Disability-Related Support Arrangements, Policy Options and Implications for Women's Equality

The Roeher Institute

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PREFACE

Good public policy depends on good policy research. In recognition of this, Status of Women Canada instituted the Policy Research Fund in 1996. It supports independent policy research on issues linked to the public policy agenda and in need of gender-based analysis. Our objective is to enhance the public debate on gender equality issues and to enable individuals, organizations, policy makers and policy analysts to participate more effectively in the development of policy.

The focus of the research may be on long-term, emerging policy issues, or short-term, urgent policy issues that require an analysis of their gender implications. Funding is awarded through an open, competitive call for proposals process. A non-governmental, external committee plays a key role in identifying policy research priorities, selecting research proposals for funding, and evaluating the final report.

This paper emanated from a call for proposals in April 1997 to study the gender dimensions of the relationship between the changing role of the state, and the changing nature of women’s paid and unpaid work and their vulnerability to poverty. Researchers were asked to identify policy gaps, new policy questions or trends, propose frameworks for the evaluation, analysis and critique of existing policies, or develop pragmatic alternatives to existing policies or new policy options.

Status of Women Canada funded seven research projects on this issue. They examine Canadian legislation surrounding women who work at home for pay, work and Aboriginal women, the social versus the economic gain associated with the social economy, women in the garment industry, disability-related policies, restructuring and regulatory competition in the call letter industry, and the relationship between unpaid work and macro-economic policies. A complete list of the research projects is included at the end of this report.

We thank all the researchers for their contribution to the public policy debate.

ACKNOWLEDGMENTS

A research team at the Roeher Institute conducted the research for this report. Michael Bach provided project direction. Mary Bunch, Sara Leiserson and Shelley Tremain conducted interviews and focus groups; they also conducted a review of scholarly literature for the study. Cameron Crawford acted as Senior Project Consultant, and conducted the demographic analysis. Mary Bunch drafted the report in collaboration with the research team.

EXECUTIVE SUMMARY

This report examines equality issues of women with disabilities and the women who provide supports to them in the context of caregiving relationships. Equality of women within and outside of the actual relationships is considered. Six criteria are advanced.

- Promote self-determination.
- Foster mutual recognition.
- Encourage respectful interdependence.
- Ensure security.
- Promote citizenship.
- Democratize decision-making processes.

These criteria formed the terms of analysis for investigating the equalities and inequalities between women with disabilities and the women who provide supports for them. The study found that while equality in relationships of support is complex and variable, the equality of women with disabilities, and paid and informal support providers is interactive and tied to factors within the system of supports.

The access of women with a disability to disability-related supports had an impact on equality in support relationships (i.e., the degree of access affected women with a disability, and their paid and unpaid support providers, and the relationship between them). Similarly, findings show that the types and qualities of the service arrangements used, and the organization of labour for paid support providers affects equality in a relationship. Based on these findings, the study puts forward the following policy recommendations.

Access to Disability-Related Supports and Services

- Increase funding allocated for community-based services to meet demand, provide more service options and offer higher levels of service.
- Develop policies that account for a holistic view of health and well-being.
- Develop coherent disability-related policies based on a social model of disability.
- Review and redesign assessment procedures to account for consumer self-determination and differing circumstances.

- Broaden the scope of eligibility criteria for disability-related supports and services to account for the complexity in women's lives, and the social and economic barriers they face.

- Ensure direct access to information about the network of supports and services.

- Put safeguards in place in order to ensure that people can engage in advocacy without fear of reprisal.

Types of Services/Support Arrangements

- Increase the availability of direct funding.

- Provide recipients with some choice and control regarding options for service arrangements.

- Address staff labour concerns including equitable wages, benefits and protections, and ensure these conditions are consistent across the types of service arrangements.

- Design new service options that offer consumers a choice about where and how they live; build more accessible housing.

- Require agencies to allow their clients control and flexibility with respect to which workers provide them with supports and when.

- Develop strategies to protect workers from discrimination or unfair firing.

- Ensure that women with a disability and their staff have conflict resolution choices and supports.

- Design service arrangements to allow consumer flexibility.

- Develop strategies to promote better communication between service recipients and service providers.

- Increase the portability of services.

- Establish a national attendant registry to address difficulties with respect to travel.

- Give women with disabilities the opportunity to use their own discretion in the hiring of family members to provide support, under guidelines and mechanisms for protection of both.

Organization of Labour

- Revisit the pay scales of support workers and reconsider any pay freezes.

- Include coverage benefits for worker’s compensation in individualized funding programs.

- Allocate funding to train support workers in occupational health and safety, and professional development.

- Develop strategies to ensure both consumer choice and control, and worker security.

- Develop new strategies for collective bargaining that are appropriate to support relationships.

INTRODUCTION

Equality is a fundamental value of Canadian society, which is given expression in the *Canadian Charter of Rights and Freedoms*. The recognition of women's right to equality in the Charter and the occurrence of other social developments and events have advanced the concrete social and economic position of women across the country. Nevertheless, women throughout Canada continue to face barriers to the realization of their equality. This includes barriers associated with access to the labour market, poverty, violence, health risks, discrimination and access to services. This report considers several of these barriers to women's equality in the context of the relationships between women with disabilities and the women who provide paid and unpaid support to them.

This report puts forth a particular conceptualization of equality, based on analysis of the lived experiences of women with a disability and the caregivers interviewed in the study, as well as current feminist and disability theory. Equality is framed in the context of caregiving relationships—both in terms of equality between women in a support relationship and in terms of the ways that relationship affects women's equality in the community and society. The way the term equality is used incorporates concepts of substantive equality (treating different people differently when necessary to ensure they enjoy equal advantage and freedom from oppression). The criteria of equality used here are meant to allow for a diversity of identities, perspectives, values and cultures of not only White, able-bodied men, but women, people with a disability and others.

This study is timely. Government cutbacks and restructuring have shifted models of service provision. In recent decades, the character of support relationships between women has changed. Certain features of current support arrangements have promoted equality for the women who receive or provide such supports on a paid and unpaid basis; other features, however, have undermined equality for these women. For example, while women with disabilities have gained more power in community-based support arrangements, which can advance their self-determination and independence, increasingly, they rely on unpaid and underpaid support. This can have a negative impact on the equality of those women providing that support in addition to the woman with a disability herself. The ways in which inequality can be reproduced for each of the women involved in a relationship of support, and produced between them, are becoming clearer. This report aims to illuminate the nature of equality and inequality in relationships of support and the factors that influence these outcomes.

Some factors are evident in the recent policy shifts at the federal, provincial and local levels that have been shown to have detrimental effects on the social and economic position of the women receiving disability-related supports, and the women who provide them. In communities across Canada, demand for disability-related supports has grown due to two factors: an increased survival rate of people born with, or who have acquired complex disabilities, and the increasing number of seniors who view placement in nursing or retirement homes as a critical last resort and who choose to remain at home with supports. Despite these demographic increases, funding for disability-related supports has decreased substantially since 1991 (and especially since 1995), albeit unevenly across the country. For example, the Canada Health and Social Transfer (CHST), which replaced the Canada Assistance Plan (CAP) and Established Program Funding (EPF), has reduced transfers from the federal government to the provinces and has made these transfers unconditional. This change in policy has led provinces to scale back the health and social services they fund. Many provinces, for instance, have devolved responsibility for disability-related supports to community boards and local governments. In addition, eligibility criteria for Employment Insurance have been tightened and the labour force development boards have been dissolved. Although some groups and individuals have resorted to soliciting donations in order to fill the resulting funding gap, this “new” strategy for accessing resources could further entrench a charity-oriented approach to disability, rather than an equality-oriented one.

In Canada, non-institutional or community-based services have traditionally been delivered through various charitable and non-profit organizations, which define the services that will be provided, where, to whom and at what point in time. These service providers develop eligibility criteria, services, schedules, standards and methods of operation, usually consistent with government policies and funding allocations. The individual who requires services has rapidly become peripheral to this process. However, a shift is under way to support arrangements funded according to an individual’s needs and delivered according to that individual’s wishes. These individualized support arrangements appear to facilitate inclusion in mainstream employment, education and employment-oriented training. To promote inclusion, individualized support arrangements often involve community development processes to adapt human and organizational resources in varying degrees. Such arrangements, however, pose many policy dilemmas.

The study combines analysis of policy documents and qualitative data to explore the complex effects of these changes in service provision on the relationships between women with disabilities and their paid and unpaid support providers. Within the context of Canadian social policy, the study investigates how inequality is reproduced through the current structuring of relationships and how equality could be promoted within them. By identifying criteria of relationships that foster the equality of women’s well-being and the broader structural factors that affect the capacity of relationships to meet these criteria, the study contributes to the advancement of equality for women with disabilities and women who provide support. The study also points out the ways in which policies fail to address the tensions between women in these relationships or actually produce polarization. It culminates in concrete, feasible policy recommendations for innovations in disability-related support arrangements that ought to redress the unfortunate consequences, or inadequacies, of current policy in this area of social services. Although the research explores the experiences of women, the findings are also applicable to men.

Chapter 1 of the report describes the methodology, including a discussion of some concerns that arose during the research process. Chapter 2 reviews critical feminist and disability theory, outlining the contextual background on which the report is premised. Chapter 3 provides a statistical overview of caregiving and women with disabilities. Chapter 4 describes and analyzes the policy context in which women receive and provide disability-related supports in Manitoba, Ontario and Newfoundland. Chapter 5 provides profile descriptions of the women who participated in the case studies and focus groups, including some of the circumstances of their lives, their relationship to disability-related supports and their community contexts. Chapter 6 describes the concept of equality developed in the report, and six criteria for equality of well-being. Chapter 7 includes the qualitative analysis of equalities and inequalities in relationships between women, and Chapter 8 examines factors that account for equality. Chapter 9 points to policy directions suggested by the research, followed by a concluding chapter.

1. METHODOLOGY

Review of the Scholarly Literature

A review of feminist and disability literature examined conceptions of equality and inequality, the nexus of disability and gender, relational approaches to equality and equality of well-being, and social policy and equality in relationships of support.

Instrument Design

Before the research began, instruments and instrument protocols were designed and pre-tested. These instruments included two short demographic questionnaires and two interview instruments. One of each of these instruments was designed to obtain responses from women with disabilities and the others were designed to obtain responses from the women who provide support to them. These research tools (which appear at the end of the report as apendices A to D) were revised and developed throughout the study. An advisory committee of women with disabilities proved especially helpful with critical feedback and suggestions, which were incorporated[1] into the initial version of the instruments.

Demographic Overview

Statistical analysis for this research was based on the Health and Activity Limitation Survey of 1991 for Adults in Households (HALS).[2] The intention was also to use Statistics Canada’s General Social Survey (GSS) Cycle 11 on Social Support. However, as the GSS data set was released much later than anticipated, the analysis has been based on HALS.

The focus of the HALS-based analysis was on situations where persons with disabilities are receivers of care from women. This includes women with disabilities who received support from other females.

Case Studies

Ten women with disabilities and their paid and unpaid support providers agreed to participate as “case studies” to explore their perspectives and experiences with respect to disability-related supports. In order to reach women for the study, we provided a brief description of the project to several disability organizations and requested that they approach any of their constituents who might be interested in participating. When potential participants requested copies of the interview guides, these were forwarded to them. In turn, the names and phone numbers of women who were willing to participate in the study were forwarded to the interviewer. In this phase of the research, criteria were identified that advance equality in, and through, the provision and receipt of disability-related supports.

Semi-structured, the case study interviews ran about 1.5 to 3 hours in length and were conducted in Ontario, Manitoba and Newfoundland. The women participating in these interviews can be categorized in this way:

Women with disabilities	10
Paid support providers	10
Professional support providers	2
Informal support providers	4

All the women interviewed were White, urban and Anglophone.

Focus Groups

Two focus groups were held in Toronto, one with five women with disabilities and the other with three paid support providers. Each group—whose participants were contacted through disability, feminist or service-provider organizations, and a network of disability activists in Toronto—ran for about three hours. The format was relatively structured; the facilitators introduced questions for discussion by the participants who were also asked to complete questionnaires, which were modified versions of the instruments that had been used in the interviews.

Most of the women in the focus groups were White, urban and Anglophone. One woman was Black and another was First Nations. Two women of colour agreed to participate, but were unable to attend for personal reasons.

Initially, a focus group of unpaid support providers had been scheduled to take place in Toronto but was cancelled due to low participant response. It proved to be very difficult to identify and locate women who provide unpaid support outside of the case study methodology. In addition, organizations that were approached for assistance had no criteria with which to identify women who adopt this role.

Policy Analysis

Policy documents produced at the federal level and by the provincial jurisdictions of Manitoba, Ontario and Newfoundland were collected and analyzed, and telephone interviews were conducted with policy experts in each of the three provinces.

Expert Reviewers

Three women, one of whom uses personal support, one who works as an attendant and one who is the mother of an adult with disabilities, were contracted to review a preliminary draft of the analysis. Each of the women chosen to be a reviewer had skills appropriate for the task of reviewing analyses of this sort and a broad knowledge of the issues relevant to the study.

From their diverse perspectives vis-à-vis disability-related supports, the women reviewed the document to assess the relative accuracy of its construal of public policies and program arrangements, evaluate its presentation of complex political issues and the degree to which it deals appropriately with sensitive issues, and judge its readability and accessibility. In addition, the reviewers were asked to comment on the content of the report, given their personal experiences with disability-related supports. Where appropriate, their input was included in the analysis.

Methodological Issues and Alterations

The interviews were successful in revealing some important findings about equality in relationships between women with disabilities and the paid and unpaid women who support them. However, a number of methodological questions emerged.

Sample Selection

In qualitative research involving a targeted group, it is a fairly common practice to select a sample through networks of organizations which represent or serve members of the group. We chose this method for a numbers of reasons: sensitivity to the personal nature of the subject matter, maintaining response confidentiality, respect for the privacy of participants and the recognition that women with disabilities have been the objects of a great deal of research over which they have had no control. We wanted to gain consent from women through personal contact in which there was no sense of duress.

The sample method effectively addresses the above issues and succeeds in identifying participants; however, it also shaped the sample in particular ways. The experiences and perceptions of the participants with a disability (all but one of whom share a link to a disability or advocacy organization) may differ significantly from women who are not connected with a disability organization. This has a number of implications. First, while all disability organizations in Canada and all of their members do not share unanimous views and experiences, a well-articulated "disability politic" exists in Canadian organizations. Through their association with disability organizations, the women in this study are likely to be involved in the discourses of this politic, and may share a common language and (perhaps) viewpoint regarding the associated issues and concerns. Second, their association with such organizations indicates access to information and resources that may be greater than that of many other Canadians with a disability. This may affect their experiences, and their interpretation of their experiences compared to women who are more isolated from a disability community.

Insofar as members of these organizations assisted us in selecting women for the study, partiality might have been a factor here. For although we gave these representatives some criteria on which to base their selection, they may have used discretion with respect to which woman would be a good candidate for this study. Further, the women who agreed to participate might have additional qualities in common not shared with those who preferred not to participate. For instance, the women who participated may be relatively more or less satisfied with their support situation and support relationships and, consequently, eager to discuss them.

In some cases, women were not forthcoming with the names of all their support providers. Typically, the reasons for withholding this information included the providers only working part time, they were too busy or did not really provide that much support. It is possible that women were less willing to pass on names of those with whom they have less equitable, or more difficult relationships for fear of repercussions. Despite extensive explanation, interview participants maintained an impression that the research was about them personally rather than about policy questions and concerns regarding support relationships. Thus, some of the women with disabilities involved in the study may have wanted the interviewer to speak only with those women they believed would represent them, and their support, in a positive light. The case study design of the project may have contributed to this perception. Women were more forthcoming with names following the interviews. Time constraints of the interviewers made it difficult to conduct additional interviews in provinces outside of Ontario; however these interviews were later conducted by telephone.

Uneven Representation

Initially, our aim was to interview a minimum of three support providers per woman; however, this goal may have been too ambitious. In most cases, only one or two paid, unpaid and professional support providers were interviewed. Our initial intentions needed to be revised for a variety of reasons. In some cases, a given consumer only received support from one woman because she received other support from men, had very low support needs or received insufficient support. In many instances, women did not access supports from professionals such as physiotherapists or counsellors. Furthermore, only two professionals who provide such support agreed to be interviewed. Others refused citing confidentiality concerns. Thus, the analysis focussed primarily on issues experienced by paid supporters who do not have professional status, that is, attendants and home care workers. This constraint on the sample actually sharpened the focus of the study, because the concerns of professionals appeared to differ significantly from that of other paid workers who cannot appeal to professional status when questions of dispute arise. The experiences around labour, opportunity and equality of the former group suggest they tend to be less marginalized and more privileged. In other words, the positioning of both women with disabilities and their in-home support staff is a critical area of equality, as both seem to be situations of relative disadvantage.

Representation was also uneven in terms of racial and cultural diversity. While the intention of the research was to include a diverse sample of women, the actual outcome signalled limitations in this regard. All the interview respondents were White women; only two of the focus group participants were women of colour. Methodologically, a more proactive approach should have been taken, which included outreach to organizations serving people of colour. In addition, the geographic representation of the sample comprised urban women entirely; no rural women participated in the study.

Only a small sample of informal support providers participated in the study. In general, women with disabilities who took part in the case studies did not refer us to women who provided this kind of support. In some cases, women with disabilities did not refer us due to the fact that they do not receive disability-related informal supports. In other cases, women with disabilities were uncomfortable referring us to the women who assumed such a role in their lives, either because they did not want to ask these women to give up more of their time than they already do or because stresses existed in these relationships—ones that they did not want explored.

The sample also lacks equal representation of women with intellectual disabilities. Although organizations, which include and represent this group of women, were contacted to approach participants, women with intellectual disabilities in only one province agreed to participate. This is unfortunate, since the experiences and concerns of these women are likely to differ from those of women with physical disabilities. Indeed, even the two women with intellectual disabilities who were interviewed had remarkably divergent experiences with supports; one required and received the least support of any of the participating respondents and the other required the most support. Thus, the findings with respect to either of these women cannot be generalized.

Only Anglophone women participated in the study. The original proposal stated that at least three research participants would be Francophone. However, due to resource constraints, these interviews were not conducted. While the research team acknowledges the experiences and viewpoints of Francophone women would have been valuable to the study, it was felt that the case study sample size was too small to capture any significant cultural difference between Francophone and Anglophone women.

Methodological Corrections

As outlined above, some methodological difficulties became evident as the study unfolded. In response, the research team altered the proposed methodology in ways that would address some of these concerns. The number of case studies was reduced and replaced by focus groups, outreach methods were altered, and external reviewers who were representative of women with a disability and paid and unpaid support providers were contracted.

Number of interviews reduced and replaced with focus groups

The proposal stated that 16 case studies would be conducted (including three Francophone case studies). However, as outlined above, during the interview process it became clear that some women did not feel they could speak freely in a methodology where their support providers were also being interviewed. The number of interviews was reduced to 10, and focus groups were developed to compensate for the six case studies that were not completed.

Outreach methods were altered

In order to select focus group participants, we employed a slightly different procedure than we had used to conduct the case studies. First, and most important, the personal link (between women with disabilities and support providers) which may have tainted the findings in the case studies was omitted in the organization of the focus groups. Support providers and women with disabilities were approached separately and had no formal connection to each other. The research team hoped that choosing participants who were unknown to each other would enable the women to speak more freely about inequity. This strategy was effective in terms of raising new issues and complexities.

In addition, a different outreach method was used. First, disability organizations and service provider organizations were approached to assist in identifying participants. Then, women involved in some aspect of an informal network of disability and feminist activists (including women connected to feminist women of colour organizations) were approached. These strategies proved to be somewhat effective in diversifying the representation of focus groups compared to case studies in terms of race, as two women of colour participated. (A number of other women of colour had expressed interest but were unable to be there.) It did not succeed however, in increasing the representation of women with an intellectual disability, Francophone women, rural women or women not connected to disability organizations. Regarding rural women and Francophone women, it was beyond the resources available to conduct focus groups in other regions. Furthermore, although the intent was to hold a focus group for informal support providers, as few organizations (if any) exist for women in this situation, we were not able to contact such women within the time constraints of the study. Regrettably, representation from these groups remained low.

External reviewers were contracted

While the use of external reviewers who were representative of women with a disability, and both paid and informal support providers was not part of the proposal, it became evident during the drafting of the report that a critique by women in these positions would be beneficial. A woman from each of these perspectives was contracted to review and critique the document. As a result, the quality and integrity of the final report improved considerably. The reviewers were an excellent source of critical feedback, informed the analysis from the perspective of specific experiences, and acted as a check and balance, pointing out, and correcting, instances of possible bias.

2. CONTEXTUAL BACKGROUND

Conceptions of Equality and the Inequality of People with Disabilities in the Canadian Context

In mainstream philosophical theories of distributive justice, equality has been measured in terms of the possession of (for instance) goods (Rawls), resources (Dworkin) and liberties (Nozick). Feminist philosophers have argued that this construal of equality is limited (Young 1990; Benhabib 1987). This is because such a conception of equality does not account for experiences of oppression (including exclusion and marginalization), which ought to be factored into any measurement of that value (Young 1990, 1987). Feminists argue that the construal of equality that mainstream political philosophers have produced reflects andro-centric biases, which exclude women from achieving the status of full citizenship and the access to resources and equal enjoyment of social goods (such as mutual respect) attendant upon it (Lister 1997; Pascall 1993; Young 1990). Feminists who argue in this way have pointed out that in terms of mainstream theories of social justice, the citizen to whom these goods and resources are owed is conceptualized as a rational, autonomous human being who engages in public transactions with others. This allegedly disinterested, value-neutral conception of the citizen, they argue, actually articulates the interests and values of non-disabled, White, European men (Young 1987; Markus 1987). As they explain it, this conception of the citizen fails to accord value to activities in the "private domain" in which women have traditionally been engaged (e.g., rearing children, doing housework, cooking and so on).

The recent writing of disability theorists and activists also draws attention to the ways the dominant notion of the citizen precludes people with disabilities from achieving equality. Disability theorists have described the ways current architectural design and infrastructural planning pose physical barriers to the participation in social life of people with disabilities. Certain cultural norms about bodily functions and appearances dehumanize them, and social expectations about activity and performance render them as unproductive, non-contributing individuals (Tremain 1996b; Barnes and Mercer 1995; Silvers 1995; Rioux 1994). Disability theorists have criticized the ways in which mainstream theories of social justice reinforce widely held assumptions about people with disabilities whose "handicaps" ought to be compensated (Dworkin 1981) and which render them deserving recipients of public charity, rather than full-fledged citizens on whom rights and liberties ought to be conferred.

In order to represent people with disabilities as deserving of public charity, those theories reproduce pervasive cultural stereotypes of them as dependent, childlike and unable to provide for themselves. To be sure, much of the theoretical work on social justice has assumed that people with disabilities are incapable of participating in the labour force, and thus, contributing to the economy. Rarely has disability been regarded in these mainstream theories as an economic issue or problematic of citizenship. To the contrary, the equal distribution of resources (such as disability-related services) to people with disabilities has been represented in those theories as the satisfaction of "special needs" (Rawls 1993, 1971) that lie outside of the circumstances of justice. In fact, research has shown that one's participation in the labour force is determined primarily by one’s access to disability-related supports, not the nature or degree of the impairment. Paradoxically, an individual must be designated as “unemployable” in order to qualify for many of those supports.

This misrepresentation of disability and the distribution of resources to people with disabilities in theoretical work on social justice reflects their marginalization in concrete social existence. Research shows, for example, that both women and men with disabilities lack adequate disability-related supports (Fawcett 1996). Persons with disabilities are nearly twice as likely to be poor (living below the poverty line) than persons who are not disabled (Fawcett 1996). Surveys and census data suggest that people with disabilities are twice as likely to rely on the social security system for personal and family income (11.6 percent compared with 5.8 percent of persons age 12 and over in 1994) (NPHS 1995) than people without disabilities. Furthermore, they tend to earn less money when employed, with only 7.6 percent making over $30,000 compared to 15.1 percent of people without disabilities who make this amount or more (Hum and Simpson 1993; see also Statistics Canada 1994a).

The construction of support to people with disabilities as “charity” or as a welfare issue may have implications for the status of those who provide them with supports and services. As this study shows, the people (predominantly women) who provide disability-related supports are precluded from achieving equality by virtue of the limited rewards and the low status of the work they do. People who worked in this sector when it was more institutionalized, were conferred higher status, benefits and wages. Currently, employment in this area reaps low wages, few employee benefits and little opportunity for career development. In addition, the support worker’s job is difficult, often an invisible social and economic contribution, and may have lasting impacts on her (or his) health. Although unions represent some support workers, the work force in this sector tends to be made up of transitional, part-time workers with limited education, and little or no organized representation. In this respect, they are also precluded from achieving equality by virtue of the various factors in their lives that might have situated them in this labour market.

Construing disability-related support as unnecessary to securing equality rights presumes that gaps left by “public charity” (paid support) can, and should, be filled by “community charity” (unpaid support). Usually the phrase “community charity” can be read to mean “women’s unpaid labour.” As the 1996 Census data indicate, women take on the bulk of unpaid support and other unpaid work in communities across Canada. The census indicates, furthermore, that caregiving constitutes much of the unpaid work women do (Status of Women 1998).[3] In general, seven percent more women do some form of unpaid work than men (92 percent compared to 85 percent). While data related to providing care to persons with disabilities were not available, 42 percent of women compared to 34 percent of men spent time providing child care, and 19 percent of women compared to 14 percent of men spent time caring for seniors. Women also devoted longer hours to such activities. Fifty percent spent over 30 hours a week doing housework or home maintenance in the week prior to the census, with five percent of this group spending more than 60 hours doing such activities. In contrast, only 16 percent of men spent over 30 hours a week on housework or maintenance (Statistics Canada 1998).

It is not clear if figures given in the census account for the enormous energy women expend fulfilling (unpaid) advocacy and management responsibilities. Regardless, it is safe to say that the inadequate distribution of resources to people with disabilities places a heavy burden of social responsibility on women, a burden that poses threats to their respective health and well-being, and their economic opportunities and securities. Thus, the challenge for policy makers is to recognize the paid and unpaid contributions of women to the support of people with disabilities, and the resources necessary for them to do so in ways that strengthen their social and economic position.

The Disability and Gender Nexus

Support service work is also devalued insofar as it is regarded as “women’s work,” that is, it reflects women’s traditional roles in the domestic domain, as homemakers, caregivers and nurturers. Despite the fact that “women’s work” requires skills and expertise, it does not tend to be given professional status. Rather, women who work in occupations (such as nursing, teaching, secretarial work) that have been traditionally female domains tend to have less status and receive lower pay than those who work in the domains that have stereotypically been considered “male.”[4] Indeed, due to systemic sexism, women generally are more apt to work in low-status jobs than are men. Due to pervasive sexism, furthermore, the majority of women who work in the paid labour force tend to earn less than employed men. In 1998, for instance, the average annual income for men was just over $34,000, while the average income for women was about $22,000 (Statistics Canada 2000a). In addition, women tend to be employed as casual or part-time workers. In 1999, more than twice as many women as men reported they worked part time (Statistics Canada 2000b).

Because women with disabilities confront systemic sexism, they are further marginalized than men with disabilities. Women with disabilities are more likely to live in poverty, to have less access to equitable employment and to education than men with disabilities (or women without disabilities). In addition, women with disabilities are more likely to be unemployed than men with disabilities. In 1991,[5] for example, 16 percent of women with disabilities were unemployed compared to 13.2 percent of men with disabilities who were unemployed. Moreover, when women with disabilities are employed, they earn less money than men with disabilities. Fawcett (1996) indicates that in 1991 65.6 percent of women with disabilities earned less than $25,000 annually; in contrast, only 38.4 percent of men with disabilities earned less than this amount (Fawcett 1996). In this respect, the wages of women with disabilities are more comparable to the wages of women without disabilities than they are to the wages of men with disabilities. Both women with and without disabilities earn an estimated 63 percent of what men earn (Barnartt and Altman 1997).

Due to systemic sexism, furthermore, women with disabilities continue to work in traditionally gendered patterns of employment. Like women without disabilities, women with disabilities tend to hold occupations, such as homemaker, secretary, nurse and teacher, that mimic traditionally female occupations (and roles) which have lower social status (Roeher Institute 1993d). Because women and their pursuits are systemically devalued, women with disabilities are less likely to receive sufficient paid and unpaid support than are men with disabilities (Fawcett 1996).[6] When women with disabilities do not receive sufficient support, their health is compromised, their labour force and community involvement is restricted, and their reproductive choices are put at risk.

