4. SURVEY OUTLINE AND FINDINGS

In addition to some general information, our questions to agencies sought to gather as much data as possible about the gender and gender-related issues of agency employees and home care recipients. For example, we asked for a gender breakdown of full- and part-time employees, casual employees, their salary ranges, occupations, whether they received benefits, turnover rate, training and so on. Almost all agencies provided gendered data for occupation, some provided salary data, but most did not provide the other employee gender data requested.

The majority of paid home care workers interviewed for our survey were women, working on a casual basis with no guaranteed hours or consistent work schedules. Of those interviewed, most paid workers lived with a partner and/or children. The unpaid caregivers, (again, mostly women) lived with partner, friend, parent or children.

In terms of a gender profile of recipients, agencies in St. John's provided this information, but only one out of eight reporting agencies in Winnipeg tracked or would disclose these figures. Information about gender and home care is not consistently monitored across the country.

As in the general population of home care recipients nationally, most recipients interviewed in our study are elderly women and adults with disabilities, followed by those who require short-term acute care (e.g., post-surgical, wound management). The majority of recipients interviewed lived alone on modest incomes and had been receiving care for over one year.

Where relevant and where the information is known, quotations from interviewees are used to illustrate our findings. These may be followed by additional information about the person speaking, such as age, location, title or background. However, sometimes such information has been withheld to protect the identity of certain persons.

Agencies, as well as recipients, home care workers and unpaid caregivers, were asked about gaps in home care services and policy changes they would like to see.

What Is Home Care and Who Qualifies for It?

This section discusses the types of home care service most commonly provided, and how and whether clients can gain access to them.

Scope of Home Care Work

Home support workers provide services such as personal care (bathing, toilet, shaving, transferring the person from one seat to another), homemaking, banking, paying bills, shopping, taking to appointments, etc. Many of them are also required to carry out more complex tasks, such as administering oxygen, colostomy care and training of new workers. They are sometimes asked to do tasks such as cleaning up after pets, snow shovelling or stoking a wood stove, which are not in their job descriptions. These extra tasks may be urgently needed, and if no family member is available, the worker may feel compelled to do them.

Generally, licensed practical nurses (LPNs) perform more medical aspects of home care, such as suctioning, blood pressure, postural drainage, vital signs, dressings, diabetic testing, colostomy care and catheter care. However, in our study we found that LPNs hired by private agencies often perform HSW work and are paid at HSW wages. Many are frustrated at not being allocated more “LPN hours.”

> *Sometimes when working as personal care attendants, we do licensed practical nurse work like colostomy care.*
>
> An LPN working as a home support worker

The services of registered nurses (RNs) and a small number of other health professionals, such as occupational therapists (OTs) and physiotherapists (PTs), are also provided to those in medical need through home care programs in these two provinces. Some other provinces offer a wider variety of services, such as dietitians and others (for an overview and provincial/territorial comparison, see CHCA et al. 1998).

“Delegated functions” are tasks normally performed by a nurse, such as giving medications, which the LPN or HSW has been trained to provide. There is a trend toward more functions being delegated to less skilled home care workers.

> *Five years ago, nurses had to do the catheter work. Now anyone can do it—catheter and dressings.*
>
> Home care recipient, male, age 52

The opposite is also true as there is also a trend toward hiring overqualified workers to do their work at lower pay scales.

> *I was fortunate that the layoffs of nurses from hospitals several years ago meant that I could get a fully qualified nurse at home support costs.*
>
> Home care recipient, male, age 53

Although these two trends seems contradictory, the common thread is paying workers the lowest possible wage.

When part of the work usually done by a professional is carried out by a less skilled worker, or when the work of a professional is labelled and paid at a lower level, this is a form of deprofessionalization. Restricted health care budgets and cost-cutting measures have contributed to the undermining of professional credentials and remuneration. Home care is vulnerable to this trend, for the most part due to privatization and competition in the industry, but also because of undervaluing work situated in the home. In some instances, we found that nurses and LPNs were being paid less than half the wage they would earn in health care institutions.

The work done by unpaid caregivers varies widely but, in many cases, it is as extensive as that done by paid home care workers. In addition to the deprofessionalization of care from higher paid and better qualified professionals to lower paid workers, care is also offloaded onto unpaid, untrained caregivers. We interviewed family caregivers who took care of:

> *everything from personal care to feeding, to diaper changing, dealing with emotional outbursts;*
>
> *all of her needs, for example, her feeding tube, dressing and bathing.*

Others spoke of transferring, meals, providing support and comfort, homemaking, giving medications (including entero-spray and complex treatments) and palliative care. They also took responsibility for managing the care, organizing worker schedules and sometimes setting up rotating shifts of family members on a 24-hour basis. These results were consistent in both survey sites.

We found that the home care programs in both Winnipeg and St. John's count on this unpaid work from family and community as a matter of course.

> *We don't measure it here but we estimate that informal family support amounts to 80% of care. This is a national statistic.*
>
> Department of Health official, Newfoundland and Labrador

Family members are not always available to pick up where government leaves off. High unemployment in Newfoundland and Labrador means an unprecedented number of people are leaving for the city or for mainland Canada. Family members who could be depended on before are no longer available.

Winnipeg has a large immigrant population. Extended family members who may otherwise have provided care sometimes reside in other countries. Winnipeg also has a large Aboriginal population. An Aboriginal person may want to stay in the city to be close to medical services, but be far away from potential family caregivers living on reserve.

Women with disabilities needing home care may themselves be the caregiver of the family, responsible for children or elderly parents, rather than people with access to a family caregiver themselves.

The Assessment Process

In Winnipeg, the assessment process is designed to be client-centred, and there is no means testing. Anyone assessed with a medical need can obtain home care services without fees. The assessment and care plan are completed with input from the client, family and other involved professionals. However, family caregivers and clients interviewed in this study did not feel involved in the process. Their perception was that someone asks questions and then tells them what they can get. Sometimes, they are not even told.

> *They visit, take the information, then hear nothing until a call saying someone will be there tomorrow morning.*
>
> Winnipeg recipient

> *I phone and don't get a call back and don't know what is going on. They make arbitrary decisions for me that are counter-productive. My needs don't seem to be a priority.*
>
> Winnipeg recipient

The assessment process used by the Health and Community Services Board (HCSB) in the St. John's region to determine seniors' eligibility for long-term care has two steps. First, the physical, mental, behavioural, social and environmental status of the person is assessed by a health professional, and a care plan proposed for home care services or admission to a long-term care facility. If the necessary hours of care exceed the ceiling for home care, the person is advised to enter an institution.

The HCSB then determines the financial eligibility of the senior. (People with disabilities do not have to meet this requirement.) Information is required from the senior regarding the type of accommodation, ownership, income sources, bank statements, RRSPs, other investments, monthly expenses, medication and equipment costs, utility statements for the past year, verification of debts and names of others with an income living in the home.

> *A financial assessment (means test) is given to seniors requiring long-term home support. A social assistance standard applies; therefore, the amount reflects food, clothing, shelter and a minimum of other expenses which often total less than the basic OAS* [Old Age Security]. *This prevents many seniors from applying and others who may apply and only have a low level of service are not eligible and have to pay privately because the cost of service is less than the contribution.*
>
> HCSB official, St. John's region

Depending on the financial eligibility and the amount of care required, seniors have to pay a portion of their assessed care. We were told that the personal contribution averages around $200 per month, and this could be for 30 hours of care or for 100 hours, depending on their financial situation. Once approved, the individual is covered for 100% of drugs and equipment required. An annual re-assessment is performed.

> *It's like signing your life away.*
>
> Unpaid caregiver, daughter, age 58

> *We refused to do the assessment. We'd both worked all our lives and felt medicare should be responsible as with people in hospitals. I don't think the government has the right to reduce a person to poverty.*
>
> Unpaid caregiver, male spouse, age 87

Some families have access to information about the assessment process and can adjust their parents' financial status so they will qualify for subsidization.

> *I knew the system and how to tap into resources and personal contacts. We had to deplete our parents' income until they reached the level where they could qualify.*
>
> Unpaid caregiver, daughter, age 49

People who are turned down for subsidized home care sometimes contact their provincial politician, who may advocate on their behalf. Some professionals in the system encourage this approach as a way for people to have their needs met. But some caregivers are fed up at having to go to such lengths to get necessary, affordable care.

> *They make rules to keep most people out and then tell people to write letters to the Department of Health and to the media to get what they need.*
>
> Unpaid caregiver, male, age 35

Problems arising from disagreements about assessments were also settled in this way in Winnipeg.

> *Because of the politics now, it seems that the squeaky wheel gets their needs met quicker.*
>
> Winnipeg agency

Most vulnerable and marginalized people are poorly served in a system in which sick, elderly and disabled people must sometimes be aggressive, well-informed, media-savvy and well-connected to get proper, timely care or to overturn unfair decisions.

Eligibility Requirements for Subsidized Care

In St. John's, where elderly recipients are means tested, respondents found the financial eligibility requirements for subsidized care too high. Workers reported frustration at the inadequate care which they see on a daily basis. For example:

> *I worked with an elderly couple, both were sick. I cared for the man and a lady cared for the woman. They only got one hour each per day and the woman got two to three hours a week for homemaking. The man tried to do too much, he fell down and broke his leg. They had no family. Their income was too high to get more care. There should have been more consideration about their family status. It's like the money issue comes before health.*
>
> St. John's home care worker, male, age 30

Another concern is that the financial assessment often leaves people without enough money for food. Several workers and agency staff said that they regularly make a stew or take food to their clients at their own expense.

