The Impact of Block Funding on Women with Disabilities

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March 1998Status of Women Canada is committed to ensuring that all research produced through the Policy Research Fund adheres to high methodological, ethical, and professional standards. The research must also make a unique, value-added contribution to current policy debates, and be useful to policy-makers, researchers, women's organizations, communities, and others interested in the policy process. Each paper is anonymously reviewed by specialists in the field, and comments are solicited on:

- the accuracy, completeness and timeliness of the information presented;
- the extent to which the analysis and recommendations are supported by the methodology used and the data collected;
- the original contribution that the report would make to existing work on this subject, and its usefulness to equality-seeking organizations, advocacy communities, government policy-makers, researchers and other target audiences.

Status of Women Canada thanks those who contributed to this peer review process.

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PREFACE

Status of Women Canada's Policy Research Fund was instituted in 1996 to support independent, nationally relevant policy research on gender equality issues. In order to determine the structure and priorities of the Policy Research Fund, Status of Women Canada held consultations from March to May 1996 with a range of national, regional and local women's organizations, researchers and research organizations, community, social service and professional groups, other levels of government, and individuals interested in women's equality. Consultation participants indicated their support for the Fund to address both long-term emerging policy issues as well as urgent issues, and recommended that a small, non-governmental external committee would play a key role in identifying priorities, selecting research proposals for funding, and exercising quality control over the final research papers.

As an interim measure during the fiscal year 1996-1997, consulation participants agreed that short-term research projects addressing immediate needs should be undertaken while the external committee was being established to develop longer-term priorities. In this context, policy research on issues surrounding the Canada Health and Social Transfer (CHST) and access to justice were identified as priorities.

On June 21, 1996, a call for research proposals on the impact of the CHST on women was issued. The proposals were assessed by Status of Women Canada and external reviewers. The research projects selected for funding in this area focus on women receiving social assistance, economic security for families with children, women with disabilities, the availability and affordability of child care services, women and health care, and women's human rights.

The call for research proposals on access to justice was issued on July 18, 1996. Also assessed by Status of Women Canada and external reviewers, the selected policy research projects in this area include a study of abused immigrant women, lesbians, women and civil legal aid, family mediation, and the implications for victims of sexual harassment of the Supreme Court ruling in *Béliveau-St. Jacques*.

The objective of Status of Women Canada's Policy Research Fund is to enhance public debate on gender equality issues and contribute to the ability of individuals and organizations to participate more effectively in the policy development process. We believe that good policy is based on good policy research. We thank all the authors for their contribution to this objective.

A complete listing of the research projects funded by Status of Women Canada on issues surrounding the Canada Health and Social Transfer and access to justice is provided at the end of this report.

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ACKNOWLEDGMENTS

DAWN Canada: DisAbled Women's Network is grateful to Status of Women Canada for funding *The Impact of Block Funding on Women with Disabilities: CHST Research Project.* We also want to acknowledge the foresight of the women at Status of Women Canada in recognizing the potential impact of block funding on women with disabilities resulting from cuts in provincial funding under the Canada Health and Social Transfer (CHST). When we heard that Status of Women Canada was funding research in this area, we submitted our proposal on behalf of DAWN Canada to find out what women with disabilities across Canada were experiencing as a result of block funding.

The work on this project was difficult and at times very disturbing. As women with disabilities, we cannot and do not want to separate ourselves from our own issues. Objectivity does not exist in a place of pain, deprivation and fear, as the cuts in federal funding erode our life support systems. As women with disabilities, block funding is very much our issue. Thank you for helping us to know the issues on a national level as well as in our personal lives. With what we have learned, we are hopeful of making change.

We also want to thank the women across Canada who organized and facilitated the focus groups: Judi Johnny in Whitehorse, the Northwest Territories Council for Disabled Persons in Yellowknife, Carol Bast in Vancouver, Beverley Matthiessen in Edmonton, Carmen Trimble in Regina, April D'Aubin in Winnipeg, Pat Israel in Toronto, Louise Brossard in Montreal, Misty Douthwright in Moncton, Glenda Maugler in Halifax, Janet Marshall in Charlottetown, and Valerie Cutler in St. John's. We are also grateful for the contributions in recording and assisting with the focus groups by Esther Millie, Duane Gates, Jayne Whyte, Silvia C. Marques, Gertrude Edem, Sheila Wright, Stacy Dunn, Estelle Reddin, Alice Madden, and DAWN Canada board members, Eileen O'Brien, Mary Williams, Doreen Demas, Robyn Artemis, Nathalie Léveillé, Kate Fancy, and Kathy Hawkins. Without the help of all these women, it would not have been possible to do this research and have input from every province and territory in Canada.

We also want to recognize the work of our translators, Helena Katz and Maryvon Delanoë, who translated our materials from English to French to enable the women in Quebec to participate in the project. As always, the materials came in late, but our translators came through with the translations in time for the focus group in Montreal and for our advisory committee members to participate in either of Canada's official languages.

Our very deepest thanks must go to the women who gave their time and attended the focus groups to share their experiences with us. These issues were difficult and personal ones for women who were feeling deep losses from the impact of block funding in their own lives. These women are afraid of losing what they have left and fearful of what will happen to them when it is gone. We realize that all the women run the risk of repercussions in their personal lives from revealing their own experiences and those of the women they know. Therefore, we have chosen not to list the names of these women for their protection.

As the project researcher, I want to give a special thank you to my friend and former co-worker, Joan Meister. As always, Joan was there to give support, to listen to my wailings, to edit my papers, and to encourage me to go on. I also want to thank Shirley Hawkes, Mary Williams, and Eileen O'Brien for their personal support throughout this process.

The advisory committee, composed of DAWN Canada board members, was a working group of women. I would like to thank each of them for their help in reviewing materials as they came pouring out of my computer, giving input, organizing women in their areas, and, most of all, for trusting me to do this work.

EXECUTIVE SUMMARY

Most Canadians are unaware of the changes brought about by block funding for health, education, welfare (social assistance), and social services, which have been consolidated under the Canada Health and Social Transfer (CHST). People most affected by these changes are those in need of health services and people on welfare and welfare disability benefits. Although these cuts affect all persons with disabilities who depend upon the social services, women with disabilities are generally in a worse position than men with disabilities.[1] The changes affect about 60 per cent of all women with disabilities on a very personal level.[2] The purpose of this research was to look at the impact of block funding on women with disabilities.

This research, based on discussions with women with disabilities in focus groups in every province and territory in Canada, shows that the changes under the CHST have had a profound negative impact on our lives as women with disabilities. Services that were already inadequate from cuts during the previous year have been cut even more since the CHST came into effect. The women in the focus groups spoke of ways the cuts are affecting women with disabilities. Cuts in home care and homemaking services are leaving women with their basic daily needs unmet. Women who depend on life support systems are being left alone for long periods of time, always with the risk of power failure. Women have fallen and have had to wait for several hours before help came. There is no help for child care and very young children are expected to take on the services that are being cut back. Women with disabilities fear losing their position as parents as the roles reverse and children become the caregivers. Women are also disturbed by the unfairness of this burden to their children. The women are finding that the availability and repair of required aids that help them cope with their disabilities have been severely cut back. Women are often required to raise part of the money for wheelchairs or other expensive assistive aids.

The women who participated in the focus groups felt that the lives of women with disabilities in institutions have become increasingly difficult. They have noticed that with cuts to staff there are obvious incidents of abuse and neglect. Women wait for long periods for care. This problem is most evident for women who have communication difficulties as a result of their disabilities. The women in the focus groups have also noticed that social programs inside the institutions and other programs that get women out into the community have been cut. Staff at community homes with 24-hour supervision are also being cut. In some cases, unqualified people have been hired as support staff. The women have also observed an increase in abuse by staff, as well as a lack of supervision.

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[1] Statistics Canada, *Health Activity Limitations Survey (HALS)* (Ottawa: Supply and Services Canada, 1991). Table: Adults with Disabilities, Aged 15-64, By Level of Individual Income [hereinafter *HALS*].

[2] *Ibid.*

Women in the focus groups have found that cuts to medical services have resulted in the closure of smaller hospitals, while large medical centres are understaffed resulting in a marked decrease in the quality of care for women with disabilities who need extra help and extra time from the staff. Women with disabilities in rural areas who depend on small local hospitals are now finding it almost impossible to travel the average one- to four-hour trip for hospital tests and treatment. Women in the focus groups felt that women with disabilities are being discharged from hospital and from day care too soon and without home care during their recovery.

Women in the focus groups commented that community support services for people with psychiatric disabilities have been cut back. As psychiatric services in hospitals disappear, the care for women with psychiatric disabilities is being transferred to the community. Women in psychiatric institutions are also being released with nowhere to go and no support system. These women often end up living on the street.

Women in the focus groups said that they live in fear of being cut off from welfare and welfare disability benefits, knowing full well that work is not a reasonable expectation for them at this time. The women suggested that hidden disabilities put women most at risk of losing their disability benefits. The women in the focus groups also commented that volunteering at local disability non-profit societies now puts them at risk of losing their benefits.

Training programs are not available for women on social assistance. The women in the focus groups felt that women with disabilities are less favoured than men for assistance under programs like the Vocational Rehabilitation for Persons with Disabilities. There is a general feeling among the women that there is nothing that a woman with disabilities can reach for without new programs targeted specifically at women with disabilities who have never been employed and who do not currently have the skills to compete for entry into the workplace.

Women in all the focus groups felt very discouraged and fearful about the present and about what lies ahead for them. They have no hope for the future and feel that their human rights are constantly being eroded by cuts to their services because there is no requirement for the provincial governments to have an appeal system for refusal of assistance by welfare and social service officers.

Introduction

In 1996, the Canada Health and Social Transfer (CHST) replaced the Canada Assistance Plan (CAP) and the Established Programs Financing (EPF). The CHST brought together the federal government transfer payments to the provinces and territories for health, education, and social services into one block of funding. This one pot of money is now deposited into the general revenue of each province and territory. Under the federal government, the CAP had shared equally with the provinces for money spent on social assistance. This is no longer the case with block funding. The CAP guaranteed the right for social assistance to everyone in need, which was determined by a needs test and gave the right to appeal if assistance was denied. The federal government withheld money from the provinces and territories if these rights were violated. With the loss of the CAP, these rights have disappeared.

To receive funding under the CHST, the provinces and territories have to honour only the principles of the *Canada Health Act* to provide health care to everyone and not to place restrictions on the length of time an individual has lived in a province or territory before qualifying for social assistance or welfare. However, the definition of need, which determines whether or not an individual or a family will receive social assistance, now rests with the provinces, as well as the right to appeal the denial of social assistance.

When the CHST came into effect, there was a loss of $4.3 billion in transfer payments to the provinces from the federal government for the years 1996–97 and 1997–98.[3] Those most affected by the transfer cuts are people with disabilities and all people who depend on welfare assistance — they will feel the cuts in their daily lives.

The impact of the changes that came about under the CHST will be far-reaching for women with disabilities. As women with disabilities, we are the poorest people in Canada with little hope of changing the situation. In the 1991 Health Activity Limitations Survey (HALS), Statistics Canada reported that 35 per cent of women with disabilities have annual incomes of less than $5,000 and over 60 per cent of women with disabilities survive on less than $10,000 a year.[4] *HALS* also revealed that women with disabilities were worse off than men with disabilities: 16 per cent of the men have incomes less than $5,000 annually, and 35 per cent of men with disabilities live on $35,000 or more a year, compared to only 10 per cent of women with disabilities.[5] A recent survey by DAWN Canada showed that 62 per cent of women with disabilities live below the poverty line whether or not they were employed.[6]

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[3] Madore, O. and Blanchette, *The CHST: Operation and Possible Repercussions on the Health Care Sector* (Ottawa: Library of Parliament, 1996) 7.

[4] *HALS*, above note 1.

[5] *Ibid.*

[6] Masuda, Shirley, *Don't Tell Me To Take A Hot Bath: Resource Manual for Crisis Workers* (Vancouver: DAWN Canada: DisAbled Women's Network Canada, 1995) 101–2.

