IN PROFILE: PERSONAL SUPPORT WORKERS IN CANADA

A REPORT TO

HUMAN RESOURCES DEVELOPMENT CANADA
OFFICE FOR DISABILITY ISSUES

FROM

RBC INSTITUTE FOR DISABILITY STUDIES
RESEARCH AND EDUCATION
RYERSON UNIVERSITY

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A basic premise guiding all of the Institute’s research is a concern with everyday relations and experiences, especially what they tell us about the society in which these relations and experiences are shaped. Institute research is not hypothesis driven, but committed to open-ended processes that build from stage to stage. Methods utilized in the Institute’s research rely heavily on talking to people, informally through conversation and formally through interviews. We favor techniques that create dialogue about experience.

These core practices enable us to break with the historical tendency for researchers to produce disabled people almost exclusively as medicalized or “other-ed” objects. Our research projects do not study disabled people as a special population. Instead we consider our disabled participants to be expert witnesses. Rejecting the focus on individual deficits, we are oriented to individuals and groups in continuous interaction with their environments. By learning from their embodied presence and participation, we seek to provide a fuller, more accurate account of society.
Research Team

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Executive Summary

Between December, 2003 and March, 2004, a research team of sociologists at the Institute for Disability Studies of Ryerson University undertook “In Profile: Personal Support Workers in Canada.” The project contributes to knowledge about personal support work by gathering current data and by developing a proposal for a longer-term, ethnographic study of worker/disabled-person teams in action.

Multiple methods were utilized to achieve these goals. These strategies included: a) literature and internet searches, b) consultations with experts, c) site visits to disability organizations, d) analysis of data, e) construction of a research proposal, and f) preparation of this report.

The research uncovered ten findings. We divide these findings into two chapters, Profile of Organizational Context and Profile of the Workers. In Profile of the Organizational Context, we deliver five findings: 1) a matrix of organizational stakeholders with vested interests in the field; 2) the absence of worker voice and organization; 3) tensions around workers rights and those of disabled persons; 4) terminology used to describe the work and workers is varied and often confounding; and 5) location of practice guided by policies that further medicalize the worker/disabled person team.

Under Profile of the Worker, we address the remaining five findings: 1) a preponderance of heavily medicalized curricula within the traditional training; 2) a lack of national certification standards; 3) the impact of an international labour force, with special focus on workers from the Philippines; 4) issues of gender, race and class are noted, as well as issues of culture and community; 5) finally, the wages and working conditions of the workers are explored.

The report concludes with recommendations for ethnographic research. We recommend the expansion of training in ways that proceed from the experiential knowledge of personal support workers in connection with that of the Canadians with disabilities to whom they tend.
Introduction

“In Profile: Personal Support Workers in Canada” is the final report of a four month study initiated by the RBC Institute for Disability Studies Research and Education at Ryerson University. Funded by the Office of Disability Issues (HRDC), its primary intent is to begin a study of personal support workers that builds from and contributes to the growth of Critical Disability Studies. Our starting point is the acknowledgement that personal support workers operating in non-institutional settings are a vital linchpin to furthering the inclusion and participation of people with disabilities in learning, work and community life.

The research team began this project focused on several key questions about personal support work: Who does it? Under what conditions? With what training? Shaped by what kind of policies? As we engaged with these questions, the sense we had of our problematic grew and sharpened. What we took up as issues for one constituency – disabled people – gradually came to take on national and even global proportions. What appeared to be a rather dry technical issue of systems organization or labour market management was revealed as a potentially explosive matter of gender, race and class politics.

We now understand the fullest possibilities of our investigation. What we are able to present in this document, however, are ten discoveries that we made in the short timeframe of this project. These we have organized - five apiece - in two profiles: one of the organizational context currently shaping the evolution of personal support work in Canada; and one of the workers themselves.

As we draw you into this complex domain, we want to highlight two dilemmas that are particularly perplexing. The first begins from our understanding that the voices of people with disabilities are often excluded from debates about their “care.” As a consequence, their needs are often determined by others. Should not their experience of personal support workers, and their preferences as a result, form the primary basis for our analysis? Certainly we hear them, at least as they are expressed by members of the Independent Living Movement. And yet what our literature searches and expert
consultations reveal is the equally disturbing absence of another important group: personal support workers. Their voices are missing in virtually all existing research. Further, there is no nationally recognized, personal support worker-run organization to recognize and work for their interests. Given that they are marginal and relatively powerless, how do we address the needs of both groups? How do we create policies that mediate this seemingly dichotomous relation?

The other major dilemma stems from our discovery that we are exploring a work form that is frequently analyzed without adequate reference to the international character of its workers. Support work gets done by an international body of workers within a global context of systematic interactions between particular regions of the world. In this report, we have begun to disclose these restructured and globalized labour dynamics. It is almost impossible to do this without addressing their raced, gendered and classed construction. By and large: women do this work; women of colour do this work; poor women do this work. If they perform it within the family, they do so as unpaid labour. If they live in a rural area the whole pattern is stronger.

The scope of the situation is staggering; multiple actors, unexpected interfaces and entrenched investments. Even so we have identified where we could make a difference. One of the original purposes of this project was to lay the groundwork necessary to position the Institute for Disability Studies to embark on a longer-term ethnographic study of the support worker and disabled person relationship. Not only have we accomplished that purpose, we have also perceived that our entry point should be within the field of personal support worker training. Specifically, there is a call for teaching and learning materials conceptualized from the disability rights perspective. This is the note on which we end the report. But before we get there, let us take you step by step through our investigation.
Chapter One
Research Activities

In this chapter we outline the methods that enabled us to write this report. We begin with internet searches and a description of the literatures, followed by our consultations, and end with a description of the site visits made during our course of investigation.

We used the internet as our starting point. It allowed us to branch out into library systems, on-line academic resources, community-based information, and government reports. Without the internet, composing a national profile would have been far more difficult. The research activities of this team thus very much started at the computer, as we typed in search words that eventually brought us to data and discovery. Typing straightforward keywords such as “education – personal support workers,” and “Home Care, demographics” eventually allowed us a national review of the data. What we learned was that educational institutions, disabled people, unions, and policy makers were all present and writing on the subject of personal support workers; but what was markedly absent was the actual voice of the personal support worker. No matter how we configured our searches, we couldn’t find an organization or essay that started from the standpoint of support worker. We realized that we would have to reorder our research to work through the voices of academics, disabled people, unions, trainers and others who were presenting their knowledge in the area. The personal support worker became the hunted on our web searches, but proved elusive. We had to rely on other mediums in order to access their voices.

What we were able to access was a number of academic on-line journals, which were downloaded and turned into hard copy. Sites that were instrumental in providing crucial reports included the Office for Disability Issues website, the Health Canada website, and the Status of Women website (see appendix for addresses). Many of the downloaded reports provided us with current data linking support work/ers to the respective areas of disability, home care, and gender equity. We also used the internet to seek out what was happening in specific communities throughout Canada, and to help us plan our site visits.
Upon receipt of the funding, the project team immediately began gathering preliminary data through internet searches and literature review. Key searches on training, employment, immigration and home care were used to draw out information on support workers and the disabled people with whom they work. Through academic search engines, we completed a thorough review of the literature and have put together as part of this report a comprehensive bibliography. Our review of the literature pulls from divergent perspectives, drawing from texts used to train support workers, to reports put together by Health Canada, Disability Studies Centres and many sources cited and itemized in the Bibliography. In the following section we cite some of the literature that makes up our bibliography. We give special notice to particular kinds of work, especially that which hones in on the worker-client relation. We divide the literature into three sections: 1) Academic, 2) Government Reports, and 3) Training Materials.

**Academic Literature**

We divide our academic literature review into two areas of study, that of disability studies and that of the social sciences. Within the field of disability studies, we relied on the works listed below to orientate ourselves towards a disability studies whose entry point is the social model. In other words, rather than disability being the inevitable outcome of a particular medical condition or diagnosis, disability is recognized as being created by the physical, economic and social obstacles that limit or preclude the full participation of disabled persons in social life. Such disability studies books include:

We also explored in depth the sociology of health literature, specifically that which dealt with home care, workers, and disabled people. We list here a variety of resources and fellow investigators that stood out from the traditional medical models of research, offering us a more holistic and radicalized way of exploring the social.

- Grant et. al. (Eds.) (2004). *Caring For/Caring About: Women, Home Care and Unpaid Caregiving*.
- Parker and Clarke (2002). “Making Ends Meet: Do Carers and Disabled People Have a Common Agenda?”
- Skar and Tamm (2001). “My Assistant and I: Disabled Childrens’ and Adolescents’ Roles and Relationships to their Assistants.”
- Ungerson (1999). “Personal Assistants and Disabled People: An Examination of a Hybrid Form of Work and Care.”