Limits on service may have all sorts of unintended consequences. For example:

> *We have two elderly women living together. One has reached her maximum* [ceiling] *for home care and the other one depends on this level of care. If one goes into a home, the other is going to be helpless. Now we don't have the ability to be flexible.*
>
> HCSB official, St. John's region

Limits on Service

In both St. John's and Winnipeg, our study uncovered strict limits on publicly funded home care services.

In Winnipeg, the home care program is intended to provide essential, although minimal supports. Case co-ordinators develop the service plan based on the functional needs of the client, as well as available client, family and community supports. The diagnosis or available financial supports are not the key considerations in developing the service plan. Consideration of alternate types of care are made if services can be provided more effectively and economically in a setting other than the client's home.

Although home care services to assess and approve clients are provided free of charge, clients must have a backup system in place. If a home care worker cancels or is unable to provide the scheduled service, then that time is not rescheduled. Private agencies are able to provide the backup service, but the client must pay. In addition, the number of hours assessed may not meet the client's actual need, in which case the client must pay an agency or find a worker for additional service.

In St. John's, there are strict limits on the hours provided through assessments for home care. The ceiling for seniors is $2,268 per month, equivalent to about nine hours per day of home support. Depending on their income, seniors might be required to pay from 10% to 90% of this amount. In the St. John's region, their contribution averages about 12% of the total assessment. People with disabilities are not required to make such a contribution to the cost of their care.

If their income and assets are above the criteria, seniors would have to turn to private care, at $10 per hour for a home support worker and $15 per hour for an LPN. Some pay for additional care by hiring untrained, under-the-table workers, such as neighbours. Some college and university students are performing informal home care work in exchange for board and lodging. Emergency post-operative or post-hospital care in the St. John's region amounts to only one hour per day for two weeks or 14 hours over a two-week period. Our study found that the funding for subsidized home care falls far short of meeting the needs. In particular, people mentioned the need for more financial aid for respite care and palliative care.

> *It is hard to get respite hours approved, especially if the client is cognitively well, or if they make a low or nil* [financial] *contribution to their home care.*
>
> Agency, St. John's

The provincial drug card, which is available to those who qualify for home care, does not cover some essentials, such as over-the-counter medications, including some psoriasis medications.

In some cases, the care that is approved during the assessment is not available. For example, one woman was supposed to be seeing a physiotherapist but none was available locally.

Table 3. Recipient Profile and Average Hours of Service Received

	Winnipeg				**St. John's**			
	Male	**Female**	**Total**	**Service: average hrs/mo**	**Male**	**Female**	**Total**	**Service***
Elderly			6,605	39	160	419	579	
Disabled under 65				39	31	38	69	
Palliative			168	80	1	6	7	
Short term acute			1,241	9	1	18	19	
Children			18	110	9	26	35	
Other					2	3	5	
Total			8,032		204	510	714	

Note:
* The information gathered on hours of service in St. John's is not reliable and not reported. Gender-disaggregated data were not available for Winnipeg.

While seniors who are admitted to personal care and nursing homes have the security of knowing they can stay there until death and receive available services on site, people receiving home support services are not as secure.

> *I'm concerned about them putting a cap on my home care. My social worker said they will and I'll have to make my own arrangements.*
>
> Home care recipient, woman, age 27

> *I have had sudden changes to the number of hours from 70 per week after my fall, to 40 and now to 31. How can I be sure it will stop there?*
>
> Home care recipient, woman age 78

Many agencies, recipients, workers and caregivers deplored what they saw as the inadequate hours of care that were assessed, which may very well be putting recipients at risk.

> *The government is ignoring my doctor's recommendations for more hours.*
> St. John's home care recipient, woman, age 78

> *A nurse arrived to check my IV and it had been out for 24 hours.*
> Winnipeg home care recipient

Home care recipients received conflicting information about what was expected. In some cases, family members were encouraged to stay with a parent during the night when no worker was there, but in another, a woman thought that if her son stayed with her overnight, her home care hours would be reduced or eliminated.

> *My son is not allowed to stay here overnight. The government wouldn't give me home care or would cut my hours if my son stayed at night. They'd say why can't he be here all the time?*
> Home care recipient, female, age 78

In both sites, the rules seemed to be designed to save money by cutting hours wherever possible, regardless of what was ultimately best for the home care recipient.

Rural/Urban Differences in Access

In the St. John's region, there were considerable rural versus urban differences in home care availability, stemming from inadequate funding and regional restructuring. In some rural areas, seniors have less access to short-term home support.

> *Regional differences and lack of resources prevent the same services being offered throughout the region in a consistent manner.* [One rural area] *can only access short-term home support for seniors with special approval.*
> HCSB official, St. John's region

There were no home care agencies at all operating in the Southern Shore area. This meant that recipients and their families had to manage their own care. The HCSB local office assisted in monitoring the hiring process, in finding substitute workers and in providing emotional support and feedback to home care workers and caregivers. The HCSB had also arranged for accounting services for clients. Newfoundland was singled out by several participants as being advanced in the area of self-managed care.

However, there were also inconsistencies in the application of rules for self-managed care. For example, recipients are not allowed to hire family members, including in-laws, to do home care work, but in some cases they did anyway.

Equity Issues

Seniors in Newfoundland and Labrador have different access to home care, depending on when their claim was established. They may receive 24-hour care in the home if their claim was established before the shift from CAP to the CHST. New entrants to the system are limited by the ceiling of around nine hours of care per day.

Several survey participants disagreed with the emphasis the assessment process placed on the number of family members, especially women, nearby and on their incomes.

> *The assessment process assumes women will do the care.*
>
> Unpaid caregiver, woman, age 55

There are more women (79%) than men (21%) receiving subsidized home support in the St. John's region. In part, this is due to the comparatively higher poverty levels of older women.

> *Senior men are more likely to have insurance…*[and to] *have pensions other than OAS and GIS. Older women were usually homemakers and did not have work pensions to supplement federal pensions, whereas many men have additional sources of income as they age because of employment benefits.*
>
> HCSB official, St. John's

We were told that senior women prefer to remain in their homes, while most men go into personal care homes when their spouse dies. The proportion of men is considerably higher in personal care homes than in home care. However, given women's longer life expectancy and their lower incomes, they still outnumber men in personal care homes in the St. John's region.

Summary: Qualifying for Care

In both Winnipeg and St. John's, there is a difference between what the governments' and regional authorities' stated intentions are in home care—to provide quality care for those in need—and the reality experienced by recipients. In both survey sites, the hours of publicly funded home care for which recipients qualified were judged by all concerned to be inadequate, and recipients must turn to family or community supports, if available.

In both survey sites, women are expected to care for family members without pay, regardless of their personal circumstances. Home care recipients are assumed to have family and community support, even if they do not.

There is differential access to home care services in Manitoba and in Newfoundland and Labrador, based on family income. Manitobans assessed to be in medical need of home care receive publicly funded care. Newfoundland seniors do not, unless they are living at close-to-subsistence level. *In a country that is supposed to guarantee access to publicly funded health care services, not all Canadians are being treated equally.*

Our interviewees believed home care should be a publicly funded health service across the country, like any health service. There should be no means testing or financial barriers to home care, nor should family support be assumed in judging the need for service. Just as access to essential surgery does not depend on the time or money of family members, neither should qualifying for home care services.

> *Listen to input from me. I'm long term and know what's good for me.*
>
> Winnipeg recipient

Delivery of Care

Waiting Lists

There were many reports of Winnipeg recipients who remained in hospital longer than necessary because of delays in getting the required supports in place.

> *It takes four days to arrange home care while the person remains in hospital. How is it more cost efficient than having home care people on call?*
>
> Unpaid caregiver, Winnipeg

Some clients reported having to pay for private care until the public system could get services in place. Delays in providing home care service are frequently the result of a shortage of workers and staff workloads, according to two Winnipeg agencies.

Waiting lists for home care seemed to be an even greater problem in rural areas outside the St. John's region.

> *In rural areas, people are less inclined to demand care and don't know what's available...the waiting list in the Eastern region around Placentia is six to eight months for home support.*
>
> Manager of a home care agency, St. John's region

Continuity of Care

In both the Winnipeg and St. John's sites, recipients want to have the same workers each day, with whom they can develop trust and understanding about their care needs. A change in workers can mean a change in qualifications.

> *Last week, my nurse was away and an LPN replaced her, but she couldn't do my meds. I had to call in a nurse from the agency.*
>
> Recipient, St. John's

Unpaid caregivers and recipients felt that it was very important to have the same caregiver on a regular schedule. This was especially important for Alzheimer clients and those with physical disabilities. Winnipeg agencies do attempt this, but it is not always possible when there are staffing shortages in addition to the challenge of providing care during regular work hours as well as evenings and weekends. Caregivers and recipients saw this as an issue that in some cases took time to resolve, but did improve over time.

Recipients with physical disabilities reported that they needed to "train" each new worker to provide their care. One recipient interviewed in Winnipeg stated she had very little time for herself. Her time and energy was spent ensuring she would have the needed care in place for her.