HALS also showed that only 40.7 per cent of all women with disabilities were working; 7.8 per cent were on Unemployment Insurance and looking for work; and 51.5 per cent were not in the work force at all. Of those not in the work force, 52 per cent wanted to find work, and 21 per cent felt afraid to work because of the risk of losing their current income. Most of the women not in the work force may have been on disability pensions. Another 15 per cent of the women felt there were no jobs, and 16 per cent had difficulty getting training and education.[7] These statistics indicate that about 60 per cent of women with disabilities in Canada are either partially or totally dependent on the welfare system for basic daily needs, such as food and a home, as well as attendant care, homemaking services, and institutional care.

Women with disabilities also depend heavily on the health care system. For many of us, our disabilities are caused by medically defined diseases, some of which are degenerative and require frequent and ongoing medical care. Many of us require medical care for problems that result from our disabilities, such as chronic pain, frequent bladder infections resulting from the use of catheters, injuries from falls, and pressure sores from sitting in wheelchairs or lying in bed.

As women with disabilities, it is important for each of us to familiarize ourselves with the changes that have taken place with the CHST. It is important to find out how these changes have affected other women with disabilities across Canada and what they have been experiencing in their daily lives. This research project was designed to collect that information. The information can help us, as individuals and as national and provincial disabled women's organizations, to define our needs more clearly and bring our concerns to the attention of the federal and provincial governments.

The results of this research include testimonials from women with disabilities across Canada about how the cuts in federal funding and the changes brought about by the CHST have affected their daily lives. About 90 per cent of the women in the focus groups knew nothing or very little about the CHST. Several women commented that the focus group discussions helped them to understand more about the CHST and how it is funded, but the discussions did not make them feel any safer. The women in the focus groups found that there is very little information available on the CHST, especially for women who use alternate formats and women in the territories who have different language needs from the mainstream.

Although most of the women were unaware of the changes in the social and health care systems or the cuts in provincial funding by the federal government that came about with the CHST, they spoke about what women with disabilities have been experiencing in their communities over the last year. Since women in each of the focus groups had similar experiences, specific examples of women's experiences are representative of all provinces and territories.

These women spoke of their own experiences as well as the experiences of the women they know. The truth of their statements was not challenged in any way. Since the focus groups were small and the participants were women who are leaders in their communities, and who are active with

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[7] Canada, *Improving Social Security in Canada: Persons with Disabilities: A Supplementary Paper* (Ottawa: Supply and Services Canada, 1994) 2.

the social services system in their provinces, they are being further protected in this report by not identifying provinces. The results of this research are simply presenting the voices of women with disabilities as they answered the questions put to them in the focus groups. The researcher cannot dispute the truth nor substantiate the truth of any woman's experience.

Women with disabilities in all parts of Canada live in fear of what will happen to them in the present and they are fearful of the future. Women are feeling depressed and insecure. They are feeling less valued as individuals and more isolated from their communities. Women feel that their human rights are being eroded as their basic daily needs are being denied and access to medical care is becoming increasingly difficult.

There have been cuts to health, education, and social services over the past few years, with cuts in 1997 more severe than in previous years. The wealthier provinces — Ontario, Alberta, and British Columbia — had their federal funding cut under the CAP in 1990, and these provinces, in turn, cut services to women with disabilities.

The 1995 budget speech announced the creation of the CHST, with the reduction in funding taking effect April 1, 1996. This advance notice gave the provinces time to prepare for the cuts in funding by cutting back on their own social services. The cuts deepened when the CHST came into effect with a loss of $2.8 billion in federal transfer payments in the first year and another $1.8 billion in the next.

Without understanding the details of the changes at the federal and provincial levels, women with disabilities are, nevertheless, very aware of increasing cuts to their social services and health care. It is important to look at what women are experiencing now as a result of the cuts and where we can or will go from here.

Methodology

The researcher designed a questionnaire entitled “Impact of Block Funding on Women with Disabilities: Canada Health and Social Transfer.” The questionnaire was used in the focus groups in all the provinces and territories. Women with disabilities who are knowledgeable about the lives of women with disabilities in their communities were invited to come to the groups to focus discussion on the services that have been affected by the changes brought about by the CHST.

The researcher also developed a focus group format that set out guidelines to standardize the manner in which these groups were conducted. This format ensured that questions were asked the same way in all the focus groups. Focus group facilitators were instructed to present the questions in an unbiased manner, ensure that everyone understood the questions, and ensure that every woman had the opportunity to talk about her personal experiences and those of the women that she knew in the community.

Twelve focus groups were held between October 1996 and February 1997, one in each province and territory. The groups were conducted by women in each area who were chosen by DAWN

Canada board members or by provincial DAWN groups and DAWN Canada affiliate groups of women with disabilities. In Alberta, the focus group was conducted through the Alberta Committee of Citizens with Disabilities, and in the Northwest Territories, through the N.W.T. Council for Disabled Persons. The researcher assisted with focus groups in Nova Scotia, New Brunswick, and the Yukon Territory because there were no organized groups of women with disabilities in these areas. A total of 75 women with disabilities and 13 women who were non-disabled attended the groups. The focus groups were representative of women in all categories of disabilities used in previous research by DAWN Canada: mobility, mental health, visual, hearing, learning, labelled mentally handicapped, hidden disabilities, brain injury, and AIDS/HIV-positive.

Although some of the experiences the women shared were personal, the women offered comments based on their knowledge of their communities. Therefore, age and economic status were not relevant. All participants were chosen to be in the focus groups because of their work and their knowledge of the disabled women's community in their areas. The focus group discussions were recorded and the information was sent back to the researcher.

Financial Assistance/Disability Benefits

Financial assistance includes welfare and disability benefits and all social services. It covers basic needs for food, clothing, and lodging, as well as disability-related needs. Attendant care, homemaking services, and child care are included in the disability-related needs.

Cuts in financial assistance affect both women and men with disabilities. However, according to Statistics Canada, more women with disabilities are affected by poverty than disabled men (35 per cent of women have incomes of $5,000 or less a year compared to 16 per cent of men with disabilities);[8] therefore, more women with disabilities are dependent on the welfare system than disabled men.

Qualifying for Welfare Disability Benefits

Women in all the focus groups said that it is harder now to qualify for disability benefits. A woman in Nova Scotia spoke about the problems in her province: “It seems there is a fear that people may be pretending to be disabled and someone may actually get benefits that they don't deserve. When applying for benefits, women with mental health disabilities are always turned down unless they have strong advocacy support.” She said that one woman who had a mental health disability was cut off from benefits because she had not seen her doctor for too long a time. “You are required to make regular visits to your doctor, whether or not you need it, just to reaffirm that you are still disabled,” she added.

Women in the Ontario and Quebec focus groups commented on the changes to the definition and to the criteria for disability and how this is imposing hardship on the women in these provinces. They felt that fewer women with disabilities are able to qualify for the benefits now. There is a feeling among women in Ontario that changing the criteria to qualify for disability benefits was

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[8] *HALS*, above note 1.

done by people who have no knowledge of the reality of living with a disability. The women in the British Columbia focus group felt that this is a way of exploiting the people who are the most vulnerable and who cannot advocate for themselves.

Losing Benefits

In British Columbia, annual assessments are conducted by social workers to determine continued eligibility of welfare disability benefits — even for such disabilities as cerebral palsy (CP) that are not going to change. Women in the British Columbia focus group noted that women with disabilities are being disqualified by social workers at these evaluations. Women with multiple sclerosis and other hidden disabilities are finding it very hard to get disability benefits. Chronic fatigue, which is the disabling factor in many hidden disabilities, is not taken into consideration as an eligibility criterion.

These annual reviews also determine whether or not the person can go to work or return to work. One woman commented: “You have to paint the worst possible picture — a person cannot be positive or hopeful. More women than men have MS and chronic fatigue and are at high risk for losing them [disability benefits]. Women are more often accused [by social workers] of malingering and are seen as having psychosomatic disorders.” This woman also pointed out that sometimes an evaluation happens on a good day and there is no consideration given to the bad days that are disabling; therefore, the assessor does not see the cyclic nature of a disability.

A woman can maintain her disability status and earn \$100 to \$200 a month (depending on the province or territory) before deductions are made from her benefits. However, in all the focus groups, women spoke of the risk of losing their disability benefits if they work part-time or go to school part-time. If a woman can work part-time or go to school part-time, she is often seen as being capable of holding down a full-time job. However, women with disabilities are afraid to look for jobs for fear of losing government assistance. Having a disability creates extra expenses and they find it difficult to manage without government assistance. In the British Columbia focus group, a woman spoke of a case where a woman with a disability asked her financial aid worker about the availability of training programs. The worker told the woman she was being uncooperative and cut her off welfare. She had to appeal to get reinstated. Once a woman is classified as employable or is capable of attending school, she loses her disability benefits and it is very difficult for her to have them reinstated — if at all. Meanwhile, women in the Nova Scotia focus group said that women with disabilities have lost their benefits because they volunteered at non-profit organizations.

There is a general feeling among the women in the focus groups that social workers assume that if a woman can volunteer, she can work. There is no recognition that volunteer work does not have the same expectations and demands for working regular hours and regular days that are not possible for some women with disabilities. A woman may be able to work for several days and not be able to work again for weeks. Other women may be able to work only for very short periods during the day. This inconsistency would not be tolerated by an employer. Volunteers are very committed but they can only work when they are able to work. Volunteerism should be seen as something that benefits the community as well as allowing disabled women to connect with the community. This is a way to help relieve their isolation and improve their self-image. Volunteerism should be encouraged and not used as a threat for discontinuing disability benefits.

A woman in the Ontario focus group mentioned a friend who lost her disability benefits because her husband has an income of $21,000 a year. “If you split that between two people, you are at poverty level,” she said. This woman is a full-time student who does not get any assistance from the government and is finding it very difficult to manage.

Women in the British Columbia focus group felt there is also a basic assumption by the social workers and financial aid workers that a person on assistance is dishonest and a woman has to prove that she is not cheating when she applies for assistance. The women also felt there is a false assumption that the guilty will not try again if they are turned down but the innocent will keep trying. But, they have found that women who are disabled quit sooner because it is so emotionally and physically draining for them that they cannot continue to fight for it. British Columbia has a “hot line” to receive reports of people cheating on welfare. There has been a steady increase in the number of reports, and the women in the focus group felt there was a general decline in compassion for all people who are on social assistance.

The government of British Columbia recently sent a letter to all persons receiving continuing personal care stating that they must sign an enclosed form authorizing the provincial government to access their Revenue Canada records; otherwise, their services will be terminated at the end of this fiscal year. Some people signed the paper thinking they were the only ones who received it. However, people with disabilities in British Columbia are beginning to organize around this issue, so it is not likely to end there.

Inadequacy of Benefits

Women in the Prince Edward Island, Newfoundland and Saskatchewan focus groups pointed out that disability benefits are already grossly inadequate. Women in Nova Scotia support this statement with their concern about the unsafe living conditions for women with disabilities in their area. Subsidized housing is usually located in the worst areas of a city. Women can afford to live only in the cheapest areas of the city, which are also the most unsafe areas. One woman commented: “There are no rights to safety or luxury.” A woman in the Nova Scotia group pointed out that one subsidized housing complex in Halifax has prostitutes working beneath their windows, and they have rooms in the basement.

Wheelchair accessible accommodations are more expensive than those without accessibility. Women with environmental allergies also have to pay more for their special living arrangements. Women in all provinces and territories felt that the welfare and social services system must change to consider the specific needs of women with disabilities that will enable them to experience a standard of living that is equitable and adequate. This would enable women with disabilities to live in safe places and in a reasonable level of comfort.

Women in the focus groups felt that there is a need for the federal government to reinstate a commitment to create new and safe social housing units for women with disabilities on welfare and welfare disability benefits. In 1993, the federal government stopped spending on new social housing units.[9] Although the federal government contributes financially to maintaining the existing units, the responsibility for doing so is provincial.[10] The provinces now are turning the responsibility for social housing over to the municipalities.[11] Consequently, there is little money for build new housing. In most provinces, social housing is already run by municipal and non-profit housing corporations.[12] However, women in the focus groups found that accessible units in non-profit housing corporations are often being occupied by non-disabled people because they are subsidizing the people on welfare assistance.

Women in the Northwest Territories focus group have found that housing is very expensive and very few are wheelchair accessible. There is a ceiling of $450 on rent for single people, who are expected to share accommodation. This “cluster living” or sharing may be helpful for some women with disabilities but it can also create stress, especially if a woman is sharing with people who are rowdy and abusive. If a woman can prove that she needs different housing because of her disability, she may be exempted.