All of these works proved particularly helpful in informing the research team, through the variety of contexts, content and methodological offerings that these works provide.
We also relied on academic literatures that did not deal specifically with disabled people, but rather profiled the health care worker and the work:

- Milligan (2001). Geographies of Care: Space, Place and the Voluntary Sector.

Other domains of literature explored included basic background in the dynamics of globalization (Almot, 1995; Arat-Kroc, 1996). We also explored the feminist literature on caring work to search for the presence of personal support workers. Clare Ungerson (1999) provides a rare and important piece of the dyadic pairing of worker and client.

We noted the absence of literature in some key areas. There is little or no ethnographic research, which might reveal in context some of the day to day dilemmas faced by actual people. Jane Aronson (in Clark, et. al., 2004) does bring in people as starting points, and is able to draw significant policy conclusions from doing so, but otherwise ethnographic studies remain few and far between.

Finally, and a point that will be elaborated upon in later chapters, there was a notable absence of literature specifically concerned with racialized clients and/or workers, very little work that contextualized/distinguished rural from urban settings, and almost nothing on Aboriginal peoples and home care. Core to our report, we return to these absences in the literature and knowledge in Chapter Two and Three of our findings.
Government Reports

We also relied on a number of publicly funded reports that have been undertaken to derive quantitative data, statistics, estimates, and projections. A number of solid reports have been produced that explore Home Care, but nothing has yet to be done that addresses our primary concern: personal support work from a disability studies perspective. Relevant reports include:

- Anderson, et. al. (1999). *Putting a Face on Home Care: CARP’s Report on Home Care in Canada*;
- Masuda, et. al., (March, 1998). *The Impact of Block Funding on Women With Disabilities*;
- Roeher Institute (Feb 2003). *Caregivers of Persons With Disabilities in Canada ... and Policy Implications*.

We found these reports to be crucial by providing us with a solid Canadian framework from which we were able to build upon. These reports provided us with the hard facts, statistics, and explanations as to how the systems of care do (or don’t) work within the Canadian context.

Training Materials

The research team also examined a number of textbooks and other training modules currently used to train personal support workers. We found the text by Hamilton, *Becoming a Personal Support Worker (2001)* to be heavily technical and medical, a theme about which we have more to write. While the team found texts that were disability-centred, such as Degraff’s *Home Health Aides: How to Manage the People Who Help You*, and Parsons’ (1996) *Duty of Care: Who’s Responsible? A Guide for Carers Supporting People with Disabilities*, these texts were not being used as training tools in classrooms in post-secondary institutions. Rather, they are attached to disability
organizations and people, and not finding their way into training schools.

**Consultations**

A first step in getting a sense of the field involved in-house discussions with the study’s co-investigators. They alerted us to certain controversies in the area, and we did discover some tensions around the issues they raised. We were strongly advised, for example, to seek out the position of the Independent Living Movement in Toronto. Also, they urged us to base some of the investigation in Winnipeg, as it is the centre of several organizations whose members work on behalf of disabled Canadians. The collaborators were also instrumental in designing the field of expert consultants.

This study was then supported by the attentive expertise of a panel of consultants. We made contact with them at the outset of the study so that they could inform us on crucial topics that needed to find their way into our investigation.

We shall refer to these consultants and their contributions with anonymity. These expert conversations did not constitute formal interviews such as those that would require Human Subjects Approval, and we have found it in the interest of the report to amalgamate their comments. In the report we will identify each of these consults, not by personal identification, but by the main subjects that they brought up for us to look out for in building our profile.

From these consults we set our focus on everyday issues that had direct policy implications. We point out how they helped orient us, and the issues that they informed us on are fleshed out in Chapter 2 and 3.

We endeavored to build our consultation base from a range of experiences, and ensured that they held a relevant experiential base from which to draw advice. One consultant was a professor of sociology who had organized a disability persons research group in Victoria. A second was a Ph.D. candidate in Public Health at the
University of Toronto, and a researcher engaged in disability issues. A third was an activist in the community who had been executive director of a non-profit agency run by psychiatric survivors. A fourth was an active personal support worker, practicing in Ontario.

These consultations, which began as unstructured conversations, coalesced into a series of themes. In turn, the research team took these themes and worked them in as issues to frame our general exploration. The consults were invaluable for allowing the research team to go to the field equipped with questions that were sure to raise lively conversation. For inevitably, they did.

**Site Visits**

Having attained a grasp of the literature and orientations from consultants, the research team set out to establish connections with representatives of key organizations in its three designated field sites outside of Toronto. It had become clear through consultations that it would be important at each site to make contact with disability rights organizations, government officials, labour spokespeople, independent living centres, and especially training programs for personal support workers. In the midst of making these contacts, we planned and carried out visits to Victoria, Ottawa, and Winnipeg.

**Victoria**

From January 26-30, 2004 Timothy Diamond, research associate, visited Victoria, B. C. to investigate programs and policies pertaining to training and working conditions for personal support workers for disabled persons in British Columbia. He visited with a consultant who has developed a project and final report that works towards a more relational approach to caring. He also conducted on-site conversations with representatives of the Independent Living Centre, the Greater Vancouver Health Authority, Camosen College, The Canadian Institute for the Blind, and a former personal support worker who had worked in several areas of the province.

**Ottawa**

Ms. Jiji Voronka made the site visit to Ottawa in the end of January 2004. She met with two members of the Canadian Union of Public
Employees who were active in the struggle to unionize support workers in Canada. Another meeting was arranged with someone within the Office of Disability Issues at Social Development. The last was with a group of people who make up the Ontario Works program that gathers welfare recipients, puts them through formal training for personal support work, then hires them out through an employment agency.

Winnipeg

In February of 2004 Dr. Diamond visited Winnipeg, Manitoba. During his four day visit he made contact with a number of organizations and associations working within the disability rights movement. Site visits included The Council of Canadians with Disabilities, The Canadian Centre on Disability Studies, the Association for Community Living, the Independent Living Centre, the University of Manitoba, and Red River College. Winnipeg is not just the geographic centre of Canada, it is also the hub from which national organizations for Canadians with Disabilities act. To engage in a site-visit there is to appreciate the community as a whole as well as for its distinct and varied organizations.

The research team benefited greatly from the sites visits, allowing us to shift contexts and broaden the scope of this report. The findings that are derived from our site visits are scattered throughout Chapter 2 and Chapter 3 of our report, adding weight to almost every area of our findings.
Chapter Two: Findings
Profile of the Organizational Context

In producing a “profile” of personal support workers, the researchers did not define nor limit the term at the outset. We left it as an open category, to be filled as our investigations, through written materials, consultations, and field-sites, unfolded. The term itself comes from the Latin, “profilare,” literally to “spin forward,” and defined in the dictionary as “to draw an outline, as in a side-view of a head or body,” and “the representation of something in outline” (Oxford English Dictionary, 1999). The term can be used as a noun or as a verb. We do both.

This chapter outlines five findings about the ways in which personal support work is organized and understood within the health care field. We start with the organizational field itself, remark on what is absent from the field, delve into this issue of workers and disability rights, explore the impact of terminology, and end with home care systems.

1) The Organizational Field

Our first finding is the organizational field for personal support workers. For clarification, we offer a figure to chart the array of organizations that provided the data base. With personal support workers at the centre, the array of surrounding organizations represent groups that have a stake in how this form of work develops and operates:

Figure 1. The Organizational Bases of the Profile

<table>
<thead>
<tr>
<th>Public Training Programs</th>
<th>Private/Career Colleges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Living</td>
<td>Disability Studies</td>
</tr>
<tr>
<td>Government Agencies</td>
<td>Disability Advocates</td>
</tr>
<tr>
<td>Employment Agencies</td>
<td>Unions</td>
</tr>
</tbody>
</table>

17
Rather than treating the organizational array of interested and involved parties as a given, we took it as an empirical question. Moving out into Canada, step at a time forward, one contact following another, whom would we meet? What organizations would come into recommendation, then into participation in our inquiry? We had first to learn whom to contact, which we did from literature and consultations. And we had to wait for responses to our overtures. Some came, some did not.

Thus, we do not posit this grouping as the only constituents of a field of interested parties. This is not a universal grouping. It is not offered here as a closed circle; many more parties could be invited into the conversation. But from this group, there were conversations to be had. We can attest that each of these organizations expressed interest in personal support work, what constitutes it, how it is trained, and how it is to develop over the next several decades. From consultations with representatives of these organizations, we take up a series of issues that are disclosed in our report.