The individuals signified as "women" do not constitute a homogeneous group (Riley 1988). Rather, women are variously positioned along lines of disability, race, class, age, sexual orientation and ethnicity. Therefore, a host of social circumstances (in addition to those which compound due to sexism and disability discrimination) must be considered in an examination of the barriers to equality that confront women with disabilities and the women who provide them with disability-related supports. While a certain woman might be oppressed vis-à-vis other women due to systemic disabilism, she might be privileged vis-à-vis some women due to institutionalized racism (Vernon 1996; Begum 1992; Stuart 1992). While women with disabilities may be similarly oppressed due to disabilism, some of them may be oppressed due to heterosexism and homophobia in addition to the oppression they experience due to disability (Tremain 1996a; Appleby 1994; Hearn 1991, 1988). Furthermore, while women with disabilities may be similarly oppressed due to disability discrimination, some may also be oppressed due to systemic racism. Recent U.S. data show, for example, that Native women and men with disabilities in the United States experience more significant barriers than non-Native women and men with disabilities when they attempt to access employment services (such as vocational rehabilitation), transportation, job training, employment opportunities and health care (Pichette et al. 1997).

Since the mid-1970s, most feminist theorists have distinguished between sex and gender in order to account for the diverse socio-cultural experiences of women (Rubin 1975; see also Kramarae and Treichler 1985; Haraway 1991). They have argued that the category of "sex" does not signify some historical, essential nature, which determines women's experience, capacity and character, for the biological raw matter of "sex" is always culturally interpreted. They refer to these historically specific interpretations of biological "sex" as "gender." That is, feminists who draw a sex–gender distinction argue against the idea that women share some common trait that makes them most suited to be nurturers and caregivers. Instead, they argue that a host of social and cultural expectations and restrictions collude to socialize females to fulfil these roles, that is, to *become* nurturers and caregivers. They argue, furthermore, that the sexual division of labour, which associates women with the private realm and men with the public realm, is linked to capitalism and the patriarchal order. In patriarchal societies, they explain, women are restricted to domains in which they must provide unpaid or cheap labour, and are confined to roles of dependency in order that their reproductive potential can be controlled.

Like the category of sex, the category of disability has come to be regarded as a social construct. Until the mid-1970s, the classification of disability was based on medical diagnosis, pathologized and individualized. Insofar as disability was construed in this way, people with disabilities were regarded as individuals in need of treatment, rehabilitation and care. In many contexts, medical diagnosis continues to be the criterion used to determine whether one should be assigned the disability status that is required to gain access to programs and services. In recent years, disability activists and theorists have produced a number of social models of disability and human rights approaches which counter the dominant medicalized conception. In these, disability is construed as a disadvantage imposed on a person by barriers which prevent equitable participation in society. The social oppression model of disability is described by Bury (1996: 25).

> [D]isability is not the resulting limitations caused by chronic illness, impairment or trauma, but the way such matters are responded to and categorized by the wider society. Disability is the product of definitions and practices that seek to exclude individuals who might be seen to deviate from the socially constructed norms of the "able bodied"…disability should not be conceptualized as an individual attribute, but as the result of "exclusionary practices."

Relational Approaches to Equality and Equality of Well-Being

To counter the andro-centrism of mainstream theories of social justice and equality, feminist theorists, such as Martha Minow, have developed relational approaches to the achievement of those values. Mainstream accounts variously conceive people as isolated bearers of rights and liberties. By contrast, in feminist relational approaches, people are conceived as fundamentally connected, and differences between them are (to a significant degree) regarded as constructed and changeable (Minow 1990). Indeed, many feminists eschew the notion of rights as masculinist. They maintain that rights-based theories are grounded in autonomous individualism, which reflects the psychosexual need of male children to separate from the female maternal body (Irigaray 1985; Gilligan 1982). However, Minow cautions feminists not to dispense with the notion of rights altogether. She argues that feminists ought instead to reconceive that value in order to develop a notion of "rights in relationship." As she writes (1990: 301):

> Autonomy, if defined as the condition of an unencumbered and independent self, is not a precondition for any individual's exercise of rights. The only precondition is that the community be willing for the individual to make claims and to participate in the defining and redefining of personal and social boundaries.

She points out, furthermore, that "all rights claims imply relationships among mutually dependent members of community." According to Minow, when the social structure in which rights are distributed is restructured in ways that equalize the social and economic positions of differently situated people, many of the problems associated with traditional conceptions of rights can be avoided.

Relational approaches do not rely on a notion of equality of opportunity, where differently situated people are treated as if they were similarly situated. Rather, relational approaches to equality hold that the different "situatedness" of people must be acknowledged, and social institutions (including law and public policy) must be restructured in order that the disadvantages which accrue to some in their relations with others who are differently situated can be addressed substantively. To account for the different "situatedness" of diverse groups of people, equality must be measured in terms of people’s enjoyment of well-being (Minow 1990; Sen 1980, 1985; Rioux 1994).

Social Policy and Equality in Relationships of Support

As this study demonstrates, relationships between women with disabilities and their paid and unpaid support providers are ones of mutual dependence and interdependence, sometimes also involving others such as children, friends, family members and so on. Thus, the social circumstances, which affect one of these groups of women, have impacts on the others. For example, some support providers have abused the women to whom they provide support. While such abuse is unacceptable, regardless of any extenuating circumstances, research suggests that many of these incidents could be attributed to stress, frustration or fatigue on the part of the perpetrators which could result from circumstances such as long or late hours, low pay, insecurity or overwork (Roeher Institute 1995a). Thus, changing the employment conditions of caregivers would not only benefit them, it may also reduce the risk of abuse of the women who receive their services. In other words, when any given woman in this complicated triangle is disadvantaged, the others are often disadvantaged either directly or indirectly.

Policies affecting women with disabilities in regards to services may affect support providers also. In addition, policies which affect paid or unpaid support providers may affect the equality of women with disabilities. While barriers to equality for women in relationships of support may be a result of policy determinants (such as disability-related support arrangements and funding) external to the relationships themselves, these institutionalized inequalities may emerge within those relationships and be enacted by the particular individuals involved.

3. DEMOGRAPHIC ANALYSIS

The statistical analysis for this research is based on the Health and Activity Limitation Survey (HALS) of 1991 for Adults in Households.[7] It focusses on situations where persons with disabilities are receivers of care from women. This includes women with disabilities who received support from other females. It also focusses on situations where people with disabilities, including females, receive help from community service agencies.

HALS allows for identification of who helped persons with disabilities in everyday activities (e.g., meal preparation, shopping, personal care, housework, personal finances). Those who provided support include family members, friends/neighbours and community-service providers. For family members, the responses can be clustered in the following groups:

- males receiving help from
  - wife/female common-law partner only,
  - daughter(s) only or
  - wife/female common-law partner and daughter(s);
- females receiving help from
  - daughter(s) only,
  - husband/male common-law partner only or
  - husband/male common-law partner and daughter(s); and
- females (over 15 years of age) receiving help from
  - community service agencies.

Using this approach, it can be conservatively estimated that 650,000 persons with disabilities received informal help with routine activities of everyday living from women in the same family in 1991, or 18.3 percent of all adults with disabilities. The estimated number of females who provided this help is nearly 720,000 persons.

According to HALS data, there were 182,0000[8] women over the age of 15 needing help with daily living activities in 1991. Of these, an estimated 330,000 females (18.2 percent) over the age of 18 received help from community service agencies. HALS does not distinguish the gender of these formal care providers.

Tables 1 through 6 show statistics on informal care in Canada. Table 7 looks at the numbers of women who receive formal care through community service agencies.

Table 1 shows that the largest number of informal female caregivers for persons with disabilities are wives/common-law partners of males who have disabilities (247,350 + 144,460 = 391,810 women) followed by daughters of females with disabilities (184,940 + 105,720 = 290,660 females).

Table 1. Persons with Disabilities Receiving Informal Help with One or More Everyday Activities from Caregivers in the Same Family

Gender, Person Receiving Help	Relationship of Caregivers to Person Receiving Help	Number of People Receiving Support	Minimum Number, Female Caregivers
Male	Wife/female partner only	250,000	250,000
	Daughter(s) only	37,000	37,000
	Wife/partner and daughter	72,000	145,000
Female	Husband/male partner only	325,000	
	Daughter(s) only	185,000	185,000
	Husband/partner and daughter	106,000	106,000
Total		975,000	723,000

Source:
Roeher Institute (unpublished) based on HALS 1991.

The research found that HALS does not distinguish on the basis of gender between sibling caregivers (i.e., brothers from sisters) nor between other family members (e.g., aunts, female cousins and grandmothers). Nor does HALS permit a distinction between mothers and fathers who provided support. HALS simply classifies such caregivers as “brother or sister,” “other relative” and “parent.” Accordingly, the figures obtained from HALS underestimate the extent of female involvement in informal care within the family, probably by a considerable margin. Some 141,834 adults with disabilities received help in everyday activities from one or more “parent” in 1991; 96,790 received support from “brothers or sisters” and 225,760 received help from “other relatives.” These latter categories are not mutually exclusive (i.e., a person could have received help from a mother, sister, aunt and grandmother).

In that HALS limits analysis of female caregiving to situations involving wives/common-law partners and daughters, the design of HALS is problematic. However, HALS does provide some information which can be used to guide analysis using instruments such as the General Social Survey. For instance, Table 2 shows that there is greater involvement of females in caregiving for males as they get older than for females. Males aged 55 and older with disabilities were roughly 50 percent more likely than females in this age range to have received help from females of the same family in everyday activities in 1991.[9]

Table 2. Persons with Disabilities Supported by Females of the Same Family, Showing Gender of Persons Served and Age Cohorts

Age Group	Number of Males Supported	Percentage of Age Group Supported by Females	Number of Females Supported	Percentage of Age Group Supported by Females
15 - 34	28,000	8.6	8,500	2.4
35 - 54	85,000	17.4	77,000	15.4
55 - 64	82,000	26.0	54,000	17.1
65 +	161,000	31.6	150,000	20.8

Source:
Roeher Institute (unpublished) based on HALS 1991.

Table 3 shows the proportion of people with disabilities according to their census family status who received help from one or more females in the same family. Those most likely to have received help in 1991 were husbands/male common-law partners, where 29.3 percent received such support. Some 48.3 percent of all situations in which females provided help in everyday activities involved husbands/male common-law partners. Female lone parents were also comparatively more likely than others to have received help from same-family females (i.e., daughters); this occurred in 20.5 percent of cases involving female lone parents as compared with the mean of 18.8 percent.

Table 3. Census Family Status of Persons with Disabilities Who Received Help in Everyday Activities from Females in the Same Family

Census Family Status	Percentage of Persons in Status Group Receiving Help from Same-Family Females	Percentage of All Persons with Disabilities Receiving Help from Same-Family Females
Child	4.0	1.7
Husband/male common-law partner	29.3	48.3
Female lone parent	20.5	5.0
Male lone parent	15.4	0.8
Not a member of a census family	15.3	23.2
Wife/female common-law partner	14.6	21.0
	Mean = 18.8	Total = 100.0

Source:
Roeher Institute (unpublished) based on HALS 1991.

Table 4 shows the kinds of activities in which females of the same family provided help to persons with disabilities in 1991. In all activities where help was needed because of disability, females of the same family played a major role.

Females of the same family were more likely to be involved in situations where persons with disabilities needed more help in everyday activities than was available to them in 1991 (Table 5). In effect, the informal care that women of the same family provided often replaced the support from community agencies. For example, only 4.6 percent of adults with disabilities (116,220 persons) received help from females of the same family and community-service providers in 1991 (e.g., voluntary and/or for-profit agencies).[10] Some 11.3 percent (398,000 persons) received help from community-service providers and did not receive help from wives, common-law partners or daughters. In contrast, 13.6 percent (486,000 persons) received help from such females without any additional help from community-service agencies.

Of all people with disabilities who reported that they needed more help with everyday activities than is available to them,[11] 31.8 percent were helped by women of the same family. In situations where the level of help was reportedly adequate, women of the same family were involved in 38.6 percent of the cases.

Table 4. Everyday Activities in which Females of the Same Family Provided Help to Persons with Disabilities in 1991*

Activity	Number of Persons Helped by Females of the Same Family	Percentage of All Persons Helped because of Disability/ Health Receiving the Help from Females of the Same Family
Meal preparation	190,000	42.8
Shopping for groceries and other necessities	320,000	43.9
Everyday housework (e.g., dusting, tidying)	300,000	43.3
Heavy chores	540,000	39.6
Personal finances	210,000	47.9
Personal care (e.g., washing, grooming, dressing, feeding)	116,000	49.4
Movement in own residence with some help of another person	54,000	58.8
Movement in own residence only with help of another person	8,000	40.4

Note:
Everyday activities would include meal preparation, shopping, everyday housework, heavy household chores, personal finances, personal care (e.g., washing) and moving about at home.

Source:
Roeher Institute (unpublished) based on HALS 1991.

Table 5. Whether Persons with Disabilities Needed More Help in Everyday Activities, 1991

	Percentage of Situations where Females of the Same Family Provided Help with Everyday Activities	
Activity	**No additional help needed**	**More help needed**
Meal preparation	18.6	32.9
Shopping for groceries and other necessities	18.6	37.4
Everyday housework (e.g., dusting, tidying)	17.2	35.3
Heavy chores	22.9	35.4
Personal finances	17.9	40.2
Personal care (e.g., washing, grooming, dressing, feeding)	18.1	48.8
Movement in own residence	18.6	47.1

Source:
Roeher Institute (unpublished) based on HALS 1991.

Females of the same family were slightly more likely to be involved with persons with disabilities who were poor than in situations where they were living above Statistics Canada's low income cutoff (LICO) in 1991 (19.8 and 18.7 percent, respectively). However, 18.2 percent of females with disabilities who were poor, who needed help, received it from other females of the same family, compared with only 15.1 percent of females who needed help and were living above the poverty line. Overall, males were more likely (22.4 percent) than females (18.9 percent) to have received help from women of the same family in 1991. For males, about the same proportion received help from females regardless of low-income status.

Females of the same family were least involved in a caregiving capacity with individuals who were employed in 1991 (8.9 percent), slightly more involved with job seekers (13.4 percent) and most extensively involved with persons who were not in the labour force (21.1 percent). Concerning people not in the labour force who received help from females of the same family, 22.7 percent indicated that one or more barriers and disincentives prevented them from looking for work (e.g., potential loss of disability income or drug plan, inadequate training, discrimination). The level of female caregiving involvement was higher than for those not in the labour force, who did not cite barriers as factors preventing them from looking for work, where only 18.3 percent were helped by females of the same family.

In some measure, these findings may be a function of the severity of the disabilities of the persons supported. Women of the same family were least likely to be involved with persons who had a “mild” degree of disability (6.8 percent) and most likely to be involved with persons with a “severe” level of disability (41.6 percent). They were more involved with persons who reported pain or discomfort than with others (25.5 and 11.6 percent respectively), and were most involved with persons reporting a severe degree of pain/discomfort (29.4 percent) than with those who reported only a mild (18 percent) or moderate degree of discomfort (26.1 percent).

Females of the same family provided support to 31.7 percent of people who used specialized aids for breathing (e.g., respirator, ventilator, oxygen) than was the case with persons who did not require such technological support, where only 18 percent received help from females of the same family. Similarly, females provided support to a large share of people who needed more in the way of aids and devices for mobility, seeing and hearing than was available (30.9 percent of cases).[12] For persons requiring no such aids or devices, or who used the devices and whose needs were adequately met, females of the same family were involved in caregiving to a much lesser degree (16.9 and 16.8 percent of cases respectively).

Some differences are observable in terms of whether persons with disabilities who needed help in 1991 and who received income through the disability income system also received help from females of the same family (Table 6). For instance, a comparatively low proportion of social assistance recipients with disabilities received help from such women (17.4 percent), roughly similar to the group not attached to the disability income system. In contrast, the proportion of other program beneficiaries receiving such help ranges from 33.3 to 45.1 percent, depending on the program.

Table 6. Proportion of Persons with Disabilities Attached to the Disability Income System Receiving Help from Females of the Same Family

Income Security Program Status	Percentage Receiving Help from Females of the Same Family
No income from disability pension or benefit programs	16.3
Canada Pension Plan - Disability benefit	37.8
Workers' compensation	38.2
Employment Insurance sickness benefit	28.9
Private disability insurance	45.1
Employer-based disability insurance	40.2
Social assistance/welfare	17.4
Veterans pension or allowance	33.3

Source:
Roeher Institute (unpublished) based on HALS 1991.

This difference may be due to the type of family composition of people helped by females and receiving various forms of income. For example, of all adults with disabilities receiving income from one or more programs in 1990, 31.4 percent were not members of census families. That is, they were living alone or with others in non-family situations, such as shared living arrangements. Depending on the program, the proportion not residing with census family members ranged considerably, the highest proportion (45.5 percent) being for those receiving social assistance/welfare. Such individuals were less likely than others to have had proximity to, and contact with, family members, including women prepared to offer help with everyday activities.

Table 7 indicates that of the nearly two million women with disabilities in Canada, just over 300,000 receive formal support from community agencies. This means that nearly 1.5 million women with disabilities (82 percent) either receive no support at all, or receive only informal support from family members and others.

Over half (58 percent) of the women who do receive formal support are women who do not live with a census family. That is, they either live alone or with people who are not family members. Thirty-eight percent of the women receiving formal supports live with partners. The least likely women to receive formal supports are those living with their parents (census family), making up only 1.4 percent of all women receiving such support. They are followed by single mothers (5.2 percent).

HALS data suggest that women in some living situations are more likely to access help from community agencies. Of all female children with disabilities who live with their families, less than four percent receive agency support. Of those who live on their own, or with people they are not related to, just over 30 percent receive such support.

Marital status also seems to have an impact on access to community agency service. Women with disabilities, who are married/living with partners are somewhat more likely to access support than single mothers (nearly 13 percent compared to 11 percent) whether or not they have children.

Table 7. Census Family Status of Females with Disabilities Receiving Help in Everyday Activities from Community Service Agencies

Census Family Status	**Persons in Status Group Receiving Help from Community Agencies**		**Percentage of All Females with Disabilities Receiving Help from Agencies**
	#	**%**	**%**
Female child*	5,000	3.7	1.4
Female lone parent	17,000	11.1	5.2
Female not a member of a census family	190,000	30.9	58.2
Wife/female common-law partner	120,000	12.7	35.2
Total receiving help from community agencies	330,000	18.2	100

Note:
* Child refers to a person 15 years or older who lives with her or his census family (i.e., this could be a 25 year old woman living with her parents).

Source:
Roeher Institute (unpublished) based on HALS 1991.

Summary of Findings

- Women of the same family are most involved in providing help with everyday activities to older adults, particularly males (most notably husbands/male common-law partners).

- A comparatively high share of female lone parents with disabilities receive help in everyday activities from females of the same family (i.e., daughters). A comparatively low proportion of these women does not receive support from community agencies.

- The most usual kinds of help provided include assistance moving about in the personal home, personal care (e.g., feeding, washing, grooming, using toilet) and personal finances.

- In many instances, the help females provide is not augmented by community services. Over two thirds of women with disabilities do not receive any formal supports from such services. In nearly one third of cases where people with disabilities need more help than is available for everyday activities, women of the same family are involved in a caregiving capacity.

- Women are more likely to be providing help to others of the same family in situations of poverty than in situations where poverty is not an issue.

- The help women provide is, in a large number of cases, for persons who are not in the labour force and for those with a severe degree of disability. In many cases, the recipients of the care report that one or more barriers, aside from their disability, prevent them from looking for work.

- Women are much more likely to be providing support to people who report pain or discomfort than to people who do not report pain/discomfort. Where pain is an issue, women caregivers are most extensively involved with people who experience a severe degree of pain or discomfort.

- A large share of people requiring assistive technology for breathing are helped in everyday activities by women of the same family. This is less likely to be the case for people not using specialized technology to breathe.

- Women of the same family are more likely to be involved in a caregiving capacity with people who have less than needed assistive devices for seeing, hearing and mobility, than is the case with people who either do not need such aids or whose needs have been adequately met.

- Women play a major role in providing support to people who receive income through the disability income system. However, they are less involved as caregivers of people with disabilities who are social assistance recipients than with others in the social security system. This finding could be a result of the fact that social assistance recipients are more likely than others to be living alone or with others in “non-family” situations and to have comparatively little contact with any family members.

- Women are most likely to receive formal support from community agencies if they do not live with their families, or if they are married. The presumption in these cases may be that they do not have as much access to support from women/girls and other family members. Women are much less likely to receive agency support if they live with their parents or if they are single mothers. Perhaps, in the former case, sufficient informal help is presumed to be available. The reasons why single mothers have difficulty accessing formal support are not clear.

4. PROFILES

Personal Relationships

The 16 women in the study who were disabled have a variety of personal lifestyles: eight live with partners (heterosexual marriages, common-law relationships and one lesbian relationship). In some cases, the partners of these women are disabled also. Eight were single. Of these eight women, two identified as lesbian. Three of the women had young children.

Paid and unpaid support providers were more likely than women with disabilities to live with partners. Of the 13 paid support providers, nine live with husbands or boyfriends, and seven of these have children. Of the four single women, one lives with friends, and the others did not discuss her living situation. Two of the four identified as lesbian. All three of the informal support providers lived with partners.

Geographic Location

All the respondents live in the cities of Toronto, Winnipeg or St. John’s, though some grew up in rural areas or small towns. While women were not asked why they moved to (or stayed in) the city, people who are disabled often move to cities so they can access services (Roeher Institute 1993d: 70). In Newfoundland, in particular, some formal support providers had moved to the city to find employment. It should be noted, that the findings of this study may not reflect the situation of rural women who may have quite different access to supports, and to employment, have different socio-economic concerns and different cultures of support in their communities. In consequence, rural women may confront different issues of equality and inequality in their relationships of support.

Employment

Five of the 10 women with disabilities taking part in the case study interviews worked in the paid labour force.[13] Of these, two had short-term contracts, one worked two part-time jobs (which are equivalent to a full-time job), one worked part time and another was self-employed. Five of the 10 women were not working. Of these, one was looking for work. Four of the five were on disability benefits, and the fifth was supported by her husband. All the working women also worked for disability organizations, or in the disability sector in some capacity. In fact, many of the women, whether or not they worked in the paid labour force, were active volunteers at disability organizations and other community organizations. This can be attributed, at least in part, to the fact that these women were contacted through the disability network.

The 10 paid support providers were attendants, home-support workers or both. Of the 10, six worked full time and the remaining four worked part time. They are responsible for a range of tasks, including assistance with personal care (getting clients out of bed, bathing, dressing and washroom assistance); with cleaning, cooking, laundry, shopping, yard work, feeding pets and doing minor repairs; with medical care (giving medications, and cleaning and maintaining medical and assistive devices); and accompanying clients to malls, parks, swimming pools and elsewhere in the community. Most of these workers do some combination of tasks in all of these areas, although some were hired for specific tasks (e.g., attending a client at a swimming class). Six of the women were hired directly by the women with disabilities for whom they worked, three worked for public home-care agencies, and one worked for a transitional housing agency.

One woman, who co-ordinates support arrangements for her sister-in-law, who has an intellectual disability, was employed full time by her husband in proxy for his sister. She describes her responsibilities.

> *I have to fill out the forms of what is the best food for her to eat, like if she has problems with bowels. I have to make appointments with the dietician, figure out is she getting enough fibre, stuff like that.... We pay her bills, buy her clothes, buy her groceries, hire her staff, have staff meetings, keep track of her medication and how it is working on her. I have to keep track of how she reacts to it.... She goes to New World fitness on the track and I accompany her, myself and another staff member. We take her to dinner or something once a week, dinner in a restaurant. We take her to her family doctor; her psychiatrist makes a home visit. Or, if she gets sick we have to take her to emergency or something like that.*

The “professional” support providers, a physiotherapist and a counsellor, both work full time. The physiotherapist works as a course instructor and supervises students in a physiotherapy learning program out of a university, which is associated with a hospital. The counsellor is self-employed in her own practice.

Of the informal support providers, three were of retirement age. One of these had worked previously and the other two had been homemakers. A fourth was employed part time/occasionally in the paid labour force and was an unpaid homemaker.

Communities and Cultures of Support

The participants in the study lived in a variety of community settings. Gender and other differences in styles of support varied from community to community. Many of the women reported that they had strong extended family connections, where family members provided each other with support regularly. Women with disabilities described family members and their support providers alike as providers of practical and (in some cases) financial support for each other. For some of these women, their families comprised their primary communities. As one woman put it:

> *Basically, we have a really good family. My father had eight brothers and sisters and they’re very close. People do a lot of things for each other.*

Participants described communities which included networks of close friends. Friends were more likely to provide each other with emotional support, though there were also exchanges of practical support, such as babysitting, driving and helping with repairs or housework. As one woman explained:

> *In my peer community it's basically just getting together. We're not a married group, so it's just a case of getting together and talking and listening and helping when needed. Like, I have a car and a lot of my friends don't, so I take people places.*

Some respondents described their social circles as encompassing churches, neighbourhoods and the disability community. For instance, at least three women with disabilities reported that their social circles comprised primarily other people with disabilities and people who work in the disability sector as attendants or activists.

Although the women were not directly asked about their support relationships with men, discussions frequently arose respecting gendered styles of support. Many of the women were eager to discuss their support relationships with men, and the kinds of contributions men make (or do not make) in their lives and communities. Their interest in this discussion signalled its importance vis-à-vis their other relationships of support. Thus, a discussion of men's roles in women's lives has been included to locate the context in which support between women occurs.

Some women reported that men and women provide both the same amounts and types of support. As one woman remarked:

> *There is no difference between what men and women do in terms of support. Husbands assist in rearing children and housework. My son-in-law does everything from laundry to floors.*

In fact, some women received substantial support in their lives from men. Five of the women with disabilities named a male family member or spouse as a primary supporter. Interestingly, some women with disabilities reported that due to their disabilities, the men in their lives have taken on responsibilities that are traditionally female, despite the fact that this is not considered typical in their communities. As one woman explained:

> *In my home it's my boyfriend who cooks and cleans, but in my community women tend to do it. With my handicapped friends we have some kind of home care. My female friends are not disabled they just do it. Raise the kids and do it.*

Some women noted a difference between the communities in which they were raised and the ones in which they now reside. One woman remarked:

> *Here in St. John's myself and my husband, he doesn't try to tell me what to do, I don't tell him what to do. But, it's totally different from the community I*

> *grew up in. Where I grew up was a small Christian community where men were the breadwinners and women looked after the men, put meals on the table, kept clothes clean, reared the kids.*

It should be noted that in some cases the gender equity a number of women claimed existed in their relationships conflicted with the experiences they actually described. That is, although some women emphasized that they experience gender equality in the types and the amount of support they give and receive, they described their activities in ways which suggested that they clearly carry a much larger burden of support than do the men in their lives. For example, some participants provide hours of emotional and practical support to their family and friends; yet, they receive little emotional and practical support in return from the men in their lives. Furthermore, others claimed that gender did not influence the way in which tasks were distributed between the men in their lives and themselves. Nevertheless, they seem to engage in traditionally gendered patterns of support. The reasons for this discrepancy are unclear. Perhaps women are misreporting the hours of support they provide. They may, for instance, be so accustomed to providing support that they do not even think of it in this way. Alternatively, they may not wish to perceive a gender imbalance in their relationships. Thus, they deny any suggestion of it in order to avoid any disruption in their lives. Indeed, one respondent became visibly distressed when the gender inequity, which structured her relationships, became evident as she began to describe her domestic responsibilities. For not only did she work a 50-hour week outside of her home, she also devoted another 20 hours a week to her domestic responsibilities. This woman could not think of a single thing that her husband or children did for her in return.

Some women reported that men and women in their communities provide equal, but different, types of support. Generally, these women (regardless of whether or not they were employed) saw their primary roles as homemakers; they viewed their male partners as breadwinners. These women tended to report contentment with this arrangement. In such cases, the women reported that the men in their lives sometimes cook or clean; however, they described the participation of the men in household chores as “helping” them with their own responsibilities.

In two instances, women reported relationships of support between women as the most significant in their communities. One woman remarked:

> *In my life and friends, I would say the majority of people who support are women. I talk to men friends but not sharing any great moment. Most women share their big and great moments with other women.*

Within the communities studied, there was limited cultural or ethnic diversity. Almost all the respondents were of European descent. Thus, it might not be surprising that very few (except respondents in Newfoundland who described strong community support as “typical Newfoundland style”) described cultural background as a significant factor in their lives.

Service Arrangements

In Canada, personal supports are provided under a number of different arrangements. Fourteen of the 16 women participating in the study received such services. Of the 14 women, seven receive services under individualized funding arrangements (also termed self-managed care or direct funding).[14] Under individualized funding, persons with disabilities receive money directly to hire staff with amounts based on an assessment of their need. People with disabilities who receive supports under individualized funding arrangements must hire, fire and evaluate their staff, as well as determine in which tasks they will engage, what their schedules of work will be and how much they will be paid. Some of the women with disabilities in the study who receive individualized funding managed their workers' payrolls themselves; others hired banks or accountants to do it. In one case, the money, which a woman received, was directed to her brother, who worked on her behalf as the "employer."

