120+ participants attend each of two weekly sessions, and the cost is simply the purchase of a City of Hamilton yearly recreation pass which is thirty-three dollars for a six month pass during the 2001-02 fall/winter season (City of Hamilton, 2001). Her program is the largest pool exercise program of its kind in Ontario. At least three of the other interviewees have actually participated in Marilyn's recreational program at one point or another. She decided to start this program out of necessity as she needed to stretch and exercise in a pool, as it is easier on arthritic joints, but no such pool exercise program was available prior to her own. Marilyn has developed a great sense of accomplishment as a result of developing her pool exercise program. Her

feelings are not surprising as Jamer et al. (1996) and Barlow & Williams (1999) have both shown that leaders of community support groups, or in this case recreational programs, generally experience many benefits, including other participants' respect, and a sense of accomplishment as a result of their roles as volunteers. In general, the support groups and other community-based supports discussed by the participants offer an integral form of employment support as they create a space where concerns and issues surrounding employment experiences, and application procedures for income support programs such as CPP-D, can be voiced and addressed with "similar others" as Sam did in her role as a support group leader. Again, experiences of support groups were varied based on whether the participant's expectation was to meet and talk with similar others, resulting in a generally positive experience, or to gain specific types of information about 'coping' strategies and assistive programs, which generally resulted in expectations which were not met.

#### **6.4 Changes and Improvements to Employment Support and Income Assistance Programs Suggested by the Interviewees:**

The participants were asked to suggest ways in which government employment policies and programs for persons with

disabilities could become more supportive of the needs of women who have acquired arthritic conditions. Each of the eighteen women had ideas about how policies can and should be changed, about new employment programs that should be implemented, and suggestions for policy-makers, which can be summarized in the eight recommendations discussed below. As none of the eighteen interviewees had applied for or received ODSP income support at the time of the interviews, their comments were generally in reference to CPP-D income support; however, whenever possible, suggestions about changes to the ODSP program, based on the interviewees' policy and program recommendations, are made.

#### **6.4.1 Flexible Work Hours**

Ten of the women indicated that policies should be developed which encourage employers to provide flexible work hours for persons with disabilities, and that policies should be more supportive of recipients working part-time flexible hours while receiving limited income support. Not surprisingly, Ann and Kim, the two women who had made flexible work hour arrangements in their places of employment, both recommended that policies and programs be put in place which support such a measure.

Margaret's suggestion is to have people work a certain

portion of a regular work week, based on their ability levels and have the government, through CPP-D income assistance, top-up their part-time income with partial income support:

Margaret: So flexible hours, yes [I would like to see a policy support them]. [With] A  $\frac{3}{4}$  work week, it's hard to support yourself, though, I know, if you're on your own and earning a woman's wage, I don't know. Unless they put some kind a income tax refund, or funding a little bit so it would give you the other quarter in some fashion. That would be good too.

Margaret, and three of the other women who recommended implementing flexible work policies, believe that the government, through CPP-D, should provide top-ups, where income support is given to provide the employee with the equivalent of a full-time employee's salary.

As CPP is a contributory benefits plan, creating a program such as this in conjunction with CPP-D, as Margaret has suggested, would restrict eligibility, allowing only those applicants who meet CPP-D eligibility criteria to participate. However, by developing a new program, not in conjunction with the CPP-D or ODSP programs which currently offer only full income support, more people can be given the opportunity to participate. The purpose of developing a program such as this is so that people with disabilities who are unable to work full-time hours are not forced to receive full income assistance and not work on a paid basis at all. Currently, the only option for income assistance, through both CPP-D and

ODSP, is to receive full benefits and not perform paid work at all, as was illustrated in Chapter Four. These women have suggested a compromise whereby people on CPP-D income support can work a limited number of hours while receiving partial income assistance. A program such as this is ideal as long as participants are able to gain flexibility both in the amount of work performed and in when the hours are worked. For example, if a program participant was to request an income breakdown of fifty percent income assistance and fifty percent paid labour, it would be essential that s/he also be able to maintain flexibility in the hours worked because such flexibility is important for women with arthritic conditions, as is discussed below.

Sean indicated that working flexible hours, in her case, would not involve a reduction in the number of hours worked on a weekly basis but would allow her to work during the times that are best for her:

Sean: If I could work 10-6, I'd be a happy camper... My best period during the day is usually in the evening. If I could do half of my job from home in my time, it would make a huge difference. I have instituted semi-flex hours anyway. I've never checked with anybody if it's okay, hoping nobody notices. I'm supposed to be to work at 8:45, sometimes I'm there for 8:30, sometime I'm there for 9:30. If I'm there for 9:30, I don't take a lunch, or I don't leave until 5:30 or 6:00. And again, I'm very lucky because I run my own office and I am a single person office and there isn't really anyone looking over my shoulder. I don't know if anybody is aware that I do that. But I know that certainly that that's not an option in a lot of other positions in a lot of other places. "8:30-4:30 honey! Take you hour lunch and be

back on time!" I know that that's not necessarily feasible for somebody with any kind pain disorder because, I know I hit a lull in the afternoon.

Sean's comments indicate that, for her, working according to her fluctuating ability levels on a given day allows her to judge when her best working hours and to complete her work accordingly; she suggested that other women with arthritic conditions might benefit from a working arrangement similar to her own. Developing and implementing flexible work policies and programs provides a way to offer supportive employment policies to persons who fall within the "grey area" of impairment and disability, as discussed earlier in this chapter. For example, Margaret's suggestion of creating a top-up program would allow people with limited abilities, those in the "grey area", to perform a certain amount of paid labour based on their level of functioning at a given time without having to resort to receiving full income assistance and not being involved in the paid labour market at all. Such flexibility also has the potential to empower employees by allowing them to choose the hours they are best suited to work based on their abilities on a given day, which was discussed by Sean.

In her study of the frequency and social patterning of work disabilities among women in Canada, McDonough (1997) established that chronically ill women will, in fact, leave



the workforce specifically due to the inflexible time schedules that dominate many places of employment. Thus, implementing policies which encourage flexible work hours may actually reduce the number of chronically ill women who leave the workforce, which could, in turn, reduce the number of chronically ill women receiving income assistance such as CPP-D or ODSP. Furthermore, Kitchin et al. (1998, p.792), in their study of the labour market and employment program experiences in Ireland, argued that "suitable employment" includes two key factors: "work that is flexible enough to accommodate people with disabilities, in terms of the number of work hours per week, and accessible in terms of getting there and building design." Thus, allowing flexibility in work hours is essential if persons with disabilities are to maintain a presence in the paid labour force. Based on Kitchin et al. (1998) and McDonough's (1997) research, and the opinions of the ten women interviewees involved in this study who recommended that flexible work hours be implemented, developing such a policy is one way that government employment policies and employers can be more supportive of women who have arthritic conditions.

There are existing Canadian labour laws which recognize flexible hours as a way of accommodating employees with disabilities in the workplace: the Ontario/Canadian human rights laws. Workplace accommodations recognized under human

rights laws include: reduced work hours, modifications to equipment, lighter work loads, and flexible work hours (Lynk, 2000). These accommodations are enforced by the duty to accommodate (which was discussed in Chapter Five). Only one of the interviewees, Ann, discussed the duty to accommodate, and the remaining seventeen interviewees did not mention it at all. Hence, the need may not be to create new policies to support flexible work hours as was suggested by the interviewees; rather, educating employers and employees about the types of workplace accommodations recognized by human rights laws is more pressing based on the interviewees' lack of knowledge.

Kitchin et al. (1998, p.796) have argued that employers' lack of willingness to "engage with issues of disability" results in them being less willing to offer flexible work hours to employees with disabilities. Informing employers and employees about the duty to accommodate may lessen such resistance to making suitable workplace accommodations. However, going one step further and providing incentives, such as tax cuts, to employers who make workplace accommodations for employees with disabilities may remove the "lack of willingness" that Kitchin et al. (1998) discuss, replacing it with a stimulus for making appropriate accommodations. Currently, the duty to accommodate is enforced on a reactionary basis whereby employees who are not

appropriately accommodated can seek legal recourse through the Canadian or Ontario Human Rights Commission (Lynk, 2000), placing the onus on the employee to take legal measures to be appropriately accommodated based on their needs. As was discussed in Chapter Five, employees who are not appropriately accommodated by their employers may choose to leave the workplace rather than legally fight for their rights for accommodation, as was the case with Sam, Nicole, Robyn, Kathryn, and Susan. Further, Ann had considered filing a complaint with the Human Rights Commission but decided not to, as she believed the process would be too physically and mentally draining, saying: "...have someone who is *really, really* healthy take them [her former employer] to court on my behalf (laughter)." By creating an incentive to accommodating employees with disabilities, the onus for enforcing disabled employees' rights would be taken off the employee and placed on the employers who wish to benefit from such incentives. Further, if incentives which are desirable to employers are offered, such as tax cuts, then they will be increasingly willing to accommodate employees on their first request, thus reducing the reactionary nature of the duty to accommodate.