Women with disabilities in Yellowknife said cuts affect women on a very personal level. “Social Services is the last stop,” one woman said. “These latest cuts take away whatever pride we had left.” She said this in response to the removal of a $20 monthly allowance for household items and $5 a month for personal items, such as toothpaste and women's hygiene products.

Disability Specific Costs

There have been policy changes on assistive aids in all provinces. The women affected feel the cuts to services frame the justification for discrimination against people with disabilities. One woman's claim for an air conditioner as a medical expense was denied until it was appealed. There are severe time-limited restrictions on glasses and hearing aids. In spite of changing needs associated with age, a woman may have to go ten years before she is allowed a new hearing aid and as long as five years to get a pair of new glasses. Some provinces don't allow hearing aids at all, while other provinces provide aids but do not supply batteries for them. These same kinds of restrictions are applied to wheelchairs, special shoes, and all other assistive aids. The situation has become worse in the last year.

In one instance, a woman needed a specialized electric wheelchair, which includes features to assist in breathing and circulation. The chair also has safety features to keep the user from falling and is constructed for maximum comfort to prevent pressure sores. The cost of the chair was

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[9] Canadian Council on Disability, *Funding Secured: Formula and Allocation Altered by Budget. Social Policy Update*, (March 1996) vol. II, no. 13, at 2.

[10] *Ibid.*

[11] *Ibid.*

[12] *Ibid.*

$24,000, and the woman's welfare disability benefits only covered half the price. She had to raise the rest of the money herself and now feels that she was forced into begging to get her needs met.

Another woman could not get a required assistive aid from social services. Money to buy the aid was given to her as a gift. When the social worker was informed, the gift was considered income and the full amount was deducted from the woman's disability benefits. The woman explained that when social workers cannot provide the required aids, they fail to realize that these “gifts” compensate for needs not met by social services. Women, however, generally feel that financial aid workers have a lot of discretion in getting money for assistive devices, and this discretion depends upon the worker's personal bias towards an individual woman.

Assistive aids are also often in need of repair. Women in the focus groups reported that the speed with which repairs are done and what arrangements for temporary devices are made depend to a large degree upon individual workers. When a woman's electric wheelchair is in disrepair or is being repaired, she often is given a manual chair to use. The woman is left in a situation where she is unable to make full use of the substitute wheelchair, which prevents her from her normal activity as well as creating risks of injury from falling or being stuck and unable to move until help arrives. Just from normal daily use, wheelchairs, glasses, hearing aids, false teeth, crutches, and all other assistive aids require occasional repair. But, since only the cheapest aids are covered and restrictions are placed on the frequency of replacement, repeated repairs push these assistive aids beyond reasonable use or safety.

Most provinces provide a dietary supplement allowance, but money allocations are made according to the disease as specified by social service regulations and not according to the symptoms. For example, diabetic, protein, and gluten categories are mutually exclusive, and a woman can only fit into one, even if she needs two or more dietary restrictions or supplements. No consideration is given to foods that produce better health.

Sharing Accommodation

It is not uncommon today to see women and men sharing accommodation based on living compatibility without any sexual relationship. However, this kind of arrangement is always questionable in the eyes of the government. If a woman with a disability is receiving any kind of government assistance while sharing accommodation with a male friend, her life is constantly under scrutiny by her caregivers and social workers.

This scrutiny is very threatening to a woman with a disability who has a comfortable and accessible home with a compatible housemate. By sharing expenses, she is able to live in an environment that gives her a sense of safety as well as social contact. She may also have help with child care that is not being provided by social services. Women commented that they are feeling increasingly threatened because it seems that social workers are scrutinizing more as they try to save money. Women are living under the constant threat of having their social assistance cut back if they share living accommodation with a compatible male housemate.

Women in the Saskatchewan focus group pointed out that this is also true for women sharing accommodations with a female housemate. Although there is no recognition of same-sex relationships in the federal taxation system to allow for income tax deductions, the welfare system does recognize same-sex relationships. If the social worker suspects that a woman is living with her same-sex partner, she may lose her disability benefits.

Hardship Assistance

Hardship assistance, or interim assistance, has been reduced in all provinces and territories. In some provinces, it does not exist at all. In provinces where hardship assistance is available, the women in the group said that it is only given in extreme circumstances. A woman in the New Brunswick focus group said that in her province, there used to be extra money for heat during the winter months but it has been discontinued. A woman in the Saskatchewan focus group said that there once was a fund to help people in emergency situations, such as the need for winter clothing or a new water heater. Now, social services pays the cost, but takes it off welfare payments at $50 a month.

A woman with disabilities in the Yukon Territory, who lives in her own house, had her heater burn out in December 1996. She is on Employment Insurance (EI) with just enough to get by at $105 a week. She has no money to fix her heater and she has not been able to get help because she is on EI. She has to find places to sleep at night throughout the winter.

Defining Needs

Under the CHST transfers, assistance can be denied based on the opinion of the local director of the welfare system. Under the CAP, there was a definition of need. With the CHST, the definition of need is at the discretion of the social worker or district manager. A woman in Saskatchewan commented: “If a woman goes in there saying please help me, I am living in my car and my children are starving, they can say `no'.” British Columbia has reserved the right to appeal but has made it more difficult to do so. The women in Quebec have defined the problem that all women with disabilities in Canada are now facing: “Before block funding there was an appeal system as well as a special protected envelope ensuring that the needs were covered,” one woman said. “Now we have consolidated funds and nothing is protected.”

Shame of Social Assistance

A woman in the Saskatchewan focus group pointed out the impact on a woman's self-image of applying for social assistance: “There is a great deal of shame in going to get assistance from social services. The financial workers try to humiliate the clients. There is a great deal of mistrust of the `social safety net' and there is no sense of security for women with disabilities.”

Summary

The social safety net that women with disabilities have relied on for many years has been removed. Under the CAP, need was defined by a needs test to determine eligibility for assistance, and there was an appeal process if a person in need was denied assistance. Both have been lost under the CHST. The cuts in federal transfer payments to the provinces are felt in all areas of financial assistance. Women in every province are finding it more difficult to qualify for disability benefits and feel that it is easier to lose their benefits. In most provinces, women are required to re-qualify annually for their disability benefits. Women who have hidden disabilities are disqualified because the disabling factors of the disability, such as chronic fatigue, are not taken into consideration.

Although most provinces allow women to earn $100 to $200 a month in addition to their disability benefits, anything over that amount is deducted from their disability cheques. Thus, women hesitate to explore the possibility of any kind of work to supplement their income or give them more security. Women also lose disability benefits if they volunteer at non-profit organizations. Volunteer work is seen as proof that a woman is able to hold down a paying job. No recognition is given to the fact that volunteer work does not have the same expectations or demands for regular hours of paid work.

Welfare and disability benefits are grossly inadequate. Women are unable to live in safe places because they must live in the cheapest possible places in the cities. Women who share accommodation in order to live in better places and have the added security of a housemate risk losing benefits because these arrangements are seen as intimate relationships.

Cuts to assistive aids for women with disabilities are also problematic. There are more restrictions on what is being covered, and there are longer periods of time for replacement of the assistive aids. Women are often required to raise part of the money for their wheelchairs or other expensive aids. In spite of changing needs, some assistive aids, such as wheelchairs and hearing aids, are only replaced every ten years.

Because only the cheapest aids are covered, there are many problems with breakage and wear. Repair of aids is often difficult to manage, and inappropriate interim replacements frequently leave women unable to function at the same level of independence as they did with their own assistive aids, which puts women at risk for accident-related injuries. This is especially true for women who use electric wheelchairs and are given manual chairs while the electric chair is being repaired.

Hardship grants have almost disappeared now. In some provinces, social services will make money available in case of dire need and then take it off the monthly cheque.

The right to appeal decisions made by social service officers is completely within the jurisdiction of the provinces. Some provinces, such as New Brunswick, have no appeal system. British Columbia has reserved the right to appeal but has made it more difficult to do so.

Women in Saskatchewan spoke of the shame of having to apply for social assistance and how they feel that financial workers deliberately tried to humiliate them.

Recommendations

Recommendations to the Federal Government:

Because women with disabilities feel that their human rights are being eroded by continuing cuts to life-sustaining care and services, the federal government must uphold the rights of women with disabilities as stated in Section 15 of the *Canadian Charter of Rights and Freedoms* by ensuring that:

- The federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

- The federal government increase contributions for social housing to assist the provinces and municipalities in providing safe and accessible housing for women with all types of disabilities and all poor women and their children.

- The federal government reinstate contributions to the provinces to create new, safe, and accessible social housing units.

- The federal government, in consideration of the extraordinary cost of living with a disability, not limit refundable tax credits for disability-related expenses to persons who are employed as stated in the 1997 budget; and that refundable tax credits be given to all people with disabilities for expenses related to their disabilities that are not covered under welfare disability benefits or other disability benefit plans or health insurance plans.

Recommendations to the Provincial Governments:

- That eligibility criteria for disability benefits be clearly and fairly defined and that this be done in consultation with members of the disability community in each province to ensure that the weight of hidden disabling factors of disabilities are recognized.

- That eligibility requirements take into account the needs of women with disabilities and the disabling factors of the disability and not be based solely on a medical diagnosis.

- That each province clarify in simple and plain language what persons on welfare and disability benefits are entitled to receive, and that this information be made available to every person who is applying for, or is already receiving, welfare or welfare disability benefits.

- That the right to appeal decisions regarding financial assistance be reinstated in every province and territory, and that every person applying for benefits be given information about their right to appeal with clear instructions on how to proceed with an appeal; and that every person already receiving welfare benefits receive this same information.

- That every person whose application for financial assistance is rejected or disqualified be given written, clear, plain-language reasons so that decisions can be appealed with clarity and objectivity.

- That funding be provided to disability organizations to assist people with disabilities in applying for or appealing decisions relating to disability benefits.

- That every person, when applying for disability benefits, or who has been refused disability benefits, be advised of organizations that can assist with the appeal process.

- That, if benefits are terminated for any reason, they be reinstated during the time of the appeal process, and if the appeal is rejected that the individual not be required to repay benefits received during the period of the appeal .

- That all disability-related costs be handled separately from everyday costs.

- That women with disabilities who share safe and accessible living accommodation not be harassed and threatened with loss of benefits.

- That provincial governments take responsibility for providing more subsidized housing that is accessible and safe.

Home Care

Home care includes attendant care and homemaking services. There have been major cuts in both these areas. A woman in Halifax discussed an incident in her city: “The system is really taking advantage of older people,” she said. “One woman had to be helped and even fed by her neighbours. She had to appear on the news before she got assistance from the government. Many times now community volunteers have to help people with disabilities at home.”

Men with disabilities are also consumers of home-care services. As mentioned before, more women with disabilities are dependent on welfare services than men. There are special issues for women as well. Women are traditionally the homemakers, and women with disabilities must be supported in that role of wife and mother. A woman risks losing her place in the family with role reversals as children take on some of her duties and her care. There are also issues of safety for the woman and her children as they struggle to cook and clean to fill the gaps left by cuts to services.

Unmet Needs

Cuts in home-care hours over the past year mean that women with disabilities are not having their basic daily needs met. This creates stress for the women as well as for the workers. Women in the Ontario focus group testified to the fact that as the quality of service goes down, women with disabilities are experiencing an increase in the incidence of abuse and neglect from their caregivers and from their families. Women from New Brunswick commented that women with disabilities are not asking for the help they need because they are afraid of being sent to a nursing home. The women in the New Brunswick focus group also noted that if a woman requires more than six hours of care a day, she is automatically placed in a nursing home. The women felt that this is not reasonable since it is cheaper to provide services at home than to send women to institutions where they will be separated from their families.

Mothers with Disabilities

Child care and child nurturing generally are not a part of home-care services and are provided only in extreme circumstances. In Ontario, this is a new service; however, there is no standard policy in place to regulate it. The service is also available in Newfoundland but is closely monitored. The women in the Ontario focus group pointed out that a woman with disabilities may not need care for herself, but when a child arrives, it is critical for her and the family to get extra help.