2) An Organizational Absence

The identification of this field of organizations leads to a second but related finding. It reaches beyond this field made present to us to ask: who is missing here? We went out into the country and found that there were no existing organizations assembled by and directly representing the voice and interests of personal support workers. We discovered an unexpected absence, an organizational vacuum. The lack of organization for personal support workers means that support workers are without peer support and camaraderie, lacking a place where they can turn to relieve or relate day to day stresses. This isolation is particularly so for those who are independently contracted, and less so for those who work for employment agencies. This isolation is also a human resource problem, since many support workers cite isolation as a core reason for leaving this field of work. We continue to explore what dimensions of organizational and policy change might help to fill that void.

As we approached the literature, the consultations, and the site visits, we did so with a particular social relationship always in focus. We are concerned here with a caregiving relation between one or more
personal support workers and people with disabilities whose social inclusion is enhanced through the connection. We start with this dual, interdependent position of worker and client, who together accomplish the caregiving regimen, both agents, both active. We seek to draw out this relationship that has been markedly absent from the landscape of literatures so far.

This focus is distinct from that of a personal support worker practicing her craft in a nursing home. It is also not the same as a worker tending to a home-bound person, nor to an elderly and infirm geriatric client. However important these domains of service may be, our purpose here is to solidify an outline of the situation of personal support workers who care for disabled adults and children who circulate throughout Canadian communities. As we shall see, focusing just on disabled people as distinct from the various others who receive care became a continual stumbling block as we approached the literature, the numbers, and the policies that claim to address them, but that render them part of a larger whole, thus effecting its invisibility.

So our purpose, in focusing on the dyadic pairing, the interconnections and intercorporealities specifically of support workers and disabled persons, calls for a shift away from studying workers lifted out of these contexts. Rather, we work towards understanding them from within the contexts of their sets of client-needs.

3) Disabled Persons’ Rights versus Workers’ Rights

One issue that became apparent during the course of our research was the apparently conflictual interests at issue between Canadians with disabilities and their personal support workers. Namely, what is best for the worker (higher wages, benefits, unionization, training professionalization) is not always perceived as being in the best interest of the disabled client.

All provinces have very real and strict numbers in place that regulate how much money or how many hours a week of support a disabled person is entitled to. The key feature of self-managed care is that it offers disabled clients who qualify a degree of flexibility in support
provision. British Columbia offers service under their Continuing Care Renewal Program (40 hours a month); Alberta offers self-managed care, but quality varies by jurisdiction (up to $3000 a month); In Saskatchewan, policy is under construction; in Manitoba, self-managed care is available for professional services (individual needs assessment made); in Ontario, programs exist for disabled adults ((average 60 hours per month); in Quebec, policy is in place for self-managed care (40 hours a week); in New Brunswick, it is a limited option (maximum $2,268 a month); in Nova Scotia, its has been piloted with consideration for expansion; in Newfoundland and Labrador self-managed care is extensively used ($3, 240 a month); In Prince Edward Island, it is a limited option (maximum four hours a day); in Nunavut self-managed provisions are an option; In Yukon there is a limited program (maximum 35 hours a week) and in the Northwest Territories information is not currently available. If a disabled person requires more money or hours than that which a province is willing to provide, the person is often advised to enter an institution.

If dealing with restricted hours, it then becomes the work of the disabled client to maximize their daily limit to ensure that all their needs are properly supported. Often the bare minimum get done and the rest (like leisure activities) gets left to the wayside. Paradoxically, then, this situation can mean that home care policies themselves are implicated in keeping disabled people in the private space of home and away from the outside community.

Likewise, disabled people are often given a lump sum of money every month to pay for their supports. Because this lump sum is often not enough, the disabled person is forced to cut corners in order to ensure that minimum support is achieved. One of the first corners cut is the support workers’ salary, in an attempt to stretch service dollars over the month. In turn, support workers wages become so low that they, in turn, are forced to find other ways to make it through the month. Government funding itself in these instances further impoverishes and marginalizes disabled people and support workers.

One of the primary goals of the Independent Living Movement has been to gain control over the services that they need to participate fully in social life. The movement identifies support work as a critical
prerequisite for disabled people to live the lives they chose. There is a demand growing from the independent living movement to exercise control over the training and working conditions of their attendants, especially those who hire them directly.

Disabled people want to develop respectful and reciprocal relations with their support worker. When hiring through employment agencies, this is often not possible due to schedule conflicts and staff shortages. Often, a number of different support workers come and go, offering little stability of care for the client. This means that disabled people have to take up the work of training each new worker in order to get their support needs met. As Morris notes:

*In self-managed care, if the recipient has to go through a home care agency to find a worker on short notice, for example for an unexpected need or because the regular worker is ill or simply hasn’t shown up, the government will not subsidize the higher cost the agency charges.* (Morris, 1999).

There is an enormous amount of work and responsibility when a disabled person is responsible for their own care, essentially becoming an employer, a ‘boss’. There are, for example, hiring, firing, teaching, managing the finances, (including tax deductions), and reporting to authorities, as several of our consultants pointed out. Nonetheless, all indications are that more and more disabled persons are choosing to take on the role, eager to embrace the autonomy that self-managed care can provide.

The difficulty is that the autonomy of self-managed care often conflicts with that of personal support workers (Sky, 1996). Under the entrepreneurial model, clients are most often not able to offer their workers extended health care benefits and a decent wage. Thus personal support workers are often faced with the dilemma: to align themselves with and work for self-managed care with a mind to disability rights, or to forsake their alignment with the disabled community for health benefits, a living wages, and all other things that the employment agencies are able to offer. These bonus dimensions of agency alignment become very attractive to the support workers. In turn, agencies will work only with certified workers. Thus training
schools, that work from the medical model paradigm, become necessary if a worker wishes to make a better living and open a wider umbrella of employment.

The issues of the labour rights of workers employed in self-managed care continues to play out in the provinces. An August 1998 Supreme Court decision in Newfoundland and Labrador granted consumers, their families, and advocates the right to be considered employers of home support workers. However, it also upheld the right of home support workers to unionize. Advocates for people with disabilities who fought the case said that unions had no place in private homes. (Morris et al., 1999). This decision has since been overturned, disallowing individually contracted workers from unionizing. This is an example of how the needs of disabled people and support workers can clash, resulting in tensions within the relationship. It leaves the disabled person and the worker – both members of marginalized groups - to negotiate over wages, when neither party has any power to end the cycle of poverty in which both parties often find themselves.

In Victoria, one of our consultants worked on “Project Inter-Seed: Learning from the Health Care Experiences of People with Disabilities.” This project and final report insisted that “the voices of people with disabilities are often excluded and their needs determined by others. Project Inter-Seed was an opportunity to intervene and create a different account, one that explores and explicates the relationship between official knowing and experiential knowing”(Campbell, 1999: 9). At its core, the project acknowledged that conflict and moving toward critical analysis is crucial if we are to improve the lifeworlds of both parties. In Marie Campbell’s words:

*the social organization of the provision of Home Support aims to further these efforts towards clients being in charge of their own lives. Our claim is that the practices of community health care are currently less supportive to people with disabilities as they are meant to be or might be. Taking the standpoint of people with disabilities is an approach that can help if is learned, treated seriously, and used within service provision as much as possible (Campbell et al., 1999: 94).*
4) Terminology

We encountered multiple and sometimes conflicting terminology for the group we are calling Personal Support Workers. A variety of job title names were used across different regions and sometimes within the same region in Canada.

There are approximately 40,000 ‘home care’ workers in Canada, but the language used to describe their work varies across jurisdiction. It quickly becomes apparent that the terminology used to describe who does support work is inconsistent across Canada – personal support workers in Ontario are to homemakers/visiting homemakers in New Brunswick and Prince Edward Island what home support aids are in Alberta. None of the language, however, distinguishes for whom the worker works: thus personal support worker is used to cover those jobs that are as varied as institutional elder care to working for a disabled adolescent. This name game makes conducting research difficult and makes us wonder: is home care attendant the same as personal support worker?; Do they do the same work?; Do they require the same training?; And what of certification? Instead of finding answers, the deeper we dove into the research, the more questions surrounding inconsistent and ambiguous language arose.

Within the disabled community, there has been debate over what terminology works best within a disability rights framework. The goal is, through language, to “find expressions for such services which portray [disabled people] as responsible and capable citizens who are in command of their lives and not as passive objects” (Ratzka, 1992: 4). The use of the word ‘attendant’ is disliked because it connotes institutions and institutional sentiments. Terms that have ‘care’ at the centre of them, such as ‘care attendant,’ ‘personal care attendant,’ or ‘carer’ are often disliked because care implies the taking care of someone who cannot take care of themselves. Rather than ‘care,’ the disabled community has moved towards embracing language that includes the word ‘personal,’ such as personal support or personal assistance. ‘Personal’ connotes that the assistance has been customized to the disabled client’s needs, and that the client is in control of what activities are delegated, how the tasks are carried out,
and by whom, when and where. Within the province of Ontario, the job title of ‘personal support worker’ is most often used, and it is generally a term with which the disabled community is comfortable.