#### **6.4.2 Job-sharing and Work from Home**

A second program recommendation suggested by seven of

the women is to create programs which allow employees with disabilities to have innovative working arrangements that meet their needs such as job-sharing and working from home. As was discussed in Chapter Five, a great deal of self-esteem and self-worth is generated from involvement in the workforce, and society places great value on people who are 'productive', therefore it is important that chronically ill women be given the chance to participate in the workforce in ways that suit their needs and abilities. Creating programs which support chronically ill women in their attempts to secure employment, such as job-sharing and work from home programs, is one way that the government can assist in facilitating the employment support of these women.

Anne feels that job-sharing would be an ideal accommodation for her because it would give her more control over the hours she works. Here she explains why she would benefit from job-sharing:

Anne: If I'm having a bad day today, you could be having a good day, so you could go to work and I could stay home. Or you could divide up [the work day] for what is best for each person. If somebody is better in the morning and someone else is better in the afternoon ... I'm generally a morning person and I fade about 1:00 [then she needs to rest]. I've learned that if I lay down for an hour, just an hour and no longer than an hour, then I can go [work] again afterwards. But if you're working and you have to lay down for an hour, it's all well and good to say, well you're working, but there's nobody here to do the housework and there's nobody here to do the shopping. All this stuff has to be done too. Where do I get the energy do to that? So, yea, it would be nice to do job-sharing [as it would

allow her more time to do housework since she lives alone and has no help with maintaining her rent-subsidized apartment].

Another interviewee, Ann, believes that working from home would be ideal in her situation as she would not be required to transport herself to and from the workplace thus saving energy and allowing her to focus on her work tasks. Ann's goal is for she and her partner to open a business that she can run from home, working for a few hours a day. Ann's belief is that by working from home, she can conserve her energy for her work duties without having to worry about transporting herself to and from a separate workplace.

Darlene believes that both working from home and job-sharing are important ways to accommodate women who have acquired arthritic conditions in the labour market because they offer much-needed flexibility in work location and work hours:

Darlene: I know for me, working from home will be my [sic] ideal because it will allow me to work when I'm good and strong and clear minded; and it will allow me to rest and not have to worry about the appearances of not being in the office and not showing up or not having to call in sick [at the office] if I can't make a shift [while working at home]. I think definitely work from home, job-sharing definitely and if you can job share with someone who has a similar condition as you, they can give the understanding and motivation [to work and get through hard times] there a little bit more. I think that if I were to job share with somebody who didn't have experience with the condition, it might be very difficult because then it would be very easy to try and maintain the performance level of the person with the greater ability than myself. Yea, I think that definitely, those types of policies as well as educating the co-workers

[about arthritic conditions] and things like that, and giving the type of support that's needed.

Darlene's negative experiences of not having her request to be moved to a work location closer to her home accommodated, which was discussed in Chapter Five, may have heightened her desire to work from home, as there's no need to be concerned with 'wasted' energy expended on driving herself to and from the workplace when working from home. In Darlene's opinion, employers and managerial staff must become educated on the types of accommodation arrangements that can benefit women in her situation such as working from home and job-sharing. Employers must be educated about the benefits, to themselves and their employees, such as increased morale and fewer sick-days used by employees, of implementing accommodations such as work from home and job-sharing in order for these types of work arrangements to be made available for disabled employees.

Government Ministries responsible for employment initiatives, such as Ontario's Ministry of Community and Social Services, need to realize the importance of these types of work arrangements for persons with disabilities and create programs which support their implementation. For example, a program could be created whereby a person with a disability who wants to work from home can register with an Employment Officer at a Canada Employment Centre (CEC) who can then contact employers listed in the Human Resources Development

Canada (HRDC) job-bank on the person's behalf to find out if any of the employers have job openings which could be done from an employee's home. A fairly simple program, such as the one described above, where government agencies can facilitate contact between employers who can offer work from home or job-sharing arrangements and potential employees, is the type of supportive program that the seven interviewees who recommended work from home and job-sharing programs be implemented desire.

Zeman (1994), in her research on the effects of unemployment and education levels on the workplace participation of Canadians with disabilities, has concluded that employment policies and programs for persons with disabilities must be designed to meet the needs of particular "target groups". Her findings are based on the fact that both gender and impairment, or ability level, impact how various "target groups", such as women with arthritic conditions, can benefit from different types employment support programs due to differences in how workplace barriers are experienced by these groups. Her findings suggest that it is not important to create policies which support *all* persons with disabilities, just ones that meet the needs of these specific groups. While discontinuing larger programs such as CPP-D and ODSP are not recommended, it would be advantageous to consider the support needs of these target groups and how they can be

met through the creation of new employment programs for persons with disabilities as such programs could increase their presence in the active workforce. For example, job-sharing and work from home programs could be developed specifically for the benefit of women with arthritic conditions and other types of chronic illnesses and musculoskeletal impairments. While it would most likely be impossible to develop employment programs which support all potential target groups based on differences in gender and impairment, due to the enormity of the task, it would be beneficial for policy-makers to consider who these different groups may be and how they can create policies which are more supportive of their diverse needs. If it can be established that more chronically ill individuals would benefit from work from home and job-sharing programs, such as the one suggested above, than just those with arthritic conditions, policy-makers should seriously consider implementing such employment programs.

#### **6.4.3 Allowing Income Assistance Beneficiaries to Work Part-Time**

The third program recommendation made by five of the interviewees is to develop new eligibility requirements for income assistance programs, such as CPP-D and ODSP, ones which



do not restrict volunteer and limited part-time employment within limits acceptable by the policy-makers acting in consultation with persons with disabilities. In Chapter Five it was found that sixteen of the eighteen interviewees experienced a re-definition of work and productivity based on their changing roles as workers and their fluctuating ability levels. Further, the prospect of being unemployed, or "roleless", and socio-economically "placeless" for an indefinite period of time while receiving full income support was daunting. It is therefore not surprising that five of the interviewees recommended developing programs which allow people with disabilities to negotiate participation in the workforce while receiving partial income support.

Ann argues that government policies must take the fluctuating nature of arthritic conditions, discussed earlier in this chapter, into account and adopt regulations that will allow for part-time work to be done while receiving partial income assistance:

Ann: It's very frustrating because I'm applying for CPP disability. They want you to be totally disabled and they said [that she is] not able to work at anytime [while receiving CPP-D income assistance]. Well, I might be able to do something [some type of part-time work] for 2 hours. I had a housekeeper come in because I can do the vacuuming [not the whole house], but I do the upstairs vacuuming one day, [and then] the next day I'm pretty much not able to do anything. So then one has to ask what is the value [of expending energy] of doing that particular thing if it wipes you out so much? Right? I have good days and bad days, I have good hours and bad hours.

Ann's concern about CPP-D eligibility requirements, and how they classify applicants, is that her limited housekeeping abilities may actually prevent her from receiving the CPP-D that she's applied for. Her concern is based on the misconception that any ability, in terms of workplace functioning or household chores, might make her ineligible for income assistance; however, as Campolieti & Lavis (2000) have shown, eligibility requirements for CPP-D have been relaxed over time, reducing the burden that one has to prove to be fully disabled at all times, so that concerns such as Ann's are based more on myth than fact. Such concerns are, however, placing additional stress on women who already have chronic illnesses and are often in financial need at the time they apply for CPP-D financial assistance.

Susan believes that policy-makers should actually encourage people who are considering withdrawing from income assistance to seek part-time employment before re-entering the full-time labour market. She thinks that this would make for an easier transition back into full-time employment, particularly if partial income assistance was continued during the period of part-time employment. Further, she thinks that it is unreasonable for people who have impairments and disabilities to be expected to return to full-time paid labour after being on long-term full income assistance. This is

because people who are in a transition back to the workplace should be able to do so slowly, starting first with part-time and then moving to full-time employment when the person is ready. The five women who recommended developing a partial income assistance program believe that doing so serves the best interests of those who have arthritic conditions by, for example, allowing a slower transition back into the labour market. This is because workers with disabilities would not be denied benefits due to demonstrating limited abilities to work part-time. Restrictions on the types and amount of part-time employment allowed while receiving income assistance will need to be assessed by the policy-makers in consultation with the policy-relevant stakeholders.

Fawcett's (2000) research on the labour market experiences of disabled women in Ontario shows that government income assistance policies and programs must allow for an easier transition between withdrawing income assistance and re-entering the labour market. According to Fawcett (2000, p.30),

Policies and programs in the area of income support/replacement must create a 'safe' environment in order to allow them to move easily from income programs back into the labour market and back again without any disruption in cash flow.

While CPP-D administrators are now trying to create such a "safe environment" by allowing income assistance recipients to receive benefits during the first three months of this

transition period back to work, another strategy for satisfying Fawcett's (2000) recommendation would be to allow part-time employment while receiving benefits, as was suggested by Susan and Ann. Allowing chronically ill women the chance to work part-time while receiving partial benefits on a limited-time basis, would allow them to see whether working full-time might be feasible, based on their experiences of part-time employment and their ability levels, or if going back to receiving full benefits and not being involved in the labour force at all is more realistic. This could create a "safe environment" for people who are in-transit between income assistance and employment because it would not force recipients to move directly from full income support to full-time employment, thus allowing for a trial period of part-time employment prior to committing to a full-time job. Furthermore, allowing recipients to work part-time would create the much desired flexibility in income assistance programs such as CPP-D that was discussed earlier in this chapter by allowing those who experience fluctuating ability levels to work when then want, and are able, to. The length of time a recipient is allowed to work part-time while receiving partial benefits will need to be determined by CPP-D and ODSP administrators working in conjunction with persons with disabilities.