Cuts in home care have placed extraordinary stress on women who have children. A young woman with a degenerative disease spoke about her fear of being put in a nursing home, which is a long way from her home, and that her children will be put in foster care if she asks for more help. She also worries about children having to take on care for her and other adult responsibilities at home. “The attendants and the social workers are always asking why the family members can't do more. Children are expected to take on a lot of care of their mothers. This isn't right as children are robbed of their childhood and given a great deal of responsibility.” This woman also spoke of the importance of maintaining her position as the mother in the family, which becomes more difficult when roles are reversed and the child has to be both caregiver and homemaker.

Women in the focus groups felt that women with disabilities who have children must have as much help as they need to keep their families together. This includes help with the children, as well as attendant care and homemaking. Priorities must be given to keeping children with their mothers and keeping mothers out of institutions to be with their children. Recognition must be given to all women with disabilities in their special role of “mother,” which does not disappear because of a disability.

Safety Issues

Women in the British Columbia focus group pointed out the hazards to women and their children by cutting home services. “Many hours of homemaking services have been lost and in some cases total loss of services,” said one woman. “If you are not designated to have personal care that substantially reduces your homemaking services. This creates a high-risk situation for accident and disease when the woman tries to cook and clean. The woman's health is affected and so is that of her family. Women worry that the burden for homemaking needs and even personal care will fall on friends and relatives.” There is also the risk of a woman losing her home if she lives in a cooperative housing complex and cannot meet her obligations to properly care for her apartment. This means that she will have to leave safe and affordable housing.

Everywhere in Canada, cuts have meant that women who require attendant care experience long periods of time being alone. Women with quadriplegia, who have tracheotomies and respirators, live with the danger of equipment failure that may be one or all of the following: respirator, phone, environmental controls, or electric wheelchair malfunctions. Women who have fallen down or fallen out of their chairs have had to wait many hours before being rescued.

Strict Rules

Many home-care workers and attendants have very strict rules about what they are allowed to do. They cannot make a trip to the store or accompany a woman outside her home even in an emergency. In some provinces, such as New Brunswick, where women are given a low-care allowance to hire their own workers, these restrictions are less severe.

Self-Management

Quality of personal care and homemaking depends to a great extent on the individual worker. In some provinces, there are frequent changes in caregivers and homemakers. This change is very stressful for the women and much of the worker's time is spent receiving instructions. Many cities, like Winnipeg, have set up different areas, and contract services out to companies in open bidding. There will be no choice but to award the contract for that area to the company with the lowest bid. Worker's wages are low and there is a high turnover, which results in poor quality of care. If a woman is able to receive the money directly to manage her own affairs, she is able to hire and train her own workers. Women in the New Brunswick focus group, who use self-management, felt that it gives consistency and better quality of service, which they cannot get from poorly managed agencies.

However, funding for self-management care is also being reduced. In Alberta, women who received $3,000 a month are now receiving only $2,000 a month, which is expected to be further reduced. “There is an assumption that the community will pick up what home care cannot provide,” said one woman. “We do not think it can, as it is not happening at the present. Real fears exist about the loss of programs and the erosion of the quality of life. Home care and other services are being cut, making it harder and harder to live independently with dignity.”

First Nations Women with Disabilities

In the Yukon Territory, home-care funding for First Nations people comes from the Department of Indian and Northern Affairs. The home-care hourly rate is $7 compared to $29 paid by social services. This means fewer hours and poor-quality work compared to the non-Aboriginal community.

Families as Caregivers

In some cases, particularly in remote areas, attendant care has to be provided by a family member. In this situation, the family member is usually not paid. This means that the family has 24-hour responsibility for the care and well-being of the woman who is disabled. There is no respite for the woman or her family, resulting in a serious situation of fatigue and stress, which can set the stage for abuse and neglect. The situation of family caregivers must be re-assessed. Family caregivers must be recognized and paid for their work, and times of respite must be made available according to the needs of the whole family.

Summary

In every province and territory, home care, including homemaking services, has been cut back. As the quality of service declines, women are experiencing more abuse and neglect by their caregivers and families. Women are not having their basic daily needs met and are afraid to ask for more hours. Many women are being left alone for long periods with the risk of failing life-sustaining equipment or injuries from falls.

In the past, self-management care, where the woman receives money directly to hire her own workers, has worked well. However, self-management is also being cut back with the expectation that the community and the family will fill in the gaps.

Young children are also expected to fill in for lost services. Women feel that is not only abusive and unfair to the children, but it removes their position as the mother of the family. Women with children must have more support to keep their families together. There is no child care assistance in most areas of Canada. In provinces where there is child care assistance, it is very difficult to access and even then the program is inconsistent.

Young women with degenerative diseases are particularly concerned about being placed in institutions far from home and having their children put in foster care. The purpose of attendant care and homemaking services is to keep women out of institutions so they can be with their families and can also be part of the community. Cuts to home-care services are putting the family lives of women with disabilities very much at risk.

There are times when family members have to provide attendant care. In these cases, family members should be paid for the service, and respite must be made available for the whole family.

Recommendations

Recommendations to the Federal Government:

- That the federal government ensure that the disability benefits in relation to home care, including attendant care and homemaking services for First Nations people, be brought in line with provincial benefits to ensure equal access and quality for home-care services.
- That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

Recommendations to Provincial Governments:

- That attendant care and homemaking services be based on actual need rather than on predetermined criteria or costs.
- That attendant care and homemaking services be based on need rather than on medical diagnosis.
- That an independent appeal process be put in place for women who are not receiving adequate hours of personal care or homemaking services.
- That more flexibility in home care be made available for women who want self-management options to receive money directly to hire and train their own attendants and homeworkers.
- That child care assistance be made available to women with disabilities who have children.
- That no child be expected to take on the responsibility for attendant care or homemaking services to justify cuts in social services, because this role reversal robs the mother of her position in the family and robs the child of his or her right to their childhood.

- That funding for the home-care needs of women with disabilities who have children be increased to maintain quality child care, allowing the family to stay together and allowing the disabled mother to maintain her parental position in her family and in her community.

- That, in cases where family members provide care to women with disabilities, the family members be paid as caregivers.

- That, in cases where family members are giving total care to women with disabilities, respite be made available for the woman who is disabled and for the family.

Institutional Care

Women in all the focus groups felt that the quality of personal care in long-term care institutions has decreased radically. They attributed this deterioration directly to cutbacks in funding from the federal government. The reduction in employees has compromised the ability of institutions to provide adequate care.

Abuse/Neglect

Women in the focus groups spoke of the ways women with disabilities in institutions are feeling the cuts in funding. The ratio of staff to residents has decreased over the last year. Given the higher workload, there is a serious problem of neglect and a high risk of physical and emotional abuse by staff. Women have to wait for personal attention to bodily functions and may be left for long periods in soiled beds or chairs. Women who need to be fed or need assistance with feeding are at risk of not receiving enough to eat or of completely missing meals while food trays are left at their bedside. There is also some question about the nutritional quality of the food that is being given to the residents in some institutions. There is the added risk of abuse of more vulnerable residents by stronger ones in an environment with less staff supervision.

A woman who lives in an institution in one of the provinces spoke about her experiences. Her life is typical of many women in long-term care institutions. She gave an example of abuse that she experienced in this facility. One night the woman, who has a disability affecting her speech, was sitting in the dining room area and the staff overlooked her and forgot to bring her supper to her. By the time they noticed she had nothing to eat, she was very upset and refused their offer of a meal. The usual snack was not offered to her at bedtime. She feels that she was overlooked by the staff at mealtime and then punished by withholding her bedtime snack because she was angry with them.

The interviewer who visited this woman in the long-term care facility noticed her lunch, which consisted of only an onion sandwich on white bread. The woman ate candy almost constantly while she was there. The interviewer also learned that the woman receives no assistance with personal hygiene, and, as a result, appears unkempt. All the responsibility for accessing physical, emotional, and rehabilitation resources falls on this woman. If she is unable to access the medical and community services, the institution does not assist her in making these links. There are some activities in the community but she does not participate in them. She feels very isolated there. This is an example of a woman who has been institutionalized but does not want to be there. “I want to get out of here. I sleep too much here,” she said.

Social Programs

The cuts to social programs and community involvement is further demonstrated by a woman in Ontario who worked as a volunteer in a nursing home. “There used to be a full-time woman who ran an arts and crafts program for seniors. That program got cut completely. The seniors' home owned two vans to provide outings three to four times per week to the seniors. These outings do not happen anymore. Instead seniors are left sitting inside all day in their wheelchairs with no outdoor activities or physical exercise.”

Isolation

Women in the New Brunswick focus group noted that as cuts to home care continue, there are fewer choices, and women live in fear of being forced into institutions. Consequently, they are not asking for the help they need. Women in the smaller provinces and in rural areas are moved long distances from their homes and families. Many of these women are unable to communicate with their families by phone or by mail. Young women are placed in nursing homes with seniors where there is little social interaction and no common interests. These women miss their children, their life partners, their extended families, and friends. It is further isolating for minority women who speak a different language and feel lost and alone outside their culture. The women in the focus group felt that when women go into an institution, it is as if they are not expected to be real people anymore despite the fact that this is now their home.

A woman in the Northwest Territories focus group commented that staff in institutions have no training and little equipment to care for people with disabilities. Commitment to an institution is based on a medical model of caring for the sick, and there is no effort to help women with disabilities become more independent. In the past, people who required institutional care were sent to facilities in the South. There is a plan now to bring the people with mental health disabilities in institutions and residential facilities back home to the North. The women in the focus group felt that little has changed since these people left and there are few supports waiting for them.

New Brunswick Government Is Challenged

Women in the New Brunswick focus group spoke about the spaces in long-term care institutions that are not being filled. A recent attempt to relocate mentally disabled persons from their communities to these institutions so outraged the parents and the community that the government had to back down. However, beginning April 1, 1997, the new plan for relocation will affect anyone just entering the system. This means that many people with disabilities who require what is considered to be a high level of care or supervision will now be relocated to institutions that will separate them from their families and their communities.

Women with Psychiatric Disabilities

While some women live in fear of being put into institutions, women with psychiatric disabilities are being discharged from institutions with nowhere to go. Women in the Manitoba focus group told of people released under the “Welcome Home Program” who found no support systems in place and ended up back in institutions. This example reflects what is happening in every province. Community support groups are also experiencing cuts to funding and some have been closed. The ones that still exist are being overwhelmed with people who have exhausted their options. Many homeless and elderly women are now in acute care facilities occupying needed spaces because there is no place for them to go.

Community Care Residences

Cuts have also affected community care residences where there is 24-hour supervision. Women in the Nova Scotia focus group commented on the cuts to staff and support workers. “There is an abusive attitude in these homes,” said one woman. “Workers don't listen to what you want and make you question yourself. There are no choices in things like when to take a bath or a shower. You are told when to do everything. There are also more conflicts among the residents with less supervision. The residents are told to resolve it or get out.”

In Nova Scotia, there are also community homes for persons with mental and physical disabilities where the staff are untrained and there is little supervision. Neighbours often complain about the noise. A murder was committed by a resident in one of the homes when the staff person was out buying groceries and the residents were left unattended. People and communities are now resistant to having these homes in their areas because they are worried about their safety.

Summary

Women in the focus groups have noticed that the quality of personal care in long-term care institutions has decreased as a result of recent cuts in funding. Abuse and neglect are becoming blatant. Special programs inside the institutions as well as community outings have been reduced and completely cut in some areas. Women with disabilities, who require what is considered to be high levels of personal care, are at risk of being moved long distances to institutions that have available spaces. These women would be separated from their families and their communities. Young women with disabilities are placed in seniors' homes where they have no social contact and share no interests with the other residents. Young women with degenerative disabilities live in fear of being moved into these institutions and are not asking for the services they need at home.

Women with psychiatric disabilities are being discharged from hospitals with no community support systems in place and no home to go to. These women often end up living on the streets or in acute care hospitals.

Women in community homes are also experiencing the effects of cuts to funding. In some homes, staff are being replaced with untrained and unqualified people. There is poor supervision, and staff are often abusive. Communities are now resisting these kinds of homes in their neighbourhoods.

Recommendations

Recommendations to the Federal Government:

- That national standards for institutional care be developed in consultation with the disability community, and that at least 50 per cent of the consulting committee be women with disabilities; and that all institutions be required to provide a level of care that meets the national standards and the needs of all the residents.