Support work can entail everything from dressing, bathing, personal hygiene, household chores, and other daily activities that a disabled person cannot perform for themselves. As Ratzka describes:

“Personal” assistance means that users exercise the maximum control over how services are organized and customize their services according to their individual needs, capabilities, life circumstances and aspirations. In particular, personal assistance requires that the individual user decides: who is to work; with which tasks; at what times; where and how. Thus, the individual user must be able to recruit, train, schedule, supervise, and, if necessary, fire his or her own assistants. Simply put, ‘personal assistance,’ means that the user is the boss (recognizing that some disabled people might need support from third persons) (Ratzka, 1992: 2).

At times, a distinction is made between house work and body work, with personal support workers willing and responsible to only do body work. In cases like these, other workers (home helpers or home chore) are hired to do house work.

A paucity of comprehensive data has been collected on the demographics of support workers in Canada. The different terminology, policies, and services across Canada, as well as the high turnover rate within the job sector, creates complexity in tracking people within the field. Further, the variety of ways in which support workers are employed makes tracking workers difficult (Krogh, 2001). For example, they may be working for individuals, employment agencies, for supportive housing, under public or private funding arrangements. What we do know is that they are predominantly women, over the age of 40, and racialized.

Who support workers are has proved elusive. That they are poor is somewhat better documented. Health Canada, in their report Human Resource Issues in Home Care in Canada: A Policy Perspective (July, 1999) underscore that “as much as 80% of all home care hours
are provided by home support workers – the lowest paid, least trained, and the only unregulated component of the home care workforce.” They indicate that child care and home support workers (lumped together) for the period 1995-2000 is the fourth fastest growing human resources category among 139 job categories, and that the need for workers is ever on the increase. The report notes that most home care workers are women, made up of new immigrants (especially from the Philippines), youth workers, older workers, and displaced hospital workers.

Our report, one of many, concludes that due to no common job titles, no standard training requirements, no common set of tasks, no standardization of privately hired workers etc. there is little wage and benefit data to be had. With some searching, we pieced together some relevant data on wages and working conditions, and we report our findings in Chapter 3.

5) Location of Practice

Another discovery was the overlap in the notions of home care and community care. The Home Care System speaks to funding support that takes place both within the home and the community at large. However, the language of “home” obscures the support taking place outside of the home – of community, work, and social settings. Subsuming the active community living of disabled people under the heading of home care renders a range of activities and sites invisible. The disabled person being supported through her day at work, the disabled person arguing with his support worker in the street, everyday shopping sprees and quiet dinners – these are the daily events for our subjects that the language of ‘home care’ fails to evoke.

In literature and policy, there is a dominant distinction between institutional care and non-institutional care. There are, of course, profound differences in their lived experiences as well. Here, however, we wish to offer the position that ‘non-institutionalized’ needs itself to be subdivided into home and community, and acknowledging that these domains overlap.
To substantiate this recommendation, we offer here a brief discussion
of the ways in which the amalgamation of community care within
home care does not serve the purpose of the profile that we are trying
to outline.

Almost all of the data that was collected over the course of research
from government agencies, public and private organizations, as well
as academic sources was accessed by using ‘home care’ as a
primary search word. This confounded us, given that the people that
we were interested in profiling, disabled people and their support
workers, were understood to us as partaking in ‘community living’ –
making their way, together as dyads, through public life. This
relationship was envisioned as a relation of support, accommodation,
and possibility, as well as of public and private negotiations. Of
course, much of the work does take place in the home. ‘Home Care’
references domestic mess, or rather the cleaning up of mess, hidden
and private mess. Bathroom care, kitchen work, and the primacy of
bed lifting. So we come to acknowledge that much of the work is
‘home’ work, the mopping up of messiness that all bodies make; work
that it often left unacknowledged. But we also feel that it is important
to acknowledge the hours that are spent active and outside of the
confines of home. ‘Home care’ terminology subsumes the other
spaces of daily living, such as career and professional life, that many
disabled people and their support workers occupy.

Most disabled people across Canada access much of their funding
and services through Health Canada. The trickle down of dollars that
eventually find their way to pay support workers originates from
Health Canada, earmarked under Home Care. The 1990 Health
Canada Report on Home Care prepared by the
Federal/Provincial/Territorial Working Group on Home Care defined
Home Care as:

An array of services which enables clients, incapacitated in
whole or part, to live at home, often with the effect of
preventing, delaying or substituting for long-term or acute care
alternatives. Home care may be delivered under numerous
organizational structures, and similarly numerous funding and
client payment mechanisms. It may address needs specifically
associated with a medical diagnosis (e.g. diabetes therapy),
and/or may compensate for functional deficits in the activities of daily living (e.g. bathing, house cleaning, food preparation). Home care is a health program, with health care broadly defined; to be effective, it may have to provide services, which in other contexts might be defined as social or educational services (e.g. home maintenance, volunteer visits). Home care may be appropriate for people with minor health problems and disabilities, and for those who are acutely ill requiring intensive and sophisticated services and equipment. There are no upper or lower limits in the age at which home care may be required, although as in other segments of the health system, utilization tends to increase with age.

As the definition of Home Care denotes, this is a service that is substantially funded through Health Canada (3%-5% of its annual budget) and thus inextricably linked to a medical model of providing services to disabled people. Turning social activities into medical problems by streaming social services through Health Canada is a problem that many disabled activists have identified as the tendency to over-medicalize their lives.

### Covering Home Care Costs: Pointers on How it Works

- Home care and community care services are currently funded by provincial, territorial, and some municipal governments, with funding support provided in part from the federal government through general transfer payments for both health and social services. This results in funding structures varying drastically from province to province.
- While the government of Canada currently provides income support to seniors (OAS/GIS) and First Nations peoples (SA) directly, it currently does not do so for disabled people. The federal government remains responsible for the income measures of CPP-disability, Federal Workers' Compensation, and Veteran Disability Pension.
- Some people pay directly out of their income for private home and community care services, usually because they do not qualify for public services or they require additional care that the public home care services do not cover.
- Self-managed care is available in certain provinces, where the province or region provides funds directly to the disabled person in need of services (providing they qualify). Then, the client is able to use the funds to hire a support worker of their choice privately, or through an agency.
- Thus, there are a number of different ways in which a personal support worker can be paid:
  - through provincial or regional services and funding
  - through federal income supports
  - through private money of which some is reimbursed through taxes

Sources: (the current Architecture of Public Programs for People with Disabilities in Canada, Jan 2004; Home Care in Canada 1999; an overview HRDC web)
One of the problems of home care is that it doesn’t distinguish its user profile: disabled users are lumped together with elder care and short-term users. We do know that more than two thirds (67%) of people receiving home care services are female. This is factored in as being the result of women living longer. Additionally, women often act as unpaid caregivers: when men within the family fall ill, women will give care and thus men are less likely to need to access government support. However, women in need of support are more likely to access outside supports, such as programs funded through home care. Home care is thus very much a gendered entity: “Home care . . . is an underfunded program teetering on the broad but tired backs of overworked and unpaid, or underpaid, women. As currently manifested, it requires women to subsidize the programs with their labour” (Morris et al, 1999: 75).

Home Care programs vary across jurisdiction, provinces and territories. They are a complex matrix of qualifications, regulations, and responsibilities that are managed by the Ministries of Health. As this chart exhibits, home care services are mediated very much by where you are located in Canada:

<table>
<thead>
<tr>
<th>Similarities</th>
<th>Differences</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Home Care falls under the responsibility of departments and ministries of health, although in some provinces and territories, responsibility for health is combined with social and community services</td>
<td>• Levels of funding for home care vary, depending on the province or territory</td>
</tr>
<tr>
<td>• Increased standardization exists within individual jurisdictions in regard to both the processing of demand and the management of services information in home care</td>
<td>• Variations among jurisdictions in the development of databases contribute to the difficulty in obtaining various kinds of data on a national basis.</td>
</tr>
<tr>
<td>• Case management functions are the responsibility of public employees</td>
<td>• The ways in which clients are charged for care varies across provinces/territories</td>
</tr>
<tr>
<td>• A common base of services exist, including nursing, personal support, and home help services</td>
<td>• The range of services available varies among provinces/territories, with services being fewer in rural and isolated areas</td>
</tr>
<tr>
<td></td>
<td>• The models of service delivery are a diverse mix of public and private sector workers</td>
</tr>
<tr>
<td></td>
<td>• Variations in policy exist, for example: client access to services, service standards and quality, equity in the provision of services</td>
</tr>
<tr>
<td></td>
<td>• The regulatory status of home care varies jurisdiction to jurisdiction</td>
</tr>
</tbody>
</table>

Canadian Home Care Human Resources Study
As can be surmised from the chart, where one is located in Canada can greatly impact what level of care disabled people will be able to access.