The women who do not receive services under individualized funding had agencies arrange and pay for their personal supports. Two different styles of agency services were used by these women. Two of the women were living in transitional housing for persons with disabilities. Transitional housing is available to disabled people as a temporary option, that is, to ease their transition from institutional or family living to living independently in the community. In addition, transitional housing is used by people who have recently become disabled.

Another two women lived in supported living (or focus) units, which are apartment complexes with in-house services for tenants with a disability. Three women accessed services in their private homes through agency outreach services, which receive funding from the government and are responsible for hiring, evaluating, firing, paying and scheduling staff for them.

Table 8: Types of Service Arrangements for Personal Support Used by Women with a Disability in This Study

Service Arrangement	Women #
Individualized funding	7
Supported living units	2
Transitional housing	2
Agency outreach	3

Only three of the 10 women interviewed for the case studies used professional services.[15] One woman referred our researchers to her doctor (who, for reasons of confidentiality, did not want to be interviewed). Another woman used the services of a physiotherapist, which she was able to access at no cost through a training program for students in the local university hospital physiotherapy program (funded by the Ministry of Health). Other women in the study who wished to receive physiotherapy were unable to do so, for they would have been required to pay for it. A third woman used the services of a counsellor/therapist, with her own practice. This woman had accessed these counselling services through personal connections and paid fees for them herself.

Disability-Related Support Needs

The women with disabilities in the study reported different types of need for disability-related support. Thirteen of the 16 women with disabilities had mobility and agility impairments and used wheelchairs; most of them required home and vehicle adaptations. Some also required technical devices such as reachers, lifts, voice-operated computers and adapted telephones. These women tended to need personal support in tasks, such as getting out of bed, dressing, bathing and going to the washroom, and assistance in household tasks such as cooking and cleaning. One woman, with no paid support, said she needed only occasional support in tasks such as budgeting, learning to cook and managing her diet (she was diabetic). Institutionalized for most of her life, another woman, with significant communication and behavioural problems who tends to be aggressive and violent toward some of her care providers, depends on 24-hour, two-on-one support in nearly all daily living activities. In addition, she receives support from behaviour and speech therapists.

The degree to which women needed assistance in these areas varied. One woman, for example, required none of these services. Another used only an hour of assistance getting up and bathing every day, and a few hours of homemaking every week. Other women required moderate attendant and home-care services for five to eight hours a day, but could perform some of these tasks without assistance. One woman, who also had complex health needs, used 24-hour support. Of the two women with intellectual impairments, one had very low support needs for a few hours each month. The other depended on 24-hour, two-on-one support.

Social Life

The respondents who were disabled had varied interests and social networks. The leisure activities they enjoyed included watching television or listening to the stereo, going to hockey games, camping, going for walks in the park, attending arts and cultural events (such as films, plays, musicals and art galleries), playing with their children, hanging out with family and friends, shopping and gardening. Indeed, some of these women had very busy social lives and large networks of families and friends. Others, however, reported they did not have active social lives. These women gave differing explanations for this lack of activity. Some reported that they were too busy with their work and family responsibilities. Others noted the barriers in the transportation system and community spaces that limited their freedom. In addition, one woman said she did not really know how to make friends. Another woman, who was interviewed by proxy through her brother, had significant difficulty communicating and relating to others, due to the nature of her impairment, and to a history of extensive institutionalization.

The paid and unpaid support providers had diverse social lives and levels of activity. They described enjoying such activities as watching television, going for walks, playing with their children, going to the gym, spending time with family and friends, participating in church activities, going to concerts, going on picnics, and attending arts and cultural events. Some had more active social lives and broader social networks than others. Those paid support providers who did not “get out much” attributed this fact to the demands and hours of their work and family responsibilities.

5. POLICY CONTEXT

Currently, policies related to disability support arrangements are in flux in Canadian provinces. Some of the changes affect women's equality positively; others pose substantial risks.

In Unison

A recent shift in approach to disability policy in Canada was marked by the Social Union Framework, signed in 1999 by the Federal/Provincial/Territorial Ministers Responsible for Social Services.[16] *In Unison: A Canadian Approach to Disability Issues* outlines the commitment of the ministers to inclusion and full citizenship of people with disabilities. The Framework is not a policy per se, rather, it sets out a "blueprint for promoting the integration of disabled persons in Canada...to make disability issues a collective priority" (p. 5). Based on the principles of equality, inclusion and independence, In Unison articulates a vision for full citizenship.

> Persons with disabilities participate as full citizens in all aspects of Canadian society. The full participation of persons with disabilities requires the commitment of all segments of society. The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well being through access to required supports and the elimination of barriers that prevent their full participation (p. 8).

Recognition is given to moving beyond income support to measures that address disability-related costs and barriers in communities and workplaces. It outlines some issues faced by people with disabilities in the areas of income support, employment and disability-related supports. For example, in terms of supports, the document identified issues such as the lack of portability of services, the lack of access to services, high costs and restrictive eligibility criteria. Policy directions with respect to disability-related supports, include:

- Promote greater access to support.
- Separate access to supports from eligibility for income and other programs.
- Offer greater consumer control, flexibility and responsiveness in support provision.
- Provide greater assistance for disability costs.

The establishment of commonly agreed principles, vision and policy directions is intended to lead social policy throughout the country. But it is as yet unclear what the impacts of this new social union will be on Canadians with a disability. The report was based on consultations with the disability community, and its recommendations look promising to the extent that they reflect what the disability community has been calling for in recent decades. However, insofar as there are no mechanisms in place to enforce these principles, it is not evident to what extent these will be enacted in policy development.

The Social Union Framework indicates new directions in policy related to disability support. As such, it deserves mention. However, since policies based on the Framework have, for the most part, not been implemented as of yet, it is difficult to say anything conclusive about the impacts of this shift on the relationships of support between women. Our research supports the concerns outlined in In Unison with respect to disability-related supports in terms of the need for better access, flexibility and portability of service. This suggests that policies reflecting the commitments of In Unison would promote equality in relationships of support.

The Canada Health and Social Transfer

Until recently, the federal government and provinces shared the costs in areas such as welfare, social services and vocational rehabilitation programs. The federal government had subsidized provincial revenues for health care and post-secondary education, and had financed the direct delivery of services and benefits (such as labour market services) and Canada Pension Plan disability pensions. The introduction of a new funding arrangement, the Canada Health and Social Transfer (CHST), significantly changed this state of affairs. The CHST, which replaced the Canada Assistance Plan (CAP) and Established Program Funding (EPF), greatly reduced federal cash transfers to the provinces for welfare, social services, post-secondary education and health-care services. With the CHST, the federal government gave provinces control over the design and delivery of these services and programs in exchange for reductions in the money it spends on them. In other words, the federal government has reduced its involvement in the social policy field, and has given provinces discretionary powers over which programs and services they will provide.

Provincial governments have begun to overhaul their welfare systems. For example, many provinces have tightened the eligibility requirements for welfare and other social assistance programs, some have introduced welfare-to-work and workfare and, in most, labour force development boards have been dismantled. In a number of jurisdictions, the responsibility to provide disability-related supports has been devolved to community boards and local governments.

To be sure, programs which provide income support to eligible persons with disabilities are more generous than other social assistance programs; however, it is not clear how easy the access to disability-related income assistance programs will remain. Because the federal government has relinquished control over which programs and services are offered by provinces, there are fears that the availability of the social safety net protections that Canadians value will not be consistent across the country, and that they could be further reduced. Furthermore, although provinces place an emphasis on disability-related support arrangements in the community (e.g., home care and attendant services), the actual availability of these services is not sufficient to meet demand.

The disability community has observed these developments in the health and social service fields with great concern. There is worry that these policy changes could further entrench poverty for people with disabilities and further entrench a charity-oriented approach to meeting disability-related support requirements, rather than an equality-oriented one. In addition, provincial fiscal restraints and an absence of national standards under the CHST could restrict access by persons with disabilities to the social supports they require to live securely, participate in communities and workplaces, and make the choices in their lives they have a right to make. In a study by DAWN Canada (Masuda 1998), women with disabilities across the country indicated concern about the impact of block funding on women with disabilities. These women felt the impact of government cuts and fear women with disabilities will be left in situations that put them at risk of health problems, insecurity and abuse, because they will not receive the basic supports they need.

Regionalization

One effect of the CHST has been the increasing regionalization of government responsibility. At the same time as the federal government decentralizes its power to provincial levels, provinces are decentralizing responsibility to regional and municipal levels. This move to increased regionalization is a response to budget cuts and is intended to reduce duplication and waste, and democratize service delivery by putting decision making in the hands of regional or local boards. These boards, which often include representatives from communities, are said to respond more appropriately to the needs of specific communities or regions. The three provinces which provided the geographical context for this study—Manitoba, Ontario and Newfoundland—are among those that have made recent transitions to the use of regionalized health boards.

Because these changes are very recent, the actual impacts of regionalization on consumers of services could not be assessed at the time of this study. However, disability organizations such as the Council of Canadians with Disabilities (1998a) have expressed concern that regionalization may compromise access to, and quality of, these services. First, health boards might make decisions which put pressure on the programs consumers use. Second, boards have limited or no flexibility to review budgets. Rather, they are allotted certain funds, and cannot raise taxes in order to gain more. Third, boards are less likely than government ministries to consider the cost-benefit impacts on individuals and their families (e.g., the psychological and economic costs) beyond health or taxpayer expenditures. And fourth, delivery of services through boards may further complicate the already complex system of access faced by persons trying to locate, and qualify for, services.

Trend Toward Community-Based Service Delivery

One trend in service delivery is an emphasis on delivery outside of hospitals or other institutional settings. For quite some time, both the independent living and community living movements have advocated for these changes. The government has responded with initiatives such as the National Strategy for the Deinstitutionalization of Persons with Disabilities, and has redirected funds from acute and long-term care facilities to community-based care. Workers have been channelled into local community-based service agencies. General hospitals have been converted to long- and short-term health care facilities. The number of staff in hospitals and other institutions has been reduced. The number of hospital beds has been reduced, and facilities, such as nursing homes, hospitals and community-based agencies, have been amalgamated (AFÉAS 1998).

Throughout the country, there is concern that increases in the number of available community-based services have fallen behind the demand. The AFÉAS and others report that, due to long waiting lists for community-based services and limitations on the amounts of support that people can receive, many do not receive the community supports they need. In Newfoundland, for example, government cuts to home-care services led to the introduction of a cap (which is set at just over $3,000 per person per month) on the amount of funds allotted for any individual's community-based service needs. This could have a number of impacts on women with disabilities. For although women who already receive more than this will not lose any of their services, those whose service needs are increasing, or who have only recently applied for service may not be able to access enough funding to meet their needs. Furthermore, although the funding cap is enough to pay for approximately 12 hours a day of care (every day) per person, women with disabilities who need more than a half day of support (every day) will not be able to get the services they need. Instead, they may have to rely more on family and friends, increasing their own vulnerability and increasing burdens placed on others in their community. The options these women have with respect to where they can receive care may be reduced (i.e., they may end up in less independent, more institutional settings).

The trend toward deinstitutionalization also has an impact on the people who provide supports. As hospitals and institutions close down, or scale down the services they provide, some workers become "redundant"; others are transferred to community-based settings, where they tend to receive lower wages, and have less access to benefits than those in the more institutional settings. Indeed, community-based, paid support workers, who currently make less than $6 an hour in some provinces, may have their wages further reduced.

Delivery Systems

Women with disabilities may use a number of different types of disability-related and other supports, including income support, personal and home support, professional services (such as rehabilitation and other therapies) and assistive devices programs.

Income Support

There is a complex set of disability income systems, including Canada Pension Plan (CPP) Disability pensions, provincial social assistance and workers' compensation. Most of these programs are designed to cover the costs of disability and compensate for the loss of earning capacity presumed to arise due to disability. One criterion that has been common to the various disability benefits is that a given person be considered "unemployable." For this reason, social assistance programs directed toward people with disabilities have seemed more generous than programs aimed at others. That is to say, on the basis of the presumption that disabled people cannot support themselves, they have been considered to deserve income assistance. However, this reasoning forces people who are disabled to trade opportunity and rights in order to access and retain their eligibility for support.

Most government income support programs are provided at a provincial level. One exception, however, is Canada Pension Plan Disability, a federal program providing benefits to people with disabilities who meet the eligibility criteria. Average CPP benefits total about $672 per month for eligible adults, and $169 per month for eligible children. CPP is available to people who have made sufficient contributions in four of the last six years and who have earned a minimum of 10 percent of each year's maximum pensionable earning (in 1998, it was $36,900). To be eligible for CPP, a person must be between the ages of 18 and 65, have a severe and prolonged disability that keeps the individual from working on a regular basis, and not receive a retirement pension. Eligibility is determined through an assessment procedure in which medical professionals review a person's disabling condition, the individual's CPP contributions are checked, and capacity to work is determined (*Abilities* 1999).

Manitoba

In Manitoba, provincial social assistance for people with disabilities is provided through the Department of Family Services, Employment and Income Assistance Division. Manitoba is unique with its two-tiered income assistance program. The first tier, the responsibility of the provincial ministry, provides income assistance to eligible people with disabilities, as well as other categories of people, such as lone parents and elderly people. Eligibility for assistance under this program is, in part, based on the condition that their disabilities "prevent them from earning sufficient income to support themselves" according to the ministry Web site (in 1999). Eligibility (the criteria for which are outlined under *The Employment and Income Assistance Act and Regulation*) is determined by a needs test which compares total financial resources of one's household to the total cost of basic necessities (as defined in the Act and Regulation). Consideration is made for basic needs such as food, clothing, personal needs and household supplies, some medical costs, housing (rent) and utilities, and some special costs if the person is an adult with a disability.

Persons with disabilities who do not qualify under employment and income assistance (e.g., if their disabilities are not deemed to prevent them from earning income) can still qualify to receive income through their local municipality under the second tier of social assistance, namely, the Municipal Assistance Program. This program, which provides people with financial assistance while they seek employment, is administered by Manitoba's municipalities, which cost-share expenditures with the provincial government. In addition, the province (in partnership with the Welfare Reform Branch) provides program delivery support to municipal administrators, and develops and supports initiatives to help clients enter or re-enter the labour market. The Municipal Assistance Program is administered in accordance with *The Employment and Income Assistance Act*, *The Municipal Act* and the *Municipal Assistance Regulation*.

The current two-tiered delivery of welfare in Manitoba is being replaced by a single-tier delivery system in Winnipeg. (The majority of Manitoba's welfare recipients live in Winnipeg.) This shift is a major component of Manitoba's welfare reform strategy. It is unclear what the impacts of this policy shift will be on women with disabilities and women who provide unpaid or paid supports to them.

Ontario

In Ontario, income assistance has recently been restructured. In 1998, the *Social Assistance Reform Act* (SARA) replaced Family Benefits and General Welfare Assistance. SARA has two components, the *Ontario Disability Support Program Act* (ODSPA) and *Ontario Works Act* (OWA).

The ODSPA is designed specifically to provide benefits for eligible persons with disabilities: eligibility is no longer contingent on the fact that one qualifies as “unemployable.” Rather, the criteria used to determine qualifications as “disabled” are restrictions in ability to function in the workplace, in personal care activities or in activities in the community. In addition, people who were already on, or who had been approved to receive family benefits, automatically retained benefits under the ODSP. If they leave the program for less than a year to earn income, they are protected and reinstated without medical review when they re-apply. Finally, people in certain prescribed categories also retained their eligibility automatically, including people who live in institutions or group homes.

New applicants for income support under this program must be assessed as having disability status for the purposes of eligibility. The following are the criteria for disability status under the ODSP.

- The person has a substantial mental or physical impairment that is continuous or recurrent, and expected to last one year or more.

- The direct and cumulative effect of the impairment on the person’s ability to attend to his or her personal care, function in the community or workplace results in substantial restriction in one or more activities of daily living.

- A person with the appropriate qualifications has verified the impairment and its expected duration, and the restrictions in the person’s activities of daily living.

Personal assessment to determine disability status involves three forms. First, a health status report of diagnosis and prognosis of disability must be completed by a doctor, psychologist or optometrist. Second, an occupational therapist, physiotherapist, nurse practitioner, chiropractor, doctor, psychologist or optometrist must complete an activities of daily living report (which indicates the impact of impairment on activities of daily living in the home, community and workplace). Third, the individual has the option to fill out a self-report. Once eligible, some persons will be subject to periodic medical reviews to maintain their eligibility for benefits.[17]

People qualifying for ODSP may receive basic needs allowances and shelter/board and lodging allowances through the program. The amount they receive depends on their marital status, the number of dependent children they have, and their family size. The maximum a single person may receive is $930 per month. People who are disabled but do not quality for ODSP may apply for the Ontario Works Program. The benefits of Ontario Works are significantly lower than ODSP benefits. The maximum financial assistance a single person could receive under the *Ontario Works Act* is $520 per month. The Ontario government, as part of an effort to contain social assistance costs, instituted a 21.6 percent welfare cut in 1995 for all people who are not disabled. Persons, who do qualify for OWA but not ODSP, become subject to OWA requirements to participate in job training/job experience programs.

The Employment Support Program, which became fully operational in February 1999, is an integral part of the ODSP. This program provides some accommodations to persons with disabilities to assist them in securing and maintaining employment.

The impacts of social assistance reform on persons with disabilities are not yet clear. Disability organizations have had mixed responses to the new provisions involved in the ODSP. Some regard the removal of the "permanently unemployable" criterion that existed under the Family Benefits Assistance as a positive move, since this may increase access to benefits, given that the notion of "substantial restrictions" is easier to meet than "permanent" unemployability. Others, however, are concerned that the new provisions could actually reduce access to benefits, because only those "restrictions" which must be considered a direct effect of impairment meet the criterion. Those who hold this view argue that this condition limits the importance of socio-economic factors, such as age, education and literacy. Furthermore, it is unclear how the qualifier "substantial restriction to areas of daily living" will be applied, for it could have a wide range of interpretations.

Newfoundland

The Income Support Division of the Department of Human Resources and Employment provides targeted services and assistance to persons with a disability. Division initiatives include supports to assist people with a disability to pursue employment opportunities. Two other support programs for which women with disabilities could be eligible, but which are not targeted specifically at people with disabilities are the Single Parent Employment Support Program and Women Interested in Successful Employment (WISE). These initiatives assist individuals (particularly women) in their transition to employment. The Single Parent Employment Support Program is a pilot endeavour that helps lone parents on income support obtain full-time employment and work toward financial independence. WISE is a community-based organization that offers career exploration programs for women to help them re-enter the work force.

Home Care and Personal Supports

Manitoba

In Manitoba, services for persons with physical disabilities, those with health needs and seniors are delivered through regional health authorities, under Ministry of Health guidelines. One service offered, home care, is described on the ministry Web site as community-based programs to deliver essential in-home support to people (regardless of age) who need health services or assistance with activities of daily living. Home-care services include multidisciplinary assessment of eligibility of services and need for care, care planning, case management, co-ordination of services, nursing service, therapy assessment, health teaching, personal care, meal preparation, respite and family relief, access to adult day care, cleaning and laundry, assessment and facilitation of personal care, and home placement.

In Manitoba, personal supports are delivered through the health authorities in three basic models. In the first, referred to as a focus unit, a public agency located in an apartment complex delivers rotation or scheduled supports to tenants with disabilities. In the second arrangement, known as managed care, agencies deliver outreach services to people in their private homes or apartments. The third model is individualized funding, delivered through the Independent Living Resource Centre. In this program, monies are given directly to the recipients of services, to hire, supervise and manage their own employees. In addition, personal supports are provided through the ministry's Long Term Care Division including the following components: general personal care home services, personal care home services for persons with special needs and respite care in personal care homes. The goal of long-term care, according to the Manitoba Health Web site (in 1999), is to "increase a person's physical, social and psychological functioning to a maximum level to promote functional independence and improve quality of life or to maintain that level."

Some services are provided through the Adult Services Branch of Manitoba Family Services, Community Living Division. The Adult Services Branch is responsible for programs and resources that support adults with physical and mental disabilities to live in the community. Services are managed through Supported Living, Day Services and Vocational Rehabilitation and are delivered through eight regional offices and over 100 external agencies.

Ontario

In Ontario, services are administered under the Ministry of Health and Long Term Care (MOH/LTC) and Ministry of Community and Social Services (MCSS) guidelines. Regulations for the *Long Term Care Act* have now been issued, and its applicability is increasing for MOH/LTC programs. The Act does not apply to MCSS programs.

Since 1996, home care and related services are delivered directly through a system of 43 community care access centres, or through community agencies. For those over 16 years of age with physical disabilities, attendant services are delivered by community agencies in three basic models: supportive housing, attendant outreach services and direct funding. These models do not involve user fees or co-payments, though consumers pay their own housing costs. The availability of these services has increased; however, long waiting lists continue to be an obstacle to consumers.

Supportive housing projects or supportive housing living units (SSLUs) serve clients with disabilities on a rotational or on-call basis in their own apartments. Under these arrangements, the building in which clients with a disability reside contains a supported housing office. Attendant care outreach projects provide prescheduled service to people in their independent homes or apartments. The SSLU staff are considered to be employees of the agency providing the service.

Direct funding is administered through the Direct Funding Program of local independent living centres and funded through the Ministry of Health and Long Term Care. A relatively new option—direct funding—was introduced as a pilot project and was formalized as an option in 1998. In this model, persons with disabilities receive money to hire, pay and manage employees to provide services to them.

Newfoundland

In Newfoundland, health services are delivered through regional health boards or regional health service boards (in Labrador and the northern part of the province). These fall under the jurisdiction of the recently restructured and newly named Health and Community Services. The Board Services Branch of the Department is responsible for the provision of services delivered through the health boards, including the operation of “personal care” homes and services to senior citizens, the provision of continuing care, mental health services and public health nursing services. The Policy and Programs Branch is responsible for the development of all provincial policy and programs related to the mandate of the Department.

Labour Laws

There does not appear to be a clear and consistent framework for the treatment of persons who work as attendants or home-care workers. Like all workers, employment standards acts and human rights acts of their provinces cover them. Some other types of legislation may also apply. In Ontario, for example, an exemption on the *Regulated Health Professions Act* enables attendants to perform tasks that would otherwise be regulated by a health profession.

These and other related protections seem to depend, in part, on the type of support arrangement under which a person works. There is some question as to how home support workers are categorized for the purposes of labour laws. They may be considered domestic labour, companions or regular workers, depending on their job tasks and whether they are working for individuals in their homes or agencies.

The status of workers in individualized funding situations is less clear than that of agency and residential workers, because of confusion as to whether they should be considered employees of the individuals who hire them, or the government that provides the funding. Generally, it is understood that they are to be employed by the individuals to whom they deliver services. As such, they fall under the category of domestic worker.

In Newfoundland, some clarification has been made with respect to the identity of employers under individualized funding or self-managed care arrangements. The policy that clarified this ambiguity was Bill 56, *Act Respecting Home Support Services Provided to Persons in Self-Managed Care*. This Bill clearly identified the people who use self-managed care as the employers of those who provide them with services. As employers, recipients of services are bound by legislation governing employment standards and human rights.

Disability organizations regard the Bill as a positive move; it eliminates the legal question with respect to employers of government-funded home workers in a way that maintains the right to personal choice for persons with disabilities. The Bill also empowers people with a disability, for it confers power over spending public monies to individuals on the basis of their daily living requirements. In short, the Bill respects principles of independent living.

Organized labour regards the Bill with caution, for it questions the impacts it will have on the rights of home support workers to adequate pay, benefits and protections. In addition, labour questions the ability of some persons with "severe" disabilities to take on the role of employers. The disability community has responded to these concerns. As Mary Ennis of the Consumer Organization of the Disabled Newfoundland and Labrador (COD) states in a response to Bill 56:

> We value our home support workers and want them to have an appropriate salary and benefits. Persons with disabilities are upset, for example, that workers still aren't in receipt of Workers Compensation Benefits (in this province). We also respect any worker's right no matter what his/her career—to job protection. We also respect their right to seek that protection from a source of his/her choice—just as we expect Government and the public to respect our rights to protection and choice (Council of Canadians with Disabilities 1999).

Employment Standards Acts

All provinces and territories in Canada have their own employment standards act which sets out regulations for minimum wage, hours of work, overtime, paid public holidays, vacation pay and termination notice/pay. The acts are similar in each jurisdiction with some variation. For example, minimum wage is set at $6.00 per hour in Manitoba $5.50 in Newfoundland and $6.85 in Ontario. For the most part, this applies to all categories of disability-support workers in these provinces, whether or not they are considered domestic workers. (Historically, domestic workers were excluded from minimum wage, but currently only Alberta and Nova Scotia retain this exclusion.) In Manitoba and Ontario (if they work more than 24 hours per week), domestic workers are entitled to receive the general minimum wage, but they may be excluded if they work less than this (HRDC 2000a).

The work arrangements of home care and other support workers have an impact on their rights under the employment standards acts. Information in this regard for Newfoundland and Manitoba was not readily available, but clear distinctions are made in Ontario where a person is considered to be a domestic worker when they are:

> employed directly by householders, not by a business or agency. A householder is someone who owns or rents the home where the domestic work is done. Domestic workers are hired to work in or around a private home. They do such things as housekeeping as well as helping to care for children and for people who are elderly, ill or disabled (Ministry of Labour 2000c).

Thus, those workers employed under individualized funding arrangements would be considered domestic workers, whereas those employed by agencies would not.

Such categorizations affect the rights of workers under the Act, as does determinations of whether a person works full or part time. For example, domestic employees who work more than 24 hours per week are covered under minimum wage, paid public holiday, vacation pay and termination notice regulations, but different rules apply to them with regard to hours of work and overtime pay (they can take paid time off instead of overtime). Domestic employees, who work 24 hours or less per week are only covered for minimum wage and termination notice (Ministry of Labour 2000b).

Those employed by a third party, such as an agency, are covered with respect to paid public holidays, vacation pay and termination notice/pay, but different rules apply with respect to minimum wage, hours of work and overtime[18] (Ministry of Labour 2000b).

Workers who are considered to be companions caring for aged, infirm or ill members of a household receive the least protection under the law. They are not covered for minimum wage, hours of work, overtime, paid public holidays or vacation pay. They are only covered with respect to termination notice/pay. However, it is unclear what type of worker would be considered a companion, so it is difficult to gauge the impact of this (Ministry of Labour 2000b).

Health and Safety

All three provinces have occupational health and safety acts; however, it is unclear which types of support workers are included under these acts. Under Ontario's act, for example, those who work directly in people's home are excluded from coverage. Section 3(1) stipulates that "The Act does not apply to work done by the owner or occupant, or a servant, in a private residence"(Ministry of Labour 2000a). This seems to imply that workers in individualized funding arrangements are not covered. SSLU staff, on the other hand, perform job tasks in people's private homes, but they work for an agency, and are covered under the act.

In all three provinces, health and safety legislation stipulates that some workplaces must establish health and safety committees, or have health and safety representatives to address concerns such as identifying and evaluating potential hazards, recommending and implementing corrective action. In Ontario, committees are required to hold meetings [section 9(33)] and carry out regular inspections of the workplace [sections 9(26),9(27) and 9(28)]. They are expected to receive employee concerns, complaints and recommendations, discuss problems and recommend solutions and provide input into health and safety programs.

The degree to which workers who deliver disability-related supports are covered under these acts depends on the type and size of their workplace. In Ontario and Manitoba, any workplace that regularly employs 20 or more workers, or has been ordered to by the Ministry of Labour must have a health and safety committee. In Newfoundland, they must do so with a staff of 10 or more (HRDC 1999a). When no committee is required, the ministry responsible for labour may instead require the designation of a health and safety representative in its place. Health and safety representatives have similar powers and responsibilities as committees.

Although policy documents were not found that discuss coverage of disability support workers under health and safety legislation, it may be inferred that those that work in institutional or semi-institutional settings are more likely to be covered than those who are employed directly by persons with disabilities. This seems to depend on the size of the staff of the agency, however. In discussions with agency staff, it is evident that, in some situations, employers may follow the guidelines set out in an act, even though they are not officially covered by it. Such guidelines include, for example, types of protections that are factual, such as protections against staff who perform an unassisted transfer of someone over 27 kg (60 lbs).

Workers' Compensation

The position of support workers vis-à-vis workers' compensation is not consistent. Attendants and home-care workers in some situations, in some provinces, are protected under workers' compensation; others are not. The more institutionalized the service arrangement, the more likely that staff had workers' compensation coverage. None of the three provinces studied has a consistent arrangement for workers' compensation for attendants in individualized funding situations. Such an arrangement is often not accounted for in the assessment of need and allotted funds, and is too expensive for employers and workers to contribute to on their own. Workers' compensation is an option in some such arrangements (e.g., the Ontario Ministry of Social Services individualized funding program for those with intellectual disabilities and their families). However, as one reviewer of this report suggests, often families do not opt for such coverage because it reduces the number of hours of service they receive.

