

# Disability income: The experiences of women with multiple sclerosis

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## KEY WORDS

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## ABSTRACT

*This paper examines the experiences of unemployed women with multiple sclerosis with three income support programmes, the Canada/Quebec Pension Plan, long term disability insurance and social assistance. Findings are based on ethnographic interviews with 23 women. Difficulties experienced with these programmes include the low level of benefits of two of the programmes, the earnings-based component of two of the programmes, and requirements in eligibility criteria that applicants be defined as permanently unemployable. The occupational consequences of disability income policies are mediated by marital and socio-economic status. For some, policies mean lives of poverty and marginalization, for others they mean lack of freedom to change jobs, to work part-time or hesitance to return to the work force. The ways in which social policies shape the individual experience of disability should inform occupational therapy intervention at the individual level. Therapists are also challenged to help create policy environments that will enhance client function.*

## RÉSUMÉ

*Cet article présente les expériences de femmes sans emploi atteintes de sclérose en plaques qui ont bénéficié de trois programmes de soutien du revenu, soient le Régime de pension du Canada/Régime des rentes du Québec, l'assurance invalidité de longue durée et l'aide sociale. Les résultats sont basés sur des entrevues ethnographiques effectuées auprès de 23 femmes. Parmi les difficultés rencontrées par les femmes par rapport à ces programmes, citons les prestations peu élevées de deux des programmes, le fait que les prestations soient basées sur les revenus dans deux des programmes et les critères d'admissibilité qui exigent que les demandeurs soient définis comme étant employables sur une base permanente. Les conséquences occupationnelles de la politique d'assurance invalidité dépendent de l'état civil et du statut socio-économique. Pour certaines personnes, ces politiques sont synonymes de pauvreté et de marginalisation, alors que pour d'autres, elles limitent les possibilités de changer d'emploi, de travailler à temps partiel ou de retourner sur le marché du travail. Les façons dont les politiques sociales influencent la personne qui présente une incapacité devraient orienter l'intervention ergothérapeutique sur une base individuelle. Les thérapeutes ont également le défi de participer à l'élaboration de politiques qui favorisent l'autonomie fonctionnelle du client.*

Occupational therapy is concerned with promoting, maintaining or restoring occupational performance. Occupation is performed within a context and persons with disabilities encounter environmental forces that enable and limit their daily activities. If we want to understand our clients and help them function more fully in their occupations, it is important to learn about their environments (Kielhofner, 1995). Occupational therapists have traditionally focused primarily on the client's individual abilities and limitations and on his/her immediate environment. The effect of the larger social, economic and political environment on clients has not been well understood. There is, however, increasing recognition that therapists need to pay much more attention to this larger context (Law, 1991; Polatajko, 1992; Townsend, 1993). This paper focuses on the impact of one aspect of this larger environment, namely disability income policies, on the lives of women with multiple sclerosis.

Multiple sclerosis (MS) is a chronic disease which affects women at about twice the rate of men (Poser, Paty, McDonald, Scheinberg & Ebers, 1984). Its typical onset is in a person's most productive working years, during the late 20s or early to mid 30s, when women may be training for a career, working full-time, staying at home to raise children or combining part-time work with domestic responsibilities. The disease has an unpredictable course, with no clear indication regarding the likelihood of remission, relapse, or steady progression (Confavrex, Aimard, & Devic, 1990). Extent of impairment ranges from little apparent incapacity to severe paralysis, with fatigue, motor symptoms and sight disturbance as the most common symptoms. Unemployment among people with multiple sclerosis is known to be 70% or higher (LaRocca, Kalb, Kendall, & Scheinberg, 1982).

Women with MS who no longer have income from employment need some form of income security to compensate for their lack of earnings. Income support programmes are described and analyzed in the literature, but there is little documentation regarding the experiences of income programme applicants or recipients, nor how particular disabilities influence this experience. This paper aims to identify the primary programmes of income support for women with MS who are no longer in paid employment, to examine their access to benefits, the adequacy of benefits, the ways in which MS symptoms influence the need for, and access to income support, and to document the impact of these programmes on their lives. Its purpose is to inform occupational therapy practice and to challenge occupational therapists to become more involved in creating social policies supportive of persons with disabilities.