> *I would like to volunteer in the community, but I don't have time because my energy is spent on worrying about who is coming to provide care and when and will they come.*

It is the same situation in St. John’s.

> *They need to provide better continuity of personnel. It’s a big burden for the family to train someone new every day.*
>
> Unpaid caregiver, St. John’s, male, age 35

Care can be interrupted due to illness or family responsibilities of a worker, lack of training of casual and weekend workers, hospitalization of recipient, and low wages and benefits, which lead to worker turnover. While most agencies place a priority on the worker–client match, some do not provide good continuity of workers.

Recipients of care have been assigned workers on weekends who do not know how to transfer the recipient (e.g., from a bed to a wheelchair) on their own without risk of injury. 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.

Another issue in the continuity of care is how effectively the transition from the hospital to the home is made. St. John’s agencies raised the question of sharing of information between the HCSB and agencies. They said they were often given inadequate background information about chronic problems or safety issues with regard to clients. In one case, a former sex offender was provided with service without the agency being informed. There was no opportunity in this case to ensure the workers had the training and comfort level to deal with the situation.

Choice

Familiar surroundings, a greater element of control and the treatment received in institutions all make home care an attractive option for the recipient.

> *I moved out of a group home and have been living independently for 18 months. It was the best move I ever made. I have a lot of responsibility now and I’m learning to manage. In the home, you’d have to tell them where you were going and when you’d be back. You’d have to go to bed when they said and get up at 6 a.m. They’d flash a light in your eyes to see if you were asleep.*
>
> St. John’s male care recipient, 39, with cerebral palsy

For elderly people or those with disabilities, home care is often seen as the least of three evils, institutionalization and living dangerously being the other two. The HCSB of St. John’s sees individual choice as an important value in the provision of home care. However, choice cannot be realized until there are viable and affordable options and supports from which to choose.

Related to the issue of continuity of care is the choice of caregiver. Agencies in Winnipeg reported that female clients usually prefer female caregivers, and that male clients generally accepted both female and male caregivers. Participants did not identify race as an issue.

However, some clients felt that lack of understanding of the English language on the part of the paid home care worker made it a challenge when critical instructions regarding specific personal care tasks were being given.

Care recipients requested that service move with them. One woman moved from her home to a supportive housing environment, but was unable to keep the same home support worker because she had moved to a different service-delivery area.

Several recipients expressed reluctance to voice concerns about their home care worker or the quality of service being provided. They felt that it might affect the amount of care they receive, or that they might be perceived as a complainer and suffer consequences.

Issues for Unpaid Caregivers

Ninety percent of the home care recipients sampled in the St. John's region named their sisters, daughters, wives or granddaughters first as the ones they call on when they need help. The gendered nature of unpaid caregiving was very clear.

There is an expectation by most families that women will fulfill the job of caring when a family member becomes ill. This becomes an even greater imperative if the woman is single.

> *Most definitely more responsibility falls on me as the daughter— even though I work full time. I get home at 4:30 p.m., wash his clothes, make his supper, etc.*
>
> Unpaid caregiver

Especially when women in the family have medical training, they are targeted to do the more complex aspects of care, such as personal care. An unpaid caregiver in St. John's reported resisting this pressure, and all of her siblings had come to share the care of their father equitably. However, she was the exception.

In addition to gender, sexual orientation, ability and age affect the ways that caregivers can provide care to their family members or friends. At least one of the unpaid caregivers in the St. John's region was a lesbian. She and her partner stayed six nights each week at her mother's house for a period of almost a year. Her mother did not qualify for subsidized care, and the family decided to hire workers for eight hours per day. The financial strain coupled with caregiving, and maintaining her job, put great pressure on her and on her relationship. The supports that were out there did not address issues which lesbians face in caregiving.

Another caregiver was dealing with a physical disability that limited her mobility. She faced more stress in caring for her father and had developed an alcohol problem. One 87-year-old male caregiver told us his back problems now made it almost impossible for him to feed his wife.

Caring for a sick or elderly family member can be a very satisfying experience for unpaid caregivers, especially when some home care services are provided.

> *My experience of home care was very positive. The quality of home care is much greater than institutional care.*
>
> Unpaid caregiver, woman, age 55, who cared for her mother and hired home care worker privately during the day, Newfoundland

Most caregivers said they were very happy to have the choice of keeping their relative in familiar surroundings. However, the option of home care involves giving up time with partners and children, missing out on career advancement at work, or even giving up a job altogether. It means added expenses that would have been absorbed by medicare if the person were hospitalized or by the state in the case of institutionalization.

> *The expectations placed on families to provide care are now too great. The system has to be more finely tuned.*
>
> Unpaid caregiver, woman, age 49

Respite Care

Paid home support workers may provide respite care, providing care and companionship to the client while the unpaid caregiver takes time for herself or to run errands. Budget cuts have seriously affected the availability of respite care in the St. John's region.

Winnipeg respondents said there was no, or not enough, respite provided for unpaid caregivers. One caregiver would like to see respite provided before a crisis situation develops. This type of proactive preventive care would have long-term benefits for both the caregiver and the client. In Winnipeg, a few hours of respite care can be arranged at no cost to the caregiver, but if longer periods of care are required, (e.g., caregiver requires surgery) then beds are available at personal care homes at cost to the client. Adult day programs also have fees attached.

> *Overnight care was unavailable, and I would go to work on two hours of sleep*.
>
> Winnipeg unpaid caregiver

Agencies agreed that there is a lack of appropriate respite care.

> *We need respite alternatives, supportive housing to bridge the gap between home and institution, service that moves with the client.*

Aboriginal Home Care

In Winnipeg, the local researcher experienced difficulty in finding Aboriginal home care clients to interview, but finally did find and interview two. An Aboriginal social worker, who had formerly worked in home care, commented that family members often take care of the recipient in the home, until more intensive care, such as that provided in a personal care home, is needed. This also raises the possibility of cultural barriers in access to home care.

Flexibility

A recurring theme was the need for flexibility in how care is provided. In Winnipeg, the care plan outlines the tasks to be carried out. Home care workers are required to follow the plan, and are not allowed to complete tasks that are not listed on the plan. This system protects the workers from being asked to do work outside their scope. However, it does not allow for flexibility in providing care. It is difficult to anticipate every specific task that may be needed.

> *Workers can't take a client to buy milk on the way home from a doctor appointment unless it is in the care plan.*

When the care is provided was also identified as an issue. A recipient with a physical disability relies on home care workers to assist with getting up in the morning, and going to bed at night. Providing this bedtime care at a time convenient for the worker and the recipient can often be a challenge.

> *I have to go to bed at 10 p.m. because that is latest a worker can come to my home. I am restricted by program policies.*

Many caregivers and recipients expressed the wish that home care workers could have more time to spend on personal care and housecleaning tasks.

> *Allow more attention to detail; time to clean ears, cut toenails.*

> *Allow more thorough cleaning, not just the essentials.*

The feeling among recipients and unpaid caregivers in both sites was that home care is a rigid, bare-minimum type of program.

Communication

Lack of communication between agencies and recipients was also a recurring theme among caregivers and recipients.

> *One worker thought I didn't need help any more, and visits were stopped without informing me. I had to call and arrange an assessment to continue.*
>
> Winnipeg recipient

Community supports for home care

The HCSB in the St. John's region provides support to individuals in the system, especially in the urban area. There is a 12-week caregiver support group, and there are several bereavement support groups. Two adult day programs are offered. Recently, there has been an increase in the number of respite beds available in a city health care facility.

In a rural area outside St. John's, the HCSB district clinic plans to hold a support group for paid home care workers. The workers and recipients in this area also can turn to the HCSB for administrative support. In the urban area, agencies are relied on by government to train workers and provide "in-service educationals" as well as day-to-day consultation when required.
The people with disabilities we interviewed in the St. John's region said they often consult organizations such as the Independent Living Resource Centre, the Canadian Paraplegic Association, the Newfoundland Association for Community Living, the Coalition of People

with Disabilities, the Spinal Cord Injury Association and the Muscular Dystrophy Association. Similarly, the Newfoundland and Labrador AIDS Committee provides support and advocacy on home care issues.

> *Younger clients are more able to organize and address inequities in care needs.*
> CHSB official, St. John's

For seniors, there are comparatively fewer organizations and programs, including the Seniors' Resource Centre, the Alzheimer Association and two adult day programs. The seniors we interviewed were not aware of their rights in terms of home care and were afraid it would be taken away from them. There is a need for more advocacy for seniors in the home care system.

In Winnipeg, a number of unpaid caregivers spoke highly of the support received from the Alzheimer Society of Manitoba. This group provides support groups, home activity programs, a provincial telephone help line and other services. Similarly, the Canadian Paraplegic Association provides assistance and support to adults with physical disabilities.

Quality control

Training of workers, quality, standardization and regulation of care were raised by all groups of stakeholders consulted in this study as areas requiring better monitoring by government.

Four Winnipeg agencies identified the need to develop and establish standards related to outcomes and quality of care.

The Winnipeg Community and Long Term Care Authority announced its intention to work toward regional accreditation by 2001, through the Canadian Council on Health Services Accreditation. This process will provide the opportunity to evaluate how it is meeting the set standards, and to measure outcomes and quality of care.