In addition, those who work in agencies attached to a building, or who provide outreach, may or may not qualify for workers' compensation. This qualification seems to depend on the degree to which the service was institutionalized, and whether employers made arrangements to pay into the compensation system.

6. CRITERIA FOR EQUALITY OF WELL-BEING IN RELATIONSHIPS OF SUPPORT BETWEEN WOMEN

Since equality may be understood in a number of different ways, and this report puts forward some new approaches to thinking about equality, it is important to explain what we mean by the term. The analysis is built around a conception of equality of well-being, focussing on the site of relationships of support between women with disabilities and their paid and unpaid support providers.

Historically in Canada, according to Justice Beverly McLachlin (1997),[19] equality has been viewed in a number of different ways. She points to recent notions of substantive equality which aim to create equality, by bringing groups situated differently to a point of fair competition through such measures as affirmative action. In other words, equality has been extended from treating everyone the same, to requiring that, when appropriate, different people are treated differently. In this view, differences are not a reason to deny people the support they need to make choices and have opportunities. Thus, social institutions need to be structured to recognize and support people's differences, address disadvantage and recognize that people's needs differ.

Substantive equality forms one part of the model of equality put forward in this report. Feminist, disability and other theorists have also given consideration to critiques. For example, that equality means more than possession of goods, resources and liberties, but also freedom from oppression (Young 1987, 1990; Benhabib 1987). Attention was also paid to addressing andro-centric biases (Lister 1997; Pascall 1993; Young 1990) and incorporating female perspectives, culture and values (Young 1987; Markus 1987) in both notions of equality, and its contexts (i.e., the "private domain"). Similarly, equality was approached with regard to disability perspectives and experiences (i.e., regard to architectural and social barriers, social expectations, attitudes and rights to access and inclusion) (Tremain 1996a; Barnes and Mercer 1995; Silvers 1995; Rioux 1994; Rawls 1993, 1971).

Relational approaches to equality and justice developed by feminist theorists, such as Martha Minow, in which people are conceived as fundamentally connected rather than isolated were also applied. Individual autonomy is thus balanced with the understanding that equality is achieved in the context of relationships between mutually dependent members of a community. In this light, we shift from an exclusive focus on individual rights in relation to the broad institutional arrangements of society (i.e., labour market and income support arrangements) and their own well-being, to understanding that, in some instances, relationships are the sites in which equality is realized. As such, equality and inequality may be reproduced through relationships. It is our contention that examination of how to better secure rights has taken too little account of the personal relationships that shape the character of daily life for women and for people with disabilities.

In summary, in this report the way the term equality is used incorporates a number of concepts.

- Equality involves treating different people differently when necessary, to ensure whatever support they need to be able to respond to opportunities.

- Equality involves equivalent access to the possession of goods, resources and liberties, and freedom from oppression.

- Values attached to equality reflect the experiences, perspectives, values and culture of not only White, able-bodied men, but women, people with disabilities and others.

- Equality occurs within a situation of social well-being, whereby people have what they need for self-determination, democratization and equality of benefit and advantage.

- Equality is realized in the context of relationships of mutual dependence.

This study looks at personal relationships of support to see how they fit into a framework for advancing equality of well-being of women in Canadian society—both women with disabilities and women who provide support. The intention is not to compare the equality of a woman in a relationship vis-à-vis another woman; nor to argue for the rights of one over the other. Because equalities and inequalities are sometimes played out in relationship dyads or triads (or even whole families or communities), equality of well-being sometimes appears polarized. Indeed, within specific relationships, equality may very well be polarized. The structures of some relationships may mean that one woman will ultimately have more power than the other within that relationship and within the broader society.

While our research does look at these issues, the aim is not to draw any conclusive evidence that women in one position have more equality than women in another position. Rather, it is to explore the different ways equality and inequality play out within these types of caregiving relationships and to examine how external factors, such as access to, or structure of, support or labour issues, or social expectations of women's roles contribute to equality in order to devise policies to promote equality for all women to the greatest degree possible.

Equality of well-being in caregiving relationships refers to a number of things. On one hand, it's equality between the specific women involved (whether or not one woman holds power over the other). It is also about the equality of either woman relative to her social context as it is affected by participation in the relationship (e.g., whether either woman is marginalized socially because of her participation in the relationship).

We do not see equality as a simple thing, which one has or does not have. Equality is complex, with multiple levels and nuances. A person may have equality in some ways but not in others, or in one moment but not in another. Equality is also, in some ways, relative. What may feel equal to one woman will not necessarily feel equal to another. Because of this complexity, the criteria of equality in the relationships analyzed for this study account not only for the diversity of experiences of women in the study, but also for their interpretations of their experiences.

These criteria were developed primarily through grounded analysis of interviews with disabled women and caregivers, as well as the Roeher Institute's previous work on social well-being (1994), and through the feminist and disability studies of citizenship and equality outlined above. The understanding and articulation of the criteria in this study are shaped by the lived experience of the women who gave their time and insight to this particular research effort.

Six criteria were identified to measure the equality of well-being of the women engaged in a relationship of support. Again, it should be remembered that these criteria refer both to equality between women in a support relationship, and the ways being in that relationship affect their equality in the community and society. The criteria are:

- promotes self-determination;
- fosters mutual recognition;
- encourages respectful interdependence;
- ensures security;
- democratizes decision-making processes; and
- promotes citizenship.

Promotes Self-Determination

Self-determination can be defined as the freedom and ability to choose one's own goals and life plan and to make one's own decisions in pursuit of those ends (Rawls 1971; Beauchamp and Childress 1983). In order to be self-determining, one must have choices and opportunities, the opportunity and support to develop one's capacities, and the means with which to achieve one's aspirations. The concept of self-determination must also encompass a recognition that some people need support through informal and formal mechanisms (such as supported decision making) in order to make their own choices. Not all people have the same capacity to express their choices, to manage decision making and to carry out decisions.

In relationships of support between women, each woman is self-determining if she can make the choice to participate or not participate in the relationship and can determine the ways in which she will participate. In addition, a relationship of support ensures that each of the women engaged in it is self-determining—if it is a relationship in which the women promote and support each other to make decisions and choices, to achieve their aspirations and to develop their capacities.

Fosters Mutual Recognition

In order to be subjects (rather than objects), humans must be recognized by another (or others) as distinct individuals, with their own desires, needs and capacities (Beauvoir 1953). Mutual recognition requires, furthermore, that differences between people which accrue by virtue of social positioning along lines of race, gender and disability be acknowledged and respected (Young 1990).

Within relationships of support between women, mutual recognition can be difficult to achieve. These relationships are conducted in a social context that is structured along deeply embedded lines of power, which produce cultural practices of discrimination and humiliation. Women with disabilities have been objectified through the medicalization of disability, and their self-esteem and sense of personhood have been diminished due to negative stereotypes that circulate about disability, and about women. They have variously been perceived as victims, as asexual, dependent, childlike, sufferers, objects of pity and burdens on society (Fine and Asch 1988; Morris 1991; Wendell 1996). Women who are support providers have been objectified as nurturers, charity workers, martyrs, servants and saints. In order to foster mutual recognition, each of the women involved in a relationship must be treated in such a way that respects their personhood and subjectivity.

Encourages Respectful Interdependence

Equality is promoted within relationships that encourage respectful interdependence. Respectful interdependence exists in relationships when there is a balance sustained between independence and interdependence in ways that ensure mutual respect and recognition. This mutual reliance must be respectful, and promote individual self-determination and independent action, rather than detract from it. In contrast, a disrespectful or pathological interdependence may lead to dependencies or co-dependencies that compromise the equality of one or both parties.

Interdependence implies an exchange. A respectful independence requires a recognition of the value of different types of contributions within the exchange. For example, provision of emotional support has value as does financial support.

Ensures Security

Equality requires that people have the security that their basic needs for income, safety and support will be met, that is, they have adequate income, safe housing, and live and work free of exploitation, abuse (including vulnerability to abuse) and discrimination. Security includes access to income support, health care, disability insurance and essential services such as personal care and transportation. Without personal security, people are not able to survive, pursue their goals or develop capacities to fulfil various roles in their lives as parent, partner, worker, citizen, etc. (Braybrooke 1991, 1987; Doyal and Gough 1991).

Security within relationships is promoted when the relationship ensures, and does not detract from, meeting financial, personal support and other basic needs. That is, women in the relationship support and interact with each other in ways that promote the opportunity and capacity of each to obtain personal security and not undermine it through abuse, discrimination or exploitation.

Promotes Citizenship

In 1950, T.H. Marshall defined citizenship in this way.

> Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed. There is no universal principle that determines what those rights and duties shall be, but societies in which citizenship is a developing institution create an image of an ideal citizenship against which achievement can be measured and towards which aspiration can be directed (p. 87).

Marshall's definition suggested that civil and political rights are not sufficient conditions for securing citizenship. Rather, Marshall argued that additional social and economic conditions are required to secure that status (Lister 1997). Some feminist authors have argued that an understanding of social and economic citizenship must take full account of the particular barriers women face to full participation in their communities and societal institutions (Pascall 1993; Young 1990; Karst 1984).

This criterion of equality refers mainly to the effects of participation in the support relationship on each woman's equality status in society, rather than a notion of citizenship within a relationship. In order to promote full citizenship, relationships of support between women must enable each of them to participate in the community. Women's participation is enabled in these relationships if liberty of movement is not restricted (e.g., a woman is not confined to her home or an institution) and if freedom of speech is not infringed upon (e.g., a woman does not face reprisal if she advocates for better wages and working conditions, or joins a union or other employee association).

Democratizes Decision-Making Processes

Democratized decision making is a process in which diverse perspectives, knowledge and interests are acknowledged, respected and taken into account. Democratization of decision making implies a redistribution of resources in order to ensure participation and to build the capacity of individuals that participation requires (Roeher Institute 1994).

Within the context of relationships of support between women, democratized decision making is achieved when women communicate effectively with each other, with service agencies and with employers. This dialogue is democratic when it involves respect for, and accommodation of, each woman's perspective, experience, needs, capacities and aspirations. Within the context of these relationships, democratization can be supported through formal and informal mechanisms, which ensure that both parties have agency in their communication, and support or recourse when communication breaks down. In the context of a relationship between a disabled woman and her support provider, democratization implies (for example) that both of the women have agency to express their respective needs and concerns, but also consider the needs and concerns of the other.

Democratized decision making between women in relationships of support means more than effective communication and consideration of the other. It means that both women have agency, or power, within the decision-making processes. Thus, for example, a woman with a disability need not rely on the "good will" of her support provider to comply with her instructions regarding how she wishes to be lifted, for example, but has the power to assert such demands.

Together, these six criteria provide a guide for examining the nature and extent of inequality and equality in relationships of support between women with disabilities and their caregivers. The next chapter turns to that exploration.

7. EQUALITIES AND INEQUALITIES IN RELATIONSHIPS BETWEEN WOMEN

Accounts provided by women in this study can be analyzed in various ways. In first interpreting these accounts, the aim was to identify their perspectives on the general criteria for equality of well-being in the relationships of support they were party to. The previous chapter defined these criteria. In this chapter, these criteria are used in a fuller examination of the accounts the women provided. Perspectives of both women with disabilities and their support providers are presented with respect to each criterion.

Promotes Self-Determination

Women with Disabilities

In this study, relationships were seen to promote self-determination on the part of women with disabilities when they were able to make choices about, and have control over who provides them with support, how much support they received, and the manner in which support was provided to them, and when. This was true in their relations with both their paid and unpaid supporters. Women with disabilities were also considered to have self-determination when their support relationships enabled them to live where they wanted and do things they liked to do, including engage in meaningful employment and participate in community life. They were considered to lack self-determination when other people were making choices for them, or in their "best interest," or when the support failed to allow them choices, and to help them realize their aspirations and access opportunities.

The equality of women with disabilities was promoted when they were able to exercise their right to self-determination by choosing which individuals provide them with support. Most of the respondents in the study agreed that the most basic condition for equality in their relationships hinged on their own right to determine with whom they would form relationships of support. This supported equality for them within the relationship, since they could choose staff with whom they were compatible and comfortable. It meant they were more likely to be able to set their own standards and to dismiss workers whose work was judged to be unsatisfactory. As one woman stated:

> *I was on government home care. [They sent a] different girl pretty much every time. They had more don'ts than do's. "We're not a Molly Maid service," came out of their mouths many times. The way they cleaned was poor: wouldn't pick up the chair or garbage can. In terms of cooking, they would come to make me a week of sandwiches in one night.*

The right to determine with whom they engaged in relationships of support was met in some women's circumstances. Women reported they were able to realize this by having full control over the hiring and firing of staff in a self-managed program. Others were satisfied that they had exercised their right to self-determination when home-care agencies respected their wishes regarding which workers they preferred, and which ones did not seem suitable. Still others felt they had little or no control over who they engaged in relationships of support. This was typical in the case of women whose support was tied to their housing. Those in transition housing and supported housing units/focus units received services from staff selected and hired by in-house agencies. These staff members served consumers on a scheduled or rotational basis. In these cases, some may have had moderate control through participation in hiring committees but, generally, they said they had to accept personal and home supports by whatever staff walked in the door. In some cases, this was also true for women who received outreach services in their private homes, depending on the policies of a given agency.

Women with disabilities also reported greatest satisfaction when they were in control of the *kinds* of tasks and varieties of tasks that their in-home support workers perform. Many wanted to hire the same women to do personal and home care, for this would be more consistent and less disruptive to their own lives. In some instances, the style of service arrangements used determines whether or not the woman has this choice. Those who receive services under self-managed care could choose to have workers perform both sorts of tasks. Those using agency-managed care were less likely to have this kind of control, or at least not without some resistance. As one woman remarked:

> *Having the same people doing personal care and homemaking has been a bit of a struggle, but I make damn sure to get it. The company gives me a lot of flexibility with little headache.*

Women had very little control in this regard if they lived in focus units or transitional housing, where agency policy largely determines distribution of job tasks. Moreover, as one woman explained:

> *Home care is weird. Someone comes in to wash your hair and it is never the same person who will give you assistance cooking—so they are paying four different women, paying for their transportation. They pay them different rates. Why not pay them all one high rate, and have them do everything? They shouldn't segmentize each task—it's way more expensive that way. People get offended being asked to open a window because it's not their job.*

Women with disabilities in this study felt that when they did not have these choices, their activities were limited, their schedules constrained, and their physical and social comfort and health compromised. Furthermore, they indicated that their dependence on informal support increased, because they felt forced to rely on others for favours to get the things they need. As one woman explained:

> *They had their rules—they could do the tub, but not the tub tiles. They weren't allowed to clean mirrors in the livingroom.... I'm sure the task sheet was done in the early 1900s. They weren't allowed to pick anything up. They insisted on using Pledge. I said, "If you're using furniture polish, you're going to lift the doily and clean the whole thing." So my sister-in-law would do the dusting.*

Women with disabilities maintain that they can more fully exercise their rights to choose when they can access services in a number of environments. When they receive services in a variety of contexts, they avail themselves of opportunities for employment, travel, leisure activities in the community and personal relationships. Some women wanted to be able to use services in places outside their own home. Others said they had a difficult time getting out of their own homes without this portability of services. One woman, who used services attached to her housing, faced barriers when she wanted to spend time with her girlfriend, especially overnight. As she explained it:

> *I have a girlfriend now, I want to stay at her place.... I'd like to stay and my services are tied to my apartment, not to me. I spent one night at her place and it cost me $60. I joke that I have to pay for sex, and my partner doesn't even get the money. The only way I can get together with her and have some privacy is to pay someone $60. Sometimes, I may need someone to come in the middle of the night. My girlfriend is also disabled and she tries to turn me, but it's hard for her so we need to have attendants come.*

In addition, women with disabilities want to control *which* tasks a worker does and how they do them. For example, they want the liberty to choose whether a worker takes them to the mall or swimming, rather than staying and cooking or cleaning for them. One woman with this liberty remarked:

> *It's self-management home care. What they do—my wish is my command. Cooking, cleaning, doctors appointments. If I'm out shopping and I need to go to the bathroom, I can make arrangements for them to meet me and help me.*

Women also want the liberty to determine the upkeep of their personal spaces,

> *I want them to lift the lamp when they dust.*

how their personal care will be performed,

> *My favourite attendant, she really scrubs you down, I prefer to get exfoliated. Others just soap you up and wipe you down.*

and how often.

> *I work in an office. I need to bathe more than twice a week.*

Women with disabilities believe their self-determination is advanced when there is *flexibility* in the delivery of their services. They felt rigid care schedules compromised their right to decide what to do and when to do it. As one woman put it:

> *No one tells you when you need to go to the can. I don't see why anyone has the right to tell me.*

Furthermore, the women with disabilities in this study wanted the option to revise their routines, be spontaneous and experience days that are as varied as other peoples, to whatever extent this is possible. One woman, for example, said she would like to be able to exchange three hours of cleaning in a week to have an attendant accompany her to the pool. Another woman said she wanted the choice to sleep in on Saturday. Furthermore, flexibility in provision of personal supports would allow women to schedule appointments, meetings or other events, because they could arrange their care around the events that often (unexpectedly) occur in their lives, rather than attempt to arrange these events around their care. As one woman, whose services are flexible in this way, remarked:

> *I get to pick my own days, own hours. Before, if I had a doctor appointment, I couldn't put it on a Wednesday. If they came in here, nobody could be here without me because they weren't coming here for me.* [Agency regulations required the consumer to be present when home-care staff were in the home.]

Support Providers

Paid support providers were seen to be self-determining when they had choices and input with respect to whether or not they were working, the kind of work they would do and for whom they worked. Their self-determination was also realized when their role in the relationship helped them realize their aspirations and promoted their opportunities. Similarly, the self-determination of informal support providers in relation to women with disabilities was promoted when they were able to choose when, how much and what type of support they provided. Self-determination was restricted when women's roles as informal support providers interfered with their own opportunities and realization of their aspirations.

Like women receiving disability-related support, the self-determination of those providing support is promoted when they are able to determine, for themselves, whether or not they participate in the relationship. For some paid support providers, this means having choices about whether or not they work in the paid labour force at all, and having choices and opportunities concerning the type of work they do. A number of women, for example, felt they had not freely chosen to participate as a paid support provider within the relationship. They did not want to be working at all, but were compelled to for financial and other reasons. As one woman explained:

> *My husband has had strokes, so I'm the sole provider for myself and my husband. I went back to work last year.*

Other women said they were working in this field because they had limited opportunities, due to their level of education, access to training or limited opportunity in a chosen field. One woman, for example, was trained as a dental assistant and preferred to work in that field, but said there were not sufficient employment opportunities in her region.

In other cases, paid support providers felt that, as much as it was important that women with disabilities choose who provides support, it was important that, as workers, they be able to have some choice regarding who they work for; some freelance attendants explained that they chose their employers carefully. They wanted to work for people they liked who had particular skills as employers. One attendant put it this way:

> *I know right away from the phone message, by what they say and the way they say it, if I want to work for them. They'll say: "Here are the hours I need, the pay…" [I prefer to work for] someone who recognizes this as my job, and sees my time as attached to money.*

The self-determination of paid support workers is further promoted when they have choices in the tasks performed for consumers. While most felt that consumer self-determination in this area was of utmost importance, they also felt that necessary boundaries were pushed in some circumstances. For example, support workers say they were expected to compensate when their client/employer received insufficient services. That is, they felt the onus was on them to respond by being flexible and doing extra tasks. The women who expressed this sentiment regarded this expectation as unreasonable. Moreover, they found it emotionally and physically draining to perform extra tasks.

Service providers may compensate for the gap in services proactively (because they recognize their clients need more support and want to help them out). They did not tend to find this problematic. Problems arose when they felt they did not have a choice about how to react to a service gap. To take one extreme example, a woman with a disability, who had developed aggressive and violent behaviours while living in an institution, received 24-hour personal support, but was not receiving the behaviour and speech therapies she needed to communicate in more positive and effective ways. As a result, the women who worked for her were not only at risk of harm, they were trying to teach her to behave more appropriately, but they had neither the training, nor the compensation of a professional therapist.

Similarly, the equality of unpaid support providers is affected by the choice they have in the types and amount of support they provide. As in the case of paid support staff, if the woman with a disability in the relationship receives inadequate levels of service, they may feel obliged to compensate. Indeed, informal support providers (partners, families, friends) were unanimous in the opinion that when the woman in their life received adequate supports, then they had more choices about when, and how much disability-related support they provided to her, if any. In some cases, it gave them time to do things for themselves. As one mother said:

> *When [she] was here, my hands were tied. Now I have a lot more freedom. Now I'm getting my house in order.*

In two cases, young women with disabilities described the positive impacts on their parents when they qualified for paid support. One explained:

> *My mother and father used to provide all my care, but I moved into a place with services. It reduced what they do.*

The other said that one of the reasons she left home was:

> *…partly to be more independent, partly to give my family a break. They got no support while I was at home.*

Paid support providers also wanted self-determination with regard to the service arrangements under which they worked. Some strongly preferred to work directly for employers with disabilities under individualized funding arrangements, and believed they had made a clear choice to do so. They felt it gave them control in determining with whom they worked and the kinds of shifts they took. They adhered to the principles of the independent living movement, and felt comfortable in a role they believed enabled their employer's independence. Despite the fact that they did not have the benefits, support and protections available to workers in other arrangements, they were willing to forgo these for the control and flexibility that self-management offers.

Not all women working under self-managed care felt they had made this choice, however. Some felt this work arrangement "ghettoized" them. They claimed to work under it because they did not have the qualifications or experience to work in more institutionalized settings. Furthermore, they regarded direct employment as a stepping stone to work in nursing homes, hospitals or transitional housing units, where they would have a "good job" with better hours, pay and benefits.

One woman wanted the option to freelance as an individualized funding attendant; however, she believed she did not have the opportunity to make this choice. In addition, she felt underemployed as an agency relief worker. She attributed both her underemployment and lack of access to individualized funding jobs as a result of racism. As she explained it:

> *I've had lots of people who don't want a Black attendant or that treat Black and Filipino attendants differently.*

Some individualized funding attendants who were White concurred. They reported that they had more opportunity for choice jobs and shifts than their colleagues of colour.

While most of the women who worked as paid support providers reported they liked their work, reports varied with respect to the extent of self-determination with regard to the conditions under which they work (such as hours of work, convenience of shifts and work environments). The number of hours worked in the home-care profession is highly variable and depends on a number of factors. In the sample for this study, paid support providers worked shifts that ranged from full-time, regular work days, to one-, two- or three-hour shifts, several days a week. In some cases, work hours depended on the choices the workers made. In others, work hours depended on the service arrangement in which workers were employed. Women who worked in semi-institutional settings and for home-care agencies were apt to work more hours for a greater number of clients. Those who worked directly for women with disabilities were apt to work fewer hours, for one person. Some were satisfied with the number of hours they worked. For these women, the work hours seemed as if they had been chosen and fit with their respective lifestyles, regardless of whether they worked full or part time.

Support workers agreed that flexibility in service provision promotes self-determination for women with disabilities. In addition, some valued the flexibility of their job (when they felt they had it) for their own sakes. In fact, some support providers worked in this sector precisely because they want flexibility in their working lives. As one participant in a focus group explained:

> *People rely a lot on students, single moms. It's an employment force where there's a high turnover. You take the job because it's flexible. It's a two-way win. By the time you burn out, you have gone to work for someone else, or back to school.*

Not all paid support providers felt they were able to choose how many hours they worked. Some were dissatisfied because they felt they worked too much; others were dissatisfied because they felt they worked too little. Those who worked too little wanted more hours for various reasons. In some cases, the rationale was an economic one: these women needed more money. In other cases, women simply wanted to "get out of the house more." In a few cases, women desired to work more because they perceived that their clients needed more hours of service, and they wished to fill this need.

Those who felt they worked too much gave a number of reasons for their dissatisfaction. In two cases, women worked for family members out of a sense of personal commitment and family obligation. They felt the disabled woman in their life would not receive enough support if it were not for them, or receive the quality of support they give her. Both of these women worked significantly more hours than they were paid for. Indeed, they reported that it was difficult for them to find time for themselves and their families. As one of them commented:

> *If she was to get more hours, hire someone else, I'd rather be a backup, she needs that and most people don't have that.... I'd rather not work for her on a scheduled basis, that's not my job, it's hard to give her the time she needs, balancing the kids and everything else.*

Another remarked:

> *I have no time for myself or my family. The situation with my sister-in-law is too consuming at times. I have no time for my grandchildren. From the time I get up at 6:30 until 4:00. When I come home from work, I'm doing [the director's] paper work and have supper. I don't even have time to go outside. On weekends, I often have to fill in shifts, or set up interviews with people for jobs as respite workers.*

Another aspect of self-determination involves not just choices and decision making in the moment, but access to opportunity, a chance to realize aspirations and develop one's capacities. For workers engaged in these support relationships, the significance of the work in relation to future career opportunities is important. Job training provides workers with skills (and consequently, opportunities) which enhance their self-determination. Women described a range of training opportunities, to which they have varying levels of access. For paid support workers, this included on-the-job-training, disability issues/politics, workplace health and safety, first aid/CPR, crisis intervention/prevention and information about impairment types. Some women (especially those employed directly by women with disabilities) said they had no access to any of these types of training except for on-the-job training. Others said their agency/workplace offered training courses. Some of these were mandatory. In some cases, they were provided free of charge. In other cases, staff had to pay for them. None of the women in this sample was paid while taking a training course, although some agencies apparently do pay for staff training.

Not all attendants felt that formal training was necessary, or even appropriate to do the work they do. Some individualized funding attendants felt formalized training taught workers an over-medicalized view of disability and of personal care jobs. They believed that the only training required to do the job is some direction in safe lifting. Some felt the only one who really knows what is needed to do the job is the recipient of the services; therefore, she should give the directions. As one attendant put it:

> *I only work for people who are self-managed. I don’t think I should need training outside of what they tell me. I am just hands. They tell me how to use them.... I do exactly as I’m told, as exactly as they tell me…. For example, catheterization. I can do it when they direct me, but I don’t know anything beyond that. It’s the same with medication.*

Certain areas of tension arise in promoting self-determination for both women in the relationship. For example, how far does the control of a woman with a disability go in terms of her choices about who provides her with support? Likewise, what is an appropriate level of control for a worker in determining who she will work for? What happens when either party discriminates on the basis of race, sexual orientation or similar factors?

At what point are a consumer’s demands or a worker’s refusals unreasonable? How do we work out the need for both women to have choices and control when the control of one seems to undermine the control of the other? Consumers and workers agree that the self-determination of women with disabilities is of utmost importance but, as a protection against abuse and exploitation of workers, some boundary is needed. How should such boundaries be defined and enforced, so they promote the self-determination of both?

Fosters Mutual Recognition

Women with Disabilities

Mutual recognition is fostered in relationships when women respect the other woman, and reject objectification and stereotypes. Ensuring their support providers have such positive attitudes is given as a reason why consumers want consistent and regular workers they have chosen. When women have regular workers, they can develop trusting, caring, respectful relationships with them. In-home support can be quite intimate. In many cases, support workers spend hours with a woman in her personal space. Women wanted to receive such support from women they liked and trusted. They wanted to feel confident they would be safe and treated with respect.

> *I get people I get along with. When I didn't have a choice, a lot of supports were pretty maternal, that is, they treated me like I was a child and they were my parent. They would tell me, you need to do this and that—take out the garbage, clean whatever. I was never happy in those kinds of situations—with 10 sisters and my parents I already grew up with 12 mothers. I don't need another.*

When women with disabilities choose who provides support, they are more likely to find workers they respect and with whom they are compatible. Women's preferences about how to keep their home or receive personal care may vary greatly; so too, may the work habits and styles of support providers. For example, one woman may prefer to instruct her support providers in their tasks, and be irritated if they make assumptions about what she wants them to do, and how. As one woman remarked:

> *I don't like workers who come in and try to take over, that treat me like I don't know what I want.*

Alternatively, a woman may find it bothersome to have to tell staff continually what to do. One woman in the study who articulated this view said:

> *I would like a staff person to pick something up off the floor, without me asking—it feels like begging. Or to see the garbage is full and just empty it.*

Mutual recognition also involves women's comfort with the boundaries set in their relationships with paid support providers. Women differ in this, but what is important is that their preferences are regarded and respected. Some women think it important to employ staff with whom they could become friends. As one woman explained:

> *She's not only my home worker, she's my friend. When you are working so closely with someone you can't ignore them as a person.*

In some instances, personal compatibility with the worker was more important to a woman than the worker's skills. One woman put it this way:

> *I'm not fussy about housework because my husband can pick up if they don't have good housekeeping skills. What I'm fussy about is how they treat us.*

Some women, however, did not believe that friendship with their workers was a priority. As one woman put it:

> *Some of my friends say you can't become friends with staff: they just work for you. [One friend], she's had the same woman for 13 years and they don't say more to each other than "fluff the laundry."*

Moreover, some women do not have a strong preference one way or the other in regard to friendships with their staff; they point to personal relationships with some staff, but not others, and satisfaction in either instance.