#### 6.4.4 Considering the Messages Sent by Programs and Policies

Four of the interviewees suggested that policy-makers at both the federal and provincial levels need to become more aware of the types of messages that legislation and policies send to persons with disabilities about their value and role in society as workers. Ann and Sean both indicated concern over the Ontario government's recent passing of legislation allowing a 60 hour work week for full-time employees. Legislating more work hours per week is a valid concern for chronically ill women, particularly those actively involved in the workforce like Sean, as they may be expected to work longer hours than their energy reserves and impairments allow. Sean had a particular interest in this issue as she was one of the four women working full-time at the time of the interviews. She voiced her frustrations with this legislation by saying:

Sean: My first instincts, if I think about it [how to make more supportive policies for women with arthritic conditions], is we need government not to do things like extending our legal work week to 60 hours. In a society where most of us are already working way more than we should be and we're all over stressed, those of us who struggle with any kind of disability from pain disorders up and down the line, sure as hell can't handle a 60 hour work week. Our government just did us a huge non-favour by legislating that.

She and Ann argue that this recent work legislation is sending the wrong message to people with disabilities, one that says

that they may be expected to work up to 60 hours per week to maintain a full-time job. Their belief is that legislation such as this is not supportive of women living with arthritic conditions as most of them would not be able to work for 60 hours per week due to the physical limitations and workplace barriers they face. While Sean and Ann's concern here is with the message sent to people with disabilities by such legislation, the impacts of such changes to the work week on the lives of people with disabilities extend far beyond the message sent. For example, by legally empowering employers to increase the number of hours full-time employees can be expected to work, legislators are potentially aiding in the creation of more disabling work conditions in practice such as increased incidences of musculoskeletal impairments due to more physical strain placed on employees as a result of the longer working days and weeks. Furthermore, some people with disabilities looking for employment may be further marginalised in the labour market due to an inability to work a sixty-hour work week which will then lessen their potential to be competitive in the workforce.

Marilyn believes that the Ontario government is showing a disinterest in issues relating to persons with disabilities because there is a lack of access to information and supports through various levels of government for persons with disabilities. Her concern is that the lack of access to

information, as described earlier in this chapter, shows that government agencies are not concerned with informing people with disabilities about the types of supports available to meet their needs, thus showing a lack of interest in disability issues. As she explains:

Marilyn: They [the government] stick their noses in just about everything else, I don't know why there can not be a ministry, a department within - probably within every government [dealing specifically with disability issues]. I think, on all three levels [municipal, provincial and federal] there should be some kind of department that you can turn to if you are disabled, if you are handicapped, if you are all of a sudden in this position. [Municipal offices need to be established] where you go to the City department and say, "okay, what is available for me for our family through the City" [in terms of supports for persons with disabilities]. You can [or should be able to] also go to the provincial or to the federal [governments, and request the same].

Again, Marilyn's concern over the messages sent by legislation rise from concerns which actually extend far beyond simple messages. Her underlying concern is that there is inadequate access to information about supports available from all levels of government. Marilyn is particularly sensitive to messages sent to the disability community by government administrators as the pool exercise program she has worked so hard to create, discussed earlier in this chapter, is being threatened by closure due to insufficient funding at the municipal level.

Currently, the four women believe that the government is showing a lack of support and disinterest in their concerns and needs. If more supportive programs and policies were to

be put in place, such as those suggested throughout this chapter, then the messages sent to people with disabilities should also change for the better; this is because Sean and Marilyn's comments indicated that the messages sent to this community are interwoven with the perceived level of supportiveness offered by government policies and programs.

#### **6.4.5 Increasing Awareness about Arthritic Conditions**

As was discussed in Chapter Five, twelve of the participants believed that members of the public as well as co-workers and employers are not well educated about arthritic conditions, their symptoms, and the types of accommodations needed in the workplace and elsewhere. In fact, disbelief and a lack of understanding from co-workers and employers about the nature and symptoms of arthritic conditions was one of the four significant workplace barriers identified by the women interviewed. Not surprisingly, given the women's overall desire to increase awareness about arthritic conditions, a recommendation made by four of the women interviewed was to increase education and awareness about arthritic conditions among policy-makers which, they believe, may in turn result in the creation of more supportive policies. This belief seems reasonable in that the more informed policy-makers are about the needs of people with disabilities, the better able they



are to create policies and programs which meet the needs of this heterogeneous group. Karen believes that knowledge about arthritic conditions must come before any new policies are developed, so as to help ensure that they will be more supportive of the needs of women who have acquired arthritic conditions. The issue of where such an education could take place, or how this knowledge should be acquired, is difficult to assess. One possibility would be to have representatives from community organizations and the medical community, those who are knowledgeable about various chronic illnesses and disabilities, in addition to men and women with chronic illnesses, develop an information workshop that policy-makers could attend in order to become more familiar with the types of policy supports that may better meet the diverse needs of people with disabilities.

Darlene and Sean also believe that increased education and awareness about arthritic conditions, such as the strategy proposed above, is essential in order to effectively support women with arthritic conditions in the workplace. However, they believe that such education must also be aimed at employers and not simply policy-makers as it has the potential to inform employers about how to effectively accommodate employees who have arthritic conditions. While there is no guarantee that disseminating information about workplace

accommodations and disabilities will actually encourage employers to make more effective workplace accommodations, Darlene and Sam both believe that it is an important first step in creating work environments which are more supportive of the needs of employees with disabilities. Darlene and Sam both encountered employers who were unsupportive of their needs and had little understanding about the nature and symptoms of their conditions. These negative workplace experiences, discussed in Chapter Five, impacted on their decisions to leave their jobs and the paid labour force. Therefore, it is not surprising that they believe that employers need to be educated about how to accommodate workers with disabilities.

Sean and Darlene have concerns about how information about disabilities and workplace accommodations, sent, for example, in the form of informative flyers created by government agencies and Ministries, will be received by employers:

Sean: The raising of employer awareness [about arthritic conditions] helps. It's a very hard one to answer [how to go about raising awareness], it depends on the employer, like people. Right?. For some employers, that awareness helps and then some employers feel very strongly about making accommodations [that accommodations should be made]. Employers on a large enough scale will make accommodations so that they can type [or present] themselves as "friendly companies" who have "good policies" [which support employees with disabilities] and are into social changes and all of those things... Other companies don't want to know [about arthritic conditions and workplace accommodations], don't want to hear

[information from educational campaigns], they don't want -- they can't afford the [costs of] accommodations. They're just not in a position to be able to afford anything that is going to possibly impact their profit margin and they don't care [in her opinion].

Darlene: I think the success of it [educating employers] is dependant on so many things: the receptiveness of the employers [to such information], of the people that [sic] [who] are being given the information, their experience with it, how it's being delivered. Everybody you talk to these days are [sic] [is] so inundated with work and paper and memos and everything else. Depending on how the information is referred [sent] to them [employers may or may not be willing to consider it]. In many cases, it may get shuffled to the bottom of the pile and never read. Where, in a lot cases, managers will read it and not share it with their staff. Or people might have a very strong bias against it [becoming informed about arthritic conditions and how to make appropriate workplace accommodations]. My father, for example, runs his own business, has employees, if you were to send a memo of that effect to him, he'd say, "Oh what a bunch of crap! Get off your fat ass and get to work, and blah blah blah." He wouldn't be the type to say, Oh wow, "I'm going to take this into account because it may be affecting my employees." I don't know how to get around that with people and their own perceptions. Education definitely needs to be a part of it. But it's a tough road [in terms of educating employers].

Darlene and Sean's comments indicate that, in their opinion, while employer education is needed, there is a danger that employers will either not pay attention to such suggestions or be in a position to implement changes to the workplace in order to accommodate employees with arthritic conditions. Their opinions are that the form the education takes is almost as important as the message it contains, and that an approach which considers the employers' perspectives on hiring and accommodating employees with disabilities is needed in order

for businesses and companies to reduce barriers for employees who have these impairments. Thus, it is important to move beyond simply informing employers about workplace accommodations and the needs of employees with disabilities and begin to motivate them to act in supportive ways. One way of doing this is through the incentive program mentioned earlier where employers who offer accommodations to employees with disabilities are given incentives such as tax credits.

One of the major findings of Fawcett's (2000, p.33) research on the involvement of disabled women in Ontario's labour market is that:

Strategies that seek to better inform the public about disability (and more precisely, about the abilities of persons with disabilities) and that attempt to improve attitudes toward persons with disabilities might also have a positive impact on the employability of persons with disabilities.

Increasing awareness about arthritic conditions among employers and employees might be able to create a more supportive workspace, one in which co-workers and employers are understanding about the nature of arthritic conditions, their symptoms, and the impairments which often develop after acquisition. What is still unclear is how such information strategies should be implemented, and the form they should take. The comments offered by Darlene and Sam, however, do remind us that there are important considerations to be made when implementing such an information strategy, such as making

it employer-friendly, in order to effectively reach both employers and employees.