In 1995, the Newfoundland and Labrador Department of Health released the *Policy Directive Manual Governing Home Support*, which established provincial standards for home support programs. While the manual provided policy direction, guidelines and sample information forms for the agencies to use in areas such as hiring, training, evaluating, compensation and reporting, there was no monitoring by government of home care agencies for more than two years. *This study found evidence that some agencies hired workers without the minimum requirement of a first-aid course, three days of orientation and practice, and a certificate of conduct—guidelines outlined in the policy manual.*

In 1998, the HCSB in the St. John's region hired a regional home support licensing co-ordinator, and in-depth audits of home care agencies are now under way. Furthermore, the jurisdiction for licensing of home care agencies is being shifted to the HCSBs.

The *Policy Directive Manual Governing Home Support* does not apply to self-managed care. The Department of Health is reviewing programs in other provinces and evaluating ways to standardize and monitor self-managed care. We were told that government is reluctant to set standards for self-managed care until employer–employee issues are clarified by the courts.

In addition to quality of care standards, one Winnipeg agency identified the need for a national health care labour force planning strategy. It suggested that this incorporate an inclusive collective agreement and labour standards, and that it should allow mobility between sites and types of care (e.g., acute, long-term and community care).

Housing/Institutional Access

In St. John's, inequities exist between home care and institutional care for seniors and people with disabilities. The ceiling for monthly care for people with disabilities is $3,000—higher than that for seniors ($2,268). When seniors reach the ceiling for home care, however, they may have more housing options than people with disabilities.

> *Other provinces have a larger economic base, so for most people who need 24-hour care, there's more money to build those kinds of environments. Acute care facilities in this province are shutting down over the next few years, so we will need more community care.*
>
> Home care recipient, St. John's

Public/Private Care Delivery

Five Winnipeg private agencies interviewed wanted to see the establishment of private/government partnerships.

> *Allow private agencies to fill in until a government home care program can provide the care.*
>
> *The best method is freedom of choice with no public/private monopolies. Need a mix.*

The agencies say these partnerships could potentially decrease the waiting lists and improve client care. However, whether they were workers, unpaid caregivers or recipients, the individual respondents all cited low home care wages as a critical problem affecting recipient safety, worker health and continuity of care. Our study found that private, non-unionized agencies paid the lowest wages to home care workers.

Summary: Delivery of Care

The concerns interviewees in both sites raised about care delivery included those listed here.

- Lack of continuity of care due to worker shortages and staff turnover resulted in home care recipients and unpaid caregivers having to train new workers, sometimes daily. Other consequences included workers being unqualified for the tasks they were sent to perform.

- Waiting times for home care ranged from four days in Winnipeg to eight months in rural areas outside the St. John's region.

- Home care allows for very little flexibility in terms of scheduling and tasks. Some recipients literally felt unclean as workers did not have the time to do more than cursory personal cleansing.

- Choice of caregiver was often not possible, and recipients felt they could not complain about quality of care.

- Regional home care authorities in Winnipeg and St. John's have undertaken steps toward setting standards and monitoring quality. To date, these measures have either not yet been implemented or are not effective.

- Respite care for unpaid caregivers is woefully insufficient, leading to burnout and health problems.

- Home care services may be underused by Aboriginal peoples.

- Community supports vary by type of illness or condition. Some recipients have no community supports for their situation or are unaware of existing supports.

Working Conditions

> *Single mothers make good workers...because they have no choice.*
> Nurse, private for-profit home care agency, St. John's

Health, Safety and Human Rights

Health and safety issues were a factor in both regional sites of the study. In both samples, health and safety concerns raised by home care workers overlapped a great deal with those of unpaid caregivers, while home care recipients raised more physical safety and financial abuse issues.

Worker safety

Workers usually work alone in client homes and report being subject to violence from recipients. One Winnipeg worker reported an incident where she positioned herself between the client and the door to ensure that she had an available escape route. In St. John's, a woman with Alzheimer disease attempted to hit a worker on the back with a piece of firewood. In another, a worker was physically threatened and told to leave the home.

Gail Rogers (1998a, b) suggests that the shift in health care delivery to the community, combined with the downturn in the fishery and high unemployment in Newfoundland, has placed more demands on social programs, and that violence against service providers in the home setting could increase. She added that replacement and temporary workers may be more vulnerable to assault, especially if they have less or no training in dealing with volatile situations.

As most home care recipients are low-income earners, they tend to live where they can afford to. A Winnipeg worker reported that she was required to work in unsafe areas of the city. Workers reported that they were able to request another worker to accompany them if they were aware ahead of time of potential unsafe home visits. One worker stated that she didn't know any of the other workers in her area.

> *We never have staff meetings, or even a Christmas party where we can all get together and meet one another.*

Health and safety concerns were not limited to fear of and physical injury at the hands of some recipients. Workers and caregivers tend to be overworked, tired and prone to injury. The work can also be physically and emotionally demanding. In St. John's, there are no sick-leave provisions for paid home care workers in the private and self-managed sectors, nor is workers' compensation available to workers in self-managed care.

The main health and safety concerns expressed by workers were:

- damage to the back due to physically lifting and transferring clients;
- stress, fatigue and burnout;
- emotional costs of working with palliative, terminally ill persons and clients with dementia or Alzheimer disease;
- eating disorders;
- fear of infection;
- isolation;
- safety hazards in the home; and
- abuse by clients.

The health and safety implications of overwork are serious, affecting not only the worker but also the client. One St. John's worker said she is afraid of getting too tired and making a mistake, or falling asleep at the wheel of her car. Several workers said they had forgotten once or twice to give a client their medications.

Unpaid caregivers

As with paid workers, the work of unpaid caregivers can be a physical and emotional strain, with all of the same health concerns. Many unpaid caregivers have no formal training in dealing with someone who is physically or mentally ill, nor are all fit enough to perform the heavy tasks associated with mobility-impaired recipients. As with paid workers, unpaid caregivers have no workers' compensation for any injury they sustain while caregiving, nor was there adequate respite care in either site to meet their emotional needs or prevent burnout. Supports for the caregiver are needed. Some caregivers are so exhausted and so focussed on the care recipient, they find it difficult to do anything for themselves.

> *I never get time alone. I am always on duty. The demands are hard to handle.*
> Unpaid caregiver, Winnipeg

> *When I get "time off," I need transportation, somewhere to go and something to do.*
> Unpaid caregiver, Winnipeg

Recipient safety

In both sites, home care recipients' concerns centred around safety and security, including theft, breaches of confidentiality and financial matters. They also reported concerns about their physical safety due to overworked and untrained paid and unpaid caregivers.

Two Winnipeg home care clients reported theft in their own homes by someone who had legitimate access. One lost some household items, another lost prescription drugs. They were unable to determine if the items had been taken by home care workers, friends or family members. In another instance, money was given to a caregiver to buy groceries, and the recipient was short-changed by $80. Likewise, in St. John's, recipients are vulnerable to abuses by workers or unpaid caregivers. The recipients interviewed in both sites were all cognitively capable of noticing and reporting such incidents to the interviewer. Nothing is known about the degree of theft and abuse of cognitively impaired recipients.

Because they have a guaranteed income, some seniors and people with disabilities are the most financially secure people in a low-income family. This has led to financial abuse, such as borrowing by family members, and the household's debt load increasing. Seniors who depend on family members for aspects of their care may be subject to emotional as well as financial abuse.

In both sites, recipients linked personal safety to the inadequate training or behaviour of workers. In Winnipeg, recipients reported that they had to ensure that the workers provided proper and safe care, and one had been repeatedly harassed by a worker.

> *I have to direct my care and watch them all the time.*

> *I am very nervous with new workers. I had one worker who harassed me and it took a long time for my concerns to be taken seriously. Eventually she was fired.*

While some supports exist for coping with abuse and other hidden costs of home care, most are located in the cities, making access to these services difficult for recipients in rural areas. Some advocacy groups do provide assistance with equipment, transportation, emotional support, counselling and referral.

Wages and Benefits

In both sites, we found that wage rates varied with unionization and whether the agency was for-profit or not-for-profit. The wage ranges in Table 4 reflect private, for-profit, non-unionized home care agencies on the lower end, and unionized public or not-for-profit agencies on the higher end.

Table 4. Employee Occupation and Wage Scales

	Winnipeg				**St. John's**			
	M	**F**	**Total**	**Hourly salary range ($)**	**M**	**F**	**Total**	**Hourly salary range ($)**
RN	0	10	74*	15.00-20.94	7	41	48	9.50-22.00
LPN	0	6	57*	10.00-17.62	3	15	18	9.00-16.00
OT	2	26	28	17.06-20.96		2**	2**	
PT	6	22	28	17.06-20.96		2**	2**	
HSW	1	18	613*	7.92- 8.86	96	396	492	5.30- 7.00
PCA	1	40	1,592*	8.87-11.04				
Case co-ordinator			84*	18.24-25.31				
Resource co-ordinator			70*	15.12-19.20				
Other			750*					
Total			3,296		106	456	562	

Notes:

* Totals do not necessarily reflect an addition of male and female staff, as two out of six reporting agencies in Winnipeg reported their total staff number only, without regard to gender. In one instance, there was also no breakdown for occupation.

** The St. John's HCSB employs 152 female RNs, two OTs and two RTs, but not all the nurses are in home care, nor are they all in St. John's, so they are not included. The two OTs and RTs are in home care in St. John's and are reported here. The other numbers reflect the reports of eight agencies in St. John's.