Women with disabilities felt the attitudes of their workers have toward people with disabilities, in general, and toward them, in particular, affect both the equality in these relationships and the extent to which they are satisfied with how their services are delivered. As women with disabilities explained, they want to receive services from workers who acknowledged their independence and capabilities, and valued these. As one woman put it:

> *She knows that I can do what I can do, I know that [she] knows her work; she doesn't try to take over me or my child. If he needs something she does it if I ask her too, but she doesn't do it automatically. I like that. She'll just offer me her hand, doesn't force help on me.*

Many of the women interviewed felt their support providers respected their independence. Some attendants expressed support for the values of independent living. Others valued independence for religious or moral, rather than political reasons. There seemed to be evidence that many support workers respect the equality of their clients. As one attendant said:

> *Doing the best job you can, to meet each person's needs is my goal; to promote independent living and meet these goals. To meet everybody's needs and expectations.*

Workers and consumers alike perceived a direct relationship between the way supports are provided (including the attitudes of workers) and the independence of women with disabilities. One woman described how her values regarding independence affected the way she performed her job.

> *I promote for her to be more self-sufficient. For example, I lowered the microwave so she could reach it and wouldn't have to rely on others. Move the oxygen closer to the bed so she doesn't need [her partner] to get up.... Maybe there's a lot of things she can do that she isn't doing because we aren't allowing her.*

While respondents in the case studies frequently expressed satisfaction with the attitudes of their staff, most reported that, at some point, they had worked with staff who were patronizing or disrespectful. The women with disabilities in the case studies described instances in which staff had treated them like objects of inconvenience, became irritated when they expressed preferences about the way tasks were to be completed or made choices about the way supports were provided, and spoke about them disrespectfully to others when out in community spaces. Staff attitudes of this sort had negative impacts on the women with disabilities who participated in this study. These ranged from irritation to fear to marginalization.

> *One woman, I think it was her style, she would rush in, move around rooms very quickly and stand there if I was too slow in indicating what I wanted. She made me very uncomfortable, my heart raced whenever she came...but I didn't want to say anything. I didn't want to know what she would do if she got upset with me.*

Women with disabilities also felt more satisfied with support providers who had an understanding of disability discrimination, and an awareness of disability issues. Some expended the energy to provide their staff with this education informally and through formal workshops. They believed that when the people who assist them have this knowledge they are more apt to respect the choices of their employers and promote their independence, and better facilitate their involvement in the community. In some cases, politicized staff made considerable effort to change community attitudes on and off the job. One support worker, who made efforts in this regard, said:

> *I try to lessen discrimination. If we go to the mall and someone is parked in the blue zone, we tell them they can't park there. Sometimes they'll tell you to F-off. I chased one fellow one time at the grocery store.*

Support Providers

Like women with disabilities, paid support providers believed that equality was promoted when their relationships fostered mutual recognition. Paid support providers wanted to be liked, respected and appreciated by the women to whom they provided services, and in society in general. Some attendants explained that in society they do not have high status as workers—a view they feel is linked to the low pay and insecurity of their jobs and to disability discrimination. As one attendant stated:

> *I can't handle my identity as an attendant. I find it difficult to talk about my work with other people. It's a lack of understanding. It's the stigma associated with disability, with personal care. People treat you as a saint or as a shit-wiper.*

As the woman above suggests, the low social status may be linked to negative public attitudes about people with disabilities. Negative social attitudes toward both groups of women may be reproduced or expressed within their relationships to each other.

Paid support providers report that, at times, their jobs required them to put aside their sense of personhood. While they said this was an appropriate expectation as a protection against abuse, they found it difficult and dehumanizing. They described their work as difficult psychologically because it required them to negotiate the balance between friend and employer, and to leave their troubles or bad mood at the door. One attendant explained:

> *I come in sometimes and I become a totally different person. I'm in a bad mood, but I'm being perky: "Hi, how are you?" It's not their fault that they had to [call me in to work because they had to] pee during a snowstorm and the transit was stopped.*

Having emotional reactions or sexual reactions was clearly not appropriate. However, support providers pointed out that sometimes things occur during caregiving that may trigger such reactions. In a discussion about being asked to provide sexual assistance to consumers (such as masturbation assistance or putting lovers in bed together) one woman said:

> *No one ever talks about the attendant or what her sexuality is in relation to what is going on in the room. I feel totally exploited half the time. They forget about our sexual presence in the room. There may be a problem socially with people with disabilities not being seen as sexual beings, but not by attendants. We know. We come into that room with our own particular sexuality and the various states that may be in. I have assisted people by calling someone, by getting them ready for sex. Certain times in my life I was having my own sexual issues and I wanted to be able to pull back. I have to come through and challenge myself.*

Some felt objectified as a resource for independence for women with disabilities, in acting as her "arms and legs." Others said they felt objectified when consumers kept them around even though there was nothing to do. Some consumers with individualized funding felt pressured to do this because they believed they would lose funding they might need later if they did not use up all their hours when they had them.

Attendants did not feel there was much that could be done about these kinds of realities. They felt they were, at least in part, a necessary downside of the job. However, they stressed that what they wanted was consideration on the part of the women they serve about the impact of such decisions on the support provider. They wanted the women who employed them to speak to them respectfully, and to see them as real people with their own issues and concerns. Attendants placed great value on working for people who were considerate. As one attendant said:

> *They want us to have disability consciousness. I want them to think about who we are as attendants. What brings us to work. I'd like them to think through who their employees are, why they are there.*

Support workers felt that the social attitudes of the women for whom they worked affected the recognition they obtained in the relationship. In this respect, racism emerged as a significant problem. Some support workers felt the security of visible minority staff was compromised due to overt, or covert, racist attitudes of some recipients of services.[20] One Black support worker reported that, on two separate occasions, clients (who did not want to receive services from a Black woman) had falsely charged her with abusive behaviour. She described one of these incidents in this way.

> *Several times I had conflict because of race. In one example, I was working at this place. I went in to give this lady her shower. I did everything. I was about to take her out of the bathroom. I was about to take her into her bedroom to dress her. She always was picky with Black people. She just started saying you f'n this; you f'n that [cursing and racial slurs]. So I covered her, and left her in the bathroom. I got someone to come with me that I work with. I ended up leaving and the other girl took over. She wheeled herself into the living room. She had banged herself on something. The other girl dressed her. Lo and behold, I was at home one day and a policeman came in. I was charged, that I had grabbed her.*

The agency for which the attendant worked had believed and supported her because the consumer in this situation had previously demonstrated racist and abusive behaviour toward attendants. In both cases, the charges were dropped because the women who made the allegations did not participate in the conflict resolution process, nor did they show up for court. The attendant felt, however, that insofar as the resolution and trial processes were aborted, she did not have the opportunity to clear her name. She believed that because her name had not been cleared, she lost shifts in her current workplace and future employment opportunities elsewhere. In addition, she spent thousands of dollars to hire lawyers, which she could not afford.

A White attendant remarked that the women of colour with whom she worked were not treated fairly. She suggested that some employers, aware that this group of workers is marginalized and underemployed, capitalize on the opportunity to fill their "difficult-to-fill" shifts (such as one-hour, early morning or overnight shifts). She remarked that it was not uncommon for White women to work all the "choice" shifts and for women of colour to work what she termed as the "shit" shifts. As she explained:

> *There are a couple of places where Black women are not securely working. They don't always bring forward complaints because they are so vulnerable. I believe some of my employers take advantage of this. A good portion of people I work for who have a "shit" shift (one hour, or night shift that could change between 10 p.m. and 1 a.m.) [fill them with women of colour]. In these shifts, you are cabbing it, so you lose any profit, but you do it so you'll get called the next time."*

Another factor that affects relationships of informal support between women is the degree to which women who provide support are recognized and compensated. Recognition takes a number of forms. The simplest and most obvious form of recognition occurs when others notice a woman's contributions to her community and express their appreciation. In addition, recognition of a woman's contributions may involve the sort of exchange of supports (I do this, and you do that), which is part of membership in a community. In more formal terms, women's unpaid contributions to the well-being of their communities could be recognized through social policy and the various taxation systems.

Encourages Respectful Interdependence

Women with Disabilities

Relationships promote equality when they encourage a respectful interdependence. People's independence and autonomy occur within the context of communities and relationships with others. Women with disabilities and support providers rely on each other for different things, and it is a criterion of equality for both that their interdependence promotes, rather than detracts from, individual self-determination and independent action.

The relationships women with disabilities have with paid support providers has an impact on many relationships in their lives. Consumers report that when they received adequate paid support, they were not required to rely on friends and family members in ways that were not comfortable for them. Thus, by virtue of their relationships with support providers, they were able to have more equitable and fulfilling relationships with family members and friends. One woman described how having sufficient paid support enhanced her self-determination regarding the kind of support she receives from others and reduced her dependence on them.

> *In terms of personal care, all those needs are met by my workers in my home. It's very difficult for a 30-year-old woman to say to her mother: "I need a bath now." It's good to have those supports outside the family. Not that family is not a good thing. In order to have your independence you need the help of others.*

Those who did not receive the paid support they needed described how the resulting dependence on their spouses, family and friends compromised their equality in these relationships. One woman explained that she had lost friends because she had too frequently asked them to help her with personal care, such as bathing.

> *Friends jump in regularly and help me get more frequent baths (bathe me).... I'm not satisfied with it. I'd rather have it as part of my paid routine. I don't feel it's fair to count on my friends. I'm not comfortable with it, but have no choice. It has affected my friendships. Some friends I have lost—they don't feel it's their role and they are right.*

Similarly, respectful interdependent relationships with informal support providers strengthened their relationships with formal support providers. In a few cases, women frequently received additional support from family in tasks such as cleaning, repairs and grooming. They reported that they felt more comfortable doing so than asking paid support providers to perform extra tasks. As one woman said:

> *My parents assist me in grocery shopping. I give them a list and they bring it to me. My parents visit once or twice a week and do some extras in terms of cleaning up. If I want a special meal, they'll do that. Sometimes, it's easier to request my parents to wash my hands extra, or extra face wash.*

In one case, a woman reported that although she received enough paid support, she did not have enough *sources* of support. She explained that although the support relationship she had with her husband was reciprocal, they relied too heavily on each other because neither of them had anyone else to whom they could turn. She said that although she cared deeply for her partner, she felt trapped and suffocated by their dependence on each other. She put it this way:

> *With my partner, sometimes I feel like I'm being suffocated; we need each other too much. Sometimes, I wish he would turn to other people rather than to me all the time. Sometimes I get so tired. He doesn't have a whole lot of places he can turn either. We're on our own.*

In general, women valued reciprocal support, reciprocity being the element that made a situation clearly one of interdependence rather than dependence. In communities, especially families, this reciprocity was sometimes indirect (i.e., a woman would be supported by a sister and support her brother, who in turn would support her sister). Regardless of how reciprocity was conceived, a sense of balance between what one gave and what one received was important. One woman described the reciprocal contributions she and her husband made.

> *I think what makes us so close is that we can help each other.... He helps me physically and I help him verbally and intellectually. I read books to him, newspapers, explain things. Anything that he needs help understanding I explain it. He drives, helps me in the washroom. I'm very independent. I don't like to have people handling me, but I don't mind it when he helps.*

Another woman described the "talk" in her informal relationships of support as the means of reciprocity.

> *Both of my aunts have been really supportive. I'll have supper at their houses. They make sure I'm eating on a regular basis.... We talk about what's going on, what's my destination. The past year I did a lot of travelling. It's mutual, I talk and they talk. My one aunt is like a second mother.*

A concern on the part of some women with disabilities was that a lack of acknowledgment of reciprocity created barriers to respectful interdependence. They were concerned that their contributions were not granted the merit of contributions made by others and that they were seen as always being on the receiving end of support. As one woman stated:

> *There seems to be an imbalance because I do need support physically. The kinds of support I give to everybody in the family with problems and situations, doesn't equal. It feels like an equality thing. They just see the physical needs as carrying more weight.*

Another remarked:

> *I supported my father all through my mother's deterioration. I've been the one who's been there to talk to him and provide support. But when it comes right down to it, he sees me as dependent and helpless. In reality, he is reliant on me. If you were to ask him, he'd say his wife is in a nursing home and his daughter is quadriplegic. One of my brothers will go over and spend an hour cleaning the eavestrough, and isn't he wonderful? The hours of support I provide don't count. I used to cook for him and I can't anymore. Certain kinds of help are valued more.*

In fact, many women with disabilities in the study reported making significant contributions in their relationships of support and their communities. The ways in which they contributed varied. They reported belonging to community organizations, providing emotional support to friends and family, raising children, doing housework and cooking, fixing things, baby-sitting and providing support to community members who were elderly or ill. Describing the friendship she has with a woman to whom she provides paid supports, one woman said:

> *She helps, she listens when I need to yell at somebody. She's more like a friend than an employer. She also baby-sits, at least once a week, sometimes overnight, a lot of times two or three hours.*

Access to supports and services enabled women with disabilities to make contributions within their relationships. Generally, women who had sufficient support had the time and the means to do things for others. Some women with disabilities do not contribute to their community because they do not have sufficient opportunity to do so, or are regarded primarily as recipients of support. These circumstances inhibit women with disabilities in attaining equality because they are positioned as dependent (rather than interdependent) when they receive informal support.

Women with disabilities who worked full time wanted to provide more support to others than they already did. But, they felt they were prevented from doing so because of the demands of their jobs. They reported that they were frustrated by the fact that they could not "be there" for their friends, spouses or children to the extent they wished.

Other women with disabilities found that respectful interdependence was compromised because others relied on them too much for support. One woman said the amount of support her friends required left her emotionally drained. As she explained:

> *I'm there to provide a lot of emotional support for other friends. I often think it would be great if I would get paid for it, because it seems I do so much of it. A lot of my friends have disabilities, and sometimes it's a real burden to carry, in terms of being able to deal with it emotionally. Most of those friends are a burden on me because I'm a good listener.*

The types of dependency and interdependency that emerge in any relationship, especially those that involve disability, can be very complicated. It is well documented that people (most often women) who take time out of the paid labour force to be unpaid homemakers or parents are at a disadvantage in terms of their earning power and career opportunities. As one couple in the case studies explained, this disadvantage is exacerbated when there is a need for disability-related support. The couple identified their own circumstances as a case in point. In their situation, the woman with a disability earns the income for herself and her partner, and she relies on her partner for unpaid support. They feel trapped in these roles and felt that a situation of co-dependency, rather than healthy interdependence resulted. As the woman with the disability explained:

> *I am very concerned about the discriminatory system whereby spouses and partners are not eligible for any recognition. That forces me…I would sometimes like not to be the principle income earner in our relationship. Maybe spend some more time doing some writing. That simply isn't possible, because my partner has not had the opportunity to establish as firm a career position as I have. And she won't ever have the opportunity—we're caught in a sense, in a certain catch-22. She's caught supporting me so that I can continue to support our household, and we're never going to get the breathing space to change that.*

Support Providers

The importance of relationships that encourage respectful interdependence is also evident with respect to support providers. In the case of those who are paid to provide supports, the reciprocity generally comes through pay, job security and job satisfaction. That they are provided these benefits according to the extent and nature of the support they provide is important. However, as is seen in the section that follows on ensuring security, this is not always the case. Many support providers reported low wages, a lack of benefits, low security and limited opportunities, though they noted the services they provided were essential to the consumers' independence. Consumers of services also noted this imbalance. This emerges as a tension in women's relationships. Nearly all acknowledged it as a problem, but felt they had very little control over it, if any.

This situation set up a strange set of dynamics within the relationships. Women with disabilities felt that since they had little control over wages and benefits, they had to cultivate personal loyalty to hold onto the services of women with whom they valued support relationships. Some women did this by establishing friendships with their support providers; others offered perks, such as Christmas bonuses, loans of their vehicle or other favours. One situation was described in which a consumer retained the loyalty of her favourite attendants by paying them more than she paid others. One attendant said she had worked for a woman who helped another attendant achieve her immigrant status. Many workers said that despite the low pay, they stayed in the job because they liked, and felt needed by, the consumer of their services. Some were politically committed to their work in supporting rights and independence; others had social or religious motivations. Some stipulated that they saw support provision as a job, and they found situations with sufficient perks and benefits to make it worthwhile. Those who didn't report these motivations (as well as some who did) were dissatisfied with the work and felt trapped in it for various reasons.

As stated earlier, reciprocity in interdependent relationships is not always direct. That workers "get something out of" a role is not the responsibility of the women receiving such services. For respectful interdependence to occur within such relationships, it is important that neither woman entirely depends on the other. As such, the availability of outside supports to workers in the form of job support and training is important. However, most women who participated in this study did not have formal support in their jobs. The one exception was a woman who worked in a semi-institutionalized setting. She reported that she received support from her co-workers, from a team of professionals (which included social workers and therapists) who were available to give workers (and clients) advice and support, and from her supervisors, whom she described as approachable and willing to accept input.

> *We have job support; we have information. Every time I need information we have a social worker, an occupational therapist and a home ecologist. Staff can go to them and clients can go to them.*

The women who worked in private homes (regardless of whether they did so through an agency or under direct employment) did not have access to these forms of support. Some described their clients as sources of support. In such situations, the women for whom they worked usually sympathized with problems related to their jobs (such as low pay and inadequate work hours). In some cases, the women listened to each other's personal problems. In one case, a woman who worked for one of her family members received job-related and on-the-job support from her husband and son. Others, however, felt they needed more support, even if this were simply a place in which to vent their job frustrations. As one worker explained:

> *I definitely would love to have support. People who work in projects constantly vent and gossip in the lounge, it's the place for that. I don't work in that kind of environment.*

Issues also arose for these women because they often failed to receive support within their communities. They not only provided poorly compensated paid supports in the work force, they also seemed to carry a large burden of the support which is provided in their communities, receiving little support in return. These women tended to be stressed and had little time for themselves. One woman described her situation.

> *Well the amount of support I give is...all of myself. I don't get anything back. I have one client who talks to me. My other two clients: I give everything. Because I'm never here, when I do get home I'm exhausted, and my home life is falling apart.... My husband doesn't come home a lot because when he comes home, the house is empty.*

Likewise, if informal supporters are relied upon too much, there can be negative impacts upon their economic and social security.

Most of the informal support providers in the small sample studied felt they had sufficient informal support. (It is unclear whether or not this would be the case were a larger sample of women to have been interviewed.) Furthermore, the relationships of support they described seemed to be fairly equitable and reciprocal. In one situation, an informal support provider said that more support was needed in order to support a sister who had been removed from an institution. In this circumstance, family members did not contribute support and the systems of organizational support that were in place when she left the institution had broken down.

Ensures Security

Women with Disabilities

The equality of women with disabilities is supported when their security is ensured within their relationships of support. Many of the women with disabilities who participated in the study described being in situations at some point in their lives where they had been abused physically or in other ways by persons providing their services. Such unacceptable possibilities are an important reason why women with disabilities want control over who they hire. They wanted to engage in support relationships with women they felt safe with and trusted. The relationship between women with disabilities and paid supporters is complicated. Women with disabilities point out that, by definition, they are in a position of vulnerability with respect to their staff. They are often isolated in their apartments and homes, seen naked or in a bathtub, lifted by another person. One woman said:

> *The attendant can drop you, drown you, scald you, walk out on you or just be rougher than necessary. Every day, I am rolled over in a position where I can barely breath and if an attendant for whatever reason chose to ignore my hand signal indicating that I had to be turned back I would be a goner. Dead. No evidence of rough stuff or anything.*

In addition, women with disabilities may be vulnerable to financial abuse. This is especially the case when they have little control over who is providing support to them and when many different people come into their homes. Not only do attendants and home-care workers have access to women’s belongings in their homes, consumers often must rely on assistance in handling money, credit cards and bank cards. A number of women with disabilities in this study reported that attendants had stolen money from them. One of these women did not know which of her attendants was the thief; thus, she was uncertain which of them she could trust. As she explained it:

> *I just had a situation where an attendant stole a large sum of money from me. The money was one thing. But now I’m thinking of everyone that comes in the door and bathes me and wipes me. I wonder which of these people has so little respect for me they would do that and think: “Ha I’ve duped you!”*

> *They're not bondable because the supervisor says it's too expensive. It could be any one of six people.*

Some women indicated that workers must be screened and that a system by which workers are accountable for job performance and inappropriate or abusive behaviour must be put into place. Users of various service arrangements raised this as an issue. Most support providers indicated that they were required to be bonded in order to be hired; however, this seems as if it would be an insufficient protection against abusive workers. Some service users were concerned that abusers would not be held accountable legally even if they were charged with a crime. One woman describes her failed attempt to prosecute a staff member who had robbed her, and expressed concern that the woman continued to work elsewhere as a support provider. She said:

> *I had a woman who worked for me who would put me in the tub and go searching through my apartment for money and stuff. It happened to others too at the building. I ended up taking her to court. I set her up. Put money in my wallet and put it in the drawer. She took the bait; I took her to court. In court the lawyer pulled money out of his wallet and paid restitution, so it got thrown out of court. The agency let her go, but they hadn't done their job in the first place and checked her references. She's probably working somewhere else; she may still be doing it.*

In another situation, a family member of one woman with a disability in the study explained that a government ministry recommended a worker for her who was negligent and abusive despite the fact that some people in the ministry office were aware that she had done wrong in the past. Furthermore, despite the fact that some people in the ministry had informal knowledge of her wrongdoing, she continued to work because no structured system was in place to keep track of workers who have caused harm, or who are suspected to have caused harm. The lack of mechanisms to track undesirable workers is endemic. As one woman remarked:

> *There's some people...that did something wrong, gave the wrong medication, were shoving clients around. The Department of Health had given the best recommendation. They don't know what they've done with another patient. And when I tell them about it, they say: "Oh my God. I didn't know she was in your house too." Another worker told me. It was too late then. I don't want them in this apartment. I don't want them here.*

The security of women with disabilities also depended, in some instances, on the presence of support providers at particular times. In this way, access to personal and home supports also contributes to safety and security. Women feared harm to themselves from falling, for example, if no one was nearby to help them get up. One woman described lying on her lawn for hours before her mother arrived and helped her. Women were also concerned that if they had to wait for services such as bathroom assists, health problems could result over the long term.

The security of women with disabilities is also affected by the conditions under which support providers work. It is specifically this type of interaction that makes the issue of equality within relationships so vital. To be secure, women with disabilities need consistent workers who do a good job, have a strong work ethic and like the work they do. They do not want to deal with staff who are sloppy, rush through their tasks, or resent the job they do, since these factors affect not only how they are treated, but also the quality of services they receive.

These factors hinge, in part, on the working conditions of staff. If workers are tired and unhappy due to poor working conditions, the quality of the services they provide is reduced. One attendant worried that she was no longer a good attendant because she was burnt out. The burnout of staff could cause safety risks for them and the women for whom they work, for they could become careless and make mistakes, which could result in serious harm in intimate care and medical care situations. In addition, burnt out workers could be more irritable, and the risk of abuse for women with disabilities could rise.[21]

The difficult conditions under which support providers often work, the low pay they receive, and lack of benefits attached to the job result in high staff turnovers, which, in turn, can be distressing for consumers. It increases the number of persons they deal with for their personal and home care, increasing the time they spend training people, escalating the risk of abuse and, generally, disrupting their lives. Nearly all the women with disabilities who participated in this study reported that they like to employ the same worker(s) regularly, for a long period. As one remarked:

> *I'd like to see more consistency and flexibility. One of my biggest pet peeves is continuity of care.*

Women with disabilities find it less disruptive when women they know well come into the home to assist them in intimate ways, for this continuity reduces the need for ongoing training. One woman described her own situation.

> *They hire girls and float them all around. A lot of different people used to come. You never knew who was knocking at your door. Now I know who is walking in my door, and if there's a conflict, then it's up to me or them, as opposed to someone else deciding whether they fit the job.*

While quite a few women had established relatively long-term working relationships, women with disabilities repeatedly stressed how difficult it is for them to retain workers over the long term with the low pay and inadequate benefits offered, or lack of benefits altogether. As one woman with disabilities described it:

> *Long-term workers are hard to get.... The home-care profession is poorly paid, just over minimum wage, so I don't expect to keep them. There's no way you can live on the wages of home care. Home workers are poorly paid. I heard other friends say the same thing, too. When you end up leaving because the wages are so poor.*

The odd hours which attendants work pose problems for women with disabilities who need services for short periods of time. A number of women in this sample had one- or two-hour shifts they needed to fill. Some were regularly left without the services they needed for that hour. For these women, no support for an hour means, perhaps, no help to get out of bed or go to the washroom. Either situation could be seriously inconvenient, uncomfortable and dangerous. Nevertheless, some women believed it was unfair to ask workers to come in for an hour or so, especially in the early morning, for only $8 or $10 or $12. One woman said:

> *I have one woman who has been working for me for a few years now and she works one hour a day, Monday to Friday in the middle of the afternoon for $12.50 an hour, and that's all she gets. She comes here; she's here for an hour. She comes on time, she knows she can't just take a day off. And she only gets paid $12.50 for that. It is hard to get high quality people at that rate of pay. You can cultivate a certain amount of loyalty, but you are not necessarily going to be able to attract and retain people.*

Not being able to access support at a crucial hour (i.e., early morning to prepare for work) or need (daily shower) may inhibit the security of a woman with a disability in society at large by restricting the opportunity to gain or advance in paid employment, for example.

Women with disabilities reported they had a difficult time finding qualified people to work for such low rates of pay. One attendant (herself qualified as a dental assistant, not a caregiver) reported:

> *I have a friend who has a diploma in this, but she doesn't work in it. She makes more working at a grocery store.... My friend figures what's the point—she has extensive training, Braille, sign language, interpreting—and she's working at the corner store.*

Support providers too were worried that their own burnout, low qualifications or lack of training may result in harm to consumers. One support provider worried that because she lacked relevant information, she might cause harm to her client. As she explained:

> *Sometimes, because I don't feel like I know everything about her machines—when she gets sick maybe it's not me cleaning the machines right.*

Another worried that she might make a harmful mistake due to fatigue, while still another described being uncomfortable with her own irritability and lack of sensitivity on days when she was tired.

Support Providers

The security of support workers, not surprisingly, is affected by the working conditions established in their relationship with consumers. The difficulty of the work they do, long hours, low wages, limited benefits and limited access to safety training (when true) impacts their physical, financial and social security, and thus their equality of well-being.

Some attendants complained of burnout. They described their jobs as hard work, which is physically and psychologically exhausting. Some worried about the impact their job would have on their own health. Many felt they could not continue to do attendant work due to their own physical decline. A number of women reported that they had developed health problems, such as back injuries, as a result of their jobs. This was especially a concern for one support worker who had a disability herself.

> *It's a job. It's very gruelling. I can't say I like it. I have a branch of muscular dystrophy. So, I find it very exhausting work, but I'm not qualified to do anything else. I find it very tiring.… But I'll do this until I can't do it anymore.*

Similarly, the security of unpaid support providers may be compromised by health risks. In one of the case studies, family members of a woman with disabilities felt their physical health was compromised by the stress involved in their support situation.

> *It's unbelievable, the hurt and the heartaches and everything like that family members are going through.... Look at my wife; she's going to find herself in the hospital. And myself. Both of us are putting up with this every day; this screaming and the beating, kicking and punching throwing the furniture around.*

The job of a support worker often involves inconsistent hours that are sometimes split up or extend overnight. Some workers were content with these arrangements because they fit with their respective lifestyles. Others felt these factors affect the kind of rest attendants can get when they are "off-duty." They complain that they are often grumpy and tired. Sometimes, they must get up very early in the morning, or stay up very late. Furthermore, they do not feel they always have much control or choice. In some cases, this was also stressful and disruptive to the families and social lives of support workers. As one worker remarked:

> *It's all work. Working straight hours. Work and shopping, and that's it. Between shopping for them, shopping for me. It doesn't sound too good, does it? It's not that great. Constantly. Right from six o'clock in the morning. I have two or three splits a day. I come home between and do laundry or housecleaning, whatever.... By the time I finish with my last client, and then I have to go clean a bank, I come home and make dinner and I'm not joking, it's about 9 o'clock. I lead a very uneventful life. I don't associate with other people. I don't have time.*

Another woman described her situation in this way.

> *I'm burnt out. I'm tired of figuring out the relationship lines. It's a very intimate job, but I'm supposed to be professional. There's no guidelines, no discussion. It's all private.... You get close to people you're working with and that's hard to figure out. It's not like you're at an office; your workplace is a home.*

Some support workers felt isolated as staff in people’s homes, where they are without co-workers and other people around them. One said:

> *I would like to get a job at the hospital because that would give me some interaction with other people. It’s very insular, that’s one thing I do miss I’m basically on my own.*

Not all workers felt this way, however. Some valued the insularity of the support situation, for it enabled them to develop close one-on-one relationships with their clients.