## Disability Income Programmes in Canada

The disability income "system" in Canada "is a patchwork of separate programmes not designed to function in a coordinated way" (Rioux & Crawford, 1990, p.106). This is partly because

programmes evolved in a piecemeal fashion in response to various social and economic conditions, such as the Depression of the 1930s and accidents related to industrialization (Torjman, 1988). The first disability programmes in Canada were Worker's Compensation programmes and Veteran's disability pensions. Injured workers and war veterans were viewed as deserving assistance because they had contributed to the country. Only much later did general programmes such as the Canada/Quebec Pension Plan (C/QPP) arise to provide benefits regardless of the cause of disability. Recent years have seen the growth of private Long Term Disability (LTD) insurance plans and programmes such as compulsory automobile insurance and criminal injuries compensation.

Insurance programmes and non-insurance support programmes are two sources of income for Canadians with disabilities who are not employed (Rioux & Muszynski, 1992). Insurance programmes compensate people for lost income. Social insurance programmes are the main disability income programmes for people whose disabilities result in an inability to continue to work in the paid labour market. Worker's compensation schemes and the C/QPP are the most important social insurance programmes; but they cover only those who were wage earners. Workers' Compensation programmes in each province and territory protect workers from loss of income resulting from disease or injury related to their jobs. The C/QPP is designed to protect workers from loss of income due to retirement, disability or death of a spouse. Contributions to the plan are mandatory for employed persons aged 18 - 65. The disability pension is paid in the event of a severe and prolonged disability, as defined by CPP. The CPP legislation was recently amended and now permits individuals to work and receive pension benefits. However, there is an earnings ceiling to prevent people from taking advantage of the system (Government of Canada, 1996).

LTD Insurance is provided by some employers through group plans and is also purchased by individuals. Employees with large employers, and those in better paid positions, are most likely to have Long-Term Disability Insurance. The level of income provided is usually in the range of 60-75% of pre-disability income. Income from the C/QPP is usually deducted from the income received from Long Term Disability Insurance. During the first 2-3 years, eligibility is frequently based on inability to perform one's previous job. Subsequently, the individual is required to demonstrate that he/she cannot do any paid job in order to continue receiving benefits (Beatty, 1992).

Non-insurance supports are government programmes which provide various benefits to people with disabilities through tax reductions, cash income or provision of transportation and equipment such as wheelchairs. Benefits may be universal, i.e. to all those with disabilities, or selective - i.e. just provided to those with low income (Rioux & Muszynski, 1992). Social assistance is the most important form of non-insurance support. It provides financial assistance to those whose

income from employment or other sources is insufficient to meet their needs. Social assistance is administered by provincial governments. The federal government shares in its costs under the Canada Assistance Plan. Social assistance is a "last resort" programme, characterized by low income payments and needs testing. Provincial rules define who is eligible for social assistance. In the case of those with disabilities, most provinces require that an applicant has a physical or mental disability that severely impedes his/her ability to be employed. If an applicant is eligible for welfare because of disability, he/she is also required, in most provinces, to qualify on the basis of the value of his/her liquid and fixed assets (Crichton & Jongbloed, 1998).

## Methods

This paper is based on a subset of findings of a larger study on employment and women with MS which consisted of a qualitative phase and a quantitative phase (Jongbloed, 1996). Fifty-four women diagnosed with MS participated in the qualitative phase. They were contacted either through a MS Clinic in Western Canada or a local chapter of the MS Society. Of these women, 31 were employed and 23 were not employed at the time of the interviews. Those no longer employed ranged in age from 21-57 years, with a mean age of 44. Eighteen of the women were in their 30s and 40s. The time the women had been out of the paid work force ranged from several months to 14 years. Six women had professional education, and had been employed in teaching, nursing and senior administrative positions; 13 had been employed in secretarial, bookkeeping, clerical and retail sales jobs. Four had been employed in semi-skilled or manual jobs. Nine of the women were married, eight were divorced or separated and seven had never married. All the women lived in the Greater Vancouver area of British Columbia. This paper is based primarily on interviews with these 23 women who were no longer employed. It focuses on one aspect of being unemployed and living with a disability, namely accessing disability benefits and living within the constraints imposed by those benefits.