#### **6.4.6 Recognizing non-Western Medical Practitioners in Income Support Application Processes**

Another policy recommendation that three of the participants made is to allow non-Western medical practitioners to complete application forms for income assistance programs such as CPP-D and ODSP. Sean, Kim and Ann believe that the reliance on Western medical practices by CPP-D administrators unfairly disadvantages those women who chose to seek alternative treatments. Their concern is that because non-Western practitioners are not recognized as medical professionals in the current application process for CPP-D income assistance, chronically ill women are then being "forced" to seek treatment from Western doctors in order to be eligible for assistance. They believe that the expertise of non-Western medical practitioners should be acknowledged by CPP-D administrators and that they should not be restricted, based on medical treatments and qualifications, in the treatments that they seek for their arthritic conditions. It is not surprising that Sean, Ann and Kim all actively sought treatment from non-Western medical practitioners, obviously impacting on their desires to recognize these practitioners in

CPP-D and ODSP application processes.

The difficulty in allowing other types of health care practitioners, such as herbalists and Chinese medicine specialists, to complete forms for CPP-D and ODSP applications is that it may be difficult to assess the nature of the practitioners' training. Furthermore, allowing practitioners trained in different medical traditions to complete such forms may create inconsistencies in the diagnostic and prognostic terminology used in reference to applicants' biomedical conditions. Therefore, differences in training and practices between Western and non-Western health care practitioners may be too great to allow both groups to give 'expert' opinions on CPP-D and ODSP income assistance applications.

#### **6.4.7 Develop Programs for People with Disabilities, Not Employers**

An interesting point made by two of the women interviewed is that employment programs for persons with disabilities need to be aimed at employees and not the employers. They both think that there are enough programs and services available for employers to benefit from financially and that in order to serve needs of employees with disabilities that, based on their experiences, programs must be tailored to them and not to employers. Anne and Marilyn's

opinions are that in order for employment support programs to work effectively, they must target the individuals seeking support and not the companies and business that may hire persons with disabilities. For example, if a wage subsidy program was to be established, such as the top-up program Margaret discussed earlier, the employee should be able to apply for the subsidy and take it with them to wherever they choose to work rather than allowing employers to apply for subsidies which are restricted to their places of employment only.

Anne's belief is that subsidized wage programs which promote the hiring of employees with disabilities, where the government and a business each provide a portion of a full-time salary, do not work as the employer may be more interested in the subsidy than in the potential benefits of hiring, for example, a chronically ill woman. While the body of literature reviewed in this study does not support Anne's concern, Sandy's (1993) study of employers who hire employees with intellectual impairments through employment support programs has concluded that employers often view such employees as 'dependents' and treat them in a child-like fashion. If employment subsidies were tied to employees rather than employers, the incidence of employers viewing employees hired through such programs as being 'dependent' on the company or their goodness could be reduced. Anne's

concern arises from her experience working in companies which have benefited from such programs, as she explains:

Anne: I don't think its good to give employers funding to hire somebody with a handicap because they will probably hire them for a period [of] time [on] contract and then find an excuse to get rid of them [when the wage subsidies run out]. I've seen it happen. They [employers] get this free labour or half-price labour and that's the way they treat you. You're half price. Then, at the end of that time, they find a way to get rid of you.

Anne's concern is that employers who participate in wage subsidy programs will hire employees for the exact length of the subsidy and not consider making them a permanent staff member after the subsidy has run out.

Marilyn believes that there are enough policies and programs which support business in Ontario, such as tax cuts and start-up funds, and not enough that specifically address the employment needs of persons with disabilities, including the job-sharing and work from home programs mentioned previously. She thinks that:

Marilyn: There's not enough done for disabled out there [in terms of policy creation]. There's a lot done for big business [such as tax cuts] and if they would do as much for disabled and the under privileged as they do for the big business, we wouldn't be in such need. We wouldn't be in such need [sic]. It's very sad to think that [there aren't enough policies and programs supporting under privileged groups]... You're not on the top of anyone's list [in terms of policy creation], [let's] put it that way.

Anne and Marilyn's opinions are that employment support programs for persons with disabilities must be person-centred



and not target employers. Again, this would involve, for example, allowing people with disabilities to apply for wage subsidies which they can then take to the employer or workplace of their choice rather than the current system of having employers apply for, and receive, wage subsidies which they can then give to the employees of their choosing. A program such as this allows the person with a disability to have bargaining power with potential employers in the form of the wage subsidy that they can take to a company. Furthermore, this type of program could be empowering for persons with disabilities by giving them a choice in the type of job they would like to hold, where they would like to work, and bargaining power to use in negotiations with employers.

Anne and Marilyn's opinions that there are enough programs and policies in existence which benefit employers are not surprising based on Fair's (2001) research on the current state of social policies in Canada. She has found that policy-makers are least accountable to those who benefit most from social policies, including wage subsidy and income support programs, as lower-income Canadians often carry less socio-economic "weight" with policy-makers than large businesses and corporations because of the large tax base funded by such enterprises. Fair's (2001) conclusion is echoed in Marilyn's comments about the need for employee-centred support programs, noting that people with disabilities

are "...not on the top of anybody's list." This is not to suggest that *only* programs which benefit employees should be implemented, but rather that the needs of *both* employers and employees with disabilities be considered in the development of support programs.

#### **6.4.8 Considering Preventative Measures**

Sam and Karen argued that employers need to implement programs designed to prevent strain on muscles and joints, and the incidence of work-related disabilities. They believe that programs such as workplace stretching sessions should be implemented as they can reduce the physical stresses and strains placed on employees, thus potentially reducing the rates of musculoskeletal impairments and experiences of physical barriers present in the workplace. Sam's recommendation is based on her own workplace experience in a warehouse style retail store, where she believes that stretching programs, if offered, may have been able to reduce or eliminate some of the damage done to her joints as a result of the heavy lifting she did on the job.

Karen explains that there are long-term benefits for employers who develop such programs:

Karen: They [the employers] think now they're saving money by not spending [on exercise programs and counselling for employees]. Well, look at all the money that they're losing [on employees not working due to

work-related injuries]. There are 1.5 million people in Ontario who are disabled, who can't get access to certain services, well that's money [the funds spent on sick days and extended leaves due to illness, injury or impairment] that they could be spending [on preventative programs]. Those people [who are on sick leave] would be working [if a stretching program, for example, could have prevented an injury from happening], they'd be paying income tax [based on their earnings rather than not paying taxes on their unworked sick days]. So you're [the government] losing billions of dollars [due to work-related injuries and impairments that could have been prevented]. By investing a few dollars now [in preventative measures], that company would actually profit [in the long-term due to decreased rates of employees becoming sick or injured].

Karen's opinion is that financial investment by employers into employees' health and well-being has long term pay-offs which include reducing the number employees injured on the job. Sam believes that a team of experts, consisting of both policy-makers and workplace safety representatives, is needed to "sell" the benefits of implementing preventative programs to both employers and employees. She thinks that such a team will be needed as employers may be reluctant to establish such programs, due to initial costs and the time employees spend stretching rather than working, until they are made aware of the long-term benefits, both financially and for the health of employees. Sam also believes that the long-term benefits of having exercise programs at work are many, including reduced rates of workplace injuries and employees who are more physically fit, and thinks that convincing employers to implement them will be a difficult and challenging task due to

their likely resistance. However, there are additional risks to employers in addition to the financial costs and loss of employee's productive time at work, namely the risk of employees becoming injured while participating in stretching and work-exercise programs due to pulled muscles and other such injuries. This is not to say that the risks of workplace exercise programs outweigh their potential benefits, but rather that careful thought and consideration needs to be given to their development and implementation.

## **6.5 Conclusions**

The discussion presented above showed that the women interviewed had a range of common and unique experiences in relation to employment and income assistance programs and of local community-based supports. There were five experiences which can be considered most 'common' among the interviewees, these include: 1) that CPP-D income assistance was the principal form of government support used by the interviewees, with three of the women receiving assistance at the time of the interviews and a further four in the process of applying; 2) all three of the women applying for CPP-D income assistance at the time of the interview found the application process to be time consuming and exclusionary; 3) a further eight of the women found the CPP-D income assistance program application

process to be generally difficult to negotiate; 4) eleven of the women had participated in local support groups and a further three women had used other forms of support such as personal support networks and internet chat groups; and 5) fourteen of the eighteen interviewees expressed that they had limited or no access to information about government employment policies and programs. There are many more experiences which can be considered 'unique' among the interviewees, these include: 1) only three of the interviewees visited a CEC when looking for employment assistance and information about government programs, two of whom found their visits to be a positive experience; 2) vocational training programs were used by only three of the interviewees, all having been funded by the WSIB; 3) one interviewee, Sam, experienced financial hardship during the CPP-D application process which was aggravated by the Doctor's fees and transportation costs incurred by the process of completing the application; 4) another interviewee, Marilyn, founded her own her own form of local support for chronically ill women, namely a pool exercise program, which is the largest of its kind in Ontario.