Just as women with disabilities need access to support services, women who work as service providers need good working conditions so they are not disadvantaged within the terms of the relationship. Workers tended to be satisfied with their job if it paid appropriately. Adequate pay increases women’s security, status and choices in their lives. This was the case with physiotherapists and other professional service providers, who were paid as much as $50,000 per annum. The rates of pay for home-care workers were, in general, low, although these varied from province to province. Workers in St. John’s, for instance, were paid as little as $5.60 an hour; those in Winnipeg averaged about $9 an hour, and those in Toronto averaged about $12.50 an hour. Some women who are disabled recognized that low pay and lack of benefits marginalized their staff. Many were concerned for their staff; they expressed the desire to provide better employment for them.

The security of support providers is also affected by their access to employment benefits and workers’ compensation coverage. These benefits variously protect workers if they become injured or ill. However, the majority of paid support providers in this study were not protected in this way. Women who provide supports and those who receive them regard both the lack of benefits and the lack of workers’ compensation coverage as significant flaws in the way that support services are currently delivered. One respondent remarked:

> *I think you should get benefits.... I think you should have medical and dental plans. It’s something you’re going to need.*

Women expressed concern that those who may become ill or injured have no protection other than the social assistance system, a system that was perceived as inadequate. Some worried that injury could lead workers to take even more marginalized employment. They were concerned that this may become a reality for many women who work in this field, since some types of support work involve physical tasks (such as lifting) which make one vulnerable to injury.

Women with disabilities receiving individualized funding and employing their own staff were concerned with the impact the lack of benefits and workers’ compensation coverage had on their workers’ security and well-being. They worried about what would happen to them if workers were to hurt themselves on, or off the job. Some felt guilty that they were not able to provide better employment conditions; they emphasized that they simply were not given the necessary funding. In addition, they described the complications that ensue because they do not have a large enough staff to purchase benefits packages, and are not able to offer their staff full-time hours which would render them eligible for such packages.

As was outlined earlier, the labour issues of workers not only have an impact on their security and well-being, they also affect the well-being of consumers they support. Likewise, the service issues facing consumers affect the security of workers. When a paid support worker's client receives the other services and aides she needs, the worker is less likely to carry out tasks that could cause her harm. If, for instance, a woman with disabilities has access to a mechanical lift in order to get in and out of bed and the bath, the amount of lifting her attendants must do is reduced, decreasing the physical stresses of the job and the likelihood of injury. Similarly, if a woman has access to physiotherapy or exercise, such as swimming, her physical comfort and capacities may be increased, and the amount of physical work her workers must do may be reduced.

What benefits the well-being of one group does not always work in the other's favour however. Some aspects of service provision that women with disabilities outline as essential to their equality of well-being come with notes of caution on the part of support providers. For example, workers caution about the notion of "absolute choice over workers." As employers, labour codes and human rights laws bind service recipients. Their right to self-determination in whom they hire is qualified by the rights of workers not to be dismissed unfairly or discriminated against. The control an employer/client has in relation to the women she hires, retains or fires can increase the vulnerability of a worker. Respondents described incidents in which they experienced conflict, where the systems in place, supposedly, to protect them were invariably inadequate.

> *I have experienced conflicts. It's been hard.... It's like fighting with a friend, and they have power over me. They can fire me, and I have a reputation to keep up. I depend on my reputation to get other work. I know who's a good attendant. It wouldn't scare me so much if my job didn't depend on it. Especially since the people are under individualized funding, there's no other party to help work it out.*

Like other members of the broader society, women with disabilities may have prejudices and may make unreasonable decisions. A worker's security may be compromised if she is fired or let go in unreasonable circumstances, such as a client's bad mood, a disagreement or racism. As one White attendant remarked:

> *When I work in places where a lot of the employees are Black, people will confide they don't want them in their apartment and they start stigmatizing.*

In fact, one focus group participant described repeated incidents in which clients did not want her to work for them because she is Black. She explained that although these clients did not have the power within the service agency to refuse her services based on race, they made repeated complaints about her, which caused her to lose shifts. She strongly believed, furthermore, that they fabricated these complaints so they would receive their services only from White women. As she stated it:

> *The White people, they can say anything they want. Clients never say anything. We [Black workers] say one thing wrong, they make a complaint. Even just saying "hey what's up?" I can't say that. You have to watch what you say at all times with certain people. They're never satisfied. They always complain.*

Neither did attendants think that flexible service provision worked in their favour in every respect. They felt that the flexibility of service provision to women with disabilities compromised their own physical and psychological security at times. Attendants were not sure how to resolve this dilemma, or if it could be resolved. Some felt that it may be a necessary downside to their job. Nevertheless, many felt they could not continue to do the job because it took a great toll on them.

> *I feel like my week is wacky.... You organize your life from pay cheque to pay cheque. I organize my life around my work. When I work night shift, the whole day I'm thinking about the fact I have to work. And you don't know when a person's going to bed. You just have to stay up, no matter how late or how tired you are.*

In addition, those who work under self-management felt as if their financial security was sometimes at risk as a result of their employer's flexibility. For example, while they felt their employers had a right to go on holiday, this had a financial impact on workers. Staff tried to organize their own holidays around their employer's holidays, but they were concerned about how to get through even brief periods without pay. They complained that their employers sometimes did not notify them in advance in order that they could arrange alternative employment. One attendant remarked:

> *I take time off whenever anyone is away. When I'd be losing money anyway. But often they don't tell you in advance because they know you'll need to find other work and they might lose you.*

Democratizes the Decision-Making Process

Women with Disabilities

Having agency in decision making within support relationships is an important equality criterion for women with disabilities. As was discussed earlier, first and foremost, it is essential that consumers of services determine for themselves important aspects of service provision. However, because they are acting in the contexts of systems and relationships, this happens, at times, as part of a process of negotiation.

The agency of consumers in such negotiation may be restricted for a number of reasons and at a number of levels. In some instances, women with disabilities felt they were not sufficiently included in the decision-making processes regarding their assessment of need for support and determinations of eligibility. They insisted that to ensure their needs are determined holistically, they should have a say in their own assessment. As one woman put it:

> *I would like to see, in terms of policy, in terms of people who require more care, I'd like to see policies more inclusive. They should have a say in assessments done on them and access to those assessments.*

The availability of supports also may contribute to the agency of a woman with a disability in her dialogue with those who provide support to her. The more dependent a woman is on another person, the less power she has within that relationship. When a woman continually needs to request extra assistance from her paid and unpaid support providers, it reduces her bargaining power in these relationships.

Agency in decision making is also affected by the structures of the support provided. In some types of support arrangements, the control women with disabilities have in setting the standards of care, and requirements that attendants and home care workers comply with these preferences, is integral to the service. Women in individualized funding arrangements were generally satisfied with this style of service provision in this respect. They hired people they felt respected this condition, trained them in how to carry out their tasks and had the power to let a worker go who did not follow directions. While some agencies also supported decisions of women with disabilities in such matters, others had rules that seemed to override the decisions of the consumer of services. This occurred sometimes even when workers acknowledged their clients' right to decide such matters.

Effective communication between women with disabilities and their support staff promotes equality for the respective parties in these relationships, and improves the quality of the relationship itself. The majority of women who participated in this study reported that communication in their support relationships was good. Many of the women with disabilities were able to articulate their needs to their staff, as well as instruct them, with regard to the way they wanted tasks performed. In turn, their staff appeared to listen to these instructions and respond appropriately. One woman put it this way:

> *My attendant is careful with the way she uses her words. I can talk to her, and she really listens. She's said a couple of things, and I've corrected her and they stop.*

Many paid support workers indicated that they too felt satisfied with the communication in these relationships.

Communication between women with disabilities and their supporters became especially problematic when there were conflicts. The way in which these conflicts were resolved to some degree depended on the service arrangements governing the relationship, as well as on the policies of particular agencies.

Paid Support Providers

Most support providers interviewed felt their participation in democratized decision making was not compromised if the women with disabilities for whom they worked had control over the tasks they performed. Nevertheless, workers felt that, at times, boundaries in their jobs were blurry, which was confusing, and uncomfortable for them. Workers emphasized that they did not want rights taken away from their client/employers; however, they wished that consumers would consider the ways in which blurred boundaries affect workers. This blurring of boundaries between women with disabilities and their attendants occurs for various reasons, one of which is the complexity of the relationship that oftentimes develops between them. Indeed, both attendants and women with disabilities described the intimacy of the situation, and the friendships that develop. Attendants reported that, because of the ambiguous character of the relationship, their employers would sometimes ask them to perform tasks which they considered to be outside of their job description. They reported, furthermore, that although they often performed such tasks, they wanted their employers to recognize that, in doing so, they had done favours for them.

In addition, attendants said that situations arose in which boundaries between them and their employers seemed not to exist at all, nor was it clear whether they were expected to act as an employee or as a friend. Attendants reported that this ambiguity often arises when they travel with employers; they regarded the role of travel attendant as confusing and demanding. In travel situations, attendants are usually paid for some of their hours, but not all of them. The trip itself is often regarded as a "perk." One attendant remarked:

> *Travelling is always complicated around having time off. Especially when you don't know if you're a friend or a worker. When you're out for dinner; when you're looking at the Eiffel Tower. With the guy who wanted to go to Italy, he was not seeing me as an attendant. He just acted as though we were going to hang out, have a good time. But I am working 24 hours a day.*

Support workers also felt there needed to be a more collaborative decision-making process, particularly when tasks come up which are not clearly a part of the job. In these cases, they wanted consumers and staff alike to have some form of communication guidelines to clarify the situation. As one attendant stated:

> *There is a distinction between a job-oriented task and a favour.... Sometimes, you do things for your employer that they could do for themselves and you think, hey you can do that yourself. They might have their reason, but you need that communication. You want there to be logic. I had a huge issue with one woman because I had to rinse her hair for a long time. She kept telling me I wasn't getting her hair clean enough, and I resented it. I knew it was rinsed. One day she tells me she liked the feeling of hot water. I loved that. That was a good reason for long rinses. I just hated her saying: "No, there's still soap."*

Questions of identity and boundaries also arise when attendants work as nurturing assistants (i.e., assist a parent with a disability to care for her or his child). One worker participating in the study explained that the boundaries involved in that triangular relationship are complicated. She explained that workers could find it difficult to be responsible for a child's care, yet not respond to the child's needs. As she put it:

> *It’s difficult if you have physical contact with this baby that needs to be bonding with the mother. The child might be crying and the mother doesn’t want you to comfort the child. It’s hard if the child is reaching out. The mother might be uncomfortable bonding with her infant with an attendant present. It can be stressful for the attendant. When is it ok for the attendant to pick up the child? If the mother says feed the child more and I’m not comfortable with it, can I refuse? If it’s getting close to lines that are abusive, where do you draw the line?*

Some attendants felt that some consumers lacked judgment regarding attendants’ own physical limits. While they recognized that the reasons may be real and concrete (for instance, some people with disabilities have never experienced full use of their own bodies), they felt service recipients should trust the judgments of their staff about their own physical capacity. One attendant, for example, described an incident in which a client wanted her to carry the refrigerator out to the garbage. Another woman noted that some employers are, in fact, conscious of these issues, though others were not:

> *One woman I work for will never want me to do anything that might hurt me. She’s a good employer. Another will push me, and will whine later and make me feel weird.*

Because issues such as these arise, effective mechanisms for communication, in which workers as well as consumers have agency are essential. As paid support providers explained, they want to work for women who are conscientious employers; in addition, they want effective and clear communication with the women for whom they work in regard to that which is expected of them, and they want agency within the terms of this dialogue.

Again, this is particularly essential when conflict arises. Most agencies have systems of incident reporting that both clients and service providers could access. Some agencies have well-developed mechanisms for conflict resolution. Some encouraged service recipients to confront attendants directly when they have problems with the ways services are provided to them. Attendants who worked under individualized funding were most apt to feel they had little or no recourse should communication break down.

The various women studied have divergent ways of dealing with the conflicts that sometimes arise within these relationships. Some may want to address their concerns to a worker or employer/client directly. Others may prefer some from of mediation. Regardless of whether a given relationship is direct, or managed through an agency, a woman with disabilities and her staff need access to a range of communication supports and choices about how to proceed in times of conflict. This range could include (for example) guidelines that advise how to proceed through a time of conflict, mediation services, communication workshops, and conflict resolution strategies and services.

Promotes Citizenship

Women with Disabilities

Citizenship includes the right to participate in communities. For women with disabilities, support relationships may be a part of their means to do so. Paid or unpaid support providers may assist women with disabilities to participate in communities by accompanying them to community spaces, assisting them with transportation, providing personal care in community spaces and in other ways.

Women with physical disabilities reported that they find it difficult to access support for community activities since they are considered leisure or recreational.

> *There's no community-based company out there to help my age group. There's no group out there for anyone who is [physically] disabled.… They say there's no funding for it.*

Nor was a woman with an intellectual disability able to access funds to assist her to participate in social and community events. Such services fall under the auspices of respite care, and she did not have caregivers who required respite. To be sure, children and some people with intellectual disabilities are able to access respite supports to participate in the community. The aim is to give their informal caregivers a break from their responsibilities, not to enable community participation. To compensate for this gap, some women with physical disabilities transfer (and get by without) some of their essential daily living services. For example, women who have paid support reported they use home-care hours to get assistance to go to community events. Those without the flexibility to make this choice either had to rely on informal support for assistance in the community or do without.

Citizenship also involves the right to liberty. The liberty of persons with disabilities is infringed upon if they are trapped in institutions, or in their homes, because they do not have the support they need to get out. Most women in the study had sufficient support to ensure their liberty to live in, and participate in the community. However, the liberty of at least one woman was at risk because she did not get enough support. The woman's brother feared that his sister would be institutionalized as he and the rest of the family "burned out" in their capacity to provide unpaid support.

> *I have to be there all the time.... I may give it up, and if I do give it up, where are they going to put my sister?*

In other situations, the equality of women with disabilities may be overtly compromised by persons with whom they have support relationships, as those people intentionally restrict their liberty. In cases where people are isolated and dependent, they may be trapped in their homes as an act of overt abuse, or because a support provider feels it is in their "best interest." This is clearly not appropriate.

Ironically, for people with disabilities advocating for oneself or others, usually considered a mark of citizenship, can put citizenship at risk. A number of respondents feared there would be repercussions if they struggled for their right to services. That is, they were perceived as troublemakers. In some cases, informal support providers worried that their family member might be punished if they spoke out and advocated for that person. One mother felt her daughter might be at risk of abuse by her attendants if she complained about the quality of service.

> *Things are not always done the right way. Some attendants don't take enough time. Some attendants need more training, under better supervision. It makes more work for me, but I don't say anything because [my daughter] says it will be taken out on her. They might scare her or something, like move her roughly.*

Members of another family feared that if they were to advocate for more support, social services would punish them by taking away their supports. Connected to other families in similar situations, they described this fear of reprisal as a trend that silenced families.

> *Families are being cut if they speak out, they're going to lose the very little they have left...that's why family members are afraid to speak up and say this stuff is happening to them.*

Withdrawing support from people who depend on it for their health, safety and well-being could seriously compromise their well-being. Mechanisms to ensure that people are not punished in this way must be built into service systems. These could include education for those who work in the system in order that they respond respectfully to advocacy. Protections could be built into the system which make it difficult for service providers to disqualify a person arbitrarily. In addition, conflict resolution and appeal procedures could be put in place.

Societal attitudes toward disability have an impact on the extent to which women with disabilities participate in communities. These attitudes may be reproduced or reconstructed within the context of relationships. Respondents in this study described different community attitudes toward people with disabilities. Both women who were and were not disabled felt that although disabilism is not as pronounced as it was at one time, there is still a considerable amount of it. They described occasions on which people treated women with disabilities in patronizing ways, stared at them, made rude comments to them, asked them inappropriate questions, and did not allow their children to talk to them. One non-disabled woman articulated her experience of disability discrimination.

> *People's attitudes are incredible. Some people are so ignorant. There are many well-meaning people who are often overly solicitous. There are many kind people who are ignorant and don't know the correct language to use and so on. There are also people who are so dense that they don't get it at all. They don't understand that she's an adult; they pat her on the head like a dog. They'll come up to her, total strangers and say: "What happened to you?" They have no manners. It's shocking and it's always upsetting every time it happens, but it happens.*

In some cases, women with disabilities are not welcomed in the community. As the mother of a young woman with a physical disability remarked:

> *I think things have changed.... They're more in the open, but they're still not accepted; not even in church.... People have asked questions like why do I keep her? Why don't I put her in an institution?*

Although in both of these situations the non-disabled woman was in clear support of the citizenship rights of the woman with a disability, we can surmise how easily a different attitude could compromise citizenship. Suppose either woman agreed with the community members. Not only would they further perpetuate negative stereotypes about disability and encourage further hurtful behaviour, but they may also have used their own power to remove rights, liberty and opportunities from the woman with the disability and restrict her participation in the community.

Women described how they encountered physical barriers, such as inaccessible workplaces, restaurants, bank machines and other community spaces. One woman commented:

> *Not that we're bar flies, not that we would go out drinking and dancing very much, but the gay part of Toronto is not accessible. Period. There is no place to go and dance and party and play with other lesbians. So there's that. Physical barriers; where we can and can't go in terms of restaurants.*

In addition, women felt that systemic discrimination in the form of, for example, barriers to economic security continues to pose problems for women with disabilities. One said:

> *I think there is a lot of financial discrimination that makes it difficult for people with disabilities to be included in the workplace so they can have a combination of disability insurance plus productive work income. People with disabilities are discriminated against trying to work by having their disability pension decreased.*

They also spoke of the sexual discrimination faced by women with disabilities. This discrimination takes a number of forms. Two of the women with disabilities referred to the discriminatory belief that women with disabilities are asexual. They said that insofar as they were not seen as sexual, they found it difficult to date. One felt as if some of the people in her life were very uncomfortable when she did go out with men. Others pointed to the risks of sexual abuse faced by some women with disabilities.

While these describe attitudes of community members outside of relationships of support, such attitudes may affect the equality of both women, and their relationship. Barriers to employment may lead to dependency not only on the income support system, but on family and friends, reducing one's agency in those relationships. Exclusion from one's community could isolate a woman with a disability from sources of support outside of her partner, increasing her vulnerability within that relationship. In these ways, issues of citizenship may affect very intimate parts of women's lives.

Some respondents also felt that members of racial and ethnic minorities who were disabled faced dual discrimination, and this may be played out in relationships of support. As one respondent said:

> *If you are Aboriginal and disabled you are probably more discriminated against than if you are White and disabled. There's probably an ethnic prejudice against Aboriginal people; there's probably beliefs that they did it to themselves, through their own actions or negligence. They think they aren't as deserving of services or services would be wasted on them. I think some service providers feel this way.*

In contrast, some respondents described the people with whom they engaged in relationships of support who promoted their citizenship by addressing barriers to community inclusion and instances of discrimination. Paid and unpaid support providers alike played this role. Sometimes, they addressed discrimination overtly, by challenging discriminatory actions or behaviour in others. They also addressed barriers to inclusion in more subtle ways. Describing the intimate relationships in her life, one woman commented:

> *At Wal-Mart, some other little girl is asking my four-year-old niece: "What happened to her?" My niece said: "What are you talking about? This is my auntie." She said: "My auntie came out of her mother's tummy like that." And looked at her, like what's the matter with you?*

One woman described her efforts to promote the inclusion of her sister-in-law with an intellectual impairment in her community.

> *I have introduced her to family and friends, people who have never had contact with anyone like [her] before. I try to get her in the public and I try to get people aware, get her back into the same stores and malls so they can get used to her and now they are starting to speak to her.*

The situation of this woman with an intellectual disability illustrates that not all families accept their disabled members. While part of her family is extremely supportive, others are not. Her sister-in-law goes on to say:

> *I would just like some of her relatives to recognize her. They don't recognize her as a human being. We have asked them for pictures so we can show her who they are; only three sent them. We're trying to make family and relatives aware of how good she can be, that she's a human being.*

Support Providers

Women who are support providers also have the right to enjoy their rights as citizens. Like women with disabilities, this involves their right to participate in communities. Women who are not disabled do not face as many obstacles as women who are disabled. Some issues, however, do arise. For paid and unpaid support providers alike, their access to the community may be restricted if their role as a support worker leaves them with little time or resources to participate in communities themselves. A number of women reported that this was the case. (This was also the case of some women with disabilities. That is not to say the woman with a disability in the relationship is herself to blame for any restricted participation of support providers in communities.)

Some paid support providers were balancing support work with other work and family responsibilities, with little support in return. Reasons were not forthcoming as to their choice to work more than one job. Presumably, well-paid, full-time work was not available to them and they needed income to supplement the money they were paid for their support services. Others found balancing one job and domestic responsibilities to be taxing. Insofar as they worked too much, this caused them stress and created situations in which they were socially isolated and did not have time to rest, enjoy leisure activities, or fulfil community and family responsibilities. In short, their equality was compromised.

As mentioned above, the right to freedom of speech without repercussion such as withdrawal of support, or harm to oneself or a loved one is an issue when support providers advocate for services on behalf of consumers. It also may be an issue for workers who organize for workers' rights. One respondent described a situation in which a worker, interested in unionization, was let go. While management cannot legally fire someone on this basis, service recipients had filed a barrage of incident reports, which largely referred to his "attitude." Consequently, he was suspended. Over time, worker, management and client relations became so adversarial that the staff member left the job permanently.

In summary, equalities and inequalities in relationships between women are clearly affected by the extent to which the six criteria for equality are met. Overall, the equality of both groups of women is ensured when relationships promote their self-determination, foster mutual recognition, encourage respectful interdependence, ensure security, democratize decision-making processes and ensure citizenship. The equality of consumers and providers of support is tightly linked. Certain conditions foster equality for both, and others foster equality for one at the expense of the other. Since the same conditions may or may not ensure equality for all parties in a relationship, it is important that as we address these conditions at the policy level, the impact of solutions within the relationship context be considered.

While relationships may be a site where equalities and inequalities are reproduced and reconstructed, structural factors outside the relationships set the conditions for equality. These are determined at the policy and program levels. The following chapter explores the factors outside relationships of support which have an impact on securing equality within the relationship.

8. FACTORS THAT ACCOUNT FOR EQUALITY

In examining equalities and inequalities in the well-being of women in relationships of support, consistent themes emerge about the broader factors shaping these relationships, and their capacity to secure greater equality for women. These themes can be organized into three main areas related to provision and delivery of supports and services:

- access to disability-related supports and services;
- types of service/support arrangements; and
- organization of labour.

Access to Disability-Related Supports and Services

Women may require disability-related supports, such as attendant care, home care, physiotherapy and other professional supports, and aids and devices. Access to these supports and services helps to foster the conditions for equality of well-being.

When women with disabilities have the range and level of services they need, their self-determination is promoted. When women receive sufficient supports, they are able to enjoy most of the same choices and control in their lives that others do, such as how they like to keep their home, what and when they eat, where they go and when. One woman described the control she gained when she got her first wheelchair.

> *I was living on the farm, about 10 or 11, I didn't have a wheelchair.... When I finally got a wheelchair I could run away from [my mother]. When I was in the stroller, I couldn't.*

Access to services promoted support relationships that enabled women to live where and how they wanted, do things they liked to do, as well as have choices and opportunities with support to achieve them. Such access also promoted respectful interdependence in their relationships with support providers. With adequate services, they are less likely to depend on others in ways they were not comfortable with, and more likely to be able to contribute meaningfully. Their security is also increased, as their vulnerability to abuse, neglect, isolation and safety risks are reduced when they have the supports and services they need. Supports and services also facilitate the participation of women with disabilities in their communities.

The access of women with disabilities to supports and services also has an impact on the women who support them, on a paid and unpaid basis. It promotes their self-determination and a respectful interdependence by removing pressures to engage in forms and degrees of support they are not comfortable with. It fosters their recognition of the capacities and contributions of the women with disabilities. It also protects their own security, as they are less likely to engage in tasks that could compromise their safety and physical health. However, many of the women with disabilities in this study indicated a need to have more hours of supports.

> *I would like to have the opportunity to use more attendant hours. I tend to be hovering at the upper limit of my entitlement for service hours and always trying to see the balance and juggle.*

Or, to have types of support for which they had been deemed ineligible.

> *I'd like my pool sessions covered.... I don't go to the pool because it's neat. I go because I want to retain what mobility I've got.*

More specifically, a number of women wanted access to publicly financed physiotherapy, for which eligibility criteria for adults appears stringent. Most of the women claimed to be coping with the level of supports they had, but felt they did not have sufficient supports to ensure their equality. In at least one case, the woman and her family were in a crisis situation, in part because she did not receive all the types of support she needed.

Factors Affecting the Capacity of Support Relationships to Promote Equality

There are a number of factors which restrict access to needed supports and services and, thus, undermine the capacity of support relationships to promote equality of well-being. These include entitlement, assessment procedures, eligibility criteria, the extent of co-ordinated access to funding and supports, and the framework for benefits.

Entitlement

Social policy and programs set guidelines for the levels of services to which women with disabilities are entitled. Government programs set caps on the amount of services consumers in general are entitled to receive. Individualized funding in Ontario, for example, sets a cap at the equivalent of 180 hours per month (roughly six hours of service per day); while managed care agency services in Newfoundland sets a cap at $3,200 per month for persons with disabilities. Regardless of assessment of need or eligibility criteria, consumers' entitlement is limited to this amount. Consumers of services may opt to receive higher levels of services under different arrangements, but they may be required to live in a particular setting, or accept styles of service arrangements that restrict their life choices and even compromise their security.

Other types of support that women may need entitlement for simply do not exist. For example, a First Nations woman with a disability explained she needed travel funding to access support from her family and community on a reserve located approximately 100 km from the city in which she lived. Since no government program entitled support recipients to such funding, she was unable to access what she described as a potentially rich source of support for herself.

Assessment procedures

One determinant of access to supports and services is the procedure for assessing or determining the need. A person, a team of people in a social services program or an agency may conduct the assessment. Furthermore, the assessment could take into account a number of different factors, such as medical diagnoses of disability or illness, determinants of physical and cognitive capacity, lifestyle and living situation. Women with disabilities felt they were most likely to access the support they required when their needs were determined holistically, with attention beyond the medical aspect of impairment and including women's personal situation.

> *Have the system on a personal level. On a system level—they look at me and say no you don't need help—but if they looked at me on a personal level, they would say she does need that help. If they look at me as a person, that would be great.*

In addition, a number of women remarked that staffing concerns should be considered in assessments if women are responsible for hiring their own staff. Some women require only a few hours of assistance for particular needs; these women find it difficult to get services because workers are understandably reluctant to go to a job for such a short length of time. One woman, in particular, had a difficult time finding someone who was willing to work for only an hour each day, in the early morning. Consequently, she was often without services and was forced to rely on family and friends. As she explained:

> *It's hard finding someone for an hour a day.… In many service agencies, there's a three-hour minimum, but in private we can't do it. The funding source does not consider that. It would be great if I could get a three-hour block, but that's not what I'm assessed for.*

Assessment procedures for the various programs and services which are currently available need to be reviewed and, where necessary, redesigned to account for the personal situations of recipients. Under a coherent policy framework based on principles of independent and community living, such procedures would enable a person's participation and input in the determination of her or his needs. Mechanisms are needed which ensure that concerns such as "difficult-to-fill" attendant hours will be taken into consideration.

Eligibility criteria

In addition to undergoing a formal assessment procedure, types and amounts of support are determined by certain eligibility criteria, which are built into various policies and programs. Eligibility for degrees of support may be determined, in part, by the diagnosis of impairment type. For example, persons with muscular dystrophy may qualify for different amounts (and types) of support than persons with cerebral palsy. To take another example, people with physical impairments may qualify for different types (and amounts) of support than do people with intellectual impairments. In addition, access to some services may be conditional on age. Both respite and physiotherapy were reported to be less available for adults than for children.

Eligibility may also be in part determined by "severity" of a person's disability. One woman stated that eligibility to receive funds for a motorized wheelchair versus a manual wheelchair was often determined on this basis. As she pointed out, those who fail to qualify for a motorized chair often experience significant barriers as a result, barriers which are not taken into consideration in the assessment process.

Like narrow assessment procedures, eligibility criteria such as this one fail to take into account the personal situation of individuals. Some individuals may need certain services, but be unable to demonstrate need within the currently accepted framework.

> *I think the resources that are made available for people with disabilities are an appalling and shameful chaos of criteria and eligibility requirements that some people fit into and other people don't fit into. It requires a tremendous amount of sophistication to even begin to navigate through the system to know where you might fit.*

A broader scope of eligibility criteria is needed in disability-related supports and services. Restrictive categorization based on disability type, age and medical diagnosis fails to account for the complexity in women's lives, and the social and economic barriers that disable them. Premises for eligibility that account for these factors must be embedded in the policy framework through inclusion of principles such as self-determination. Furthermore, these must be reflected in the specific program and service guidelines.