- That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

Recommendations to the Provincial Governments:

- That women with disabilities be given as much support as they need to stay out of institutions and remain at home with their families, since this is not only better for the woman and for her family, but is cheaper for the province to provide home care than to place women in institutions.

- That entering a long-term care facility be the free and informed choice of the woman and not the decision of the government or her family.

- That, if a woman decides to go to a long-term care institution, she be given the choice of being near her home and family.

- That programs for social activities in long-term care institutions and in the community be considered a necessary part of the overall care.

- That programs be funded in long-term care institutions to assist residents to participate in social activities both inside and outside the institution.

- That special attention be given to the social and family needs of all women in institutions by assisting women to stay in contact with families and friends in their home communities.

- That special attention be given to concerns for minority women to ensure that these women have contact with their cultural communities.

- That funding be restored to long-term care institutions for adequate staff to provide quality care for all residents.

- That strict standards of personal care, cleanliness, and nutrition be enforced in all long-term care institutions, including community homes.

- That minimum standards be set and enforced for various levels of qualifications and training for all staff positions in long-term care facilities and community homes.

- That all cases of abuse or neglect be thoroughly investigated by an outside independent person and that criminal charges be laid where appropriate.

- That any woman who has experienced abuse or neglect receive counselling from an independent counsellor of her choice from outside the institution.

- That provincial advisory committees be established to monitor the care in all long-term care facilities and community homes, and that the advisory committees consist of at least 51 per cent people with disabilities, of which at least 51 per cent are women with disabilities; and that these advisory committees be given the power to hold institutions accountable for quality of care.

Health Care

Cuts in medical services have resulted in long waits to get into hospitals for medical and surgical treatment. For women with disabilities there are added difficulties in getting health care. Medical services generally are inaccessible to women with disabilities.[13] Doctors' offices are often in inaccessible buildings, and medical offices and hospitals do not have the proper examination tables that are accessible to women with disabilities.[14] Consequently, women with disabilities do not get the routine examinations and treatments for women-specific problems.[15] Uterine and cervical cancer may go undetected without routine PAP smears.[16] Furthermore, women with disabilities are not receiving information on PAP tests, sexually transmitted diseases, birth control, or information and help for sexual assault or other forms of violence.[17]

Although hospitals are thought to be wheelchair accessible, this is not always true. A hospital in Prince Edward Island is typical of many hospitals in Canada. There are very few accessible washrooms in the wards. A woman explained how this often creates a difficult situation for women who use wheelchairs: “If you are in a ward or semi-private room, you have to chase all

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[13] DisAbled Women's Network Toronto, *Health and Disabled Women: A Symposium For Change* (Toronto: DAWN Toronto, 1992) 12–14.
[14] *Ibid.*
[15] *Ibid.*
[16] *Ibid.*
[17] *Ibid.*

visitors out so you can go to the washroom, because it is almost impossible to get a wheelchair in the bathroom and close the door. This really affects your dignity."

Deteriorating Quality of Care

It is logical that cuts in staff adversely affect the quality of health care in hospitals. With less staff, large hospitals are overloaded as they absorb patients from hospitals that have been closed, as the provinces try to save money to compensate for the cuts in federal funding. The resulting deterioration in care impacts on women with disabilities differently than on non-disabled women. Women with disabilities often require additional care — not for their health problems but because of their disabilities. In Ontario, a woman with cerebral palsy and related medical problems had to be admitted to hospital for a few days. She signed herself out of the hospital every evening in order to go home and receive personal care from her attendant — care that hospital staff would not give her.

Class Distinction

Women in the British Columbia focus group felt that there is a class distinction in medical care in hospitals and for medical services outside the hospital. Women who are the most vulnerable are the worst off, especially women with communication difficulties. The women spoke of the lack of interpretative services for women who are deaf/blind or for women who are deaf. In some hospitals, women have their hearing aids taken away and locked in the safe. Women who have their ability to communicate taken away from them have no control over decisions about their health or their lives. These kinds of discrepancies in patient care are intensified as hospital staff become overworked.

Patients Released Too Soon

In all focus groups, women felt that patients are being released from hospitals much earlier than they should be. This is true for day surgery as well as hospital admissions. This situation is very problematic for women who have disabilities and for seniors who have no one to care for them. Women in the Nova Scotia focus group commented that it is very difficult, and often impossible, to get 24-hour assistance even for short periods. Some women may have neighbours and friends to help them, but many women with disabilities are very isolated and do not feel comfortable asking for help. These women feel that the hospitals must take more responsibility when discharging patients to ensure that they have a place to go to and have care while they recuperate. Women in the Nova Scotia focus group also commented that they knew of patients with disabilities who have gone home to be cared for by their partners who are also disabled.

Limited Services in Small Medical Centres

Small medical centres cannot provide a broad range of specialized services. Travelling to larger cities or out of province for medical consultation is difficult and worrisome for women with disabilities. The experience of a woman in Prince Edward Island is similar to that of other women in small centres. “There is no specialist on PEI who is familiar with my disability. Every two or three years I have to go to Toronto to see a specialist, the only one in North America familiar with my disease. So far the provincial government has been covering the cost of these visits, but I am worried that I will lose this financial assistance, and then what will I do? The last time I went, the whole trip was scheduled for two days. This was totally exhausting and it took me months to recover. A week should be allowed for this kind of trip; otherwise, it is too difficult and stressful.”

Hospital Closures

The closure of small hospitals and community health centres has had a dramatic effect on women with disabilities. As small hospitals close, transportation for all patients to the large medical centres is difficult. This seems to be especially true for the smaller provinces. Women in the New Brunswick and Nova Scotia focus groups pointed out that for women with disabilities, it is sometimes impossible to get accessible transportation for the long trips to receive medical attention. If a woman does manage to get to the hospital for scheduled tests or treatments, there may be long waits before or after appointments. Women with disabilities who are not able to cope with these problems will decide to do without medical care.

In the Manitoba focus group, a woman pointed out that First Nations people come directly under federal funding. In many rural areas, the roads are so poor that it is impossible to travel on them in wheelchairs, and it is difficult for anyone who uses a wheelchair to get out of the community for any kind of health services.

Closure of Specialized Departments

Departments for specialized care are being closed in some of the large medical centres. For example, women in the Nova Scotia focus group spoke about the closing of the psychiatric ward at a Halifax hospital. As a result, there is no infirmary to provide short-term crisis care for psychiatric patients. Patients who are taken to the hospital after a suicide attempt are kept only overnight. Day-care psychiatric patients are discharged as soon as possible with no alternatives. Psychiatric care and counselling are being shifted to the community. As more and more people are released from hospitals, there is a greater demand on community services, which have also been cut back over the last two years. Women with disabilities are particularly at risk for abuse and sexual assault because they spend much of their time on the streets and, in many cases, are homeless.

Medications

Women on disability benefits are covered for prescription medications. Where generic drugs are available, only these drugs are covered. If a woman has a reaction to the drug, she is able to get the more expensive brand after a 48-hour trial period. Women have found the generic drugs to be slower and to have more side effects than the more expensive brands, so they prefer brand-name drugs.

A large number of drugs, such as ulcer medication, were previously issued only by prescription and are now over-the-counter drugs. This change creates problems for women who still take these medications but now have to pay for them. There are also problems for women with quadriplegia who are at high risk for osteoporosis. The preventative treatment requires calcium, magnesium, and vitamin D, which are not covered under disability benefits. Additionally, prescription drugs for the latest and best treatment for osteoporosis are not covered under social assistance. In Prince Edward Island, the provincial pharmacy has a “special request drugs” policy. Drugs on this list will not be covered without a special meeting for social services to approve the cost. The meetings are supposed to be weekly but one disabled woman had to wait six weeks for approval for special eye drops and then had to go to another pharmacy to get the prescription filled.

Women in the Ontario focus group commented on the $2 fee each time they get a prescription filled. Women on social assistance cannot afford this cost, especially if prescriptions need to be filled frequently, which is especially troublesome for women on long-term medications. Women with psychiatric disabilities are going off their medications with the risk of recurrence of their symptoms.

Women who have AIDS fall into a special category because of the number of drugs and the expense of the drugs that they have to take daily. Part of the AIDS and HIV-positive treatment is a combination of several drugs known as the “cocktail.” Some of these combinations run as much as $1,700 to $2,000 a month. These cocktails have already shown promising results and are the best hope for women with AIDS or who are HIV-positive for relieving symptoms and prolonging their lives. However, these drugs are not covered in all the provinces for women who are on welfare disability benefits. Therefore, all women with AIDS or who are HIV-positive do not have access to the most effective treatments available. Women who are HIV-positive or who have AIDS feel that this is very much a judgment call by the individual provinces and one that severely discriminates against all persons who have AIDS or who are HIV-positive.

Physiotherapy

In most provinces, if not all, people on welfare and welfare disability benefits can access physiotherapy only in hospitals and only if it is an acute or injury-related problem. A woman in the British Columbia focus group explained that women with problems related to a disability, such as multiple sclerosis, are not considered to be in crisis, so physiotherapy is not covered on their disability benefits. “Maintenance care is not allowed even though physiotherapy can enhance one's life,” said one woman. Women in several focus groups mentioned that hospitals have such long waiting lists for physiotherapy that there may be as much as an eight-month delay. With hospitals closing, access to physiotherapy is becoming even more limited. The women in the British Columbia focus group also noted that women with disabilities, who are not on social assistance, may find that many private clinics are often not wheelchair accessible. Women in rural areas where small hospitals have closed are now finding it impossible to travel long distances for physiotherapy treatments.

Health Care in the Yukon Territory

Women in the Yukon focus group reported that the Yukon Territory has had a relatively stable medical care system because the government had a $30-million reserve, which has delayed the effects of the CHST cuts. A new hospital was opened recently in Whitehorse with an attached extended health care facility. Medical coverage pays for medical evacuation to large medical centres for critical cases as well as medical evacuation from smaller communities to the medical centre in Whitehorse. As in the provinces, the same restrictions apply on coverage for drugs, and physiotherapy is only available at the hospital in Whitehorse.

The women in the Yukon focus group also commented that the new hospital has purchased an electric shock treatment machine over the protests of the disability community in Whitehorse. The disability community was not only opposed to the electric shock machine being brought into Whitehorse, but they felt the money could have been better spent on a dialysis machine, since people needing this treatment have to go to Vancouver or Edmonton.

Summary

Women with disabilities have always had a problem accessing medical services. Doctors' offices and hospitals do not have special examination tables that are accessible to women with disabilities. Women with disabilities who use wheelchairs generally do not get the routine health care that other women receive. Serious problems, such as cancer of the cervix and uterus, go undetected because women are not receiving PAP tests and thorough physical examinations. Women with disabilities are uninformed about women's personal hygiene, sexually transmitted diseases, and birth control. There are no interpretative services for women who are deaf/blind or women who are deaf. Women who use hearing aids have them taken away and locked in a safe during their stay in hospital. All these inequalities are worsened by cuts to health services as a result of the CHST, as well as cuts in the previous year before the CHST came into effect.

Health care for all women has been seriously compromised in all provinces by closure of small hospitals and cuts to staff in hospitals that remain open. These closures and cuts have dramatically affected care for women with disabilities who require extra help because of their disabilities. Early release from hospital is also difficult for women with disabilities who have no family to care for them at home. The closure of small hospitals has made it very difficult for women with disabilities in rural areas to access medical services, and has made it impossible for women to receive physiotherapy, which is only covered if it is administered as hospital outpatient care.

Cuts to psychiatric services have been particularly difficult for women with mental health disabilities. Responsibility for psychiatric care is being turned over to community support services, which have been, and continue to be, reduced. Women with psychiatric disabilities are very vulnerable to abuse and sexual assault because they spend a lot of time on the streets without help or support.

Because the Yukon government had a $30-million reserve, cuts to health care have not yet been felt in this territory. Although there are the same restrictions on physiotherapy and coverage for generic drugs only, a new medical centre has opened in Whitehorse, and medical evacuation is provided from rural areas into Whitehorse and from Whitehorse to large medical centres in Alberta and British Columbia.