The reasons for the women's varying experiences of employment and income assistance and local support programs were several:

- The women had a general lack of knowledge about, and

access to information regarding, the types of employment supports available to assist persons with disabilities, such as CECs and the services they offer, in Ontario. The lack of co-ordination between government Ministries, uncovered by Fair (2001) in her research on social policies in Canada, may aggravate this lack of access to information as programs and policies are not generally advertised in a central place. Further, as Marris's (1996) research on the lives of chronically ill women has demonstrated, access to information is tied to socio-economic status which means that those with less education and financial resources are more likely have poor access to information about programs and therefore will be less knowledgeable about the supports available for their use.

- Anne had several negative experiences of vocational training programs which included being encouraged by WSIB administrators to open her own crafts business and not being successful in finding employment in areas in which she has received training such as building management. Anne's inability to find employment after receiving training is not surprising given Kitchin et al.'s (1998) finding that vocational programs in Britain do not generally

lead to full-time well-paid employment. Further, Groce's (1997) study of vocational training programs in the developing world has reminded us of the importance of considering local labour market needs in the creation of such programs, as disabled women are all too often encouraged to produce handicrafts in lieu of being trained in vocations which are in demand in the local area.

- Eight of the women found that the CPP-D application process is difficult to negotiate, due in particular to the amount of administrative work, and time, involved in completing forms. Their concerns are best summarized by what Hyde (2000) has called intensified social control, whereby creating lengthy application processes for income assistance applicants is a way for program administrators to exert control over applicants. Though eligibility requirements for CPP-D have been relaxed over time, the recent changes to the application process continue to pose barriers for program applicants.
- Sam's financial hardship was aggravated by expenses incurred during the CPP-D application process. Further, Ann found CPP-D forms and information to be written in an inaccessible language. One factor which may have contributed to these negative

experiences is that there is generally a socio-economic and socio-spatial 'distance' between the lifeworlds of policy-makers and program applicants which makes it difficult to policy-makers to foresee barriers posed by policies and programs. Fair (2001), in her research on economically marginalised Canadians' experiences of social policies, has concluded that this 'distance' means that policy-makers are generally unable to comprehend the daily spaces and experiences of those for whom social policies are created. Therefore, policy-makers may not have realized the inaccessible language used in CPP-D forms or the potential for financial hardship caused by expenses in the application process for income assistance.

- Experiences of support groups tended to vary based on the motivation for attending. For example, those participants who enjoyed the contact with 'similar others' generally had positive experiences, while those who wanted to learn specific types of information, such as strategies for requesting workplace accommodations, which was not provided tended to have negative experiences to report.

Each of the eighteen participants offered suggestions as to how existing employment and income support policies and



programs for persons with disabilities could be improved so that they can better meet the needs of women who have acquired an arthritic condition. Eight major recommendations were made by the women interviewed which involve changes to current policies, suggestions for new employment programs, and recommendations for policy-makers:

- Ten of the women suggested that programs and policies which support flexible work hours be developed. This recommendation was not surprising as McDonough (1997) has shown that chronically ill women may chose to leave the workplace due specifically to a inflexibility in work hours, and Kitchin et al. (1998) have argued that flexible work hours is one of the two basic components of "suitable employment" for persons with disabilities. However, human rights legislation currently exists, known as the duty to accommodate, which recognizes flexible work hours as an appropriate accommodation for disabled workers. Thus, the more pressing issue is to inform employees of their legal rights to accommodation and to enforce the duty to accommodate by offering incentives, such as tax breaks, for those employers who make appropriate accommodations prior to being taken to court. Taking such measures may reduce the incidences of employees leaving the

workforce due to inappropriate workplace accommodations being made, which is what had happened to five of the interviewees.

- Seven of the women recommended that job-sharing and work from home programs, such as the type discussed earlier in this chapter, be developed. Though such programs may not benefit *all* persons with disabilities, they should not be discounted. As Zeman (1994) has concluded, it is best to implement support programs which target specific groups, based on gender and impairment, rather than be concerned with developing programs which will meet the needs of all people with disabilities.
- Five of the women recommended that income assistance recipients be allowed to work part-time while receiving partial benefits. Developing such a program is one way to address Fawcett's (2000) call for programs which provide a "safe environment" for recipients who are in transition between receiving income assistance and becoming involved in the full-time labour market because it allows recipients a chance to perform limited paid labour before deciding whether or not to fully withdraw from income support.

- Four of the interviewees recommended that policy-makers become more aware of the messages sent by policies and programs to persons with disabilities. For example, Sean was concerned that recently legislated sixty-hour work week is sending a negative message to people with disabilities about the value placed on employees who can work long hours. However, the 'messages' discussed by the women were linked directly to larger issues of how programs, policies and legislation negatively impact persons with disabilities; therefore if programs and policies are made to be more supportive of their needs then the messages they send will also change.
- Four of the women recommended that policy-makers and employers need to become better informed about arthritic conditions in order for more supportive work spaces and policies to be created. This is supported by Fawcett's (2000) finding that increased awareness about disabilities can reduce negative social attitudes about person with disabilities and may have a positive impact on the employment experiences of women with disabilities. This recommendation was not surprising given that a desire to educate co-workers, employers and the public has been expressed throughout this chapter in

addition to Chapter Five.

- Three of the women recommended that the expertise of non-Western health care practitioners be recognized in the application processes for CPP-D income support. Each of these women had used non-Western health care practitioners in the treatment and management of their arthritic conditions. The difficulty with allowing a variety of health care practitioners to complete application forms for CPP-D income support is that there may not be consistency in the terminology used when completing the applications or in their diagnostic procedures.
- Two of the women suggested that employment support programs need to target employees with disabilities rather than employers so that potential benefits, such as wage subsidies, are tied to employees and not specific workplaces. For example, if a person with a disability was granted a wage subsidy, s/he could use it as form of bargaining power with potential employers. The desire to create such programs is not surprising as Fair's (2001) research on social policies in Canada has concluded that businesses and corporations hold much more socio-economic "weight" with policy-makers and that often policies are made which favour employers over

others.

- Two of the women interviewed suggested that policies which support workplace exercise programs should be developed as they may reduce the incidence of musculoskeletal impairments caused by workplace activities. However, the benefits and drawbacks of creating such programs need to be carefully considered before a determination on whether or not such programs should be implemented is made.

The eight policy recommendations, program suggestions, and recommendations for policy-makers discussed above have serious implications for existing government supports and future policy directions in Ontario and Canada. Most importantly, they suggest that women who have acquired an arthritic condition do not want to be restricted to the conventional policy categorizations inherent in CPP-D and ODSP income and employment support programs which restrict persons with disabilities abilities to either receiving full income support or being involved in full-time paid employment. The program recommendations above show that women with arthritic conditions believe they would benefit from a wider variety of employment support programs, ones which support flexible work hours, working from home, job-sharing, and working part-time while receiving partial income support. They want programs which stress their abilities and what they are able to do,

rather than those which encourage full income support.

One of the most surprising and unexpected findings of the interviews is that fourteen of the eighteen interviewees did not think that they had adequate access to information regarding government policies and programs for persons with disabilities. Such lack of access to information has left them poorly informed about the programs and policies which have been designed to support persons with disabilities. This finding was surprising because examining these women's access to information about government policies and programs was not one of the main interview goals.

Further, this lack of access to information has left the women less knowledgeable about such programs. For example, only one participant was aware of the existence of the ODSP and the fact that she may be eligible for its income support program, which may be due to the fact that she had better access to information. The women had little knowledge about the employment support programs (or non-income assistance programs) offered by CPP-D, including its vocational rehabilitation programs, as the comments made by at least half of the interviewees showed that they were only aware of its income support program. This lack of access to information about, and knowledge of, government-funded programs and policies for persons with disabilities is troubling as it shows that the onus for gathering information

about such government programs has been placed on these women, for example, having to search for information on their own using the internet - women who are disabled, chronically ill, experience mobility limitations, and often have to conserve their energies in order to complete tasks of daily living. Expecting these women to access information via the internet or Ministry offices is unreasonable given their chronic pain and fatigue. Fawcett's (2000) research on the labour market experiences of women with disabilities in Ontario shows that the lack of access to information experienced by the women interviewed in this study is not unique, and that chronically ill women throughout the province have experienced difficulty in accessing and acquiring information about support policies and programs.

In addition to the need to improve the existing support policies and programs for persons with disabilities, the findings suggest that information about the programs and their eligibility must be sent to those who may be eligible, otherwise the programs will only be used by the few who have managed to become informed on their own. Most likely, the primary reasons for a lack of access to information is that women who are less educated do not have the fiscal resources, such as the ability to purchase a computer and internet connection, or the training to gain access to policy and program information. It was shown that the four best-informed

women who were interviewed for this study had all participated in post-secondary education, although they were not the only women with post-secondary educations, which also supports Fawcett's (2000) finding that women with disabilities who are better educated are also better able to find out about policies and programs from which they may benefit.

The next chapter, Chapter Seven, is the final chapter presented in this thesis. This chapter discusses the significant findings of this study, and the implications of this research project for future geographic and social scientific research as well as for policy-makers.