Two investigators and a research assistant conducted semi-structured in-depth interviews with these women to explore different aspects of their lives including work experiences, income issues, housing and personal relationships. Interviews which took place in the women's homes and ranged from 1-2 hours in length, were tape-recorded, transcribed and computerized to facilitate data coding and categorization. Intermeshing of data collection, analysis, and problem definition is an integral feature of qualitative research (Glaser & Strauss, 1967; Hammersley & Atkinson, 1983). The two investigators and the research assistant identified and discussed emerging themes from the interviews they conducted and then organized the themes into categories. The three team members coded each transcript independently. Final coding of data

occurred during team meetings. Any inconsistencies in coding were discussed and resolved at that time. The software package Hyperqual was used to code data.

Quantitative methods were used during the second phase of the study, the purpose of which was to examine employment history since diagnosis with MS, difficulties experienced at work, and sources of income for those no longer employed. In this phase questionnaires were mailed to all 864 women aged 19-60 who had attended a MS clinic in Western Canada. The response rate was 66%. Only two sections of the quantitative phase of the study are relevant to this paper, namely the sources of income of women no longer employed and the percentage of these women who indicated that receipt of benefits influenced their decisions not to return to work.

## Findings

Findings from the qualitative phase of the study focus on the experiences of the 23 women who were no longer employed. The sources of income of women in both phases of the study were disability benefits from the C/QPP, long term disability insurance (employer & private), social assistance (disability benefits) and other personal income. Many women derived income from more than one source. Since the quantitative phase of the study included a large number of unemployed women ( $n=163$ ), percentages of women in that phase receiving each type of income are shown in Table 1.

Analysis of the qualitative data revealed some common themes. A large proportion of women experienced difficulties related to accessing benefits, the adequacy of benefits, other constraints and fatigue. Each of these themes is discussed below.

## Accessing benefits

To access benefits from the C/QPP, long term disability insurance or social assistance, applicants had to meet certain eligibility criteria and be assessed by a physician. The restrictiveness of the definition of disability for eligibility for C/QPP benefits was problematic for 10 of the 23 subjects in the qualitative phase of the study who received C/QPP. A woman of 26 who had been working at a car rental agency said, "I've been getting brain-stem attacks, and they affect my vision, my speech, my balance and they make me tired and weak. At work I couldn't take a rest if I wanted to and when I have an attack, I'm supposed to stay in bed for a month or two." The doctor told her that he didn't want her to work any more. She tried to get C/QPP disability benefits, "but the government says that I'm not disabled enough. They told me to get an easier job. Well the job I had was as easy as you can get. I mean, I'm just sitting behind a desk and writing out forms." She was thus appealing her eligibility.

The experiences of the 10 women in the qualitative study who applied for long term disability benefits varied. Four reported problems accessing benefits, the other six did not.

**Table 1**  
**Sources of Individual Income of Women No Longer Employed (N=163)**

	Percentage of women in quantitative study receiving income from various sources
Disability pension, Canada/Quebec Pension Plan	77
Long term disability insurance (employer & private)	44
Social assistance (disability benefits)	11
Other personal income	15

Some women felt victimized by the requirement that after 2 or 3 years they had to prove themselves incapable of working at any job (not merely their previous jobs). One woman said,

*"There is a problem with the long-term disability people. Of course, it's their business, and I understand, they want you off the plan; ..... After two years, in order to stay on long term disability, you have to prove you are not able to do ANY form of work whatsoever. So if my doctors say I can sit in my electric wheelchair on the corner, one hour a week and sell pencils, I will be cut off all my benefits. If they find out about my volunteer work, I'm cut off all my benefits...I want to enroll in a time management and stress management course, but I can't. As soon as I take that, I'm cut off all my benefits - I can't risk the rest of my life without any income. So you're totally victimized."*

In order to access social assistance disability benefits, applicants have to demonstrate financial need and disability. Financial need is assessed through a needs test in which income and required expenditures are determined. Most social assistance recipients experienced the assessment of financial need as intrusive. One person said "They look at your bank statements, and because they have my bank account number, I assume that they could go in and check my balance anytime." Another said "You're forced to lie about how much money you have in the bank, and then they check up on you, hoping to trip you up."

An individual is allowed to access disability benefits once a physician has issued a medical certificate indicating that he/she is unable work. Fatigue, a central symptom in multiple sclerosis, is invisible but potentially debilitating. It was difficult for some physicians to understand the impact of something that they could not see. This added to the complexity and discretionary elements in the assessment process. This caused problems 6 of the 23 participants.