One of our consultants was the first to raise location within Canada as crucial to impacting supports. Being a client living in a rural or remote area can have a deep impact on what supports are available. Further, being a worker in a rural area can pose special problems, such as long travel time from job to job, all of which is unpaid. We know that the rural areas have difficulties accessing support. The truth of the matter is that there is often no appropriate service to people living in rural areas, and many disabled people are forced to relocated to more populated areas in order to access support.

One issue is how to get personal support workers out to rural areas. A recent report for the Ontario government called *Small, Rural, and Remote Communities: The Anatomy of Risk* urged government action. As Solomon reports (2004: FP 19), increased support for the older and less mobile residents who might want to stay in their home communities should be a right.

In a study by Blakely and Jaffe (2001) of the Prairie Women’s Health Centre of Excellence, entitled *Coping As a Rural Caregiver: The Impact of Health Care Reforms on Rural Women Informal Caregivers*, the authors suggest that “rural women informal caregivers find themselves in a difficult situation. These women have to cope not only with the restructuring of their health care system but also of their communities. This study reveals that these changes are altering caregivers’ social lives, their work, and their health.” They conclude that “rural caregivers need social support, that family supports are often not available to the caregiver.” They suggest that policy needs to be reformed to recognize “that rural caregivers tend to be older and have their own health problems,” and that “caregiving is work, and financial remuneration ought to be provided for it” (Blakely & Jaffe, 2001: 12-13).

In this chapter we have outlined five findings related to organizational context: the stakeholder field, the absence of an organization for personal support workers, potential conflicts between rights of
disabled persons and personal support workers, issues of terminology, and location of practice. In chapter three we offer findings related to the workers’ training, certification, and social characteristics.
Chapter Three: Findings
Profile of the Workers

This profile became a socio-political one. Its efforts to draw an outline of who does what work have led to issues of training; certification; international borders; of gender, class, and race, culture and community; and to issues of wages, unionization, and working conditions. We have endeavored to ask “how are personal support workers embodied as a part of the social fabric?” Answers often were expressed for us in terms of these social dimensions. This chapter profiles those who make the work happen, but who often get omitted from analysis, lost in the fray: the workers.

1) Training

One of the discoveries of this research is that training programs throughout Canada vary widely, and are not coordinated nationally. We have also learned of a growing demand for coordination of training.

There are no standard training requirements for personal support workers across the provinces. Five provinces (British Columbia, Saskatchewan, Ontario, Quebec and Manitoba) have training requirements which range from a 22-week community college program in British Columbia to 2-years of on the job training in Saskatchewan. The remaining provinces and territories have no mandatory training program. For example, in Alberta only a competency test is required. Even with this sketch, we have also found the requirements as they appear in text may not always match how they are played out in actual work settings.

For instance, in Ontario the official policy is that training and certification are necessary for work in the field. This is true, but only if one wants to work within institutional settings. Again, here is an instance in which amalgamation and decontextualization leads to conclusions we wish to avoid. If one markets through independent contracts, or advertises in the classified ads, clients are free to hire at their discretion, regardless of credentials. Thus, while many provinces have implemented mandatory training policies, their impact is slight on independent support work providers.
Further, many disabled people living in communities are able to hire independent workers. This situation would seem to suggest that those undergoing formal training end up in more regulated employment environments, such as institutions and supportive housing. These spaces are very often not exclusively for disabled persons; rather much of the support work is elder care. We conclude that the training that support workers receive in training schools is not specific to the needs or cares of disabled people living in the community. Rather, it is often institutionally and age-biased.

Another of the problems we uncovered with training is that it is not transferable. Due to this lack of standardization of training across the provinces and territories, if a worker undertakes training in one province (and pays the often substantial tuition fee) then moves to another, her certified training is likely not to be accepted. This problem presents a barrier to disabled people as well as to workers. Freedom of movement for both is already hindered by numerous socio-economic issues. We heard this scenario repeated on more than one occasion: a disabled person works exclusively with one worker. The disabled client moves across provinces. The support worker would like to follow the client, but is unable to do so due to these transferability restrictions. This situation ensures that the user has little control of the service, forcing disabled people to follow the service rather than the other way around.

The research team talked with two experts in the field who were the co-directors of an Independent Living Centre. They introduced us to a wealth of resources on self-management, and discussed at length their position on training. These experts said that they would rather undertake the task of training their support workers themselves than to have them go through some type of professional medicalized training. They went on to express two of the most radical possibilities in reference to policy implications. One, that formal training should be abandoned and turned over to Independent Living Centres. The other, to contest the presumption that attended services are a ‘benefit,’ and that they should rather be considered civil liberty issues.

During one of our site visits to Ottawa, we discovered a unique training program that streams welfare recipients into support worker
training. The City of Ottawa identifies group sectors that are experiencing human resource shortages (such as support workers); the city goes through a process of screening its workfare participants; the city funds the tuition and costs of training, directly paying the college; the employment agency in turn hires those who have completed the training, and the once-welfare-recipients-now-trained-support-workers are committed to the agency for a minimum of three months. Proponents of the program would say that it gets people off welfare and grants disabled people a larger pool of labour to draw on. But the research team wonders whether funneling welfare recipients into jobs that they might otherwise not be interested in is the solution to the worker shortage in the field. The last thing that disabled people need is support workers who have been coerced into the field. No good work relationship can come of that.

The social movement among disabled people towards independent living has problematized the role of personal support worker. As mentioned, Independent Living Centres typically express skepticism regarding professionalization of this workforce, and a strong desire to be involved in training workers. This position can be problematic for personal support workers. As a labour force, they often struggle with low wages, minimal benefits, uncertain work environments and difficult schedules. Professionalization is one way for them to develop, and an organizational base is one way to start that path.

Yet, people with disabilities and their organizations argue that the philosophies underpinning training for personal support workers emphasize medical care rather than interpersonal relations, institutional rather than home care, and aged persons more than those who are younger. Training schools frequently use nursing homes as sites for hand-on instruction. This locale leaves students lacking experiences for working with disabled persons who are active in the community. Displeased with this situation, disabled persons argue for a radical reformulation of curricula based on different content and learning materials. Few such alternative resources exist, oriented particularly to personal support workers working with disabled persons.

The goal is for training materials to shift away from the emphasis on physiological and clinical interventions and skills, and to move
towards the interpersonal, cultural, and policy contexts within which
the care relation takes place. Our review of the literature suggests
that the training materials have yet to catch up to this more social
approach to support. For example, Hamilton (2001) has produced a
widely used text, entitled *Becoming a Personal Support Worker*. In it
disabled people are not treated as a distinct clientele, nor is the
community of any reference. Rather, personal support work is
abstracted into a set of tasks that once learned can be plugged into a
variety of settings. These skills are predominantly physical, as in
principles of oral care or shaving, and the measurements involved in
taking vital signs. The client is presented in a generic way, spanning
wide variations of groups, including infants, the elderly, and those in
need of palliative care.

We did find a number of noteworthy training models in our
investigation. In Winnipeg, our contact at the Canadian Centre on
Disability Studies offered us several of their recent publications,
including their project to develop training programs in organizational
development and disability policies in Canada and the Ukraine
(Khomenko and Nickel, 2003). We had a preliminary conversation
about the coordination of training programs within Canada, and this
representative orientated us to a number of training programs within
the Winnipeg area.

One model was a training module that the Independent Living Centre
in Winnipeg had developed, called the Personal Attendant
Community Certification (PACE). This course diverges significantly
from the more medicalized training practices and materials. The 175-
hour curriculum graduates what it calls Independent Living
Attendants. In their curriculum, 42 hours of training are devoted to
“community consumer directed training,” so that the support worker
can better know how to negotiate the goods and services that can
enhance her client’s social inclusion. Other colleges, such as
Victoria’s Camosen College and Red River College in Winnipeg,
address training students who will be working specifically with
disabled communities. We strongly encourage that more research be
undertaken to map out the array of training programs around the
country, not least to cull their best practices and to begin the long-
term strategy of national coordination.
2) Certification

A cornucopia of diplomas and certificates are offered from a variety of different locales: on the internet, and from private and publicly-funded colleges. Programs vary widely and are isolated from one another. We noted a demand among almost all parties with whom we spoke, disabled persons, support workers, educators and advocates, for national coordination of training. In the United States, there is a developing movement for a national Personal Assistance program (Weissman, et. al., 1992). We suggest that such a program is called for in Canada as well.

As has been noted, certification is most commonly required only in more formal and structured work environments, such as in institutional settings. In such cases where formal training is required, many students undertake it in privately operated colleges. A number of nationally-based schools offer provincially-recognized certification in a short amount of time, but for a high price. Alternatively, in Winnipeg the research team discovered a two-year training program, Disability and Community Support Workers, offered at Red River College that was one of the most comprehensive and tailored training courses discovered by the research team. We feel that certification can be a good thing, provided that the training that it entails involves a disability-rights orientation.