## **Chapter Seven**

### **Conclusions**

#### **7.1 Introduction**

This chapter offers concluding remarks on the findings and implications of this study. First, a discussion of the study's significant findings is presented. Following this is a discussion of the implications of the findings for employment and income assistance programs for persons with disabilities in Ontario. Then the implications of this findings for future geographic and social scientific research are presented.

#### **7.2 Significant Findings**

There are many findings of significance for geographers, feminist disability scholars, and social scientists based on this study. These significant findings are discussed below.

##### **7.2.1 Changing Experiences of Employment and Spaces of Daily Life**

This study has been able to shed light on the

workplace and paid employment experiences of women who have acquired an arthritic condition in a particular place, namely the City of Hamilton, Ontario. It was found that the women interviewed had gained a great deal of self-esteem and self-worth from involvement in the full-time and part-time paid workforce. Those no longer able to work struggled with how to re-value themselves based on what they are able to do, rather than de-value themselves based on their dis-abilities. For example, Ann discussed learning how to place value her role in the household, where she is able to perform light housework chores and meal preparation, as being an important household contribution and a valuable form of labour. Furthermore, those women who were no longer employed or able to work found themselves to be leading a socio-economically and socio-spatially placeless existence. This is because, due to being unemployed, they do not have a socially recognized place in society or a physical workspace in which they can produce paid labour. The struggle over negotiating and re-defining societal notions of 'productivity' and 'normalcy', where value is placed on people who 'do' perform paid labour as being the norm and not on those who 'don't' work, may have contributed to periods of depression experienced by seven of the interviewees. Internalized societal values, such as the value placed on healthy and productive workers, affected the women's abilities to deal with their changing life spaces and

employment experiences after acquiring an arthritic condition.

Experiences inside the workplace affected the women's abilities to maintain paid employment. For example, those women who did not have appropriate accommodations made by their employers left the labour market without choosing to pursue legal action, primarily due to the time and energy involved. The two women who found physical workplace barriers to be most oppressive, Diana and Vicki, 'remapped' their workspaces, as termed by Dyck (1995), in order to maximize their abilities and energy levels throughout the working day, thus finding their own ways to accommodate their needs. However, most of the interviewees found social workplace barriers to be more oppressive, such as employers' attitudes about disabled employees and co-workers' lack of understanding about the severity of arthritic conditions; these barriers created difficult working conditions for the interviewees. For example, Karen's co-workers were not understanding of her need to take 'extra' breaks during the working day to regain her energy, often complaining about these breaks rather than attempting to understand why they were needed.

Furthermore, experiences outside of the workplace affected the women's abilities to negotiate their roles in the labour market. Experiences in spaces of health care were of great significance as Doctors were in a position to determine whether those who had applied for CPP-D income support were

dis-abled enough to leave the paid labour force and receive income support, or if they should be able to remain in the workforce. Spaces of health care had also become places of extreme struggle over these women's identities as chronically ill women. Ann and Marilyn had both engaged in what Frank (1998) has termed conscious management of appearances in such spaces, whereby they wore make-up and nice clothing to Doctors' offices to demand respect, and to contest societal notions of how chronically ill women should appear, and how they are viewed in the eyes of Doctors as being patients and not people.

### **7.2.2 Experiences of Government and Local Supports**

In addition to increasing our understanding of chronically ill women's experiences of the workplace and spaces of daily life, this study has also investigated these women's experiences of government-funded employment and income assistance programs and local community-based supports. CPP-D income assistance was the principal form of government support used by the interviewees; however, a small number of the women had also participated in vocational training programs and had visited CECs. The application process for CPP-D income assistance was perceived by eight of the women to be difficult to negotiate due to the time involved in completing forms and

the amount of administrative work involved. Campolieti and Lavis (2001) have shown that although eligibility requirements for CPP-D income assistance have been relaxed over time, the amount of administrative work has steadily increased. Hence, the lengthy and time consuming application process was most likely being perceived by the applicants as being a form of what Hyde (2000) has called intensified social control. This occurs when social assistance programs have lengthy application processes are created by administrators which then restrict an applicant's ability to complete the necessary paperwork.

The most common type of local support used by the women interviewed were support groups designed for people with arthritic conditions. The experiences of these groups varied between those who had participated. Differences in experiences were generally based on what the motivation was for joining a support group was and whether or not one's expectations were met. As Sam's comments showed, these groups do provide spaces in which employment experiences can be discussed and participants can be informed about the local and government supports available to assist them.

The women experienced a general lack of knowledge about government employment programs which was most likely enhanced by a lack of access to information. Fourteen of the eighteen interviewees expressed that they had inadequate

access to information about the government programs and policies available for people with disabilities. It was hypothesized that poor co-ordination between government Ministries and offices, which was argued by Fair (2001), may have contributed to this lack of access to information as policy and program-relevant information is not made readily available in one specific location. The women recommended that information packages about local supports and government programs and services available for people with disabilities be developed by government offices, working with local services agencies and men and women with disabilities, and distributed from Doctors' offices. It was not surprising that this location was suggested as a distribution point. Marris (1996) has argued that chronically ill women *expect* to be able to get health and well-being information from their Doctors.

### **7.2.3 Using Experiences to Address Employment Policies and Programs**

The women were asked to suggest changes to existing government employment policies and programs, and make recommendations for new programs, that would be more supportive of the needs of women with arthritic conditions based on their personal experiences of paid labour, daily life spaces and government programs. The most common

recommendation, made by ten of the interviewees, was to develop programs and policies which support people with disabilities working flexible hours. However, human rights laws, or the duty to accommodate, already recognize flexible work hours as a way to accommodate people with disabilities in the workplace. Therefore, it is important to inform employees that this legislation does exist as the women generally seemed to be unaware of it. Furthermore, incentives which encourage employers to make appropriate workplace accommodations, such as tax breaks, should be put in place so that they are more likely to want to accommodate workers with disabilities. The other most common policy suggestions made by the women were to develop programs which support job-sharing, working from home, and working part-time while receiving partial income assistance.

The programs most strongly desired by the women are ones which allow people with disabilities to negotiate their participation in the workplace in ways that meet their needs and abilities. For example, by using one's home as a workspace, the energy that may once have been spent on commuting to and from the workplace can be redirected into completing work tasks from home. The women's changing experiences of the workplace and their roles as 'productive workers' discussed earlier showed that re-valuing their abilities to perform labour based on what they are able to do

is important. Therefore, creating programs and policies which support chronically ill women in their attempts to be involved in the paid labour force, such as the ones mentioned above, based on how much paid labour they are able to perform and where they are best able to work is of the utmost importance.

### **7.3 Implications of Findings for Employment and Income Assistance Programs and Policies in Ontario**

There are many implications of this study for the ODSP and CPP-D, for policy-makers, and for the federal and provincial governments. Four such implications are presented here which draw on the discussions presented Chapters Four, Five and Six.

#### **7.3.1 Clarifying ODSP and CPP-D Eligibility Requirements**

One of the main implications of this study for government employment support policies and programs in Ontario is that the application processes for the ODSP and CPP-D must consider the needs of individuals who have illnesses which result in fluctuating levels of ability. In taking such needs into consideration, eligibility requirements will need to be able to accommodate the nature of their changing degrees of impairment and symptoms such as pain. In other words, policy-makers should not view applicants in the absolute terms of



being 'fully disabled' or 'not disabled' at all times. Concerns over meeting eligibility requirements for income assistance arose among the group of women interviewed based on uncertainty over whether or not their fluctuating ability levels would render them ineligible. For example, the three women in the process of applying for CPP-D income assistance were not certain about whether their (dis)abilities would meet eligibility requirements that they perceived as being strict and inflexible. However, these perceptions are most likely not true. Campolieti & Lavis (2000) have shown that eligibility requirements for CPP-D income assistance have been significantly lessened over time which have allowed a broader range of applicants to meet eligibility requirements including those who experience fluctuating levels of ability and impairment over time.

The issue at stake here may not involve *changing* such eligibility requirements as much as it involves *clarifying* these requirements for applicants in the process of applying for income support. As was demonstrated in the women's comments, fourteen of the eighteen women interviewed believed that they didn't have adequate access to information about employment and income assistance policy and program information. Perhaps if these women were better informed of recent policy changes, such as CPP-D's changing eligibility

requirements, and the implications of these changes for their abilities to meet eligibility requirements, there would not be such concern as they would be better informed about the criteria by which applicants are evaluated. These changes, and how they apply to women with chronic illnesses such as arthritic conditions, should be explicitly stated in application packages for ODSP and CPP-D income assistance to ensure that there is no misinformation and that applicants know the criteria by which they are being evaluated. Furthermore, a toll free hotline should be set-up to address applicants' questions and concerns about issues such as eligibility requirements.

### **7.3.2 Creating New Employment Support Policies and Programs**

A second significant policy implication of the interviewees' workplace experiences, and the results of other related research studies, is that new types of employment support policies and programs need to be developed. There are two distinct types of programs which should be considered for development by policy-makers: those which support a variety of workplace accommodations to be made for employees with disabilities such as flexible work hours and job-sharing, and those which work in conjunction with existing income support programs, including CPP-D and ODSP, to allow recipients to

receive partial benefits while working part-time. Ten of the women interviewed suggested that people who have acquired an arthritic condition would benefit from flexible work hour arrangements because they allow for people to adjust their work hours based on their fluctuating levels of ability and fatigue. A desire for work from home and for job-sharing programs, such as those outlined in Chapter Six, to be developed was expressed by seven of the interviewees. Further, four of the interviewees recommended that income assistance beneficiaries be allowed to work part-time while receiving partial benefits.