*According to one woman, her first neurologist asked her, "Do you want to go to work?" And I'd said, "well you know, basically it's not up to me. I might want to go to work but I'm not able to right now." It was mainly fatigue. And he had me seeing the unit social worker, and why it was I didn't want to work ... And meanwhile he would only sign my letters for the insurance company, for*

*like a month at a time, well so the money keeps stopping.' She said, in contrast, her second neurologist was completely different and he said "Look, this is it; its not going to get any better, it's not going to change, this is the story. She is disabled." Physicians exercise considerable discretion in the assessment process. Some physicians were much more liberal in their evaluation of the impact of the disability than others.*

## Adequacy of benefits

Some of the women had individual income and nine lived in households in which there was an additional source of income. However others had to cope with reduced income. The level of income replacement from long term disability programmes is typically in the range of 60% - 75% of pre-disability income. The C/QPP benefit consists of a flat sum plus an earning-related component which equals 75% of the retirement pension to which the individual would have been eligible (Government of Canada, 1996). The fact that benefits are based on employment earnings works against women with MS who may have worked part-time because of fatigue and other symptoms associated with MS, combined part-time work with domestic responsibilities, or taken time off work to raise a family. One woman explained it this way, "I stayed at home and raised my family. I did tailoring and house painting on my own. So I wasn't a contributor for 16 years, and that greatly affected my C/QPP disability pension."

Social assistance benefits are below the poverty line (Government of Canada, 1996). The activities of women on social assistance were severely curtailed by lack of income. One woman described her situation this way

*"How can you be healthy if you don't have the money to be healthy? On social assistance, you're on the poverty line. I'm just existing. If I was working, I'd be able to visit and go and do a few things. This way I can't do anything. I don't even have the bus fare, you know."*

Another said, "The MS Society sent me information. In fact, they sent me the whole book, because I haven't got the money to go down there."

One woman explained how being on social assistance disability benefits constrained her social activities, "If I want to

go somewhere some friends are going, I have to sit down and say 'Is this going to be worth it to me?' because if I go and do this event, am I going to be short for the rest of the month?"

Physical disabilities, fatigue and limited income constrained what some women with MS were able to do. Some felt despondent, bored and isolated and they lacked self-worth. Those who were divorced, separated or never married were more likely to find it difficult to maintain social networks than those who were married. They also experienced greater financial constraints related to housing than the married women and were more likely to move to less costly housing and to rent rather than own a home. (Of the 10 individuals who owned homes, 7 were married; of the 7 people in rental housing, 1 was married.) Several women had applied for government subsidized co-operative housing where monthly rents are approximately 25% of income.

One single woman on social assistance disability benefits (\$600 per month) rented a room (for \$100 a month) in a house and also looked after the owner of the house, an 82 year old woman. She said her occupational therapist had not addressed how she could cope living on a reduced income.

*"She talked about coping with the disease, like don't climb the stairs, like reserve your energy, all that kind of thing. And that's all good, but when I go back to my little room I have to face this economic thing; and I have to face these psychological things, like I haven't even got into looking at having a relationship with someone."*

## Other constraints

Insurance companies do not cover clients for conditions which pre-existed their insurance coverage. This meant that women who had long-term disability insurance when diagnosed with MS felt unable to change employment. One woman applied for a new job and was told that since she had MS, she could not receive short or long term disability coverage through that employment. She said

*"So, I was really upset. It makes me feel like a prisoner where I work. Not that I don't like what I do, but my opportunities are limited, very limited. In fact I'm where I'm probably going to be forever. I don't have a choice."*

Because the course of MS is uncertain, some women were afraid to return to the work force once they had established eligibility for disability payments. Fifty four percent ( $n = 88$ ) of the women in the quantitative study who were no longer in paid employment, identified loss of current income as a factor that discouraged them from looking for work. They felt they could not afford to lose the financial security they had. This dilemma kept some women with MS unemployed.

The structure of disability benefits provided through social assistance in B.C., created disincentives for work for some women. Some people with MS have significant drug costs and while they receive social assistance disability benefits, the

costs of these drugs is covered. However, while receiving these benefits they are not allowed to work. Since coverage of drug costs was worth several hundred of dollars per month to some women, it was a better financial decision to remain on benefits than to return to work.