Recommendations

<u>Recommendations to the Federal Government:</u>

- ♦ That the *Canada Health Act* be reviewed and strengthened to ensure that all provinces and territories provide adequate care without unreasonable delays and that adequate care be accessible to all persons in Canada, including women with disabilities.
- ♦ That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

<u>Recommendations to the Provincial Governments:</u>

- ♦ That all hospitals have appropriate examination tables that are accessible for women with disabilities.
- ♦ That routine women's health care and routine tests may be done at hospitals for women with disabilities who need accessible examination tables.
- ♦ That funding be made available to cover all expenses for women with disabilities to travel to medical clinics, hospitals, and large medical centres for necessary diagnostic tests and treatments; and that women with disabilities be allowed appropriate rest time before returning home.
- ♦ That attendant care and/or assistance be provided at the woman's request if she must travel outside her home community for medical diagnosis and/or treatment.
- ♦ That hospitals be required to ensure that women with disabilities have adequate home care before they are discharged.
- ♦ That 24-hour home care be made available to women with disabilities who are being discharged from hospital or from day surgery until the women are able to care for themselves.

- That community support be adequately funded to provide support for women with psychiatric disabilities who have been discharged from psychiatric institutions and hospitals to help them adjust to life in the community.

- That women with psychiatric disabilities not be discharged from hospitals and psychiatric institutions without adequate and careful cooperative planning for living accommodation and community support.

- That all extra fees for drug prescriptions or user fees of any kind be waived for women who are on welfare, welfare disability benefits, or other disability benefits that do not cover these costs.

- That all women with serious and life-threatening illnesses, including women who are HIV-positive and women who have AIDS, be provided with the most effective and up-to-date treatments and drugs without consideration of cost.

Education/Employment

Post-secondary education funding is a component of the CHST. The impact of the funding cuts under the CHST on women with disabilities is direct in terms of meeting the needs of students with disabilities on income assistance while attending school. Cuts may affect the availability of assistive aids, attendant care, interpreters, note takers, readers for classrooms and studying, and the accessible transportation needs of women with disabilities who want to attend post-secondary schools or job training programs.

The Risks of Going to School or Training for a Job

The women in all the focus groups commented that women are experiencing increasing difficulty in seeking help for post-secondary education and job training. Women with disabilities who are on welfare disability pensions and want to go to school with the hope of getting a job and becoming self-sufficient are being discouraged at their first attempt to get help. In Nova Scotia, a woman spoke about her experience of going back to school while getting welfare family benefits. She was allowed $100 a week to help her with educational expenses, but the amount was deducted from her family benefits. With $400 a month deducted from her benefits, there is nothing left to live on.

A woman in Toronto, who intends to go to university, was informed by her social worker that her status as a full-time student would disqualify her for welfare family benefits. She will have to apply to the Ontario Student Assistance Program (OSAP) for living expenses, books, and tuition. OSAP will provide $10,000 a year, but the woman would lose all her welfare disability benefits. By attending school, she will have shown that she does not require disability benefits and may not be reinstated if she fails to complete university or does not find employment.

Women in the Quebec focus group noted that this province has also cut post-secondary students off welfare. Students have to study full-time and apply for financial assistance under the Student Loan and Bursary Program. Part-time students have also been cut from welfare.

One woman in the Quebec focus group informed the group that the *Social Assistance Act* was changed in April 1996 and amended in August 1996 to cut welfare payments from people found to be capable of working. Those who cannot work and have been medically diagnosed as having a disability face new hurdles. To obtain supplementary assistance for education and job training, applicants must qualify under at least two of three new socio-professional criteria: age (over 45 years), education (minimum of Grade 12), and employment history (must not have worked in the past seven years). The woman also informed the group that the *Comité Inter-entrepris pour l'intégration au Travail Quebec* (CIIT) has identified several businesses for the *Travail Quebec* back-to-work programs. However, this program is like a double-edged sword because of the new socio-professional criteria for eligibility. Even participating in a three-month job program organized by *Travail Quebec* could disqualify a person from disability or welfare benefits.

There is a general feeling among the women in the focus groups that even with the extraordinary expenses of having a disability, they cannot consider attending post-secondary institutions or job training programs when they are threatened with losing their welfare disability benefits. Once a woman with a disability has been declared fit to work or go to school, it is very difficult, and sometimes impossible, to get lost benefits reinstated. The women felt there must be a safety net for women who try to attend school or try to hold a job but cannot because of their disabilities. Women must be assured that they will be able to receive welfare benefits if their disabilities prevent them from becoming economically independent.

The Canada Pension Plan now has a policy that assists women with disabilities to return to the workplace for a three-month trial period. Women who cannot hold down a job are not penalized with loss of benefits. This kind of policy is what women want to see put in place for welfare disability benefits. The women in general feel that they must not be coerced into taking post-secondary studies and job training with threats of having their disability benefits terminated and then have their benefits removed as soon as they enter these programs. This is a double bind that leaves women on welfare disability benefits helpless to make changes.

All women in the focus groups across Canada felt that the welfare system is an unfriendly one that traps women with disabilities in poverty. They expressed fear of entering education and training programs. They felt that there must be changes to make all work training and education programs accessible to women with disabilities. As a result, women may need flexible work hours, job sharing, and part-time work. Women in Alberta called on the governments to change their philosophy of income support from one of punishment and threats to one of helping and encouraging every woman, with one or more disabilities, to fully participate in society, including school, work programs, employment, and at the community level.

Accessing Educational Institutions

At the focus group in the Yukon Territory, a woman commented that a woman with disabilities who is on social assistance can get one year of schooling. But there are spaces in the college that are not being filled and women are not being given the opportunity to use them. She noted that there are no special services in the Yukon for students who have disabilities. This restricts the disabled students from developing their potential or even being able to enter educational classes or job training.

Women in the Northwest Territories focus group stressed that many Northerners do not have a high school education and are chronically unemployed. Most education facilities are not accessible to women with disabilities and there are no teachers who can teach in sign language or who are able to teach Braille to assist students who are blind. Assistive aids to help disabled students are uncommon in the Northwest Territories. Training programs give priority to Aboriginal people, but all people with disabilities are screened out. "Being disabled in the North means being on social assistance," said one woman.

One participant in the Manitoba focus group said that a woman with a disability may be able to get some assistance in the classroom because of extreme difficulty but it is not seen as a right for her to have it. The woman pointed out that the problem of education and job training is being seen as the responsibility of the individual who has the disability and not spread across the whole of society. "The trend now is *not* to invite people with disabilities to join the community but rather to look at the costs of including people with disabilities."

In the Saskatchewan focus group, women felt that there is a lack of part-time courses for entrepreneurs. Although there is a grant for high-need part-time students, it seems to be directed more at single mothers, and women with disabilities are not taking advantage of it.

Effective Programs Being Closed

Women in all the focus groups suggested that programs designed specifically for people with disabilities are also being cut. An example was given by women in the Manitoba focus group. There is a program at the Winnipeg Education Centre for men and women with disabilities, where an average of 30 students were graduating annually. The success rate of the graduates finding jobs was higher than on the main campuses. This program was one of the first things to be cut under the CHST. In another year, the centre will not be able to function. Women in the focus group in British Columbia commented that the computer training program at the Pearson Hospital has been cut. Now, the only program is through Neil Squires and it is entry level training only.

Many women commented on the need for programs such as Vocational Rehabilitation for Persons with Disabilities (VRPD) that are separate from rehabilitation. VRPD was the only program that gave enough help for a person with a disability to go to school. It covered tuition, books, special aids, living expenses, and other disability costs. However, tuition is no longer covered under VRPD. Women feel that they have not had equal access with men who have disabilities to VRPD, so there is a need for programs aimed specifically at women with disabilities. Programs must be open to all women with disabilities and must meet all the needs of women with disabilities who are funded under these programs.

EI Is Not for Women with Disabilities

Women in the focus groups spoke of the way that Employment Insurance (EI) retraining programs leave them out. Most women with disabilities are not lucky enough to have had jobs and to be on EI. Increasingly, women are saying that the governments must put similar programs in place for women with disabilities who do not qualify for EI. All programs must be fully accessible to all women with disabilities who are on social assistance and welfare disability benefits without jeopardizing their disability income. Women with children must receive adequate help with child care to enable them to participate in all training programs.

Loss of Hope

Even for women who have managed to complete post-secondary education, the job prospects do not seem very promising to one woman in Prince Edward Island. She felt that women with disabilities are not chosen for employment because the competition is between an able-bodied person and a disabled person. “The able-bodied person is chosen first,” she said. With little hope of getting a job, there is little incentive to go to school. Women are asking the federal government to strengthen and enforce the *Employment Equity Act* to hold the federal government and the provinces legally responsible for equal access to employment and advancement within the workplace, and equal access with men who have disabilities.

Early Education — A Handicap

Although primary education is not funded under the CHST, women are also troubled about cuts at this level. A woman in Prince Edward Island raised the issue of inaccessible schools arresting the potential for education and employment at a very early age. Women in Manitoba have the same worries for their children as they see the rights of the most vulnerable, “the kids with special needs,” being eroded. “Now they are saying that it is too expensive to have special needs kids in school,” said one woman. “They are cutting speech pathologist and other support systems in the schools.” Adults with disabilities who were disadvantaged in their early childhood education will need special courses to bring them up to a level where they can enter job training programs. Women may need several years of support to complete secondary education before they can pursue careers.

Summary

The road to independence is through education and employment, but women with disabilities are trapped in a no-win situation. Women will lose their benefits if they attend post-secondary education or job training, either part-time or full-time. Once a woman with a disability has been declared fit to work or go to school, it is very difficult, and sometimes impossible, to get lost benefits reinstated. Women cannot take the risks of losing the only security they have on welfare and disability benefits by applying for financial assistance to further their education with the hope of some day becoming employed.

Government-sponsored training programs are limited to people on Employment Insurance (EI). These programs are available to very few women with disabilities. Women in the focus groups identified a need for EI-type programs for women with disabilities — programs that do not threaten them with loss of welfare disability benefits. Incentives for women with disabilities to explore the possibilities of post-secondary education and employment must be rewarding rather than punitive with threats of loss of disability income. All programs must be fully accessible to women with disabilities and take into account the fact that women may need flexible work hours, part-time work, or job sharing. There must be adequate support to make all programs accessible to women with disabilities who have children.

Women with disabilities want to work and they want to attend post-secondary schools and job training programs. Education is not seen as a right for a woman with a disability, and the barriers to education are seen as individual problems rather than a social responsibility. This attitude of governments, all education institutions, and training programs is reflected in the cuts that eliminate assistance to women with disabilities.

All the needs of women with disabilities must be considered if governments are going to ensure that women with disabilities have equal access to education, job training, and job entry. Women want to see the federal government amend the *Employment Equity Act* so that it will hold the federal government and every province and territory legally responsible to ensure that all people with disabilities have equal access to all job entry opportunities and advancement within the workplace, and that will guarantee that women with disabilities have equal access with men who have disabilities.

All governments must change their philosophy of income assistance from one of punishment and threats to one of helping and encouraging women with disabilities to fully participate in society.

Recommendations

Recommendations to the Federal Government:

- That the federal government amend and strengthen the *Employment Equity Act* to make the federal government legally responsible for ensuring equal access to employment opportunities and employment advancement, and that women with disabilities are ensured equal access with men who have disabilities to all federally funded programs.

♦ That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

<u>Recommendations to the Provincial Governments:</u>

♦ That all provinces and territories introduce employment equity legislation that gives equal access to employment entry opportunities and employment advancement opportunities for all disabled persons, and that women with disabilities have equal access with men who have disabilities.

♦ That incentives to work be rewarding and not punitive measures such as cutting off benefits if a woman goes to school, enters job training programs, or volunteers at a non-profit society.

♦ That supports be put in place to assist women with disabilities to attend school or job training, such as subsidized day care, assistive aids, and attendants.

♦ That provincial and territorial governments establish programs similar to Vocational Rehabilitation for Persons with Disabilities, which are the responsibility of the education system and not the rehabilitation system.

♦ That all programs be fully accessible to all women with disabilities and that consideration be given to the need for part-time studies, part-time work, job sharing, and flexible hours.

♦ That all funding sources take into consideration the extra expenses associated with having a disability and adjust the funds appropriately to cover these extra costs to include expenses for tutors, interpreters, readers, assistive aids, and other personal needs associated with the disability.

* That in view of the fact that women with disabilities have experienced difficulty in accessing funding for post-secondary education, all government-financed programs must ensure fair and equitable access for all women with disabilities.