The call to develop policies and programs which support flexible work hours, job-sharing and working from home is not restricted to the recommendations made by the eighteen interviewees in this study. McDonough's (1997) research on the participation of chronically ill women in the Canadian labour market has shown that a lack of flexibility in work hours is one reason why chronically ill women may choose to leave the labour market. Zeman's (1994) study of the impacts of being disabled on the labour market participation of Canadians has concluded that employment support policies and programs should focus on targeting the needs of specific groups, such as those with arthritic conditions, rather than developing a few programs which fail to meet the needs of all persons with disabilities. Fawcett's (2000) investigation

into the experiences of women with disabilities in Ontario has demonstrated a need for employment programs to be implemented which create a "safe environment" for those considering withdrawing from income assistance, which could be addressed by allowing recipients to receive partial benefits while working part-time in an attempt to assess whether or not they should return to the full-time labour market. The findings of these other research studies, in addition to the women's experiences discussed earlier in this chapter, support the recommendations made by the women interviewed in this study: that policies and programs need to support measures other than vocational training and full income assistance, such as those discussed above, in an attempt to meet the diverse needs of Ontarians with disabilities.

### **7.3.3 Reassessing the Application Process for CPP-D**

A third policy implication based on the findings of this study is that the application process for CPP-D income support should be reassessed. As was discussed in Chapter Six, eight of the women interviewed experienced the application process as being exclusionary and inaccessible. The reasons for these experiences were many: the language on CPP-D income support application forms is inaccessible, the amount of administrative paperwork is overwhelming, and the

cost of having Doctors complete the necessary paperwork is a financial burden.

The experiences of the CPP-D income support application process shared by the women interviewed indicate that they perceive this process needs to be reviewed. Though eligibility requirements for CPP-D income assistance have been lessened over time, the actual amount of administration has increased (Campolieti and Lavis, 200). Further, the costs incurred by applicants may seem minimal to policy-makers and CPP-D administrators when, in fact, they can be a financial burden as all applicants for CPP-D income support are unemployed. Fair (2001) suggests that such flaws in Canada's social policies occur when the socio-economic and socio-spatial distance between policy-makers and those who benefit from the policies are great. In other words, policy-makers may not comprehend the financial hardship created by paying for a \$50 medical report when they experience lifeworlds of socio-spatial and socio-economic privilege which do not include trips to food banks or living in socially assisted housing projects. The application processes for CPP-D income support must be reassessed by policy-makers, in conjunction with community service agencies and support recipients, to ensure that they exert the minimum level of "social control" necessary, that the language used is as accessible as possible, and that there is no financial burden on applicants.

For example, a waiver system could be put in place where Doctor's can waive the applicant from having to pay the fee and expense CPP-D instead.

#### **7.3.4 Increasing Access to Policy and Program Information**

Although there are many policy implications that can be drawn from this research, the final one which will be discussed here is the need for the government to better inform citizens with disabilities about the policies and programs available for their assistance. As was discussed in Chapter Six, fourteen of the eighteen women interviewed believed that information about government-funded employment and income support programs is not easily accessible. Further, those who were best able to gain access to this information had been involved in post-secondary education. This finding supports Marris's (1996) conclusion that access to information is intertwined with one's socio-economic status and education level. Both the fact that many of the women were not well-informed about supports available to them and that fourteen of the women believe that information about social supports is not easy to access is cause for concern and must be addressed by government Ministries and offices at the municipal, provincial and federal levels. As discussed in Chapter Six, one way to overcome this problem is to distribute information

packages created by the government, local service agencies and people with disabilities in the local community, with information about all types of supports available to them at Doctors' offices.

#### **7.4 Implications for Future Social Scientific and Geographic Research**

It was discussed in Chapter Five that experiences within spaces of health care can impact on chronically ill women's abilities to maintain employment. We need to continue to explore how experiences within one space of daily life can impact on others. For example, how do experiences in the home impact on paid labour, or how do experiences in social and recreational spaces impact on experiences of health care? The more we can learn about the interconnectedness of such experiences, the better able we are to 'map' the lifeworlds of chronically ill women and their interwoven spaces of daily life. This study has started to explore some of these connected spaces and experiences, however this type of research needs to be continued by geographers and other social scientists in order to being to more fully understand the disablement process and experiences of disability.

Throughout the discussion presented in the previous two chapters, it was shown that co-workers and employers'

attitudes posed significant barriers in the workplace. Co-workers and employers often reacted with disbelief and a lack of understanding in relation to the women's arthritic conditions and their severity. Furthermore, these women's employers frequently exhibited an unwillingness to appropriately accommodate employees with disabilities. We need to better understand why such experiences occur and if they are tied at all to notions of people with disabilities as being unproductive employees or unemployable. If we do not truly understand the roots of such workplace and attitudinal barriers then we will never be able to effectively address them through education, the dissemination of information, and other measures.

Furthermore, it was shown that employers are not always willing to accommodate employees with disabilities in the workplace. As was discussed in Chapter Five, at least five of the interviewees left their jobs due either to inappropriate accommodations being made or a resistance to requesting accommodations from employers perceived to be unwilling to accommodate employees with disabilities. One suggestion to overcome this unwillingness offered earlier is to develop an incentive program for employers who choose to make appropriate accommodations prior to having legal action taken against them. However, we need to have a better understanding of why employers are hesitant to accommodate



disabled employees and what, if anything, can be done to make them more willing to do so. For example, what type of incentive would encourage them to appropriately accommodate employees with disabilities? We can never truly address how to encourage employers to make workplace accommodations without consulting them about their experiences and insights into the issue.

It was hypothesized earlier in this thesis that policies and programs which are created to assist persons with disabilities but, in practice, are not supportive of their needs may be due, at least in part, to the socio-spatial and socio-economic distance between the lifeworlds of support recipients and policy-makers. We need to research this distance and find out if it does impact at all on policy-maker's decisions or recipient's experiences of policy. Understanding this difference will help put policy-maker's and program recipient's experiences into context, and can assist us in conveying to policy-makers why certain programs and policies should or should not be developed or implemented.

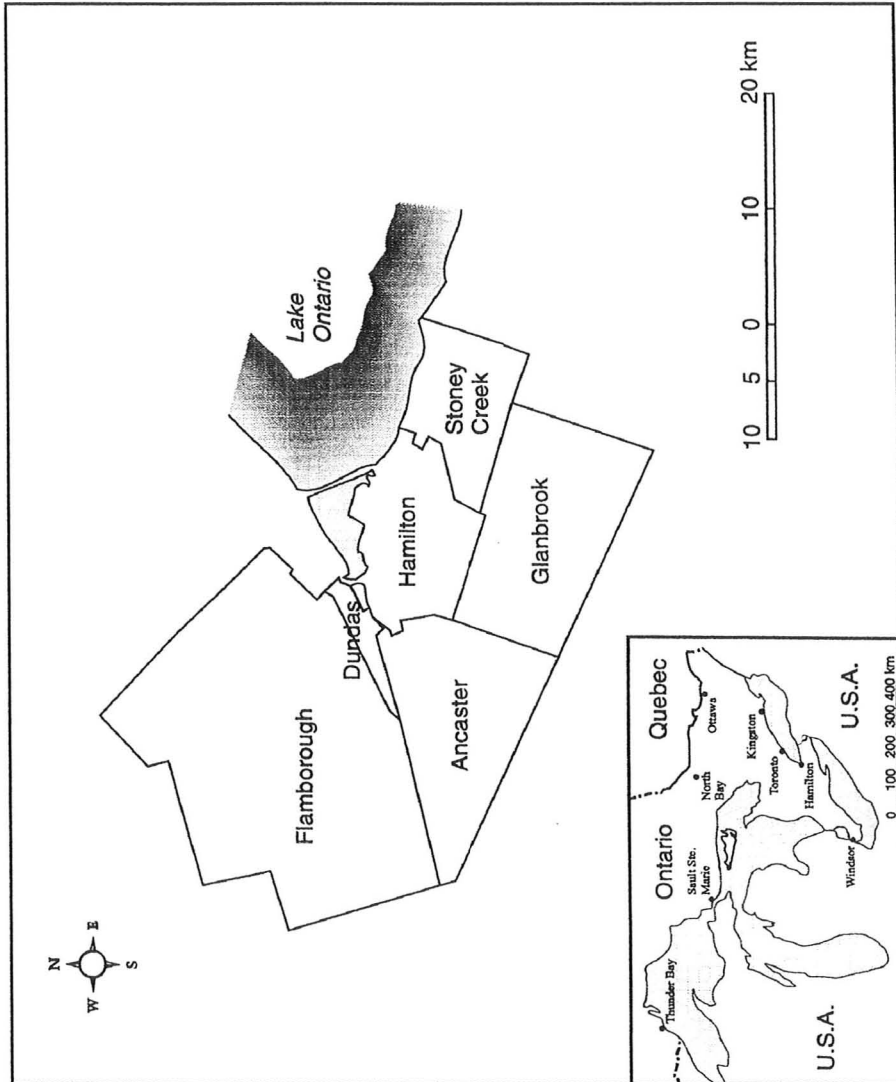
As was discussed in Chapter Six, the women interviewed for this study experienced a lack of access to government policy and program information. Such a lack of access to information has impacted on their abilities to be knowledgeable about the employment supports available to assist them. One cannot help but wonder how common this

experience is among marginalised groups in Canadian society and space? We also need to explore how, if at all, access to information varies over space. For example, is information more or less easier to access in rural and remote communities? Furthermore, we need to establish whether or not better access to policy and program information results in higher levels of program use. Knowing how access to information varies between groups and over space may also strengthen the argument made in this study, which is that information must be easier to access as chronically ill women do not have the time or energy to seek out information on their own, as it applies to these other groups.