## Fatigue

Fatigue is an important, almost universal problem in MS, which makes full paid work impossible for many with MS. Women whose spouses had high incomes felt more free to leave employed roles or work part-time than those whose spouses had limited incomes or those who were divorced, separated or never married. What many women desired was part-time work and partial disability benefits. However social assistance, most private disability benefits (and at the time of the study, C/QPP) are structured in such a way that the person has to demonstrate an incapacity to work in order to access benefits. Only one subject reported being allowed by her insurance company to work part-time. She received \$779 long term disability insurance per month and was allowed to work part-time and keep \$361 of her \$650 pay, which resulted in a total monthly income of \$1140, which she considered adequate.

Fatigue also affected the amount of energy women had to contest what they considered inequitable allocation of benefits. One woman had been off work for a year before she applied for long term disability insurance from her insurance company, and was given \$350 per month instead of \$700, because of the delayed application. She said "I was sick. I was really tired at the time and I didn't have the energy to worry about that. It was easier to say, what the heck, I don't care!"

## Discussion

As indicated above, a number of women experienced difficulties related to accessing benefits and adequacy of benefits. The qualitative phase of the study was not intended to be statistically representative and findings cannot be generalized to other people and settings. However, issues which arose from the findings may well be important in other settings and with other samples. This section discusses factors related to how disability is determined and how benefit programmes are structured in Canada.

## Determination of disability

Stone (1984) points out that in all societies, workers are regarded as more deserving than non-workers. Each country has two distributive systems, one based on work and the other based on need. Most people meet their needs by working. However, each society has to decide when people are in need and how much money to give those in need. Those with disabilities may be in need. However, disability has always been problematic because it can be feigned. Since the nine-

teenth century, physicians have been assigned the role of determining when someone should qualify for disability benefits. This was because advances in scientific medicine offered new diagnostic techniques such as the stethoscope and x-rays which could distinguish between genuine disability (or inability to work) and "feigned disability" (Stone, 1984).

The three disability programmes most frequently used by women with MS require a physician's report to establish eligibility. Both the physician and the government/private agency allocating benefits have to be convinced that the woman's symptoms and functional abilities render her incapable of working. Agencies want to allocate benefits only to those with "legitimate disabilities". Symptoms are generally viewed as legitimate only when their parameters can be defined and tangibly displayed in the form of test scores (Monks, 1989). A woman may have a combination of disabilities (such as weakness, incoordination and fatigue) which limit her ability to work, while the visible disabilities on their own do not. Because fatigue, one of the major symptoms of MS, is invisible, disability benefit claims by people with MS are likely to be subjected to more scrutiny than claims of people whose symptoms are all visible.

Disability rights advocates say that the current disability determination process gives disproportionate power to the medical profession. The disability community supports revision of current procedures so that self-declaration of disability would become the norm. A peer counseling process would be a way of having the self-declaration validated (Government of Canada, 1993).

## Structuring of benefit programmes

To be eligible for benefits from a disability income programme, the applicant has to be declared unemployable. When Canada's major national social programmes were introduced in the 1960's, people with major disabilities were viewed as unable to engage in competitive work. Though perspectives regarding the abilities of people with disabilities have changed, at the time of the study (1993/94), disability income programmes such as the C/QPP, social assistance in BC and long term disability insurance had not altered fundamentally to reflect these emerging views (Crichton & Jongbloed, 1998). Unemployability was still the eligibility test and this was a major barrier for many women with MS. Fatigue is a common symptom in MS and many women with moderate physical impairments, consequently wished to work part-time. Their wishes were influenced, too, by responsibilities such as child care and housework, work primarily performed by women. At the time of this study they were unable to access income support from the C/QPP, social assistance and most long term disability programmes unless their disabilities rendered them completely incapable of employment. Women's choices were to continue working full-time, with considerable strain, or to work

part-time and forego half their income. Women living in households with another source of income and women with high individual incomes could more easily afford to choose the part-time option. Single women in low paying jobs had few options.