Co-ordinated access

Most women had difficulty trying to access services because of a lack of information about what was available. Some women reported they had been forced to wade through various levels of agencies and government departments in order to get what they needed. One woman suggested that the resources do exist, but the problem is the indirect routes women have to go through to get them. She suggested that people with disabilities need to gain more direct access to services, with less bureaucracy, and more control over available resources.

> *I suspect in my heart of hearts, that it's not so much that we need more resources, I think we need more control over those resources we do have. We need less infrastructure and more direct access to what we need.*

Because of the myriad of disconnected programs and eligibility criteria, the process of accessing supports is often difficult and complex. Women with disabilities find they need to be knowledgeable about which services are available, as well as how to navigate systems funding and delivery. Some women are left with inadequate services not because these are unavailable, but because they lack the expertise to access them. While many of the women in this study said they did have enough support to "get by," many also said this was because they are vocal self-advocates.

> *I'm doing it now, I'm speaking out.... I'll bloody make sure you're listening. I'll go to the provincial level and if I don't get through, I'll go to the federal level. I'll make sure they're taking down notes.… I'll get supports.*

Because of the sample selection procedure, many case study respondents were strongly connected to disability organizations and the independent living and community living movements. They may not be representative of the broader disability community. Many recognized this, and felt that though they had self-advocacy skills and a sense of entitlement to support, not all people did. They worried that those who were not in a position to fight for supports were not receiving what they need. One woman put it this way:

> *It also requires remarkable and sometimes extraordinary self-advocacy skills to persuade people that you are a force to be reckoned with, that you are entitled to, and worthy of, service. As someone who has really developed that, I recognize it isn't a skill everyone has.*

The findings suggest information about the network of supports and services needs to be more widely available. The routes of access to supports, and information about supports, need to be direct, and involve as little bureaucracy as possible. In order to accomplish this, a single entry point to provide comprehensive information about funding and services could be helpful. Another strategy may be to hire service co-ordinators who could work for women with disabilities to identify the available services which best match their needs.

Framework for benefits

Though an ideological basis for disability-related policy has recently been articulated in In Unison, it is not yet reflected in the funding and delivery of disability-related supports and services. Despite the fact that government increasingly shows a commitment to the principles of independent and community living, which is realized through emerging individualized funding programs, the distribution of funds demonstrates a lack of attention to the whole picture involved in health and well-being. Moreover, different programs reflect these principles to varying degrees, and mix them with principles that reflect medical and functional models of disability through, for example, their eligibility criteria. In some cases, government funding for short-term programs may support one approach for a specified period, but is not supported over the long term. In addition, although there is money for immediate support, such as attendant services at home, there are no measures to ensure people's future health, such as support to participate in activities that promote fitness, or that are considered leisure or recreational.

For example, many women in this study regarded their access to programs that enable them to stay fit as access to therapy. In fact, some women were emphatic that fitness activities (such as swimming) should be considered therapy because these activities keep them in condition. The women did not construe this as a "right" to fitness because they could not use fitness as a rationale with funders. It should be noted, however, that fitness is recognized in health promotion strategies as enhancing the health of the general population and lessening the risk of heart disease and other illnesses. As with anyone else, the barriers to fitness experienced by women with disabilities could result in future health problems. This threat to the health of women with disabilities not only risks compromising the well-being of each of them, it will incur costs to health-care budgets in the future.

A more coherent philosophical base for policy needs to be developed. The transition from institutional to community-based care, and from a medical to a social model of disability needs to be consistently reflected in the network of related policies. Policies are needed which account for a holistic view of health and well-being, and which consider the importance of fitness and leisure to physical and emotional well-being.

Addressing Access Issues

Ensuring that women with disabilities access the supports and services they need fosters the capacity of support relationships to promote equality of well-being. As we have seen, in order to promote greater equality of well-being, issues related to entitlement to supports, assessment procedures, eligibility criteria, access and the framework of benefits must be addressed. This will require policy and program development that questions the current ideological basis of programs, and that is based on clear and consistent principles of human rights and criteria of equality of well-being such as those outlined throughout this paper.

The main reason women with disabilities do not have the supports and services they need is a lack of government funding. Since most women with disabilities are often not in a position to purchase essential services on their own, they rely on government-funded programs. In recent years, people with a disability have felt the pinch of government cutbacks in a number of service areas. As described in the policy section of this report, provincial governments receive less money and more responsibility for such services under the CHST. The redirection of funds from institutional to community services does not reflect the actual need for services. Moreover, while those currently enrolled for such services feel the impacts of this to some degree, it is anticipated that the upcoming generation of consumers will face magnified eligibility and access issues. This compromises the equality of support providers who are expected to compensate for service gaps on an underpaid or unpaid basis, as well as consumers who may be left underserved.

Government cuts are a real issue in the lives of these women. The call for more funding for services was unanimous among respondents in this study. For some, the problem had reached a crisis level. In the following situation, government had committed funding for a project to move people from institutions to the community. This commitment did not last beyond the actual project, however, and money was not annualized to continue over the long term.

> *There were millions of dollars set aside for those people, and the big promotion was, that the sky was the limit. Now we need this for my sister, and they're saying no, there's nothing we can do. And you don't even know who you have to go to request it.... Now you've got the social workers saying to you: "The bottom has dropped out of it, we only can do so much." So where is all the support now for people like my sister?*

Social policy is needed that recognizes the importance of funding supports and services for people with disabilities. While it is true that supporting people to live independently in the community is more cost-efficient than medicalizing care in institutional settings, community-based services need to be funded to the extent that the supply matches the increasing demand. More money needs to be directed toward support services in general, in order that more service options are available generally, and higher levels of service are available to those who need more of them. Otherwise, the personal and social costs from diminished health and well-being will mount even further.

Types of Services/Support Arrangements

There are a number of styles of service arrangement from which people with a disability can choose. Women in this study primarily used individualized funding, managed care or agency outreach, focus unit support and transitional housing supports.

Service arrangements have an impact on the equality of both providers and recipients of services. It is here that much of the tension in the relationship between these two groups emerges. The situation is complex. Sensitive issues prevail for both those who provide services in homes and those who receive them. Women with disabilities require certain elements to be in place to assure their self-determination, mutual recognition, security, respectful interdependence, participation in democratized decision making and citizenship. For example, they are at risk of abuse, theft and exploitation if they do not have certain types of control over services; and of insecurity, discomfort and health problems if they do not receive them when and how they need them. At the same time, those who provide support services are vulnerable to issues such as prejudicial hiring, arbitrary firing, exploitation and unclear boundaries.

Factors Affecting the Capacity of Support Relationships to Promote Equality

Some issues with respect to the rights of service recipients and workers are difficult to resolve. In this section, we have tried to represent fairly the often-conflicting sides of a number of these issues.

Service options

Much debate has arisen with regard to which style of service arrangement is best, or which most effectively enables independent living. The findings in this research, however, suggest that women want to have choices about the service arrangements into which they enter. Women’s preferences varied in accordance with the types and amounts of supports they needed, their respective lifestyles, personalities and living situations. Some women considered self-managed care as the best possible arrangement. One woman describe her satisfaction with a self-managed care program in this way.

> *I hire, fire, evaluate..... I’m assessed yearly for how much I need by provincial home care.... Self-management is growing and growing. It’s even up to me how much I pay an hour, how I pay, who I pay. Even the Royal Bank works for me. I hired them to do my payroll.... I love it. I would never go back on government program again, unless I absolutely could not hire anybody. It works out so well for me.*

Others, however, prefer another arrangement. Some women, while interested in the control and flexibility that self-managed care allows, did not want the responsibilities that came with it. In the remarks quoted below, one woman explains why she chose to receive managed care from a home-care agency.

> *When you hire your own staff, you have the headache of hiring and firing. I’d rather spend my time doing something constructive, like studying or working.*

Choice of support arrangements is important because women's needs and preferences change over time. For example, one woman was content to live ("for the time being") in a transitional housing building that supplied a range of personal and professional supports. She felt that since she had never lived on her own before, she should have this environment to learn what needs she has, and what she likes. Furthermore, she considered this to be a temporary requirement and had begun weighing her options. Another woman explained that she switched from managed-care to self-managed care when she and her partner purchased their own home. With this change from one service arrangement to another, her needs for support changed in terms of location of service provision, as did her desire for the privacy of her family.

While some women believed they had choices over the service arrangements they used, others felt restricted in their choices, in part, due to lack of availability. The sample used in this study does not reflect the actual distribution of available choices, nor is the availability of individualized funding programs consistent from one province to another. In Manitoba, for example, of the thousands of people who receive disability-related supports, only about 100 of them access individualized funding through the self-managed care program. In the sample used for this study, three of four respondents in Manitoba used self-managed care.

Women with disabilities need a range of service options from which to choose—options that fit their lifestyle and needs. Women with disabilities say they should have the option to access services under individualized funding, with whatever support they need to make it work for them *and* the option of flexible, managed care that allows them choice and control. Furthermore, respondents suggested that not only should they be able to make choices between existing arrangements, but there should be more, and different options available to them than currently exist. One suggestion was the use of individualized case management, where a case manager, who works for an individual with a disability, co-ordinates her or his access to services.

> *There needs to be more individualism and case management. There's such fragmented services, lack of case management for individuals with disabilities where case manager would integrate and co-ordinate services and integrate communication between suppliers of services.*

Quality of available service options

Choices with respect to service arrangements may also be restricted by the quality of the available options. The quality of support programs/types varied among the provinces. Hence, many of the respondents in this study felt as if they did not have good alternatives from which to choose. In Manitoba, for example, women described managed care as less desirable, because service management agencies there did not give clients choice and control with regard to the workers sent to them. In addition, these agencies had rigid, inflexible scheduling and task descriptions. In Newfoundland, where similar agencies introduced a greater degree of client choice and control, women with disabilities indicated greater satisfaction with this option. In Newfoundland, managed-care agencies have had to compete with self-management programs for clientele. One way in which they have done so has been to offer such control over services. The Newfoundland experience illustrates that people with disabilities want choice, control over and flexibility of the services they use. Self-management is merely one model conceived to implement these principles.

While most of the women spoke highly of self-managed care options, some found the administrative tasks, the liability and the risk that they would be left without services combined to make such programs too much of a burden. Of those who were using self-managed care, approximately half felt they would be better off with administrative support. Of those who used managed care, nearly all said they did not choose individualized funding because the administrative burden was too much trouble.

> *I'm on self-managed care. It's a wonderful program, allows me flexibility. But it's a pain in the butt because I'm responsible for paperwork. I'd throw that away. I'd like to have the control over hiring and firing, but hand the administration back to the provincial government. If they would leave us the control. Right now it's all or nothing.*

Other women did not have a problem with requirements to report *per se*. In some cases, the procedures appeared more complicated than they needed to be. The complicated ways in which services are arranged at the program level seem to be designed for the convenience of the funder, not the recipient of funds. This was especially a problem for users of self-managed services who had to deal with payrolls and reporting procedures.

> *The format [of payroll reports from the bank] isn't acceptable to the individualized funding program, which means I then have to pay an accountant to basically take the apples and put them into oranges, or put them in the appropriate category so all the reports that go into the funder are in the same format. To me it seems inefficient, but I suppose necessary from the bureaucratic standpoint. So reporting is a bit of an annoyance.*

If some of these options were organized differently, they might become real choices for more consumers.

Regardless of the terms under which women with disabilities receive supports, they want their arrangements to be structured in ways that enhance their equality including:

- choice in which individuals provide support;
- control over tasks performed;
- flexibility of services; and
- portability.

Choice in which individual's provide support

As noted earlier, equality for women with disabilities is promoted when they have control over who provides them with support, regardless of whether they are employers or recipients of agency care. Women achieve such control more easily under some styles of service arrangement than they do under others. They have the most control over the delivery of their services when these are provided under individualized funding. Funding should, therefore, be directed in ways that will expand the availability of this funding option so all the women with disabilities who would choose it may do so. Furthermore, policy should recognize that women have the right to choose staff when they receive outreach supports. Thus, government guidelines to agencies could require that agencies offer clients as much flexibility and control as possible in this regard.

Strategies must be developed which ensure that the enhancement of choices for women with disabilities does not entail that workers become subject to discrimination or unfair firing. Strategies of this sort might include programs that aim to educate employers/service recipients about racism, human rights codes and employment equity with regard to the sector that serves them. In addition, these strategies might involve mechanisms to resolve disputes or conflicts concerning alleged discrimination and enforcements to ensure that workers are protected. Women with disabilities and workers could access these mechanisms when such situations arise. In individualized funding situations, the administrators of services (usually independent living centres) or third-party community-conflict resolution organizations could manage programs of this sort.

Control over tasks performed

Respondents agreed that regardless of whether consumers use individualized funding or agency services, they should be the ones who decide which tasks staff perform and when. Women with disabilities were emphatic on this point. Furthermore, their staff strongly supported the rights of women with disabilities to self-determination and felt they exercise it appropriately when they give direction to their staff. Those whose jobs involved a particular task (e.g., attendant care at the local swimming pool) felt that clear and undisputed boundaries existed between them and the women for whom they worked. Those who provided a range of types of in-home services, from personal care to housekeeping, felt that the diversity of tasks was appropriate. Furthermore, they believed it was appropriate that their clients/employers have the right to decide what tasks their workers will perform and when they will perform them.

To the greatest extent possible, this control should be built into programs. To avoid confusion in these relationships of support, mechanisms should be in place which clearly outline the range of tasks consumers and staff consider appropriate. In addition, strategies to promote communication, or address conflict, should be in place and readily available to the parties engaged in these relationships.

Flexibility of services

Of the currently available service options, individualized funding allows women with disabilities the most flexibility. Promotion of these options increases the equality of women with disabilities. Other styles of service arrangements could be designed in ways to allow consumers as much flexibility as possible. Workers in this field acknowledged that negative impacts of flexibility on staff appear difficult to address. As the previous section indicates, workers were most concerned that their employers/clients be aware of the ways in which flexibility can affect them, and that they take these into consideration. Strategies to promote better communication in these relationships, and mechanisms which provide resources and train consumers to be “good” employers or service managers could address some of the workers’ concerns.

Portability

Women with disabilities need their supports to follow them, rather than follow their supports. If women with disabilities are to participate meaningfully in the community, they must be enabled to take their support services with them into a variety of environments. Those who use services that are tied to their living arrangements must have options which include the choice to have the accompaniment of staff to community places, or access to outreach services when they need them. Women with disabilities are entitled to enjoy the rights to be where they want and to sleep where they want that others already enjoy.

With respect to travel, one woman suggested that some of the barriers which women with disabilities experience, and the issues which attendants in the study mentioned, could be addressed through the creation of a national attendant service registry. Through such a registry, travellers could make arrangements in advance. In addition, home attendants would feel less pressure to take on the stresses that can arise when they travel with their employer.

In general, portability of services was not a major area of concern for attendants. Some individualized funding attendants spoke of the difficulties with respect to travel. They reported that travel with an employer meant long, difficult hours with unclear boundaries. They nevertheless acknowledged that they could choose not to accept work that involves travel.

Location of service arrangement

Respondents felt that when they have choices about where they will live and receive services, their well-being is promoted. In some support arrangements, services are linked to a person’s housing option. This is the case with “focus units” and SSLUs (apartment buildings with in-house service provision for tenants with disabilities). Some people with disabilities find they can only access the supports they need in this setting; thus, restricting their choices about where and how they live. Furthermore, even when they can access services in their private homes, choices may be restricted by the lack of physically accessible housing and high housing costs. In addition, many people are required to move to, or remain in particular areas (usually cities) in order to access the supports they need. For these reasons, people with a disability have recommended that government funds be directed to create new, accessible housing.

> *More housing for people with disabilities. Right now the federal and provincial governments aren’t keen to start new housing projects. People are stuck where they are living and with the supports they have even if they hate it. People need to know they can change their life if they need to. I didn’t like the feeling of not being able to move. People need self-control and choices.*

One respondent recommended that funding be made available so people with a disability could organize and create new service options that would give them more choices about where they live.

> Hopefully, there will be enough funding for individuals to get together and choose where they would like to live versus going to places already established—and sharing services with people in areas they choose.

Addressing Support Arrangement and Delivery Issues

The main issues associated with support and service delivery, and arrangements are associated with the available options and assurances that women are able to make real choices among these options. This means an expansion of options such as direct and individualized funding, which are presently available for a limited number who qualify under very particular eligibility criteria. It also means improving the quality of other options, including managed outreach supports and supported and transitional housing according to criteria women with disabilities have outlined—choice over support providers and support tasks, flexibility and portability of services, and democratized decision-making processes.

Public administration

There are barriers to such processes. Some respondents felt that "the system," or government personnel who promote and develop support options and assess eligibility, have their own preferences with regard to which options should be available, and to whom. In an interview for this study, a policy expert from a disability organization in one province suggested that while disability organizations tend to favour strongly the self-managed care option, the authorities in charge of these programs do not promote self-managed care. Disability organizations speculate that this resistance may be due to paternalistic attitudes (such as the belief that disabled people cannot really handle the responsibilities of self-managed care) and fear of job loss that would result from lessened workloads and redistribution of the responsibilities involved.

In one situation, a woman with a disability and her family believed they experienced pressure from the government to switch from self-managed (family-managed) care to home-care agency services, or a group home. This woman and her family felt the authorities blamed them for managing the care badly. According to the family, they were doing the best job possible, given the labour constraints with which they were working. They also suspected that punishment was exacted against them because they advocated on behalf of their family member, rather than accept the situation. As one family member of this woman explained:

> *So now they're...trying to put [home-care agency staff] in these homes, take out the rest of the workers from these homes, and force people like myself to just give up on my sister and put her into a group home. Because I'm having such a problem with overturning staff working under the conditions they're working under, no workers and no pension, low rate of pay.*

It is important to note that the woman in this situation had an intellectual impairment. While the sample was too small to indicate a clear finding, it is possible that women with intellectual disabilities and their families face greater policy and program barriers in their efforts to maintain control over their supports than women with physical impairments do. This issue is worth further investigation.

Impacts on workers

Another serious issue arises with respect to the situation of workers within these arrangements. Like the women with disabilities in this study, paid support staff valued some aspects of individualized funding arrangements, and other aspects of managed care arrangements. Many paid support workers liked to work in situations where the disabled woman was their employer. They felt this arrangement allowed them choice and flexibility and facilitated respectful, caring relationships. Nevertheless, they pointed to a correlation between fostering equality of women with disabilities and compromising equality for support workers. As is evident in the following section, the organization of labour in the program types that most promote consumer equality seem to offer the least benefit and security to workers. Some of the very qualities of service delivery that women with disabilities say are criteria of their equality—control over who they hire, flexibility and portability—may increase workers' vulnerability and job stress. This polarization does not have to happen. Strategies need to be developed that promote the capacity within support relationships for equality of well-being of both parties.

This study alerts us to the need to pay attention to the experience of workers. A significant number of respondents, who were paid support providers, dreamed that one day they would work in some form of institution. In the context of disability rights and the independent living movement, this suggests an emerging dilemma. It should be noted that in Newfoundland, where women with disabilities seemed to have the most options, the workers had the lowest pay, the least security and the fewest benefits. In a province, such as Newfoundland, with high unemployment and low government-stipulated pay rates, there may be a lot of people willing to work under these conditions. Interestingly, in Newfoundland, it did not seem to make much difference to worker security whether they worked for agencies or directly. Social policy must address the labour concerns of staff in order to ensure that they have access to equitable wages, benefits and protections that are consistent across the styles of service arrangement.

Multiple roles

The question of whether or not family members should be allowed to work as paid support staff for members of their family is an issue in service arrangements and staffing. Policies relevant to the issue vary from one care arrangement to another and from province to province. This situation emerges as an issue in the context of individualized funding programs. Generally, spouses are not eligible to be paid for support; however, other family members may be.

Two positions in this debate have emerged. Both positions were raised during interviews, albeit briefly and incompletely.

Some people think family members should not be paid as support providers. They argue that in such a relationship both the provider and the receiver of support would enter into uncommon positions of dependency to each other. This dependency might make both of them vulnerable and restrict their self-determination. In other words, it might compromise their equality. If persons with disabilities (especially those facing challenges advocating for themselves) receive supports from family members, their access to, choices about and control over those supports may be compromised. It may be extremely complicated to confront or dismiss staff if they are one's spouse, parent or sibling. Furthermore, the emotional complexity, history and power relationships within a family could be exacerbated within a paid relationship. In some cases, families may also have control over a person's living space, their finances and their right to consent to medical treatment. Reliance on them for paid care could amplify existing imbalances of power—and abuses of power. Families do not always concur with individuals about what is in their best interest. Furthermore, situations of abuse arise in families. An absence of outsiders, who might provide support, could increase the isolation of people living in abusive situations, increase the likelihood of abuse and reduce the chances that abuse will be reported.

Relationships of this sort may also disadvantage family members who are paid to provide support. They may feel pressured to take on responsibilities and stress in their lives that they do not want. As one woman who provides paid support to a family member said:

> *I'm not satisfied. Definitely not. I'm thinking of quitting but my sister-in-law depends on me. Some pre-arrangement is needed. I'm definitely satisfied with the support I provide, but I feel that it is too much. Too stressful. I need to do too much.*

In this study, some paid family members said they might not have chosen paid employment if their relative had not needed them. For instance, as one woman explained:

> *I don't do this for the income, I'd rather be home with my kids than work.*

Within relationships in which a family member provides paid support, a blurring between formal and informal support roles could occur. Paid roles may lead family members to take time away from responsibilities to other family members, and to their own leisure time. In addition, family members might feel obligated to provide considerably more support than that for which they are paid. Furthermore, other family members may reduce the amounts of informal support they provide for their family member with the disability because they see the role of supporter as formally belonging to one person.

On the other hand, both consumers of services and family members wanted the right to make the choice about formalizing a support relationship within families. They implied that rules prohibiting this choice were paternalistic and removed their right to self-determination. In the context of other family-related transactions, such as paid child care, home repairs or home businesses, which variously carry some of the same risks as those listed above, families may choose to hire other family members. Why, then, is provision of disability-related supports any different? Indeed, for people who live in rural areas and have less access or choice regarding support provision, the right to hire family members may be a necessity, rather than a choice.

Some women may prefer to hire family members, rather than strangers. They may feel safer and more comfortable when they hire people who love them to provide intimate care and spend time with them in their homes. Insofar as they pay the family members they rely on for support, this may equalize relationships by moving them from situations of dependency, to reciprocal exchanges of resources. Nevertheless, women with disabilities in this study who supported the right to hire family members cautioned that safeguards would need to be in place due to the complexities outlined earlier. As one woman explained:

> *I would support hiring family members, but there would have to be a system where the person receiving the support felt in control without feeling threatened. If there's an issue, what do I do? Squeal on my dad? Then it blurs the relationship I have with that family member and other family members too.*

Even the women who said they preferred not to work commented that their formal arrangements as paid family members had significant advantages. They felt, for instance, that since they would do the work anyway, they might as well get paid to do it. In addition, they believed they knew better than other people how to provide their family member with the appropriate care; thus, they would have less reason to worry about their loved one. One woman commented on change to policy that allows family members to be paid.

> *For me that's a good change, I know she's taken care of. I know she's eating and not out of a can. I know her machines are taken care of, and we don't worry about it.*

Arrangements of this sort worked well in relationships in which both parties put energy into negotiation of the responsibilities and different roles involved. One respondent reported:

> *We have to draw the line between what the sister-in-law does and the worker does.... She does understand that my kids need me. Once she asked me: "Does your job come first?" I said: "You come before the job. I don't come to get paid; I come to get away from everything at home."*

In one situation, a woman had worked as a paid attendant for her partner before they became involved romantically. She lost income when she became disqualified as a paid support provider; yet, she continued to provide the same kind of support. Although she had become financially dependent on her partner as a result, she was not recognized as a dependant within the federal tax system, which did not distribute the same entitlements to individuals in lesbian and gay relationships as it did to those in heterosexual relationships. As she described it:

> *[Changes in my partner's service arrangements, from paying out of pocket, to agency care, to individualized funding] had a big impact on me, because I used to get paid and now I don't. I'm caught between a rock and a hard place, because if we didn't tell the direct funding people about the nature of our relationship, if we lied, I could get paid. We don't want to do that, so we lose at the provincial level and at the federal level. Because at the federal level our relationship isn't recognized anyway, but at the provincial level it is, but if we declare it then I don't get paid. Basically, I've lost my income, but I still do the work.*

Debate continues with regard to the question of whether people with a disability should be entitled to hire their family members as support providers. It would seem that insofar as equality for women includes their right to make decisions for themselves, women with disabilities must decide whether or not they will hire a spouse, parent or sibling as one of their support providers. In order to protect both consumers and their family members, the potential difficulties and harms that may occur should be clearly outlined. Furthermore, mechanisms should be in place to ensure that both parties make an informed decision, and do not feel under pressure to give or receive services in this arrangement. In addition, mechanisms should be in place to address situations of conflict.

Organization of Labour

The organization of labour also impacts the equality in relationships of support. These concerns affect both the consumers of services and those who provide services to them. The working conditions, rate of pay, job benefits, training, career opportunities and job status of the paid support workers who participated in this study had a significant, and direct impact on their equality. Furthermore, these conditions indirectly have an impact on the equality of consumers and unpaid support providers. In addition, the organization of labour gives rise to some major areas of tension in relationships of equality between consumers and providers of services, including disagreements around institutionalization versus community-based care, and unionization.

The respondents who work as personal and home support providers tended to do so in fairly marginalized employment conditions which compromised their security and status in their communities, and the relationship with the women for whom they work. Both workers and their clients expressed concern over this situation. Within the framework of the current system, structures do not seem to be in place with which to resolve these issues, except at the expense of people with disabilities. As noted above, both groups find this state of affairs unacceptable.

While the sample of professional service providers was too small to indicate any clear findings, it appears they face different, perhaps fewer issues of concern with respect to labour conditions. They are more apt to have adequate pay, benefits, training and career opportunities than in-home support providers.

Factors Affecting the Capacity of Support Relationships to Promote Equality

Rate of pay of support workers

The rate of pay of support workers is generally low, though it varies. This has negative consequences for workers’ security, as well as their choices and opportunities in life. Workers in St. John’s, for instance, were paid as little as $5.60 an hour. Those in Winnipeg averaged about $9 an hour, and those in Toronto averaged about $12.50 an hour. These are the average rates of pay for support workers in the major cities of the three provinces studied and are probably higher than rates for this work in other parts of these provinces. A number of factors seem to determine the pay rates for attendants including differences in standards of living between and within provinces, different policy standards set by ministries and the type of employment arrangement under which support is provided.

The most well-paid attendants worked for public agencies and belonged to a staff group. That is, the more institutionalized the care, the better paid the staff. In fact, of the paid support providers who participated in the study, the one with the highest pay ($12.50 an hour) worked in a semi-institutional transitional housing unit. She was one of the few support workers in the study who had a benefit package. Some paid support providers were well aware that the low rates of pay they receive correspond to the move toward community-based services. One woman said:

> *It's no big secret we are getting ripped off. It's no big secret that we are a labour force that's doing jobs that nurses had. I don't feel I'm being fairly treated.*

Addressing the inadequate pay of support workers would promote equality not only for workers, but also for women with disabilities. Governments need to revisit the pay scales and pay freezes of workers in this sector. Funds must be made available to raise the hourly rate of pay, as well as to take account of the unique situations which home care involves. In addition, issues regarding one-hour shifts, on-call work and night shifts must be accounted for in assessments of level of need, in order for agencies or employers with disabilities to compensate adequately those workers who fill these time slots.

Benefits and workers' compensation

The lack of employee benefits and workers' compensation coverage for workers in this field signals a missing piece in current social services policy. Many workers are not covered; yet, they are at high risk of injury. Policy should ensure that appropriate levels of funding for benefits and workers' compensation are allocated to managed care programs and individualized funding programs. This is happening, to some extent in some provinces, but has not been fully implemented.

As the trend moves away from institutional care to community care, the likelihood that workers receive these protections declines. In this study, workers in the most institutional settings were the most likely to receive benefits. None of the women who worked directly for consumers[22] had benefits, and few qualified for workers' compensation. Those who worked for managed care agencies tended to receive workers' compensation coverage but not benefits, although some agencies do offer benefits to staff. One woman who participated in the study worked at an agency that provides benefits; however, she did not qualify for these because she worked part time.