Home care agencies may provide orientation and training to new staff, and then lose them to institutions which can offer higher wages, guaranteed hours and regularly scheduled shifts. The private home care agencies surveyed in St. John's paid nurses anywhere from $9.50 per hour to the hospital rate of $22 per hour. The average rate was $14 per hour. Licensed practical nurses, who earn about $11.50 per hour in institutions, were paid a starting wage of $9 per hour.

> *Workers are a transient group because of the low rates of pay.*
>
> Home care recipient, St. John's region

In the St. John's region, almost all respondents, whether they were managers of private agencies, family caregivers or home care workers, wanted the wages of home support workers to be increased. Wage levels have declined during the last five years, while the expertise required of home support workers has increased, with more functions being delegated by nurses. *All* of the Winnipeg respondents—workers, unpaid caregivers and recipients—commented that they thought home care wages should be higher.

> *Pay better wages to attract good people who will stay.*
>
> Winnipeg

In St. John's, home support workers are paid from $5.30 to $7 per hour, including 4% vacation pay and an 8% wage increase passed in the provincial budget in 1998. Wages have not improved significantly since the strike of 1996-97 when the average wage was $5.57. One worker told us that an agency tendered by government five years ago, gave a pay raise of $0.25 every six months, and his wage went up to $7.50 per hour. Wages were reportedly higher for self-managed care, but this was only in the case of non-subsidized care. One female worker said she could earn $8.50, and one male worker said he could earn $10 per hour when self-employed. Issues, such as gender discrimination in wages, are overlooked when there is a lack of adequate monitoring and regulation of work.

Poverty is an issue for home care workers, especially for single women. Three out of four single, female, home support workers and LPNs told us that they have trouble making ends meet. The only single mother with children at home had her earnings supplemented by social assistance.

> *At the nursing home, I made $11.50 per hour as an LPN. Now I make $5.77 per hour from the* [home care] *agency, or $8.50 when I'm self-employed.*
>
> Home care worker, St. John's

Even though they often work with infectious clients, St. John's home care workers do not receive sick leave. Nor do they earn vacation leave. For most workers, the 4% vacation pay is rolled into their wages. If they do take time off, then, it is at their own expense. This encourages workers to work year round and contributes to fatigue and accidents. It also means that employees who work while they are ill may be infecting clients with already weakened immune systems.

> *Five years ago we got paid for a half day if we were off one day sick, but now we get no sick pay.*
>
> Home care worker, St. John's, male, age 40

Workers in private and non-profit agencies are covered by workers' compensation. Those in the self-managed sector are not covered. In 1998, the Government of Newfoundland and Labrador announced that it is committed to bringing in workers' compensation for self-managed care.

Hours of Work

> *Home support workers are often called in on their days off and on the spur of the moment...this is one of the most difficult aspects of the job.*
>
> An LPN working in home care, St. John's

Many home care workers work one-hour shifts, with eight shifts per day, stretching from 8:30 a.m. to 10:30 p.m. Many work for 12 days and then get two days off. Some work up to 50 hours per week. At least half of home care workers have other home care work, and some hold down three jobs, in order to survive.

Overtime pay is not permitted, according to Newfoundland and Labrador government home support policy. To get more work, many are employed by two different agencies. Others work for an agency and also work privately for an individual client.

> *Agencies do not receive compensation for overtime hours of workers from the Health and Community Services Board...even though some people work 48 hours a week.*
>
> HCSB Official, St. John's

Breaks are a problem in home care work. There is no one to relieve a worker on a long shift. Although some home care workers are working long hours, on the other side of the spectrum, some are not assigned enough hours to make ends meet. There is a high proportion of casual and part-time work in home care. In our sample, 60% of nurses, 83% of LPNs and 37% of home support workers worked on a casual basis. They were not given regular hours of work and had little control over their hours.

> *You can't turn down a shift when you're on your own like I am. You need the money. There are times I haven't had food to eat.*
>
> Home care worker, single woman, St. John's, age 58

Some Winnipeg workers said they must work fewer hours because of their own unpaid family responsibilities.

> *I am only able to work part time because I am a family caregiver.*
>
> Winnipeg worker

One worker, a single mother, told of how she had worked with one client for 18 months, five days a week. When the client died, the agency did not have many hours of work for her. Yet it was unwilling to give her a layoff, even though she would have had a higher income on Employment Insurance than on the few hours per week the agency was giving her.

It seems contradictory that with the high demand for home care, the waiting lists and the claims by agencies that they are short of staff, that many experienced home care workers are working fewer hours than they would like.

Terms of Employment

Workers in both sites often mentioned the many out-of-pocket expenses they incurred in their work. This included professional licences and fees ($95 per year for an LPN in St. John's); updating first-aid and CPR courses, immunizations including hepatitis A and B ($100), gas expenses and buying food for poor clients. Recipients sympathized with the financial situations of home support workers.

> [At least]...*give workers a bus pass to assist with transportation costs.*
>
> Winnipeg home care recipient

However, two male workers who had been working in home care for up to 10 years told us they filed their income tax claims as self-employed subcontractors to the agency. This enabled them to deduct gas, clothing, meal and car expenses. The agency provided an income tax form supporting their claims. We were told that this practice used to be more common among the agencies but was curtailed due to increasing staff turnover. The women we interviewed, even those who had worked in home care for six or more years, had not been offered this arrangement by any agency.

Training and Career Development

The Winnipeg Community and Long Term Care Authority offers an 18-month training/in-service plan. Supervisors identify staff they feel would benefit from training. Not every worker is selected. Information about upcoming workshop opportunities is provided in a newsletter, and staff can then request to attend. Some staff develop specialty areas, such as working with clients with dementia, bowel/bladder routines or swallowing disorders.

Private agencies usually provide training on the job. One of the larger private agencies reported that they are developing creative ways to provide training opportunities for their staff in-house. One-hour training sessions are available biweekly—the same session will be presented several times during the day, allowing staff to work around their schedules so they can attend. Workers attend these sessions as unpaid time.

Home care work does not provide an obvious career path or management access. This limits the type of employee attracted to the positions. Some home support workers who have been identified as having skills to increase their training to the level of a home care attendant will receive training from the WCA, but that is the only career movement possible.

According to the Newfoundland and Labrador Department of Health's *Policy Directive Manual Governing Home Support*, agencies are required to provide four days of orientation for new workers. This includes a first-aid course, two days of introduction to home health care, personal care, privacy and confidentiality, and one day of practice with an experienced worker. Before being on the job for six months, agencies are required to ensure that employees have completed 120 hours of training. The components of this training are detailed in the manual. New workers who have already completed an HSW training program are supposed to be given one day of orientation about agency policies and procedures. Agencies are also required to provide regular in-service sessions or focussed training. This is the theory. We found the practice is overwhelmingly different, and home care workers in both sites frequently lacked the appropriate training.

> *Some workers come in off the streets…came in to me the same day they were hired.*
>
> Home care recipient, St. John's

> *Workers need more education and training about disabilities and also people skills.*
>
> Winnipeg recipient

> *Last week my nurse was away and an LPN replaced her, but she couldn't do my meds. I don't mind showing people how to poach eggs, but they should have qualifications* [for the complex medical tasks].
>
> Home care recipient, St. John's

> *I felt that I had to train the workers who came to care for my mother.*
>
> Unpaid caregiver, Winnipeg

> *The agency sent in someone incapable of doing the work and I had to call in a friend. The wages are low and people are hired off the street and not trained. Agencies are supposed to train but sometimes they don't. I train. If the government paid more, you'd get more qualified people.*
>
> Home care recipient, St. John's

> *The caseworker has education but no practical knowledge of how to help me cope with my situation.*
>
> Home care recipient, Winnipeg

There are no guidelines or monitoring for training of workers for self-managed care. The onus is on the recipient to do the training.

> *They've learned the specifics of my care but I find a big difference in the training of workers in the Intensive Care Unit at the hospital and of the personal care attendants in my home. I try to tell them as much as I can, but I don't want to scare them. When I have to train them, sometimes I'm lax. Then it can become dangerous for me. For example, trach care should be done twice a day but I sometimes left it for three days and I would get more flus.*
>
> Home care recipient, St. John's, female, age 37

Agency managers, workers and caregivers who were surveyed in the St. John's region, felt that a mandatory home support training course should be subsidized by government, and that there should be more training and support provided to unpaid caregivers.

Many home support workers interviewed would like to go to college and get their LPN, but feel they cannot afford it. One male worker had taken time off, obtained a student loan and completed the one-year LPN training. Fortunately, he did not have children and he lived with his mother who received a pension, so his costs were low. For single women and mothers, the costs of returning to school are higher.

The number of LPNs working in the eight responding home care agencies in St. John's was very low, at only 18. Some of them were getting only a few "LPN hours" per week, and the bulk of their hours were at lower, home support rates.