In our study, only one of 23 individuals were permitted to combine part-time work with receipt of partial benefits. This embodies a view that people are totally disabled or totally able-bodied. In reality, however, people fit on a continuum of ability to work (Lonsdale, 1990). By not allowing those with disabilities to receive partial benefits as well as employment income, disability programmes deny people the satisfaction and economic self-sufficiency that they might gain from participating in the labour force part time. When economic rationality is the centre of society, self-esteem and involvement in the life of the community are connected to paid employment. Those with disabilities who are not in the paid labour force are distanced from core values (Borsay, 1986). The disability community in B.C. lobbied for changes in legislation to enable persons with disabilities to undertake employment opportunities without making themselves ineligible for any income support. Before 1995, a person could not receive social assistance disability benefits in B.C. unless declared "permanently unemployable" and his/her disability was "apparently permanent". Handicapped has been redefined to emphasize the duration, rather than the permanence of a person's disability. This change recognizes that many people with disabilities such as MS, have periodic remissions. Second, the criterion of unemployability was removed, thereby acknowledging the employment potential of people with disabilities (Government of British Columbia, 1995).

In April 1995, the federal government altered legislation related to disability because the way it was structured created disincentives to work. Now those on C/QPP disability pensions can do volunteer work, attend school or university and be given a three month transitional period of continued benefits after having become employed (Government of Canada, 1996).

## Adequacy of benefits

Long term disability insurance plans generally provide greater income protection than the C/QPP or social assistance. However, it is not mandatory that employers offer their employees long term disability coverage. Consequently less than half of the population has this benefit. High income earners such as those in management positions and unionized workers in the public sector and large manufacturing operations are more likely than other employees to have long term disability insurance as an employment benefit (Rioux & Muszynski, 1992). Benefits provided by C/QPP are extremely low; consequently, some recipients also require social assistance. Those who depend entirely on social assistance for their support live below the poverty line (Fawcett, 1996). To be

equal, to participate in the community and be self-determining, people need an adequate income. With poverty comes marginalization. However social assistance benefits are kept below the poverty line on the assumption that poverty will motivate people to "make something of themselves" and rejoin the labour force (Rioux & Crawford, 1990).

MS typically affects women in their late 20s or early 30s and frequently results in women leaving employment in their early 40s. Leaving employment approximately 20 years before mandatory retirement age has several economic disadvantages. Employment income is lost. Income from private insurance plans is calculated as a percentage of predisability earnings, which are lower at age 40 than they would be later in life. Also, the C/QPP has a flat rate component as well as an earnings-based component which equals 75% of the retirement pension to which that individual would have been eligible (Torjman, 1988). The earnings-based component works against women in two ways; many women work fewer years than men do, because of childrearing or elder care responsibilities; and many work part-time. Both factors result in lower total earnings and lower C/QPP disability pensions for women than for men (Crichton & Jongbloed, 1998). Women with disabilities have a higher poverty rate (29.5%) than men with disabilities (20.9%) (Fawcett, 1996).

The issue of adequacy of benefits needs to be placed in a larger context. Disability income policies are inequitable. Currently, the income of persons with disabilities depends on whether they became disabled at work, in a car accident, had contributed to the C/QPP before becoming disabled, or are war veterans. The majority of people with disabilities are not eligible for benefits from Workers' Compensation, Automobile Insurance, C/QPP or War Veteran's programmes and consequently receive provincial social assistance benefits which are so low that many recipients live in poverty (Government of Canada, 1996).

The current disability system fails to recognize that all disabled people need adequate income replacement regardless of cause of disability (Government of Canada, 1996). The Obstacles Report (Government of Canada, 1981) identified the need for a comprehensive disability insurance system. In 1982 a joint federal-provincial study was conducted with the mandate of assessing the feasibility of starting a national disability benefit programme. However, the reports of this study have not been made public (Muszynski, 1988).

There are several barriers to the development of a comprehensive disability insurance system. First, it is not a priority of the federal government. Second, reform in this area requires agreement of the federal, provincial and territorial governments and consensus is not easily achieved. Third, the legal profession and the private insurance industry benefit from the current system and oppose the move to a comprehensive scheme. Both groups have strong input into the political process, and government is reluctant to antagonize them

(Prince, 1991). Occupational therapists also benefit from the system as it is. Lawyers and insurance companies are primary sources of income for occupational therapists in private practice in this country. Groups representing people with disabilities are less powerful and less well-organized and have concentrated primarily on improving separate plans (such as Worker's Compensation and Social Assistance, etc.).