♦ That government-sponsored scholarships and bursaries be created for women with disabilities to offset the increasing costs of tuition and supplies, and that receiving a scholarship or bursary not affect in any way other educational funding or disability benefits.

♦ That women with disabilities who have children be given special consideration for assistance in furthering their education, so they can either enter, re-enter, or stay in the work force.

- That job training programs similar to those offered through EI be made available to women with disabilities who are on disability benefits, without any risk of losing or incurring cuts to their benefits.

- That assistance be given to women to cover the costs of part-time studies at post-secondary institutions without jeopardizing disability benefits.

- That no financial assistance for post-secondary education or job training, either part-time or full-time, jeopardize disability benefits in any way unless the educational assistance temporarily replaces all the benefits during the school or training period only.

- That post-secondary education and job training for women with disabilities be recognized as a fundamental right, and the extra costs of having a disability be recognized as barriers to attaining this right.

- That all post-secondary institutions, in recognition of the rights of equal access for people with disabilities to post-secondary education, ensure that all educational environments and media are made accessible, and provide all assistance needed to meet the needs of students with disabilities to give equal access to post-secondary education.

- That, since women with disabilities do not have the same potential to raise tuition fees and to pay back student loans as non-disabled students, and considering the onerous costs of having a disability, the repayment period of all student loans incurred by women with disabilities be adjusted according to individual capabilities to repay.

- That women with disabilities who were deprived of early education because of their disabilities be given all necessary support to attend adult education classes through primary and secondary school levels.

Discussion

It is impossible to describe the fear and the anger of the women who shared their experiences in the focus groups across Canada. Some women were not able to complete the task in one session because the issues were so stressful for them. A woman in Halifax said at the beginning of the focus group that “women feel very fearful and live a day at a time. We can't even think of tomorrow. We are losing services so quickly and we are always in a state of fearing what will go next.”

There was nothing good or encouraging that women with disabilities had to say about the changes that came about with the CHST. Women who need assistance with daily living fear losing the already inadequate help they have. Women who are being deprived of adequate care hesitate to ask for more hours. Young women with degenerative diseases worry about being institutionalized and seeing their children placed in foster homes.

Women cannot begin to think about school or work as long as they struggle with cuts that have taken away their social safety net. The first priority must be to attend to the daily life- sustaining needs of women and their children. Therefore, medical services must be made accessible to women with disabilities without long waits. Women must receive an adequate disability income to live in safe places, to buy nutritious food for themselves and their families, to meet the needs of their disability with assistive aids, assistance for themselves, and assistance with their children. Women on welfare assistance have a very low self-esteem and feel they have little value in society. Unless this changes to give women on welfare and welfare disability benefits a sense of security and worth, they cannot face the bigger world beyond the scope of their disabilities.

For women with disabilities who dare to take the risks, there is nothing to reach for without new programs targeted specifically for women with disabilities who have never been employed and who do not currently have the skills to compete for work force entry or in the workplace. Other women who have completed post-secondary education need help as well. They are not able to compete for jobs on an equal basis with non-disabled women. These women would benefit from work force entry and re-entry programs for their level of education and skills.

The budget for 1997–98 committed the federal government to maintain $12.5 billion for future years rather than $11.1 billion of the 1996 budget until the year 2002–3. There is $150 million over three years, to be allocated to the provinces on an equal per-capita basis, for innovative pilot projects in the delivery of health care. The finance minister suggested two areas: home care and drug coverage. This could give some relief to women who are not covered for drugs, especially women who are HIV-positive and who have AIDS, and it could make some positive change in home care. How this money is spent will be decided jointly by Canada's health ministers.

Three conferences are planned for 1998 to address the issues of home care, drug coverage, and integrated health systems. The 1997–98 budget committed $100 million to the Community Action Program for children and the Canada Prenatal Nutrition Program, and $50 million for the Canada Health Information System.

There is no guarantee that any of this money will filter down to the community level. There is a great need to provide community drop-in centres to fill the gap for people released from hospital but who are unable to function in society without help. Hopefully this money will be spent at the community level to benefit the members most in need of help. However, it must be remembered that pilot projects by their nature are temporary and may benefit only a few chosen communities.

The big news in the 1997 budget was the refundable tax credits for people with disabilities who are already employed. There were no tax refunds for persons who are unemployed and who also have “onerous” disability-related expenses that are not covered by insurance or social services. Funding for Vocational Rehabilitation for Persons with Disabilities will continue for another year and at the same level. However, women in the focus groups felt that women with disabilities have not had equal access to the program and were not hopeful for the coming year. After this year, it is to be replaced by a new program that has an employability focus.

The budget also offered an additional $30 million over the next three years to develop partnerships in the private sector in conjunction with the provincial governments, which are responsible for social assistance. We are sceptical about how much this will help women with disabilities unless there are some innovative programs that lead to long-term employment. Programs in the past that subsidized employers to hire people with disabilities were not successful in getting long-term employment. As soon as the subsidy stopped, the employment was also terminated.

Women with disabilities need to get schooling and job training that is geared to the market and to get job experience that will lead to competitive employability. But women must have guaranteed support throughout this process before they can risk losing their disability benefits. There must be a guarantee that, if for some reason they cannot complete the process to independent security, the social assistance will be available for them to fall back on. Women who are working at low-paying jobs also require continued assistance from the government to meet their daily needs. A refund at tax time is not enough to sustain a woman in a low-paying job who has “onerous” disability costs on a daily basis.

Women who do not have the skills or who do not have emotional support cannot be intimidated and punished into successfully joining the work force by the threat of discontinuing their disability benefits. The Canada Pension Plan now allows people to work three months without losing their benefits to see if they are able to return to work. Several women have tried this because they wanted to go back to work but found that they were no longer able to hold down a job. This kind of policy for women with disabilities who are on welfare disability benefits would take the fear out of trying to work and let women with disabilities explore their potential in the work world.

The Deficit, the Debt, and Where We Go from Here

All the changes in the last few years have been introduced to reduce the deficit. The federal finance minister announced in the 1997 budget speech that the deficit would not exceed $19 billion for 1996–97. This amount is down from $42 billion in 1993–94 and is $9.5 billion less than in 1994–95. Additionally, the deficit for 1996–97 is $5 billion less than was predicted. This news sounds very exciting as we enter the next century, but the deficit is only a small part of the bigger picture.

The deficit means that the government spent $19 billion more than it had in the bank in 1996–97. When we reach zero deficit, it will mean that the government has spent only as much as it has received in revenues in that year. The minister hesitated to say in the 1997 budget when we will reach zero deficit and what cuts will have to happen before we get there. What happens when we do get to zero deficit? Then it will be time to start paying off Canada's national debt, which was $574.3 billion as of March 1996.

The national debt is the accumulation of all federal deficits since Confederation. The figures for 1995–96 show that $115 billion of the debt is owed to foreign creditors. Canada has the highest foreign debt relative to the size of the economy of any major industrial nation. Interest payments alone represent 29.5 cents of every dollar in revenue collected by the federal government. In 1995–96, the interest paid on the national debt was $46.9 billion.[18] As a result, the federal government is worried about Canada's credibility on the world market.

The focus of the current government is to get all Canadians into the work force and ease the burden on social services. The cuts that we have seen over the last few years will stay with us. The governments have mismanaged the people's money for decades, and now the most vulnerable are bearing the cost as cuts to health and social services are being fed to the deficit and to managing the interest on the national debt.

We are entering a new era when there will be little money coming from the federal government. It is a time when we must set our priorities carefully and speak with one voice about the needs of women with disabilities. We must not allow the federal government to abrogate its responsibility to provide health care and to provide the basic needs for all people with disabilities, all poor children, and all poor women and men in Canada.

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[18] Department of Finance Canada, *Fiscal Policy, Deficit, Debt, Government Spending and Revenues: Finance Glossary of Frequently Used Terms*, rev. ed. (Ottawa, July 1997) 1.

APPENDIX A

Summary of Recommendations

Financial Assistance/Disability Benefits

Recommendations to the Federal Government:

Because women with disabilities feel that their human rights are being eroded by continuing cuts to life-sustaining care and services, the federal government must uphold the rights of women with disabilities as stated in Section 15 of the *Canadian Charter of Rights and Freedoms* by ensuring:

- That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

- That the federal government increase contributions for social housing to assist the provinces and municipalities in providing safe and accessible housing for women with all types of disabilities and all poor women and their children.

- That the federal government reinstate contributions to the provinces to create new, safe, and accessible social housing units.

- That the federal government, in consideration of the extraordinary cost of living with a disability, not limit refundable tax credits for disability-related expenses to persons who are employed; and that refundable tax credits be given to all people with disabilities for expenses related to their disabilities that are not covered under welfare disability benefits or other disability benefit plans or health insurance plans.

Recommendations to the Provincial Governments:

- That eligibility criteria for disability benefits be clearly and fairly defined and that this be done in consultation with members of the disability community in each province to ensure the weight of hidden disabling factors of disabilities are recognized.

- That eligibility requirements take into account the needs of women with disabilities and the disabling factors of the disability and not be based solely on a medical diagnosis.

- That each province clarify in simple and plain language what persons on welfare and disability benefits are entitled to receive, and that this information be made available to every person who is applying for, or is already receiving, disability benefits.

- That the right to appeal decisions regarding financial assistance be reinstated in every province and territory, and that every person applying for benefits be given information about their right to appeal with clear instructions on how to proceed with an appeal; and that every person already receiving social benefits receive this same information.

- That every person whose application for financial assistance is rejected or disqualified be given written, clear, plain-language reasons so decisions can be appealed with clarity and objectivity.

- That funding be provided to disability organizations to assist people with disabilities in applying for or appealing decisions relating to disability benefits.

- That every person, when applying for disability benefits, or who has been refused disability benefits, be advised of organizations that can assist with the appeal process.

- That, if benefits are terminated for any reason, they be reinstated during the time of the appeal process, and if the appeal is rejected that the individual not be required to repay benefits received during the period of the appeal.

- That all disability-related costs be handled separately from everyday costs.

- That women with disabilities who share safe and accessible living accommodation not be harassed and threatened with loss of benefits.

- That provincial governments take responsibility for providing more subsidized housing that is accessible and safe.

Home Care

Recommendations to the Federal Government:

- That the federal government ensure that disability benefits for home care, including attendant care and homemaking services for First Nations people, be brought in line with provincial benefits to ensure equal access and quality for home-care services.

- That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

Recommendations to the Provincial Governments:

- That attendant care and homemaking services be based on actual need rather than on predetermined criteria or costs.

- That attendant care and homemaking services be based on need rather than on medical diagnosis.

- That an independent appeal process be put in place for women who are not receiving adequate hours of personal care or homemaking services.

- That more flexibility in home care be made available for women who want self-management options to receive money directly to hire and train their own attendants and home workers.

- That child care assistance be made available to women with disabilities who have children.

- That no child be expected to take on the responsibility for attendant care or homemaking services to justify cuts in social services, because this role reversal robs the mother of her position in the family and robs the child of his or her right to their childhood.

- That funding for the home-care needs of women with disabilities who have children be increased to maintain quality child care, allowing the family to stay together and allowing the disabled mother to maintain her parental position in her family and community.

- That, in cases where family members provide care to women with disabilities, the family members be paid as caregivers.

- That, in cases where family members are giving total care to women with disabilities, respite be made available for the woman who is disabled and for the family.

Institutional Care

<u>Recommendations to the Federal Government:</u>

- That national standards for institutional care be developed in consultation with the disability community, and that at least 50 per cent of the consulting committee be women with disabilities, and that all institutions be required to provide a level of care that meets the national standards and the needs of all the residents.

- That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

Recommendations to the Provincial Governments:

- That women with disabilities be given as much support as they need to stay out of institutions and remain at home with their families, since this is not only better for the woman and for her family, but is cheaper for the province to provide home care than to place women in institutions.

- That entering a long-term care facility be the free and informed choice of the woman and not the decision of the government or her family.

- That, if a woman decides to go to a long-term care institution, she be given the choice of being near her home and family.

- That programs for social activities in long-term care institutions and in the community be considered a necessary part of the overall care.

- That programs be funded in long-term care institutions to assist residents to participate in social activities both inside and outside the institution.

- That special attention be given to the social and family needs of all women in institutions by assisting women to stay in contact with families and friends in their home communities.

- That special attention be given to concerns for minority women to ensure that these women have contact with their cultural communities.