> *The longer I work in home care and the less hours I get paid as an LPN, I could lose my LPN licence. I'm going to have to go back to upgrade my LPN...I may have to do the whole course again.*
>
> Home care worker, St. John's, female, single mom, with a disability, age 40

The phenomenon of "delegated functions" also affects the career development of workers in health care. It means that aspects of health care work are being taught to home care workers by nurses, on a client-specific basis. The liability for delegated functions rests with the individual nurse who does the training. While this trend means that the home care worker learns new skills, how are those skills integrated with previous training, and how are they formally credited to her or his skill set? One government official interviewed responded to this issue by saying:

> *...the government doesn't create career paths.*

Winnipeg agencies reported that well-trained and qualified staff are not available to be hired. However, due to the low wages and prestige associated with home care work, it is likely that well-trained, qualified and upwardly mobile staff are working in more financially rewarding areas. You get what you pay for.

Gender and Other Equity Issues

Female workers, even those trained as LPNs, mentioned that they felt stigmatized in home care work, because of being women and working in a domestic environment.

> *You'd get more out of digging a ditch than you would caring for another human being. It's because it's women. They think of women as servants. You're a servant girl. It drives me crazy when they call me "girl."*
>
> Home care worker, St. John's rural area, female, age 50

Gender differences also persist in the kinds of work female and male home support workers do. Male workers do less homemaking and more personal care. Often male workers care for male clients. We found that less homemaking is required by male clients because most of them are living with a spouse, who performs the work with no pay. One St. John's agency estimated that 95% of male clients have a spouse living at home, while fewer than 50% of female clients do. There was an assumption that female workers were less able to do transferring, but all of the women workers in our sample transferred regularly.

> *A lot of female workers do homemaking. There's less of this among male workers. I do more transferring and lifting as a male worker, but sometimes I have to call others in to assist me.*
>
> Home care worker, St. John's, male, age 30

Several survey participants recommended that training for workers and caregivers should address communication skills and issues of discrimination on the basis of gender, race, age, economic status, size and sexual orientation.

> *As a worker you have to respect the privacy of the home. If you haven't come to terms with sexual orientation, you have to decide if you can work in a gay household.*
>
> Home care worker, St. John's, female, age 40

Summary: Working Conditions

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. *The priority recommendation delivered to us by* all *the Winnipeg individual respondents and most of the St. John's respondents was to raise the wages of home care workers. Another priority was improving the adequacy of training for home care workers.*

Other issues raised include:

- unionization and not-for-profit care as a means of raising wages;
- gender bias and stigma of the work and those who perform it because it is "women's work";
- lack of consistently enforced labour standards;
- significant health and safety risks, including risk of violence, injury, infection, emotional disorders for both paid and unpaid caregivers;
- health and safety risks to home care recipients due to overwork and fatigue on the part of workers;
- lack of benefits, including sick leave and workers' compensation, particularly for self-managed care workers; and
- financial abuse of home care recipients by some paid and unpaid caregivers.

> *I would like to see home care work coveted as desirable work.*
>
> Winnipeg home care worker

Costs

Inadequate Public Funding for Services

In Winnipeg, seniors, people with disabilities and others with a medical need for home care qualify, in theory, for publicly funded care, while seniors in St. John's are means tested.

Recipients and their families, in both locations, picked up the additional medical and other costs of home care for which there was little or no public funding. The public system provides a minimal level of care, and some clients are able to purchase additional services through private agencies. These costs may be covered through extended health care coverage, or if applicable, through insurance and other programs, such as Manitoba Public Insurance, the Workers' Compensation Board (WCB), or Veteran's Affairs. However, not everyone qualifies for other programs, has private insurance, nor can afford to buy additional home care services.

In St. John's, some agencies work mostly with publicly subsidized clients while others work solely with private clients. On average, about 50% of the clients in this sample were subsidized and 50% financed their care through insurance plans, Veterans Affairs Canada or personal savings. This information was not available for Winnipeg. Agencies were unable (or unwilling) to disclose any gender breakdown in terms of how many of their clients were receiving government-subsidized service, and what percentage of service was provided by government. As well, they were unwilling or unable to say what proportion of the agency's budget is used for the direct care of clients.

In Winnipeg, changes in public funding for equipment purchases have made it difficult for recipients on fixed incomes to afford certain types of equipment. Agencies agreed.

> *Equipment funding is problematic.*
>
> Winnipeg agency

In the St. John's region, many interviewees fell into the gap between public funding and self-financing. Long-term publicly funded home care is available only to seniors with very low incomes, and the number receiving it decreased from 800 in 1994 to 203 in 1998. Private for-profit care is prohibitively expensive for many.

The needs of recipients are not all met through publicly funded home care in Winnipeg either.

> *There is a lack of commitment by government to provide the required funding for home care.*
>
> Winnipeg agency

One Winnipeg home care worker reported that her clients are sometimes required to pay for expensive medications for intravenous therapy or chemotherapy. These drug costs would be covered if they were in hospital. The same was true of some, but not others, in St. John's.

> *Many people stay in hospital rather than go home due to the costs of equipment and drugs.*
>
> Home care worker, St. John's

Table 5. Home Care Service Rates

	Winnipeg (only two agencies agreed to supply this information)		**St. John’s (eight agencies responding)**	
	Hourly rate charged to client by agencies ($)	**Rate paid to agency by government ($)**	**Hourly rate charged to client by agencies ($)**	**Rate paid to agency by government ($)**
RN	23.00-28.50		18.00-23.00	20.00
LPN	18.00-23.00		14.00-16.00	16.00
OT				
PT				
HSW	10.00-11.95		7.88-10.00	8.76 (5.84)*
PCA	11.00-14.95			9.93 (7.01)*
Companion	10.00-10.95			7.88 (5.84)*
Other		VON ~33/visit	VON 30/RN visit	

Notes:
OT and PT information was collected for Winnipeg, but due to the small sample size, for the purposes of confidentiality, the information is not being reported.
* The numbers in brackets indicate the rate paid to individuals for their self-managed care. The Government of Newfoundland and Labrador gives home care recipients a lesser amount to find their own home care than it would pay an agency to provide home care.

In St. John’s, there were more costs associated with self-managed care in the city than in the rural area. In one rural area, clients were subsidized to use an accountant to do their payroll and remittances. In the city, clients are left to manage complex financial issues as employers on their own or to hire someone to do it at their own expense.

In both sites, there are restrictions on the type of service that is publicly funded.

> *Services like massage therapy and chiropractor visits help me to remain at home, yet I must pay for them myself.*
>
> Winnipeg home care recipient

> *In the old system, you could get companionship* [respite]. *Now you can’t. We’re going backward.*
>
> HCSB official, St. John’s region

Some of these services—which are essential to the comfort of the chronically ill, those in pain, recovering from cancer treatments and other debilitating conditions, those who are lonely, isolated and frightened, who have little human contact—are viewed as “extras” or “frills.” They are not publicly funded, even though those not confined to the home would have access to publicly funded psychiatric and other support services. Those with private insurance would have access to massage therapy for medical purposes, but those who are unemployed, poor or otherwise not covered by insurance, have no realistic access to these services.

This study has confirmed that people with lower incomes have less access to health care.

Costs to Unpaid Caregivers

In Newfoundland and Labrador, only 2% of people requiring support services due to illness or disability receive help from Human Resources and Employment. Most care is done by mothers or sisters, informally, through the family (Howell 1998).

All the unpaid caregivers interviewed in our study had to make major changes in their lives.

> *We lost my husband's income. He couldn't work or get a pension, and had no insurance, so I kept working full-time. I changed my shift to 4:00 p.m. to 12:00 a.m. It took a lot of worry off me, that I had an income, but I was very anxious to retire and have more time to care for him. The day I turned 65 was the day he died. I had to get up most nights. I don't know how I did it. I prayed a lot. Often I wouldn't sleep because he would wake up when I got home from work at midnight and be up all night.*
>
> Unpaid caregiver, St. John's, woman age 66

This woman's husband had terminal cancer. They did not qualify for home care because she had an income, even though it was only $10 per hour. Like her, many women are sole caregivers, whose children have moved away.

One family caregiver in Winnipeg reported that she had given up her full-time job after three years of juggling family caregiving and job responsibilities. While her employer was supportive, she was unable to do her work on two hours sleep, and overnight care was not available. She retrained in a more flexible job, at a lower rate of pay. She experienced losses in terms of potential retirement savings and pension eligibility, among others, in order to provide care for her ageing parents.

Caregivers often find that their careers suffer due to the demands of home care, and some women have felt compelled to give up their jobs to perform unpaid caregiving duties. Family members are called on when a paid home care worker is sick, and they sometimes have to take time off work themselves.

> *I missed opportunities for professional development, such as conferences. My career advancement was put on hold. I know a woman who gave up working to care for a husband with Alzheimer disease.*
>
> Unpaid caregiver, St. John's, woman, age 55

Stress can keep a caregiver on edge all the time through trying to make ends meet on a low or fixed income, worry about the person falling, not eating properly, or smoking or drinking against medical advice. Caring for people with dementia or Alzheimer disease adds to the stress, as they are unpredictable and have to be closely monitored.

Caregivers often miss out on family and social life. In some cases, families break under the stress. Yet in some ways, caregiving is a unique opportunity for building family relationships.

> *The kids didn't suffer. They became involved in his care, especially when I slipped a disc. It brought our family closer together, but there were difficulties. Our brothers frequently needed reinforcing. We had to have family meetings every two weeks.*
>
> Caregiver, St. John's, woman age 49

For elderly caregivers, providing home care can be extremely taxing on their physical health.