The final implication for future geographic and social scientific research is that we must understand how common or unique these women's recommendations for policy and program change are based on those made by other groups. For example, do women or men with other types of impairments or chronic illnesses also desire employment programs that support flexible work arrangements, working from home and job-sharing? Or, would they prefer completely different supportive policies and programs to be created? If it can be established that other persons with disabilities would benefit from the policies and programs recommended by the women in this study, then a stronger case for their development can be made. However, if these women's suggestions are fairly unique, then

wen can investigate how different experiences of disablement, paid employment, and employment programs result in totally different policy and program suggestions. While it was acknowledged early on in this study that workplace experiences and experiences of disablement are heterogeneous, we still know little about how experiences of employment policies are similar or different among people with disabilities. For example, the most common employment program recommendation made by the women in this study, that of supporting flexible work hours, was also commonly recommended by the participants in Kitchin et al.'s (1998) study of experiences of employment programs in Donegal, Ireland among people with varying impairments. It is important that other such studies be produced so that comparisons between the policy recommendations and policy experiences of people with disabilities in varying geographic locations, and those of different genders, races, ethnicities, and socio-economic backgrounds, can be examined.

Appendix 1: Map of the City of Hamilton



Appendix 1: The recently amalgamated City of Hamilton includes Hamilton and the former municipalities of Flamborough, Dundas, Ancaster, Glanbrook and Stoney Creek.

## Appendix 2: Interviewee Release Form

Hi, my name is Valorie Crooks. I am a graduate student researcher from the School of Geography and Geology at McMaster University who is working on a project studying the relationship between employment policies and the employment experiences of women with Arthritis. The purpose of this in-depth interview is to gain a better understanding of how you, a woman with Arthritis residing in the Hamilton-Wentworth area, have been able to utilize existing government employment policies and initiatives to facilitate your search for employment.

This project is being supervised by Dr. Vera Chouinard who works in the School of Geography and Geology at McMaster University. I am the principal investigator of this project and I can be contacted by phone at 529-XXXX or e-mail at crooksva@mcmaster.ca should you have any questions. My faculty supervisor can also be reached by phone at 525-9140 x23518 or by e-mail at chouinar@mcmaster.ca.

Thank you for your willingness to participate in this research project. Your participation is very much appreciated. Just before we start the interview, I would like to reassure you that as a participant in this research project you have several very definite rights.

- First, your participation in this interview is entirely voluntary.
- You are free to refuse to answer any question at any time.
- You are free to withdraw from the interview at any time.
- The actual interview tape recording and full interview notes will be made available only to myself, my faculty advisor and assistants involved in transcription. All original notes and audio tapes will be stored at my residence and will be kept until no further data interpretation is needed.
- Excerpts of this interview may be made part of the final research report, however your real name will never be cited in the final project.

I would be grateful if you would sign this form to show that

you accept these terms of participation in the project.

\_\_\_\_\_ (signature)

\_\_\_\_\_ (printed name)

\_\_\_\_\_ (date)

Please send me an executive summary based on the results of this research report. (circle one) YES / NO

Address report should be sent to : \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

*This research project has been reviewed and received ethics clearance through the McMaster Research Ethics Board (MREB), participants with concerns or questions about their involvement in the study may contact:*  
MREB Secretariat, Telephone: 905-525-9140, ext. 24765  
Office of Research Services E-mail: grntoff@mcmaster.ca

### Appendix 3: Interview Guide

1.
  - a. In general, what has your employment history been? More specifically, what has your experience been with employment over the past 10 years?
  - b. Have you found your employer(s) willing to accommodate your needs (if employed after symptoms of Arthritis have been present)?
  - c. As your employment status has changed has others' views of you as a "worker" changed? If so, please explain. Has your view also changed? How?
  - d. What have your job search strategies been? Have these strategies change over time or space? If so, how?
  - e. How did/how has your understanding of your job and yourself changed since acquiring Arthritis?
  - f. Have your beliefs about how is responsible for helping you find and maintain employment changed over time?
2.
  - a. Has your meaning or understanding of employment changed at all since being diagnosed with Arthritis? If so, how?
  - b. What do you believe are the greatest impacts on disabled women's employment? Physical barriers, social barriers, or others?
3.
  - a. What do you believe to be the greatest, or most serious, barrier to getting and maintaining employment for women who have acquired Arthritis? Why do you think this is so?
  - b. What do you think would be the best method to go about reducing or eliminating this barrier? How effectively do you think the federal, provincial and local governments are currently working to reduce this barrier?
  - c. Are there other significant changes that have taken place in your life which have affected your ability to be employed in any capacity?
  - d. Have you experienced changes in your access to, or eligibility for, government supports or services that have affected your ability to maintain employment?
4. To the best of your ability, have you ever received government or other assistance in these types of situations: finding employment, job training, physical

- accessibility, transportation to and from work, discrimination, or other types of employment supports?
5. Did any of these initiatives assist you in your search for employment or improve your ability to secure employment? If so, how?
  6. How satisfied were you with the government programs and other types of employment initiatives that you've utilized? Where were the supports or assistance you've utilized based?
  7. How satisfied are you, in general, with the variety and type of government funded employment supports available? Why are you satisfied, or not satisfied? What could be done to increase your satisfaction?
  8.
    - a. Are you aware of any employment policies, programs or initiatives that you've benefitted from which have been cut or downsized since you've utilized the service, or ones that you are no longer eligible for that you have used in the past? Which ones?
      - I. Do you wish this change was not made to the service? Why, or why not?
      - II. Do you think that you would still currently use the service if the types of services had not changed, or you were still eligible?
    - b. Are you aware of any other types of government supports and assistance (particularly ones that have affected your employment status) that you've benefitted from which have been cut or downsized since you've utilized the service, or ones that you are no longer eligible for that you have used in the past? Which ones?
      - I. Do you wish this change was not made to the service? Why, or why not?
      - II. Do you think that you would still currently use the service if the types of services had not changed, or you were still eligible?
  9.
    - a. Of all of the government employment supports that you've used, which one(s) have been most helpful in assisting you to search for and secure employment? Why?
      - I. Are there any that you did not find helpful?
    - b. Of all of the other types of supports that you've used, which one(s) has been most helpful in assisting you to search for and secure employment? Why?
      - I. Are there any that you did not find helpful?
  10.
    - a. Do you feel that the current employment supports are serving you in the best manner possible?
      - I. Is there a type of assistance that you would like that these programs do not offer?
      - II. Have you found these programs to be



accessible and easy to utilize?

III. Do you find the administrative processes (paperwork) involved in these programs to be easy to handle, or too difficult?

IV. Are there enough government employment supports in the Hamilton-Wentworth area to help you participate in employment? Please explain.

b. Do you feel that other types of supports are serving you in the best manner possible, and that they have not deterred you from acquiring and maintaining employment?

I. Is there a type of assistance that you would like that these programs do not offer?

II. Have you found these programs to be accessible and easy to utilize?

III. Do you find the administrative processes (paperwork) involved in these programs to be easy to handle, or too difficult?

IV. Are there enough supports, in general, in the Hamilton-Wentworth area to help you participate in employment? Please explain.

11. a. What would be the best type of support that employment policies and programs could offer to specifically assist women with Arthritis in acquiring and maintaining employment?
- b. Are there other types of non-employment supports that government policies and programs could offer to women with Arthritis to assist with acquiring and maintaining employment?
12. Is there any other aspect of government employment policies, supports, initiatives or programs that you would like to discuss? Any additional problems or positive points that you would like to raise?

#### Appendix 4: Free and Tree Interview Nodes

##### Free Nodes:

- access to information
- accessible housing
- administration
- age
- barrier reduction
- current employment
- cut services
- disability insurance
- disincentives
- educating public
- employment history
- employment programs used
- fibromyalgia
- health care
- hidden disability
- ideal supports
- impairment
- lupus
- multi tasking
- Ontario government
- osteoarthritis
- PATH employment
- physical accessibility
- point of diagnosis
- rheumatoid arthritis
- self as worker
- social barriers
- transportation
- work area
- workers compensation
- working in health care
- workplace accommodation
- workplace barriers

##### Tree Nodes:

- self worth:
  - depression
  - therapy
  - self esteem
- local support:
  - support groups
  - social networks
  - swim therapy

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