- That funding be restored to long-term care institutions for adequate staff to provide quality care for all residents.

- That strict standards of personal care, cleanliness, and nutrition be enforced in all long-term care institutions, including community homes.

- That minimum standards be set and enforced for various levels of qualifications and training for all staff positions in long-term care facilities and community homes.

- That all cases of abuse or neglect be thoroughly investigated by an outside independent person and that criminal charges be laid where appropriate.

- That any woman who has experienced abuse or neglect receive counselling from an independent counsellor of her choice from outside the institution.

- That provincial advisory committees be established to monitor the care in all long-term care facilities and community homes, and that the advisory committees consist of at least 51 per cent people with disabilities, of which at least 51 per cent are women with disabilities, and that these advisory committees be given the power to hold institutions accountable for quality of care.

Health Care

Recommendations to the Federal Government:

- That the *Canada Health Act* be reviewed and strengthened to ensure that all provinces and territories provide adequate care without unreasonable delays and that adequate care be accessible to all persons in Canada, including women with disabilities.
- That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

Recommendations to the Provincial Governments:

- That all hospitals have appropriate examination tables that are accessible for women with disabilities.
- That routine women's health care and routine tests may be done at hospitals for women with disabilities who need accessible examination tables.
- That funding be made available to cover all expenses for women with disabilities to travel to medical clinics, hospitals, and large medical centres for necessary diagnostic tests and treatments, and that women with disabilities be allowed appropriate rest time before returning home.
- That attendant care and/or assistance be provided at the woman's request if she must travel outside her home community for medical diagnosis and/or treatment.
- That hospitals be required to ensure that women with disabilities have adequate home care before they are discharged.
- That 24-hour home care be made available to women with disabilities who are being discharged from hospital or from day surgery until the women are able to care for themselves.
- That community support be adequately funded to provide support for women with psychiatric disabilities who have been discharged from psychiatric institutions and hospitals to help them adjust to life in the community.

- That women with psychiatric disabilities not be discharged from hospitals and psychiatric institutions without adequate and careful cooperative planning for living accommodation and community support.

- That all extra fees for drug prescriptions or user fees of any kind be waived for women who are on welfare, welfare disability benefits, or other disability benefits that do not cover these costs.

- That all women with serious and life-threatening illnesses, including women who are HIV-positive and women who have AIDS, be provided with the most effective and up-to-date treatments and drugs without consideration of cost.

Education/Employment

Recommendations to the Federal Government:

- That the federal government amend and strengthen the *Employment Equity Act* to make the federal government legally responsible for ensuring equal access to employment opportunities and employment advancement, and that women with disabilities are ensured equal access with men who have disabilities to all federally funded programs.

- That the federal government introduce legislated common standards across Canada for the administration of the Canada Health and Social Transfer (CHST) funds that have been formulated through public process, which surpass those of the Canada Assistance Plan (CAP), and which will be enforced through the federal spending power.

Recommendations to the Provincial Governments:

- That all provinces and territories introduce employment equity legislation that gives equal access to employment entry opportunities and employment advancement opportunities for all disabled persons, and that women with disabilities have equal access with men who have disabilities.

- That incentives to work be rewarding and not punitive measures such as cutting off benefits if a woman goes to school, enters job training programs, or volunteers at a non-profit society.

- That supports be put in place to assist women with disabilities to attend school or job training, such as subsidized day care, assistive aids, and attendants.

- That provincial and territorial governments establish programs similar to Vocational Rehabilitation for Persons with Disabilities, which are the responsibility of the education system and not the rehabilitation system.

- That all programs be fully accessible to all women with disabilities and that consideration be given to the need for part-time studies, part-time work, job sharing, and flexible hours.

- That all funding sources take into consideration the extra expenses associated with having a disability and adjust the funds appropriately to cover these extra costs to include expenses for tutors, interpreters, readers, assistive aids, and other personal needs associated with the disability.

- That, in view of the fact that women with disabilities have experienced difficulty in accessing funding for post-secondary education, all government-financed programs must ensure fair and equitable access for all women with disabilities.

- That government-sponsored scholarships and bursaries be created for women with disabilities to offset the increasing costs of tuition and supplies, and that receiving a scholarship or bursary not affect in any way other educational funding or disability benefits.

- That women with disabilities who have children be given special consideration for assistance in furthering their education, so they can either enter, re-enter, or stay in the work force.

- That job training programs similar to those offered through EI be made available to women with disabilities who are on disability benefits, without any risk of losing or incurring cuts to their benefits.

- That assistance be given to women to cover the costs of part-time studies at post-secondary institutions without jeopardizing disability benefits.

- That no financial assistance for post-secondary education or job training, either part-time or full-time, jeopardize disability benefits in any way unless the educational assistance temporarily replaces all the benefits during the school or training period only.

- That post-secondary education and job training for women with disabilities be recognized as a fundamental right, and the extra costs of having a disability be recognized as barriers to attaining this right.

- That all post-secondary institutions, in recognition of the rights of equal access for people with disabilities to post-secondary education, ensure that all educational environments and media are made accessible, and provide all assistance needed to meet the needs of students with disabilities to give equal access to post-secondary education.

- That, since women with disabilities do not have the same potential to raise tuition fees and to pay back student loans as non-disabled students, and considering the onerous costs of having a disability, the repayment period of all student loans incurred by women with disabilities be adjusted according to individual capabilities to repay.

- That women with disabilities who were deprived of early education because of their disabilities be given all necessary support to attend adult education classes through primary and secondary school levels.

APPENDIX B

About DAWN Canada:
DisAbled Women's Network Canada

DAWN Canada: DisAbled Women's Network Canada was founded in 1985 by a group of women with disabilities from across Canada. DAWN Canada is a national non-profit, cross-disability organization of women with disabilities. We are affiliated with provincial DAWN groups and other disabled women's groups in Canada and internationally. For the past 12 years, the focus of DAWN Canada has been in the area of research, with the goal of defining the concerns of women with disabilities and developing materials and programs to address these concerns.

The objectives of DAWN Canada are as follows:

- to be the voice of women with disabilities in Canada;
- to provide support, information, and resources to women with disabilities in Canada;
- to enhance communication and awareness among women with disabilities, and between the disabled consumer movement and the women's movement, of the needs and concerns of women with disabilities in Canada;
- to educate and raise general awareness in the general public regarding the needs and concerns of women with disabilities in Canada;
- to educate and raise awareness of women with disabilities, all organizations dealing with issues affecting persons with disabilities, and all organizations dealing with issues affecting women to ensure equal access to all goods and services is provided;
- to reach out and remain sensitive to the unique needs of all women with disabilities, including native women, black women, South Asian women, Asian women, and other linguistic and ethnic minorities, including Franco-Canadian women, immigrant women, women in institutions, lesbians, single parents, and other women with disabilities in Canada;
- to provide role models for girls with disabilities and to encourage and support them as they develop into mature and independent Canadian women;
- to promote research on all issues affecting women with disabilities in Canada;
- to work in cooperation, whenever possible, with others who share our concerns for equality and social justice in Canada; and
- to liaise with women with disabilities internationally.

APPENDIX C

DAWN Canada Research Guidelines

1. The need for research is determined by the disabled women's community.

2. Research must always benefit women with disabilities.

3. Research must be done by members of the disabled women's community because members:

    a. know the issues and priorities of the community;
    b. understand the day-to-day reality of women who are disabled;
    c. understand the social and political dynamics of the community;
    d. can analyze data within the framework of these dynamics.

4. Research action resulting from the research must be directed toward making positive change for women with disabilities.

5. Research participants will be given the results of the research in an accessible format if they so desire.

DAWN Canada feels that, in the past, the needs of women with disabilities have been defined by professional researchers in the medical, rehabilitation and social sciences. We feel that these professional researchers working in an academic environment have missed many of the issues of concern to women with disabilities because they have little understanding or knowledge of the day-to-day lives of women who live with a disability. We believe that social research, in particular, has often been done for the sake of research or to gain academic credits and not with the intent to improve the lives of women with disabilities. Therefore we believe that social research which is to be done in the disabled women's community must be community based. This means that the research must be done by a woman with a disability who is knowledgeable about the disabled women's community, understands the reality of having a disability and has made a contribution to improving the lives of women with disabilities. In consultation with other members of the disabled women's community these researchers will have a better understanding of what issues need to be addressed, will be more sensitive to the participants and will give a better analysis of the research results.

DAWN Canada also feels that any social research can only be analyzed within the context of the whole life of a woman who has a disability as well as within the dynamics of the disability community. We also believe that all participants have the right to fully understand the reason for the research, what will be done with the research results and to receive the results of the research in an accessible format if they so desire.

APPENDIX D

Advisory Committee

DAWN Canada: DisAbled Women's Network Canada

Board of Directors

Eileen O'Brien, Chairperson
DAWN Canada

Kathy Hawkins, Vice-Chairperson
DAWN St. John's

Nathalie Léveillé, Secretary
Action des Femmes Handicapées Montreal

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RESEARCH REPORTS FUNDED BY STATUS OF WOMEN CANADA ON THE CANADA HEALTH AND SOCIAL TRANSFER (CHST) AND ITS IMPACT ON WOMEN

Benefiting Canada's Children: Perspectives on Gender and Social Responsibility
(Des prestations pour les enfants du Canada : perspectives sur l'égalité des sexes et la responsabilité sociale)
Christa Freiler and Judy Cerny
Child Poverty Action Group

Qui donnera les soins? Les incidences du virage ambulatoire et des mesures d'économie sociale sur les femmes du Québec
(Who Will Be Responsible for Providing Care? The Impact of the Move Toward More Ambulatory Care and of Social Economic Policies on Quebec Women)
Association féminine d'éducation et d'action sociale (AFÉAS), Denyse Côté, Éric Gagnon, Claude Gilbert, Nancy Guberman, Francine Saillant, Nicole Thivierge and Marielle Tremblay

Women and the CHST: A Profile of Women Receiving Social Assistance, 1994
(Les femmes et le TCSPS : profil des femmes à l'assistance sociale en 1994)
Katherine Scott
Centre for International Statistics, Canadian Council on Social Development

Women and the Equality Deficit: The Impact of Restructuring Canada's Social Programs
(Les femmes et le déficit en matière d'égalité : l'incidence de la restructuration des programmes sociaux du Canada)
Shelagh Day and Gwen Brodsky
Day, Brodsky and Associates

The Impact of Block Funding on Women with Disabilities
(L'incidence du financement global sur les femmes ayant un handicap)
Shirley Masuda
DAWN Canada

Women's Support, Women's Work: Child Care in an Era of Deficit Reduction, Devolution, Downsizing and Deregulation
(Le soutien aux femmes, le travail des femmes et la garde d'enfants à l'ère de la réduction du déficit, du transfert des responsabilités, de la réduction de la taille de l'État et de la déréglementation)
Gillian Doherty, Martha Friendly and Mab Oloman
Doherty Inc.

RESEARCH REPORTS FUNDED BY STATUS OF WOMEN CANADA ON WOMEN'S ACCESS TO JUSTICE

A Complex Web: Access to Justice for Abused Immigrant Women in New Brunswick
(Une toile complexe : l'accès au système de justice pour les femmes immigrantes victimes de violence au Nouveau-Brunswick)
Baukje Miedema and Sandra Wachholz

Lesbian Struggles for Human Rights in Canada (not published)
(La lutte des lesbiennes pour la reconnaissance de leurs droits fondamentaux au Canada) (non publié)
Ann Robinson and Sandra Kirby

L'accès à la justice pour des victimes de harcèlement sexuel : l'impact de la décision *Béliveau-St-Jacques* sur les droits des travailleuses à l'indemnisation pour les dommages
(Access to Justice for Sexual Harassment Victims: The Impact of *Béliveau St-Jacques* on Female Workers' Right to Damages)
Katherine Lippel and Diane Demers

Getting a Foot in the Door: Women, Civil Legal Aid and Access to Justice
(Un pied dans la porte : les femmes, l'aide juridique en matière civile et l'accès à la justice)
Lisa Adario
National Association of Women and the Law

Family Mediation in Canada: Implications for Women's Equality
(La médiation familiale au Canada : ses implications pour l'égalité des femmes)
Yvonne Peters, Sandra Goundry and Rosalind Currie
Equality Matters! Consulting