> *I have no life at all. My only life is caring for my wife, but it causes great distress to me. Because of a back surgery, I can't even feed her now.*
>
> Unpaid caregiver, St. John's, man, 87

Women are generally under more pressure to make adjustments to their lives to accommodate relatives who need care. Those in our study who had paid work were particularly torn, but they felt it was important to resist the pressure.

> *Paid work gave me a lot of support and qualified people to talk to. I sometimes wonder how I would have managed if I wasn't working.*
>
> Unpaid caregiver, woman, age 66

> *I think it's better for women to work and pay someone else to do the care. If I'd been at home, I'd have felt really alone and isolated.*
>
> Unpaid caregiver, woman, 55

Women and other family members who do unpaid caregiving require the support of an affordable home care system, respite care, support groups and educational workshops.

We discovered a grim example of how the network of home and institutional care and associated costs can have a debilitating impact on an unpaid caregiver. A Winnipeg woman under 65 had to place her spouse in a personal care home, as he needed more care than publicly funded home care would provide. Personal care home costs are based on family income, so she had to pay a significant portion. The remainder did not leave this woman enough to remain living in her own home. Her options were to go on welfare, or to legally separate from or divorce her spouse, so that he would get the care he needed and she would not be homeless.

Cost to Recipients

Most Winnipeg recipients interviewed did not express as much concern as St. John's recipients that home care placed additional financial burdens on them, in large part because there is no means testing to qualify for home care in Winnipeg. Recipients with physical disabilities and high needs, however, reported greater personal financial burdens. The other issue to keep in mind is that many home care recipients have low incomes to begin with, whether it is their age or state of health that keeps them from earning income.

Home maintenance is one of the unmeasured costs to home care recipients in Newfoundland, where there is a high rate of home ownership. While rent or mortgage payments are considered an allowable expense, recipients of subsidized care who are homeowners are not allowed any deductions.

> *The nurse said I had to get a liner for my chimney. It cost me $500. I applied to Newfoundland and Labrador Housing Corporation, she said they have grants for seniors and low income, but I've had no reply in months. I also need windows and paint and have to pay for that myself.*
>
> Home care recipient, St. John's region, woman, age 77

Poverty is a harsh reality for home care recipients we interviewed, particularly the means-tested elderly recipients in Newfoundland. The woman in the above example pays $260 per month toward home care from her Old Age Security cheque of $800 a month. The remainder of her income has to cover food, utilities, transportation, supplies, repairs and the liner for her chimney.

Other costs include building wheelchair ramps and adaptive devices so people can be mobile and live safely in their home. Additional costs of a mattress and supplies such as over-the-counter medications were not covered by the subsidized care. Transportation is another extra cost. Even with subsidization from the City of St. John's, the Wheelway van costs $2.50 per trip, which is prohibitive for someone who can't even afford food.

One St. John's recipient also said the drugs she took for HIV/AIDS were all covered by the drug card, while this was not the case in all provinces. We found in our survey that women over 65, receiving only public pension income, have great difficulty on their fixed incomes as user fees creep in and costs increase. This was the case in both research sites.

> *I have seen clients that have to choose between paying for drugs, buying* [adult] *diapers or buying food.*
>
> Home care worker, Winnipeg

Recipients of care, unpaid caregivers and workers all talked about feeling isolated. Some were virtual prisoners in their own apartments or homes. New approaches are urgently needed to address the emotional, financial, psychological and physical costs of home care.

Costs to Workers

We found a startling inequity in pay rates between home care and institutional care. If you change a colostomy bag in a client's home, you get one wage. If you perform the same act in a hospital, you get a higher wage. Because of hospital closures and downsizing, many health professionals have no choice but to work in home care, which, unfortunately, is considered to be the lowest rung on the health care hierarchy.

We found in both sites that extensive out-of-pocket expenses are incurred by home care workers: gas and maintenance of a vehicle, occasional food for the client, credentials such as first-aid and CPR training, professional licences and immunizations. And there is the cost of being ill or becoming injured, especially when not covered by workers' compensation.

> *I lost income because I was off the job for six months for foot surgery.*
> Paid home care worker, woman, age 58

Many of the workers interviewed do not earn a living wage in home care, through a combination of low wages and casual hours. Some had another job, sometimes two, to make ends meet. The other job is often with another home care agency, working on weekends, at a cost to the worker's health.

Several workers also mentioned the emotional strain of working closely with terminally ill or people living with HIV/AIDS. After a death, there is a difficult period of adjustment and bereavement. Dealing with dementias and violent clients is another aspect of home care which takes a toll on workers. There is no stress leave available, or bereavement leave when a client to whom a worker has developed a strong emotional bond has died.

Other costs have to do with the lack of labour rights in home care. Workers may be unnecessarily restricted in the workplace.

> *I'm not allowed to use the phone at work, even to call home. It's hard on a long shift when I want to check on the kids.*
> Paid home care worker, single mother, age 40

Home care workers, particularly home support workers, have no voice in the industry. They have not been integrated into management systems, and they are rarely consulted in the assessment process. When they are hired independently, there are no systems of feedback in place, and the care is not effectively monitored.

The rights and needs of recipients and workers sometimes clash. For example, most Newfoundland recipients favour self-managed care, and organizations for people with disabilities in that province lobbied against unionization of home care workers to give recipients more control over care. However, the resulting lack of advocacy for home care workers coupled with the inadequate monitoring of labour standards by the province leads to problems. For example, one recipient interviewed had not been informed about her responsibilities as an employer, such as her obligation to pay workers for statutory holidays. It leaves vulnerable, casual workers with the responsibility to negotiate directly with their vulnerable elderly, sick or disabled clients over fair wages and working conditions, with neither side being fully aware of labour law and standards, employer and employee rights and responsibilities.

Looking at the many costs of home care to the paid workers, in terms of their health, well-being, low wages, working conditions and their own subsidization of their work, it is no wonder that this study also found a high turnover in home care work.

Summary: Costs

When governments claim that home care is cost effective, they are not factoring in the costs to recipients, workers and unpaid caregivers. Our study found these facts.

- Home care workers are subsidizing their own work by being expected to cover expenses, and supplementing inadequate state support of clients by sometimes buying food for poor clients.

- Home care recipients and their families must frequently pay for medical devices, over-the-counter medications, transportation and other expenses. This has left some recipients with the unsavoury choice of having to choose between paying for their drugs, bladder control undergarments or food.

- Unpaid caregivers sacrifice their own income, career advancement and pension credits to provide care for relatives. Other unpaid caregivers who keep their paid jobs work double shifts—one for pay, and one at home for no pay. One caregiver for a while worked 22 out of 24 hours per day, until she could no longer manage.

- Many paid and unpaid caregivers report serious health effects, but the long-term health, social and financial impact of home care on caregivers has not been measured.

- The physical burden may be especially difficult for elderly unpaid caregivers, some suffering from their own health problems, to provide care for an incapacitated spouse.

- Many paid home care workers are also unpaid caregivers in their own homes, contributing to exhaustion.

- The allowable expenses for home care subsidies for seniors in St. John’s are not set at a realistic level and contribute to the poverty of these elderly people, who are mainly women.

The primary concern and an area of complete agreement for all of the interviewed public and private agencies, recipients, workers and unpaid caregivers in both Winnipeg and St. John’s is that public funding for home care services is inadequate to meet the need.

5. GENDER ANALYSIS OF HOME CARE POLICIES AND REGIONAL DATA

> *It's a woman-dominated field, both in the clients and workers, and probably that's why it's not considered to rate as high as institutional care.*
> Manager of private home care agency, St. John's

Gender characterizes the field of home care. Not only are most paid and unpaid caregivers women, but more than two thirds of those receiving home care are women. Of the latter, our study found that more women than men rely on subsidized home care. For example, in the St. John's region, 79% of seniors on subsidized care are female, and 69% of those served by private agencies are female. As well, over 90% of the private home care agencies where we did interviews are managed by women, and government officials dealing with home care issues also tend to be women.

Despite the fact that home care policies and practices have an enormous impact on women, government commitments to equality between women and men are largely absent from home care considerations.

Gender analysis is absent or underdeveloped in current home care policy and research in the following ways.

- Data on gender are not always available, especially for paid workers. Many home care studies do not track gender at all, even though it is a central issue.
- Assumptions are made that families will take on home care responsibilities, which rely primarily on women's unpaid labour and reflect a stereotype and expectations about women's roles.
- Where gendered data exist and women's unpaid labour is recognized, little or nothing is done to alleviate the burden on women.

This chapter first deals with key gender issues unveiled by our research, and then provides direction to policy makers on applying federal gender-based analysis guidelines to home care.

Key Issues

This section examines the gender implications of the key findings of the St. John's and Winnipeg research and literature review, and adds the analytical perspective and knowledge of home care programs across Canada of the experts and national organization representatives interviewed from the Ottawa site.

Home Care and Who Qualifies

Systems of home care rest on the unpaid and underpaid work of women

The most salient point about home care is that it relies for its current underfunded existence on the unstated assumption that women will work for low or no pay to care for others.