We have also made an initial inquiry as to how personal support workers, once certified, go about finding employment. We discovered several ways that workers find work, and again make note of the lack of coherence and coordination in these options. Among them, potential workers can search the Human Resources Development Job Bank, newspaper classified ads, specialty newspapers like “Hospital News”, caregiver agencies, school placement services, through worker’s compensation, and through the various provincial welfare to work programs, like Ontario Works, and finally, for those with access to the internet, web links (national and international, see, for example, Caregivers.ca).

Certification remains somewhat of an enigma in terms of how it plays out for the number of different parties and organizations that are impacted by it. Some provinces have obviously felt the need to
implement standards; others have not. Certification has been deemed mandatory in certain settings; not so in others. Some workers might find the requirement increases their profile as professionals; others might find the costs and testing more of a burden. Some disabled people might feel reassured working with someone who is certified; others might feel that certification is simply another way of medicalizing their support. This issue begs to be explored in an ethnographic format, where real people can be asked questions that can only be hypothesized in this format and setting.

3) International Impacts

One of our most important findings in building this profile has been that many personal support workers in Canada come from outside of its borders, and from certain regions more than others. More than one of our consultants alerted us to the emerging global dimensions of the workforce. One offered articles (Arat-Koc, 1999; Gupta, 1994) which are among the few pieces of literature that address globalization in relation to Canadian home care. Global tributaries feed the pool of personal support trainees and practitioners. Indeed, almost any form of paid labour in Canadian society should now be contextualized by its global dimensions (Albrow, 1996). Workers from regions in the Philippines and certain Caribbean countries especially feed our labour pool, thus inextricably intertwining immigration and labour policy.

Although it is acknowledged that large numbers of personal support workers are indeed immigrants, government policy, teaching and learning materials, and the literature in general has not incorporated the effects of globalization into the equation. One of our recommendations is that new learning and teaching resource materials be devised with these global dimensions in mind. Their developers must always be mindful that support work gets done by an international body of workers, within a global context of systematic interactions between particular regions of the world.

Given that the workforce is pulled from around the globe, many disabled people find themselves dealing with language barriers and communication problems: when personal support workers struggle with the English language, it makes for more work for the disabled
person when giving support instructions. Conversely, as Canada becomes more ethnically diverse, “many members of minority ethno-racial communities are not even aware of the existence of home care services” (Morris et al., 1999: 59). Thus both sides of the dyad feel the impact of globalization.

Within the context of a global economy, Canadian employment strategies have been implemented in an attempt to harness support workers from an international arena. As a result, immigration policy has changed to enable workers from outside of its borders to come to Canada provided that they work within the home care field. In our research, we found an abundance of employment agencies advertising over the internet that targeted both home care workers abroad and Canadian clients who desired their services. Web sites such as www.a-procare.com offer information to both buyer and seller of support labour.

The headlines of these websites offer promises to Canadian clients who are struggling to find and retain support workers: “Direct hire from Philippines/Hong Kong,” “Overseas Caregivers will sign one year employment contracts . . . making them more reliable.” Much is made of the fact that the one-year contracts foreign workers must sign in order to be permitted entry into Canada are cost-saving: most contracts promise little more than a thousand dollars a month, minus room and board. Further, the Philippines has stiff training requirements (minimum of 750 hours of full-time classroom training and 240 hours of on the job training), offering workers who are well trained for fewer dollars. These agency sites are also littered with practical data: “Processing time for Caregivers coming from the Philippines 4-6 months,” “tax deduction for employers,” and the dubious “Foreign caregivers are very grateful for the opportunity to come to Canada and are willing to work harder” (www.a-procare.com/el/htm). The particular ways in which these foreign-born workers are portrayed must take into account issues of race, gender, class and culture: and acknowledge that the culture of home care itself depends on such social constructions.
9) Gender, Race, Class, Culture and Community

Across consultations, one of the key themes that all consults noted was the gender dynamics that permeate both the work and the relationships. Further, the work is done primarily by women (and some men), often foreign-born, and that gender and race therefore pervade relationships within the dyad. Thus, any profiling of the workers must always be mindful of the multiple identities that both constitute and affect support workers lives.

Many of the employment agencies offering overseas labour (such as www.nfld.net/pcil/applicants) supply biographies and photographs of Philippine residents (mostly women) wanting to be hired for home care work in Canada. These biographies tell stories that are highly gendered and operate within racial and cultural stereotypes. These biographies and CV’s conjoin women, Philippine culture, and racial discourses, creating these ‘types’ of people as the ideal for home care work: submissive, tranquil, and belonging to a culture that is innately capable of taking care of other peoples’ needs. Further, the snapshots posted of these women (both portrait and full-body shots) put the viewer in the position of shopping for human labour, as if cargo or mail order brides.

Currently, home care depends on the intersecting oppressions of gender, race, class, sexuality, and ability. The value of work goes unrecognized; unpaid; underpaid; and marginalized workers who enter the field because of limited options remain marginalized because of the ghettoization of the work. Because of the gendered nature of the work (care, cleaning, cooking), the skills that support workers have are devalued and overlooked. Many racialized women, single mothers, newcomers to the country and the like find themselves taking up the work that allows them best to balance their lives: mothers unable to afford child care looking for part-time hours and a flexible work week; foreign–born nurses whose degrees hold no value here find a place in home care where they hold the skill sets yet make far less money and benefits. Further, because there is little regulation of support work, the gender and race discrimination in wages is overlooked and remains unresolved. The home care system is set up so that it depends on the subjection of often racialized and impoverished women with few options other than to take up the work.
Thus home care is an active and contributing factor in maintaining working women in poverty.

Home care services are exceedingly problematic to the Aboriginal communities of Canada. As Morris *et al.* notes: “Services were not culturally sensitive leading to under use of services among urban Aboriginal peoples and some ethnic, racial and linguistic minority communities. Women in these communities frequently are the home care system (Morris *et. al.*, 1999). Within Canada:

*The incidence of disability among Aboriginal people is almost twice that of other Canadians. Aboriginals with disabilities are continually being caught in debates and battles over jurisdiction and responsibility. Clearly Aboriginal people with disabilities are not able to access timely and appropriate services. Direct transfer of funding to First Nations for investment in disability related supports is critical. As well, the needs of Aboriginal peoples living within other jurisdictions must be given priority (Council of Canadians with Disabilities, Feb. 2003: 1).*

One problem of concern that relates to Aboriginal communities in particular is that many of them live in rural and remote communities, and as such are unable to access support services. This is also a gender issue, as women in these communities, as in all communities, tend to pick up the care work when it is not forthcoming through governmentally-funded programs. This unpaid and often unrecognized work further contributes to the impoverishment of women. If family members cannot pick up where services do not exist, disabled aboriginals are often forced to move out of their communities and into city centres in order to access care. This is a huge problem as it can lead to loss of native language and customs. It has been recognized that “an aboriginal person may want to stay in the city to be close to medical services, be far away from potential family caregivers living on reserves” (Morris, 1999). Appropriate government policy directives are imperative to redress the lackluster commitment to Home Care in Aboriginal disability communities.

One of our consultants offered insight into just how multiple identities, culture, and community impact the relationship of personal support worker and disabled client. She explained how they often came to
know one another through informal communities, in group settings, through friends, or trail and error. Many support workers also come to know their clients through more formal settings like supported housing. “A really great support worker,” according to our consultant, “should be able to blend into a number of different social situations, modifying and monitoring their behaviors in order to fit in.”

It is crucial, this consultant went on to note, for a queer-identified disabled person to have access to support workers who are comfortable with the client’s sexuality. Further, that within this intimate work “dance” that neither person feels offended, or offends the other. Thus, a great personal support worker must be able to resist judgment when helping their clients participate in sexual, religious, and other intimate struggles and celebrations of the everyday.

This consultant explained how specific communities and cultures tend to get to know and share support workers who are glad to work within certain settings. Further, that disabled people come to know that certain support workers are best to work within the household, while others are better for church services, and thus that support workers suitability depends on ever-shifting contexts. Thus, one support worker will be hired by many within the disabled communities for cleaning, while yet another will be predominantly hired for community events.

This consultant characterized hiring, firing, and managing support workers as negotiated through communities in Toronto. Rather than relying on agencies or classified ads. Disabled people come to find support workers through contact within the community: through supportive housing, at community events, through word of mouth and through friendships. She placed emphasis on how client identities (such as race, class, gender, sexuality, ability) have a huge impact on who gets hired as support workers. In a city as diverse as Toronto, a gay Black disabled person might have less of a struggle finding a harmonizing support worker, but in smaller communities, identity politics can hinder getting good support. But the consultant emphasized that support workers can also be deeply transformed by the people they work with, and that through the experience of
‘traveling’ with multiple clients with multiple identities, many support workers, with time, shift their mindsets.