The issues of workers' compensation are complex. The control women with disabilities have over tasks performed by support providers may be compromised by rules and regulations tied to worker protection. Some of these protections are appropriate and necessary and devised to avoid injury. However, sometimes they seem arbitrary or misplaced within the context of these relationships. Furthermore, such guidelines sometimes remove choices from workers, as well as consumers. For example, one woman who had workers' compensation coverage said she felt pressured to avoid a certain task her client needed her to do. She feared that since the task fell outside of her job description, she would not be covered if she were to injure herself in the course of performing it. Note that the task to which the woman referred was not an extraordinary one, such as moving heavy furniture. To the contrary, the task was tipping the woman's wheelchair up and over an uncut curb. She remarked:

> *You're covered if you get injured doing the things you are supposed to. At her house, there's no cut curb. I could possibly hurt myself getting her over the curb.*

She went on to remark that she did this regularly, despite the lack of coverage, because she and the woman for whom she worked would have been unable to leave the house if she did not do it. Other respondents pointed to similar guidelines prohibiting workers from cleaning mirrors, dusting under table ornaments, etc. None complained of guidelines that seemed appropriate to them, such as those concerning heavy lifting. It should be noted that workers and consumers alike supported protections for workers, but felt that, within reason, such protections should not compromise the self-determination of either women with disabilities or workers.

Women in both groups stressed that benefits and protection for workers should not be gained at the expense of women with disabilities. They believed that women with disabilities should not pay out of their own pockets for such coverage. Furthermore, they believed worker protection should not compromise the level or type of service received.

Job training and support strategies

The importance of job support and training to workers was somewhat ambiguous. Workers appreciated support, especially from supervisors and co-workers. Some attendants who did not have access to co-workers or supervisors (e.g., those who work under individualized funding) indicated that they would welcome support from other paid support providers, perhaps in the form of an attendant association. They noted that workers in this sector would probably not organize in this way because most of them did not identify as attendants, nor see this as permanent employment.

Some workers regarded access to training in injury prevention as a way to promote the safety of support providers. Courses in raising awareness and disability issues would sensitize support providers to the concerns of their clients, such as the systemic discrimination confronted by people with a disability, and might promote more empathic, better relationships between them. They agreed that some types of training, most notably occupational health and safety training, would be beneficial. To reiterate, most attendants believed that training programs that medicalized disability should be recognized as inappropriate. Some attendants believed that access to awareness training about disability issues from a disability rights perspective, and to training in conflict resolution/prevention would be assets. These courses, they suggested, should be readily available, free and, where appropriate, workers should receive remuneration for their time attending them. In addition, attendants thought that consumers themselves should have access to training and instruction on how they can become better employers and on how they can resolve conflicts.

Addressing Labour Organization Issues

Addressing the working conditions of paid support providers, while still ensuring that women with disabilities can exercise their right to control their services will not be simple. Indeed, these seemingly conflicting needs have become a source of pronounced disagreement between the two groups of women. Paid support providers believe that women with disabilities do not want to think about these issues because they fear they will lose the right to live independently, a right for which they struggled so long and hard. Some are angry and feel their clients/employers disregard them and their concerns. Some (even as they promoted and supported independent living) claimed that the Independent Living Movement is adversarial toward attendants. They felt that people with disabilities approached issues surrounding support services with an “it’s us or you” stance. They contended, moreover, that people with disabilities must begin to advocate for support workers’ rights alongside their own.

Women with disabilities, on the other hand, felt that workers blamed them for working conditions over which they had no control. They did worry, as support providers suggested above, that their own rights and access might be compromised by attention to labour concerns. They were cynical about the commitment of governments to provide enough resources that they could get the supports they needed and ensure adequate pay and benefits for the workers. Many also expressed concern for their workers’ situation. They felt, moreover, that the low status of their staff reflected their own devalued status in society.

Consumers as employers

Paid support workers felt that service recipients with a disability need to take their role as employers more seriously. When they worked for good employers, who paid attention to the fact that they had responsibilities toward their workers, and who took workers’ situations and motivations into account, problems associated with their jobs were reduced. As one worker put it:

> *People need to learn how to be employers. They don’t know how to direct their own care to manage employees. Working for someone who knows how to treat you as an employee is very different from working for someone who doesn’t.*

Other paid support workers were not as concerned with these issues. They were satisfied with part-time work, and felt they were at stages in life where the types of hours they were required to work suited them. They considered their jobs as temporary or transitional. It should be noted that the workers who expressed the most satisfaction with their work and the least concern for these issues were also the ones who hoped to move on to more institutionalized work. They were less politicized, less aware of disability issues in general and less likely to advocate for disability rights. They did not seem to understand the concept of independent living. The workers who were frustrated and angry about their jobs were those who were most attached to the disability community, and who upheld the right to independent living.

Some women with disabilities in this study were very aware of, and concerned about, worker issues. But, they felt helpless to address these concerns. They indicated that they need services and they need them to be delivered in a certain way. Many had lived without adequate services for an extended time and were determined not to return to that unacceptable condition. Furthermore, they felt that even when they were in control of the dollars for services, programs and policies determined their eligibility and the levels of funding they received. Nevertheless, many women with disabilities knew it was in their best interests, as well as the interests of their workers, to find solutions. One woman with a disability remarked:

> *The work support people do is very important, and is unrecognized, under-utilized and underpaid. I've done a course on it, and I've done a lot of advocacy. I'd like to see a compromise worked out in terms of meeting needs of people with disabilities and workers.*

Creative policies need to be developed which address these issues. Because of the polarization between women with disabilities and paid support workers that increasingly exists, a team comprising members of both groups might strategize most effectively around these issues. One attendant suggested embarking on a dialogue between women with disabilities and workers. As she noted:

> *What I would love to do is just to talk more and get together more. When attendants and consumers get together we fight. Usually workers are tired and pissed off, and consumers feel misunderstood and have their own crap to deal with. I'd like to see what biases the attendant care community has, how I treat [consumers] and what I expect, to figure out a more creative way to work together. We hang out with them more than our friends. We hang out with their kids.*

A woman with a disability suggested that a support network be developed for people who use direct funding in order to share workers. A network of this sort would enable people who use individualized funding to offer workers better hours and working conditions. She described the network she imagined in this way.

> *I would like to form a support network around people trying to find their own workers. There's an informal support network but they meet during the day. I'd like to make it more formal—sharing workers—assist them to get more hours, and assist other consumers. It could be a collective of consumers/employers who as a group would contract workers.*

Institutionalization versus community-based services

The relation between rate of pay and the degree to which services are institutionalized is emerging as a source of conflict between women with disabilities and their paid staff. Due to the way the system is currently arranged, the more independent women with disabilities are, and the more control they have over their own service provision, the less secure are the working conditions of their staff. In other words, the equality and well-being of one group is positioned in opposition to the equality and well-being of the other group.

Over the past few decades, service options for women with disabilities have grown considerably. Many of the women in this sample had progressed from institutionalized settings, to semi-institutionalized settings and on to community-based contexts of support. The less institutional the arrangements, the more control, independence, security and opportunities there were for a good quality of life. As the analysis throughout this report has shown, control, independence, security and opportunity are conditions for the equality of women with disabilities. Over the last decade—one in which these conditions have been promoted—the equality of women with disabilities has increased; it will continue to increase if these options continue to grow and improve.

The conditions of employment for women who provide supports have deteriorated as the opportunities and independence of women with disabilities have increased. Women who worked in the old-style institutional settings had better pay, benefits, access to training and support, structured work schedules, access to co-worker support, more work and a higher employment status overall. With the progression to community-based supports, the status of women providing such supports has consistently diminished. In short, the equality of support workers is in jeopardy.

Many personal care and home-care workers described their career opportunities as limited. As one put it:

> *Really it's a dead end job. There are no opportunities, but at my age what else do I need?*

Indeed, those who think there are career advancement opportunities in this field conceive them in terms of a transition to more institutional settings. This frame of mind is indicative of the severe tension between the needs and goals of these two groups. One worker in the study stated:

> *If I want to, I can go to work for home care, now I have the experience and I have experience with people with disabilities, go into nursing homes and that.*

Policy must be developed which recognizes and addresses this tension. It is essential that the equality of women with disabilities is promoted; however, their equality need not, and ought not to come at the expense of the equality of their staff. Some strategies to alleviate this tension seem simple and clear. One strategy is to increase the policy-stipulated wages of support providers. In addition, other innovative, new strategies should be introduced, such as the creation of freelance support providers' guilds or associations that could manage benefit packages and workers' compensation schemes.

Unionization

In discussions of staff pay and benefits, some women broached the issue of unionization. Unionization was a sensitive topic that very few women addressed; those who spoke about it did so very carefully. None of the home-care workers participating in the study were members of unions, nor did any of the women with disabilities who participated receive unionized services, although some had in the past. The majority of workers did not want to unionize. They regarded unionization as a betrayal of their clients. Furthermore, they believed unionization complicated the job. One agency worker said:

> *Staff don't want it. Why bring one in if you don't need it? Unions come in with their own problems and guidelines and create more problems.*

Nevertheless, even workers who resisted unionization of their work recognized that the introduction of a union could result in wage increases for them. As another woman noted:

> *Some people are tangled up in unions, and some aren't. I know a union guy, he gets $16 an hour, and I get less than $6.*

In addition, workers recognized the bargaining power they could gain from membership in a union. For instance, one remarked:

> *I gotta do all those tasks a nurse does, except injecting, and they're going on strike to make $25 dollars an hour. I only make $5.67.*

The women with disabilities who broached the issue of unions felt unionization compromised their services. Two of the women, left without essential services during strikes, were adamantly opposed to unionization of support workers. One woman explained her transition to individualized funding.

> *I went on it because, when home care went on strike, I swore I would never be stranded at home for three days because I had no staff coming in. They were out, left us high and dry. There were a lot of us, let me tell you.*

Another woman believed that unions tend to restrict the flexibility of services and the control over them.

> *The last few years I was there, they unionized. There was a bit more to it than wages and benefits and stuff. It was probably one of the most difficult times I had. You need a lot of knowledge about labour laws and stuff to negotiate a contract. When I looked at the agreement with Steelworkers it was really medical and really institutional. I don't know what else to tell you, except individualized care is more flexible.*

Only one employer advocated for unions: the family members of a woman with disabilities who act on her behalf as the employer in an individualized funding arrangement. They did not want their relative to be left without services during a strike, or be restricted in their work with inflexible care provision guidelines. However, they felt something drastic needed to be done because they were so outraged at the situation of their workers. As one family member asked:

> *Why is it that workers' compensation is put in place for [home-care agencies] and not our workers? Why is workers' compensation put in place only for the unionized people? Unionized got everything. They've got the whole works, medical the whole works. As far as I'm concerned, those people are doing the same job as our workers. They stay together. But people in the homes like this; the staff is not allowed to strike, to protest this. This is a private home. I think they should be, and say: "To hell with the government, we have to do this to be recognized."*

Workers were concerned that unions impose overly rigid job descriptions on workers. According to one paid support worker, unionized agencies and projects were no more popular among workers than they were among consumers. Workers believed restrictions with respect to tasks they were permitted to perform not only affected them, they also disempowered users. When paid support workers are subjected to rigid restrictions with respect to task performance, their involvement in the negotiations that govern their roles in these intimate settings is taken away from them. Furthermore, under some circumstances, such restrictions increase the job insecurity. If they choose to perform tasks outside of their job description, they could face reprimand or lose their benefit coverage if they were injured.

There is a clear and recognized need to address the low pay many support providers receive, their lack of benefits and job insecurity. A worker remarked:

> *I'd like to see a compromise worked out in terms of meeting needs of people with disabilities and workers.*

In this study, neither women with disabilities, nor their workers seemed to think unions would offer mutually agreeable terms. In traditional work settings, unions aim to equalize the balance of power between workers and their bosses by protecting the former and giving them bargaining power over the latter. In the case of community-based settings, however, the "bosses" are persons with disabilities, who are also without formal power.

In some settings, and in the case of some job types, unions work well for their members. However, in the case of disability supports, where governments fund the services that control the rates of pay workers receive, other measures may be more effective. Further research and analysis is required to determine what these alternatives might look like. One woman suggested the formation of co-operatives for attendants and home-care workers. As she put it:

> *I would like for there to be better linkages. I'm not talking in terms of a union so much as to be part of some co-operative enterprise, whereby attendants would have access to resources and to peer support that I don't see them getting. And coaching, and mentoring. That sort of thing.*

9. POLICY DIRECTIONS

Analysis according to the six criteria of equality of well-being points to some of the impacts of social policy on equality and inequality between women in relationships of support and for these women in society. The factors that account for equality, outlined in the previous chapter lend themselves to a number of clear, feasible policy directions for the future.

Access to Disability-Related Supports and Services

- Women with a disability in this study were clear in their demand for policies that promote their independence and self-determination including more funding for disability-related supports, increased service options and higher levels of service for those who need them. Furthermore, they called for policies that account for a holistic view of health and well-being, which consider the importance of support for fitness and leisure to physical and emotional well-being.

- Policy for the provision of supports and services to people with disabilities must be coherent. The network of related policies that govern their lives must consistently reflect the social transition from institutional to community-based care and the philosophical move from a medical model of disability to a social model.

- The assessment procedures of the various programs and services must be reviewed. Many of these ought to be redesigned to account for the personal situations of recipients. Within a coherent policy framework based on principles of independent and community living, these procedures would be designed in ways that enable persons with disabilities to participate in the determination of their own needs, in the context of their lifestyles and relationships.

- The scope of eligibility criteria for disability-related supports and services must be broadened. Restrictive categories based on disability type, age and medical diagnosis fail to account for the complexity in women's lives, and the social and economic barriers that disable them. Premises for eligibility which account for these factors must be embedded in the framework of policy through the integration of principles such as self-determination; furthermore, these principles must be reflected in specific programs and service guidelines.

- Women with disabilities should not need to be experts in policy in order to get the supports and services they require. Information about the network of supports and services must be made widely available. Furthermore, routes of access to these supports and services must be direct; that is, access to them should involve as little bureaucracy as possible. One strategy which could accomplish this is the introduction of a single entry point to services, one which has information about all of the services available at any given time. Another strategy that could be implemented is the provision of service co-ordinators accountable to women with disabilities to identify what services are available and best match their needs.

- Freedom of speech is a citizenship right that must be enforced proactively. Safeguards must be in place to ensure that people can engage in advocacy without fear of reprisal. When support to people who depend on it for their health, safety and equality is withdrawn, their well-being could be seriously compromised. Mechanisms must be incorporated into systems to ensure that people are not punished in this way. These mechanisms should include the education of those who work in the system to respond respectfully to advocacy. In addition, protections could be built into the system that prevent the arbitrary removal of a person's eligibility for services. Conflict resolution and unwieldy appeal procedures could also be put in place.

Types of Services/Support Arrangements

- Consumer control of services is more easily achieved under some forms of service arrangement as opposed to others. Consumers have the most control over their services when these are provided under individualized funding (self-management). Funding should be distributed to increase the availability of individualized funding so people who want this alternative can choose it.

- Women with disabilities must be given the option to receive services under individualized funding, with the supports they require to make it work for them *or* to receive services under flexible managed care that stipulates provisions for recipient choice and control. Furthermore, there should be additional options. One to consider is individualized case management, where a case manager who works for a certain individual with disabilities co-ordinates the individual's access to services.

- Social policy must be developed which addresses the labour concerns of staff in order to ensure that they have access to equitable wages, benefits and protections. These conditions of employment should be consistent across the various forms of service arrangement.

- New service options should be designed so people with disabilities have more choices with respect to where they live and how they receive services. To facilitate the implementation of these options, funds should be redistributed in order that more accessible housing can be built.

- Policy should uphold the right of women with disabilities to choose their staff when they receive outreach supports. Ministry guidelines could require agencies to allow their clients control and flexibility with respect to which workers provide them with supports.

- Strategies should be developed to ensure that support workers do not become subject to discrimination or unfair firing. These strategies should include programs designed to educate employers/service recipients about racism, human rights codes and employment equity. In addition, strategies to ensure job security for workers could take the form of mechanisms for conflict resolution and to enforce the terms of agreement that arise from that process.

- Women with disabilities and their staff must have choices about how to resolve conflicts, and they must have access to a range of communication supports that expedite conflict resolution. These communication supports, which should be made available to women in managed care or individualized funding situations, could include guidelines for procedures, mediation services, communication workshops and conflict resolution strategies and services. In individualized funding situations, the administrators of programs (usually independent living resource centres) could manage these procedures. Alternatively, third-party community conflict resolution organizations could be contracted to facilitate these procedures.

- Service arrangements should be designed in ways that allow consumers the greatest degree of flexibility possible in their support provision.

- Strategies to promote better communication between service recipients and service providers should be developed. Training in ways to be “good” employers or service managers should be provided to consumers.

- The portability of services must be increased. Those who use services tied to their living arrangements should have options to engage staff to accompany them to community places or to access outreach services when they need them.

- To address the difficulties that can arise with respect to travel, a national attendant registry should be established. The existence of such a registry would enable travellers with a disability to arrange support services in advance. In addition, a national registry would relieve home attendants of the stresses that can ensue when they travel with their employers.

- Women with disabilities should be entitled to use their own discretion with regard to whether or not they hire a family member to provide support. To protect consumers and their family members, ministry guidelines should be developed which clearly outline the potential difficulties and harms that can arise when individuals with a disability hire family members to support them. In addition, mechanisms should be in place to ensure that both parties make an informed decision, and do not feel pressure to give, or to receive, services under these circumstances. Furthermore, mechanisms should be in place to address conflicts that might arise when a relationship of this sort has been entered.

Organization of Labour

- Governments must revisit the pay scales of support workers. Moreover, governments must reconsider the pay freezes that have been in effect for workers in this sector. Funds should be distributed that would raise the hourly rate workers receive, and that would account for the unique circumstances in which they engage in their work. Shift premiums and shift differentials that account for night shifts, on-call work and one-hour shifts should be introduced. Furthermore, these incentives must be incorporated into assessments of level of need so agencies or employers with disabilities can adequately compensate those workers who fill these time slots.

- Policy should distribute the funds necessary to build benefits and workers' compensation into managed care and individualized funding programs. (This might already be the case in some provinces in regards to publicly funded agencies.) Benefits and workers' compensation should not come at the expense of the consumer, in hours of service or cost. Furthermore, regulations should be designed to protect against restricting the self-determination of women with disabilities.

- Funding should be allocated to train support workers in occupational health and safety. In addition, funding should be allocated to provide workers with professional development, such as awareness training of disability issues and instruction in conflict resolution/prevention.

- Attention needs to be paid to the polarization conditions that ensure the equality of women with disabilities but that may compromise the equality of paid support providers. A fuller examination of the continuum of options that ensure consumer choice and control but protect the security of workers needs to be made. For example, the issue of unionization should be more fully explored. Possibly, new creative strategies for collective bargaining could be devised that are appropriate to support relationships and the equality of all the parties involved.

10. CONCLUSION

This study examined equality issues in the relationships of women with disabilities and the women who provide supports to them. Equality of well-being in relationships of support was the guiding framework for analysis. This concept includes not only an equivalent distribution of resources, it accounts for the issues of marginalization and oppression faced by individuals and groups and for the fact that people are situated differently. In this view, equality requires that, when appropriate, different people be treated differently and be provided the support they need to achieve well-being. Furthermore, as people are fundamentally connected and mutually dependent, equality is viewed in the context of relationships between people. The six criteria for equality of well-being formulated for this study suggest that relationships:

- promote self-determination;
- foster mutual recognition;
- encourage respectful interdependence;
- ensure security;
- enable citizenship; and
- democratize decision-making processes.

The study was premised on a recognition that relationships between women with disabilities and their paid and unpaid support providers happen within a social and policy context. Barriers to equality for women in relationships of support are a result of policy determinants, such as disability-related support arrangements and funding, that are external to the relationships themselves. However, these institutionalized inequalities may emerge within those relationships and be enacted by those involved. Policies, which affect the equality of one group, affect the equality of the other.

Recent policy shifts at the federal, provincial and local levels are determining the social and economic position of women who receive disability-related supports, and the women who provide these. While demand for disability-related supports has grown, funding has declined. The Canada Health and Social Transfer (CHST) reduced transfers from the federal government to the provinces while giving provinces control over social service programming. In response, provinces have scaled back the health and social services they fund, devolved responsibility for disability-related supports to community boards and local governments and restructured programs.

Women with disabilities may use a number of different types of disability-related and other supports, including income support, personal and home support, professional services, such as rehabilitation and other therapies, and assistive devices programs.

The focus in this report was on home care and personal supports as they are delivered in Manitoba, Ontario and Newfoundland. Three basic models were used in all the provinces, though these models may differ slightly from place to place. The first was supportive housing.

Under these arrangements, the building in which clients with disabilities reside contains a supported housing office that delivers rotation or scheduled supports to the tenants. The second service delivery model was managed outreach in which people live in private homes or apartments in a variety of locations, and an agency sends workers to deliver services to them on a scheduled basis. The third model was individualized funding, where monies are given directly to the recipients of services to hire, supervise and manage their own employees.

There does not appear to be a clear and consistent framework for the treatment of persons who work as attendants or home-care workers. Like all workers, they are covered by labour codes and human rights acts of their provinces. However, other related protections seem to depend, in part, on the type of support arrangement under which they work. Domestic labour laws may be applied to home support workers, particularly those working under individualized funding arrangements. The Ontario *Regulated Health Professions Act* recognizes the work in which attendants engage by allowing them to perform certain tasks, even though it does not cover them. Some workers may also be covered under provincial occupational health and safety acts. However, it is unclear which, if any, types of support workers are included under these acts.

To determine equalities and inequalities in relationships between women, qualitative data were analyzed to explore in what ways the six criteria for equality were enabled or restricted in these relationships. It was found that the equality of consumers and providers of support was tightly linked, with certain conditions fostering equality for both; other conditions fostered equality for one at the expense of the other. It was also found that while structural factors outside the relationships set the conditions for equality, whether or not the criteria for equality were present, was played out within the relationships of support themselves. Relationships are where equalities and inequalities are lived.

This research showed that the equality of consumers and providers of support alike are affected by the access women with disabilities have to needed supports and services, the arrangements under which these are delivered, and the organization of labour of the persons providing the supports.

The research suggests a number of areas where policy reform is needed:

- the structure of entitlements;
- assessment procedures;
- eligibility criteria;
- co-ordination issues; and
- the framework of principles for disability-related supports.

These issues may be addressed through the development of new protocols and guidelines in these areas, but the main issue that needs to be addressed is funding. Not only is funding needed for such revisions; funding increases are required to provide more benefits for more persons. However, governments are in the process of cutbacks, not increases.

In terms of types of service and support arrangements, it was clear that equality for women with disabilities was promoted when they could choose between a variety of options that contained certain elements. These elements included choice in which individual's provide support, flexibility of services and portability. These were most often found in individualized funding arrangements, which need to be more widely available, but should also be incorporated into other options in the short term to the degree that it is possible, given that funding reform is a long-term effort.

Some of the very qualities of service delivery that women with disabilities say are criteria of their equality—control over who they hire, flexibility and portability—may increase workers' vulnerability and job stress. These issues are difficult to resolve, and creative strategies in service arrangements are needed to ensure the equality of both parties in the relationship. This is an area that deserves further exploration.

The organization of labour also affects the equality in relationships of support. Difficult working conditions, low pay, limited access to job benefits, limited training and career opportunities, and the low job status of paid support workers had a significant and direct negative impact on their equality. Furthermore, these concerns indirectly have an impact on the equality of consumers by restricting both the quality of services they receive and their access to supports, and by leading to sometimes untenable demands on their unpaid support providers, often family members, partners and friends.

The organization of labour leads to considerable tension in relationships between consumers and providers of services. There appears to be a growing polarization of views on this issue. In the way that the system is currently arranged, the more independent women with disabilities are, and the more control they have over their own service provision, the less secure are the working conditions of their staff. In other words, the equality and well-being of one group is positioned in opposition to the equality and well-being of the other group. Community-based services need to be delivered in ways that promote the equality of both groups. These concerns gave rise to discussions of unionization, another highly sensitive issue. Women with disabilities felt that unionization would restrict their equality significantly, and were strongly opposed to it. Workers were somewhat ambivalent on the issue. They pointed to the increased security and agency of unionized workers, but also felt that unions, in their current form, were an inappropriate measure to address their issues. Both groups agreed that the labour concerns of workers needed to be addressed in some way.

While the full impact of changes resulting from the CHST and restructuring at provincial levels are as yet unclear, what is clear is that their impacts are being played out in women's homes and communities within relationships of support. The need to recognize and address the mutual impacts of disability-related policy on women engaging in these relationships is urgent. The health, well-being and equality of a growing population, and of the labour force, are at stake.

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ENDNOTES

[1] Special thanks to Mary Ennis at the Coalition of People with Disabilities (COD) Newfoundland, and Dot Spencer at the Independent Living Resource Centre (ILRC) Newfoundland.

[2] According to the HALS Children in Household Survey for 1991, there were 534,430 children living with family members that year. Published information on patterns of caregiving in these households is not available, however. See CICH 1994.

[3] HALS does not distinguish on the basis of gender between sibling, extended family and parental caregivers. This results in underestimating the extent of female involvement in informal care within the family, probably by a considerable margin.

[4] The types of occupations held by men and women are still as gendered as they were in the 1950s. The 10 most common jobs for men in 1996 were truck driver, retail salesperson, janitor, retail trade manager, farmer, sales representative (wholesale trade), motor vehicle mechanic, material handler, carpenter and construction-trade helper. These account for 20 percent of all jobs held by men. The 10 most common jobs for women in 1996 were retail salesperson, secretary, cashier, registered nurse, accounting clerk, elementary teacher, food server, general office clerk, babysitter and receptionist. These account for 32 percent of all occupations held by women in that year (Statistics Canada 1998).

[5] More recent statistics on the situation of persons with disabilities are not available, since Statistics Canada stopped conducting the Health and Activity Limitation Survey (HALS) after the 1991 Census year.

[6] The Health and Activity Limitation Survey of 1991 for Adults in Households (HALS) indicates, for example, that women are 50 percent more likely to provide care for men than for women who are aged 55 or over and disabled.

[7] According to the HALS Children in Household Survey for 1991, there were 534,430 children living with family members that year. Published information on patterns of care giving in these households is not available, however. See CICH (1994: 149-167).

[8] This number and related statistics do not include approximately 70,000 women who, for a variety of reasons were not assigned status on the census family variable.

[9] A variable was derived on the basis of the questions on social support to identify whether daughters or wives/female common-law partners provided help in *any* day-to-day activities.

[10] A variable was derived on the basis of the questions used in Section C of the questionnaire to identify whether persons surveyed received help from a community agency in *any* day-to-day activity.

[11] A variable was derived to identify whether respondents needed any help in *any* day-to-day activity because of their disability, whether they were receiving an adequate level of help across *all* day-to-day activities and whether they needed more help than was available to them in *any* day-to-day activity.

[12] A variable was derived to identify the need for aids/devices across all the pertinent screening questions in Section A of the questionnaire and in Section B question clusters 1 - 9. Respondents were classified according to whether they needed *any* device, whether their need for devices was adequately met for *all* kinds of devices required and whether there was *any* need for devices that had not been met.

[13] The women with disabilities who participated in the focus group were not asked questions regarding their employment status.

[14] For consistency throughout the report, we have used the term "individualized funding" as the model including direct funding and self-managed care programs, unless referring to a specific program.

[15] Professional service use was discussed in the focus group of women with disabilities; some women did mention that they use such services.

[16] Quebec was not involved in the development or signing of the document, though it shares the concerns raised in the report.

[17] It is unclear whether beneficiaries in this group will be able to go off ODSP temporarily to pursue employment opportunities without having to repeat this process.

[18] The documentation did not specify what these differences are.

[19] An early approach viewed equality as similar treatment for people similarly situated. This view allowed for the categorical assignation of rights (rights for men but not women, White people but not Black people, etc.). Equality was later viewed as equality of opportunity, whereby all people, undifferentiated by race, gender or other characteristics should enjoy equal opportunity to be achieved through the removal of legal and institutional barriers to access of these opportunities. However, this model failed to recognize that people experience different circumstances, and not everyone is in a position to benefit from the opportunities.

[20] Racism is also an issue in relationships where service recipients are visible minorities and their workers are White; however, since the interviews and focus groups comprised primarily White women with disabilities, complaints of race discrimination toward women with disabilities did not emerge.

[21] While we contend that burnout may contribute to the likelihood of abuse, this is not to suggest that this, or anything else, excuses abuse in any situation. Abuse is always unacceptable, and burnout should not remove a worker's accountability in such matters.

[22] Policies, which govern benefits and workers' compensation, vary according to the province/territory and agency that administers and distributes them. A reviewer of an earlier draft of this report pointed out that the Ministry of Community and Social Services in Ontario, for example, builds dollars into the sums which consumers who access individualized funding receive in order that their staff have coverage under workers' compensation. The reviewer commented, however, that this coverage required a lot of paperwork for the consumer, who received fewer service hours as a result; furthermore, she explained that the coverage was an option, not a requirement.

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