## Implications for occupational therapy

The goal of occupational therapy is to promote a sense of self-efficacy by developing effective interaction with the environment (Trombly, 1995). However, disability is not merely a personal limitation which the person needs to overcome or compensate for. Disability also arises from the failure of the social environment to adjust to the needs of people with disabilities (Hahn, 1986). There is a profound linkage between the social environment and health. High socio-economic status, social support and control have a high positive correlation with health; whereas low socio-economic status, social isolation and lack of control are associated with illness and disability (Evans, 1994).

Disability income policies penetrate the lives of women with MS who move from employed to unemployed status, by influencing the adequacy of their income, by stipulating that individuals may not receive partial benefits and work part time, and by inhibiting return to the work force by those who fear losing benefits and future eligibility for benefits. Women with MS who have moved to unemployed status have to reconstruct their lives to gain a perception of efficacy in new roles and activities. This includes contending with physical disabilities, fatigue and the lack of structure and social contact provided by work, and possibly limited income. It is difficult to regain a sense of efficacy when one does not feel in control of one's body, one's fatigue and one's income.

Occupational therapy intervention can occur at the individual level or at the level of the larger social, economic and political environment. Intervention at the level of the individual requires more than advising the person how to conserve energy or how to alter the kitchen or bathroom. It demands awareness that individual experiences are interwoven with social structures; and that the choices women make about how they will spend their time are contingent on the social context in which they find themselves. It means finding out what is important to each woman, what she would like to be able to do and what personal and environmental constraints exist for her. Social-economic status and marital status may mediate the impact of disability on occupation. The process of enabling occupation for some would include exploring options for involvement in low-cost community activities, and ways of establishing and maintaining social relationships.

In terms of intervention at the level of the economic and political environment, occupational therapists could become

involved with disability advocacy organizations who are attempting to bring about change in disability income policies. Townsend (1993) argues that occupational therapy's vision is to promote social justice, and that we need to become involved in advocating for and bringing about change.

The reasons for infrequent involvement of occupational therapists in influencing government policies, legislation, and conducting public education campaigns is likely to include lack of knowledge, the fact that such work falls outside job responsibilities, and lack of time, compounded by the fact that occupational therapy is largely a female dominated profession and women still bear the major responsibility for housework, child care and elder care. However, therapists could become familiar with the contextual issues of importance to the particular clients they serve, and then support a local, provincial or national organization of people with disability which promotes the interests of that group.

The recognition that the problems confronting those with disabilities emerge in large part from environmental rather than functional impairments, indicates the need to expand the study of disability and occupation to include variables in the social, cultural, political and economic environment. Multidisciplinary research is needed to examine the complex interplay between individual characteristics and the environment.

## Conclusion

In B.C. women with MS who are no longer part of the paid labour force receive income from the C/QPP, long term disability insurance and social assistance programmes. Women experience a variety of problems in relation to these programmes. These difficulties include low levels of benefits from two of the programmes, the earnings-based component of two of the programmes, the requirements in the eligibility criteria and the discretionary features (e.g., physician assessments of disability) of these programmes.

The current disability income system is inequitable. The income of a person with a disability is not primarily based on need. It depends partly on the cause of the illness/injury. Past efforts to introduce comprehensive disability insurance have failed because of the lack of commitment of the federal and provincial governments and the power of vested interests. It is unlikely that comprehensive disability insurance will be introduced during this time of deficit reduction. However this means that many people with disabilities live in poverty, which has a major impact on health and occupation.

Because insurance companies do not cover pre-existing conditions, many women with MS who have long term disability insurance coverage feel constrained to remain in the same job. Many of those who have established eligibility for disability benefits fear returning to the work force even if they are able to do so because of loss of benefits and possible future difficulty re-establishing eligibility. There is no provision

for part-time work and receipt of partial benefits, reflecting a view that people are totally able-bodied or totally disabled.

If occupational therapists want to understand a person's occupational behaviour they need to understand the environments in which that behaviour occurs. Therapists should be aware of the numerous potential effects of disability income policies on occupation, examine the particular ways in which each client's activities are affected by these policies and assist the client to engage in occupations which are important to her and which are physically and financially feasible. Therapists are also challenged to help create environments in which their clients can function optimally. This is a political process. Policies reflect fundamental values in society; and change will require changes in attitudes and values about persons with disabilities. Therapists can help influence attitude and value change by educating others about the abilities of those with disabilities and about the right to adequate income of those not in the labour force. They can also influence the decisions of policy makers by engaging in advocacy with those living with disabilities.

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