5) Wages and Working Conditions

The Canadian Union of Public Employees (CUPE) estimate that there are about 40,000 home support workers across Canada. Personal support work is one of the lowest paid jobs in the health sector, but makes up the largest (80%) workforce within home care. The national average of wages for support workers who are public employees in 2003 was $14.41, for private not-for-profit $11.66, and private for-profit $12.04. Thus the overall national average of hourly wages for support work in Canada in 2003 was $12.71. These wages, however, vary drastically depending on which province you live in.

Examples of wage rates for unionized home support workers, by province:

<table>
<thead>
<tr>
<th>Province</th>
<th>Range of Hourly Rates (base to top rates)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
<td>$8.00 - $10.56</td>
</tr>
<tr>
<td>British Columbia</td>
<td>$13.43 - $17.11</td>
</tr>
<tr>
<td>Manitoba</td>
<td>$7.92 - $8.86</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>$7.50 - $8.30</td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>$7.17</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>$6.25 - $12.78</td>
</tr>
<tr>
<td>Ontario</td>
<td>$7.13 - $10.13</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>$13.42 - $14.40</td>
</tr>
<tr>
<td>Yukon</td>
<td>Not available</td>
</tr>
<tr>
<td>Northwest Territories</td>
<td>Not available</td>
</tr>
</tbody>
</table>

From Carp’s Report Card on Home Care in Canada 2001

Many home care agencies lose their staff to institutions which offer higher wages, guaranteed hours, regular scheduled shifts, and benefits. This is bad news for the disabled community, as committed support workers leave community care for institutional jobs, usually the last place that disabled people want to be. Thus, while support workers in general are in high demand, the labour shortage is
especially felt in community settings, which offer the least in wages and benefits.

There have been and continue to be attempts to organize and unionize personal support workers throughout Canada. In general, those support workers who are unionized are attached to supportive housing, institutional care, and employment agencies. Support workers who are hired independently by disabled people are not unionized, and thus generally make the lowest wage and lack any benefits. Unionized support workers make an average of $1.50 an hour more than their non-union counterparts.

The Canadian Union of Public Employees (CUPE) continues to work towards organizing support workers across Canada. During our site visit to Ottawa, we met with two CUPE representatives who were sensitive to the issue of how disabled people are often forced to fight the unionization of support workers simply because many cannot afford their service if workers receive a higher wage. Thus, in order to secure support, disabled people often find themselves in the uncomfortable position of being anti-union, and by extension, anti-worker.

By interviewing support workers, CUPE has identified the three primary working conditions that workers site as needing to improve: compensation for travel time; better wages; and improved benefits. CUPE is eager to tackle these issues, but support workers prove difficult to organize, given their marginalization, transience, and the fact that many support workers are illegally working in Canada(www.cupe.ca/www/HealthCareFundingCuts/4600).

But low wages are not the only factor troubling many support workers. The working conditions and environments that support workers enter every day are always unpredictable, and often undesirable. Given that many disabled clients are poor, many live in substandard housing conditions. Given that the clients’ home is the support workers’ work environment, this translates into a poor working environment for the worker. Context matters. Depending on where both workers and clients live, the dyad often have specific concerns. For instance, data has correlated high unemployment rates
in Newfoundland to the high incidence of violence against home care workers (Morris, 1999: 41).

One of our consultants directed us to explore all of the invisible labour that takes place in this work, on the sides of both the worker and the client. This consultant was aware of how crucial the work of coordinating many schedules is to the execution of good personal support work. She made particular reference to transportation and all that is involved in making it a successful endeavour. Her point was that a conscious recognition of all of the invisible labour that takes place between the dyad needs to be acknowledged, recognizing that it is work that is de-emphasized, devalued, and often unpaid.

Personal support workers express a number of concerns in relation to their safety, some of which include: damage to the back due to physically lifting and transferring clients; stress, fatigue and burnout; emotional costs; fear of infection; isolation; safety hazards in the home; and abuse by clients (Morris, 1999: 41). Worker dissatisfaction is a concern for disabled communities as it affects the continuity of care, results in waiting lists, staff shortages, health risks and diminished quality of care. The well-being of the disabled client is directly dependent on the wellness of the worker, and when one is encumbered, the dyad suffers. Morris et al. acknowledge, in their substantial report The Changing Nature of Home Care and its Impact on Women’s Vulnerability to Poverty just how interconnected the relationship is:

There is a chicken-and-egg phenomenon at work here. Home care occupations, particularly home support work, are low-paid, low-prestige, isolating, female-dominated occupations in which home support workers, especially, are not adequately trained, work casual hours and have no hope of career advancement. As a result, there is a shortage of well trained staff interested in home care work, with the corresponding labour shortages, inadequate care, waiting lists and risks to client safety. Those workers who are well trained and qualified are dissatisfied because their work has been deprofessionalized and their wages are far below what they would earn performing the same duties in an institution, leading to a very high staff turnover (Morris et. al., 1999: 49).
While wages and working conditions leave much to be desired, many caregivers are not being paid at all. The issue of family members as caregivers first came to our attention during conversations with our consultants and collaborators. We were told of a situation where a personal support worker subsequently became a family member of the disabled client, and thus was no longer able to be paid for her work. There is much controversy as to whether this rigid distinction, that family member cannot be paid for their work, should be loosened as a matter of policy. Restrictions and provisions vary by province. In Ontario, our consultants made it clear that the distinctions are rigid. Currently the policy is no compensation in wages or reimbursement, save for a tax deduction.

In British Columbia, we were told that some family members can get reimbursement. These persons must demonstrate to the Greater Vancouver Health Authority that alternative services are not available. This flexibility has greatly enhanced the provincial home support services’ ability to serve the needs of rural residents.

Another entree of this research team to the workings of home support was the participatory action research reported by Campbell, et al., (1999). In Project Interseed’s program, persons with disabilities and personal support workers (not necessarily teams) were brought into the research at every stage, and each stage was an inquiry into disabled persons’ lived experience with obtaining home services. The research team was based in a client’s home and listened to discern the social organization of services present or absent in the disabled persons’ talk and descriptions, including descriptions of forms that permeate every day life in search of home support.

On the other end of the country we found noteworthy a study done at the Maritime Centre of Excellence for Women’s Health (Campbell, Bruhm, et. al., 2001). The authors suggest that

Rather than positioning unpaid family caregivers at the periphery of homecare policy, this study acknowledges their central role. Insights gathered from a group of 46 family members caregivers in rural Nova Scotia point to a pressing need to recognize and support the contribution of this unpaid, almost exclusively female, sector of the
health care system. The caregivers we spoke with report that the system does not value their role as primary caregivers, nor does it provide them with appropriate information, training, services, and urgently needed respite care (Campbell et. al., 2001: 9-11).

It seems that the payment of family member care is an active debate that continues to take place across the country. Policymakers will have to deal with it as no longer can they or anyone assume that there is available, let alone unpaid, (female) labour in households.
Chapter Four
Recommendations

Standard Recommendations

Many reports before ours have recognized the issues that home care workers and clients struggle with under Canada’s currently unregulated or under-regulated arrangements for Home Care. Our literature review found a number of recommendations made to authorities that called for action to improve the state of Home Care in Canada (see Grant, et. al., 2004; CARP, 2001; Canadian Home Care Human Resources Study, 2003; Morris, et. al., 1999). Year after year, Canadian reports identified similar problems and issues. Lining these reports up one can see the same list of Home Care recommendations that have consistently not been acted on. We support the recommendations that continually turn up in these reports, recognizing them as goals that need to be acted on in order to improve the lives of both clients and workers.

1. Legislation: The federal government should work with the provinces, territories, and other stakeholders to develop home and community care legislation and policy agreements that are based on the principles of the Canada Health Act (accessibility, portability, universality, comprehensiveness, and public administration): i.e. a Canada Home and Community Care Act. Home care would be publicly funded, based on need, and provided on a non-profit basis.

2. Research: A national survey undertaking an inquiry into the costs and benefits of home care in all provinces and in various communities (sensitive to race, class, gender, ability, and sexuality) needs to be conducted. It should include an audit of current home care systems, including an in-depth probe of working conditions of support workers and living conditions of clients.

3. Training: An enquiry into the required training and certification of personal support workers within each province and territory needs to be undertaken. Dialogue between workers, unions, clients, trainers, and other stakeholders needs to take place in order to establish what direction should be taken in terms of mandatory training. The debate
over what is best for whom, professionalization versus deprofessionalization, needs to take place.

4. National Standards: National standards for both workers and clients need to be established, setting minimum levels of wages, training, support, and funding access across provinces and territories. Organizations of support workers need to be established in every province and territory, acting as a locus of support, organizing, and information on things like accreditation and training.

5. Human Rights: Measures need to be taken to acknowledge that personal support work is most often done by women, many of them foreign-born women of colour. This marginalized workforce comes up against particular problems and issues that need to be addressed. Many are confronted with the violence of racism, sexism, homophobia, classism, and the like on a daily basis in their workday, which is met with no recourse. Measures must also be taken to improve access of home care for rural, immigrant, linguistic minority, First Nations, poor, and the gay and lesbian communities. Similar to workers, clients are often met with the racism, sexism, homophobia, classism and ableism while receiving their support.

6. A National Disability Related Supports Plan. Our visit with the Council of Canadians with Disabilities affirmed their strong support, along with twenty other national organizations, for a disability-related supports program. According to their Plan, “there is no fixed set of disability-related goods or services, rather it is open-ended. A good or service becomes “disability-related” when it is used to assist a person or persons in overcoming barriers associated with a disabling condition (Council of Canadians With Disabilities, Feb., 2003, p.1). Their position is stated clearly:

Advocacy associations of persons with disabilities, parent organizations, and service providers have come together and agreed that investment in disability related supports is the priority of the disability community. All agree that a National Disability Related Supports Plan is essential to the full citizenship of persons with disabilities (Council of Canadians, 2003: 1).
Taken together, these recommendations constitute a strong direction which we would further elaborate with the following additional recommendations drawn from our project.

**Recommendations from the Research Team**

1) **Adequate wages and income support**

Policy-makers must address the fact that the care-giving connection often consists of poor women meeting poor women. This issue shapes all others. Both parties, separately and together, have much to gain by improvements in their respective financial bases. As Henderson (2004, p. L5) reports, “In 1993, the absolute maximum annual Ontario support payment to a single person who could not work because of disabilities was $11,160. Today that amount is unchanged… On $930 a month, people with disabilities have to pay for food, rent and utilities, not to mention essential health care supplies, services and equipment not covered by OHIP.” From their study of home care, Armstrong and Armstrong conclude that “payment is critical. What the costs of care are, who pays and how they pay are all questions that need to be addressed…” (2004, p. 41-42).

2) **Clear and consistent naming**

In working toward national consensus, we suggest research and dialogue aimed at a common language for personal support work. A consistent name would provide a piece of the puzzle for consensus building. From our fieldwork we emerge with three nominees for a common name that might be discussed and/or adopted. One is the name we have used throughout this report, and used officially in some provinces and the federal government as well as in several other countries. That is Personal Support Workers. The other two are being developed in Winnipeg, the hub of much disability-related activity. One is the “Independent Living Attendant;” the other is “Disability and Community Support Workers.”
3) Clear identification of community-based work

We suggest that community-based personal support worker be identified as a distinct job classification. Otherwise, community-based work becomes amalgamated conceptually and operationally with institutionalized work. Statisticians, academics and policy makers can inadvertently make the disability and community support worker invisible. The specialized skills needed to deal with community contingencies falls from view.

4) A national organization

We recommend the founding of a national organization dedicated to the specific interests and needs of personal support workers who tend to disabled persons in Canadian communities. Other professions benefit by having this kind of representation, in the form of professional associations and unions. The provision of support nation-wide is weakened by the absence of any organization put together by and promoting the interests of personal support workers.

5) Training from a disability rights perspective

We recommend that effort be put towards re-conceptualizing teaching and learning materials that can be shared by personal support workers and Canadians with disabilities. As a result of this project, the Institute for Disability Studies has already submitted a research proposal that specifically addresses issues of personal support worker training from a disability rights perspective. Our alternative training would spend a considerable work addressing equity-related issues. The resources we envision include new classroom materials, reading and visual resources.

6) A national forum on standardized credentialing

We recommend that a national forum discussing standardized credentialing be established for personal support workers. Discussion is beginning to emerge around coordinated and articulated training among a consortium of programs based around the country, to be linked through web-based coursework. Students and educators alike are seeking to establish a movement in training from certificate, to
diploma, to allied arts degree. In our own fieldwork we found schools that are eager to send their students toward advanced study.

Because of our specific expertise, several of the team’s recommendations are focused on future research.

1) A process of dialogue

We see the need for research with both disabled persons and support workers “that explores and explicates the relationship between official knowing and experiential knowing” (Campbell, 1999: 9). At the Institute, we will continue to develop and search for conceptual and methodological designs in which the dichotomy of rights between caregivers and care-receivers that we experienced in our fieldwork is brought into question rather than taken for granted.

2) International research

We recommend the funding of research that would investigate the global linkages around which personal support work is currently constructed. The Institute is eager to explore the experiences of foreign-born and foreign-trained personal support workers, together with the people whom they attend. Presently, these international dynamics do not find their way into the professional literature or the teaching and learning resources available to students.

3) Race-conscious research

Studies that explore the racialized context of the care-giving relation are urgently needed as the racial and ethnic composition of Canada becomes ever-more diverse. The personal support workforce consists largely of women of colour who make low wages. Beyond this, we know little about specific ethnic mixes, and how they might vary in different parts of the country.
Conclusion

In this research we examined literature and websites, consulted experts, conducted site visits, collected written materials, wrote a research proposal and constructed this report. In this document, we have pointed to current controversies in the development of personal support work for Canadians with disabilities. Along with summarizing existing data, our research disclosed gaps in knowledge and data, and made suggestions as to how they might be addressed. We proposed directions for future research, emphasizing a recommendation that training be given consideration as a topic worthy of future research investment. On that suggestion we especially promoted the New Disability Studies, with its links from experience to policy, as a conceptual and methodological framework to guide future research.

As this preliminary investigation draws to a close, we conclude that our search disclosed gaps in the existing data. More importantly, however, is the discovery that the voices of experience from Canadians with disabilities interacting with personal support workers is woefully lacking. If, as we suggested at the beginning of the report, personal support workers became the hunted, they remained only somewhat less elusive at the end of the inquiry.

We found out something about how they are accounted for in government and academic reports. We also found out that spokespersons from organizations that represent and provide services for disabled persons have deep concerns with how the profession of personal support worker is to be supported in the future.

What we did not find, either through literature or through organizational representation, were the voices of the workers and clients explaining, in context, the conditions and relations of their labour. While rich qualitative accounts of everyday life exist to portray a wide variety of contexts, like nursing homes, mental hospitals, homelessness, community development, no such accounts to date exist that allow outsiders a glimpse into the intricacies of
everyday caregiving for Canadians with disabilities. Without such textured expressions of how current policies are lived out in Canadian communities, discussions of policy and its impact runs the risk of remaining abstract and disembodied.

In the future, we hope for systematic investigations that would begin in peoples’ everyday circumstances in order to study the social policies that shape them. Although we have begun to locate some specifics of the personal support worker/ disabled person relation, it is not until we can understand them from the inside, from their actual experiences, that we can begin to put faces on this profile.
Appendix One
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Appendix 2
Web Links

The Gender/Race/International Labour link: Profiling the Worker:

www.a-procare.com/filipino_nannies.asp

www.meridiansearchgroup.ca

www.inter-place.net/employer10

www.caregivers.ca/caregivers/cg/pub/caregivers/Employers/whywe.htm

www.personalcareontario.com

www.ccsinternationalplacement.com

www.spunk.org/library/pubs/1r/sp001716/labside.html

Profiling the work:

www.swc-cfc.gc.ca/about/about_e.html

www.hc-sc.gc.ca/english

www.bls.gov/oco/ocos173.htm

www.menominee.nsn.us/Job/Jobs/Jobdescriptions/JobsAgDivPersCareWrkr.htm

www.howtocare.com/home_care.htm

www.jobfutures.ca/noc/print/647.html

Sites dedicated to workers rights in the Home health Care Field:

www.ourtimes.ca/features/02_oct_nov.html
Sites pertaining to disability rights and Home Health Care:

- www.drac.on.ca/
- www.cailc.ca

Web resources on Home Care Access by province:

- British Columbia – www.healthservices.gov.bc.ca/assisted/index.html
- New Brunswick – www.gnb.ca/0048/english/directory/depts1.htm#Long_Term_Care_Program
- Newfoundland and Labrador –
  Health and Community Services
  West Block, Confederation Building, 1st Floor
  P.O. Box 8700 St. John’s NF A1B 4J6
  (709) 729-0623
- Northwest Territories –
  www.hlthss.gov.nt.ca/content/About_HSS/authorities_index.htm
- Ontario –
Prince Edward Island –
www.gov.pe.ca/infopei/onelisting.php3?number=20304

Quebec -
www.ophq.gouv.qc.ca/Bureau/D_Guide_SAF.htm#Nos%20besoins%20de%20depannage


Yukon – www.hss.gov.yk.ca/prog/ss/home.html
Appendix Three

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