> "We're kind of exploiting the family. It's not official, but it's implicit. Services are being provided at an increasingly fast pace so the demand can be met. As patients are discharged early, it's the family that picks up the slack, usually women."
>
> Montréal hospital social worker, quoted in AFEAS, 1998

Our results were consistent with literature documenting the under-funding of health care services and, in this case, of home care. We found that underfunding, among other consequences, led to tight eligibility requirements for home care, particularly the means test for seniors in St. John's and limits on number of publicly funded hours of service available according to assessments in both Winnipeg and St. John's. Because home care recipients' needs are not being met, those who can afford to may supplement their subsidized hours with private services for which they pay fees or rely on family members, mainly women, who personally provide the care at their own expense.

National Anti-Poverty Organization former acting assistant director, Kapil Khatter, MD, confirms that in many places, home care services are not adequate, especially with recent hospital downsizing and bed closures. The demand is high and waiting lists are long (Khatter 1998). As stated earlier, low-income people, mainly women, are much less able to afford private services while they wait for publicly funded home care.

Gender bias in the assessment process

Our study did not discover any overt gender bias in the assessment process. However, the manager of a Toronto home care program we interviewed said: "From my perspective, assessments don't consider caregivers' needs and capacities. They don't consider whether the family can really maintain this person. A woman might be doing 20 hours of work when she's only really able to do 10" (Go 1998). She says there is a gender bias in the assessment process. When the case co-ordinator assigns hours, he or she tends to think, "Yes, this person has a wife, so you can manage with four hours instead of six or eight." Male relatives may not be expected to perform the same number of hours of personal care, or any at all.

Eligibility/access: those poorly served

There are many barriers to access to home care. First, not everyone has a home. The homeless and transient populations, who are frequently in dire need of medical and support visits, are very poorly served (Lysne 1998).

> "I do a lot of public education with seniors in the Chinese, Portuguese, Spanish-speaking communities. I always ask them, 'How many of you have heard of home care?' There will be three of 300."
>
> Go 1998

People in rural areas have reduced or no access to formal home care. When they are discharged from city hospitals, they have more difficulty in getting help when things go wrong at home, and they are far away from medical services of any kind. As such, ill and dying people who live in rural areas may be quite resistant to going home (Roe 1998).

Home care is not portable, as some provinces have residency requirements. If an elderly woman who needs help wants to move to Toronto to be with her daughter who could provide support in addition to home care services, she is not covered. She would have to call the VON or another agency and pay for home care services privately (Roe 1998).

Access to home care for specific types of illnesses and conditions also varies by province and territory. Some “have-not” provinces do not have equipment for home care services (IV therapy, pain monitoring, dialysis), so people must stay in hospital for those treatments (Roe 1998).

There are also language barriers to access in home care. Many members of minority ethno-racial communities are not even aware of the existence of home care services (Go 1998). Education and literacy also have an impact on awareness of, and access to, palliative care in the home (Lysne 1998).

As most home care recipients are women, obviously women have access to home care. However, some women have less access than others. Our own research found gaps in rural areas and for Aboriginal peoples.

A holistic health care approach

A gender analysis also looks at gender trends, and determines whether the current policy or issue fits the trend. Unfortunately, in this case, the trend toward deprofessionalization of services does fit the larger trend in the female-dominated health care field at large (Armstrong and Armstrong 1996).

Nurses report a task fragmentation in home care among various players. The nursing profession involves a wide range of care, but this is being broken down into technical tasks (AFEAS, 1998). Assembly-line models of health care can be short on care.

> Service users report appreciating care providers who have time to listen and talk, who get to know their particular needs and with whom they have stable relationships. It is sobering to realize, therefore, that it is exactly these personalizing aspects of care provision that are being squeezed out of home care services as cost-cutting leads to the speed up and intensification of home care workers’ jobs (Aronson and Neysmith 1997).

A gender analysis is more than examining gendered data in light of what we know of women’s and men’s social and economic circumstances. It also means paying attention to women’s wisdom, the qualities and perspective that come from thousands of years of socialization to perform caregiving functions.

What we have in most current discussions of home care is a rather clinical approach that deals with processing patients as if they were sides of beef in a meat-packing plant. Tasks are divided between professionals and non-professionals. What is seen as important is physical care (Armstrong and Armstrong 1996).

However, emotional and social support, for which women have traditionally been responsible, is one of the *primary* determinants of health. It is not a frill. Evidence clearly and repeatedly indicates that people who are ill recover more quickly and are more resilient to stress and illness when this type of support is provided (House et al. 1988; Kulik and Mahler 1989; Fontana et al. 1989; Baron et al. 1990; Cohen 1988). Social isolation and loneliness is as great a risk factor for death as smoking, obesity, lack of exercise, high blood pressure and high cholesterol levels.

Controlling for the effects of these medical risk factors, as well as age and physical health, people with few or weak social ties were twice as likely to die during the period of a research study than those with strong ties (House et al. 1988). Social support also provides relief from psychological distress for people facing stressful events (Holahan and Moos 1990; Rodin and Salovey 1989). Merely talking about painful experiences and emotions is therapeutic (Pennebaker 1990).

In no jurisdiction are psychologists sent to the home. Currently, nurses may be providing some of this type of support, but there is a drive to quantify services and cut this type of "time-wasting" workout. When caring, listening and socializing are cut out of the services provided by home care professionals, a basic ingredient of healing is also cut. In the absence of any such formal support, cleaners are performing this emotional support work often with no training, no recognition and no additional pay.

As important as psychological and emotional support for the recipient of home care, is the provision of such support for unpaid caregivers. Interviews with unpaid family caregivers found that many feel isolated. Although respite care is frequently cited as a need by volunteer caregivers (Sky 1996), it is underused (Chappell 1993). We need to find out why. Is it unavailable, unpalatable, inaccessible or all of the above? Do unpaid caregivers feel guilty about taking time for themselves?

Psychological, social and emotional support for the paid caregiver is rarely if ever discussed in the literature, yet it is another important need. In a hospital, colleagues can talk to co-workers about their cases and gain their insight and advice. When paid caregivers do the rounds of private homes and are isolated from each other, there is far less peer support. They are given no time to grieve after the deaths of recipients to whom they may have become attached. The emotional ups and downs of home care staff as their clients improve, worsen or die, go completely unrecognized.

The type of intimate care required from many home care recipients can be embarrassing for both parties when provided by a family member (AFEAS 1998), for example, when a woman has to change her dad's diapers. Some people are in the position of having to care for parents or family members who have been verbally, physically or sexually abusive toward them.

Some people, mainly women, may be taking on the care of a family member out of a feeling of duty, obligation or guilt, not because they are equipped or desire to provide this care. Women's traditional roles set them up for these situations. Men are not expected to quit their jobs or abandon their lives in order to provide intimate 24-hour per day care for a family member.

> "Wherever there is narrow scope and narrow eligibility, people fall through the cracks."
>
> Go 1998

Many provinces place a limit on the number of hours per week of home care service that will be publicly funded (NUPGE 1998). However, this number of hours may not be enough for many recipients, as we found in our study. As a result, low-income Canadians are discriminated against because they cannot afford to pay for extra services (Khatter 1998). Most low-income Canadians are women. Women with disabilities, Aboriginal women, and some ethnocultural and linguistic minorities are particularly vulnerable to poverty.

The industrial meat-packing plant model of home care also means time is allotted by the home care provider for specific duties, but not for all the duties that a home care worker will be asked by the often-incapacitated recipient to provide. A Montréal home care worker providing homemaking services put it this way.

> I worked in home care for six years, and we visited two people a day. Now, home care workers visit five or six people a day. How can you build a relationship with people when you spend less than an hour with each person? You feel like your only role is to drop in and give someone a bath. Home care workers don't have time to escort people or help them with their budgets. There's no time to provide any real support. No time to listen to people. It's just the bare minimum (AFEAS 1998).

> *I dread the day that I won't get any more help.*
>
> Winnipeg home care recipient

Someone who is homebound may need other services, which may be expensive or hard to get in the home—hairdressing, massage, foot care, etc. Their needs may vary according to their conditions and individual situations. Services that improve people's well-being and self-esteem and keep them integrated in society may help in their recovery or the maintenance of their health.

Arbitrary limits on the hours of service have three principal consequences from a gender perspective.

- Paid home care workers, mainly female, may be doing a great deal of work for free, or rather, at their own expense, especially when unforeseen events require them to work longer than was agreed in the original home care plan.
- Family members, mainly women, are expected to pick up the slack, whether or not they are willing or able to do so.
- Home care recipients, mainly women, may be going without adequate care.

Limits on the number of home care hours are incompatible with the goals of equality for women and for persons with disabilities. Limits on services are not just the result of budgetary restraints. They reflect priorities of governments.

Home care should be viewed as a part of the overall health system, not as a shift from one type of care to another, with resulting cuts to other types of care. An investment in home care may mean a further deterioration of institutional facilities. Masuda (1998), in her discussions with women with disabilities across the country, identified a significant problem of women with disabilities who are institutionalized: they are frequently isolated from their families and communities. If institutions close because of enhanced home care, women in small communities may have to travel even farther and be even more isolated if institutional care is required.

> "When you're an old lady, frail, maybe a little bit helpless, you haven't the gumption to stand up against a person who's coming to do a service and say: 'That wasn't good enough.' You just let it happen."
>
> Elderly woman quoted in
> Aronson and Neysmith, 1997

Unless the government is willing to pay for 24-hour per day home nursing assistance and major modifications to homes, the need for some institutional facilities will always remain for those for whom home care is inappropriate.

Métis National Council of Women President, Sheila Genaille, points out that people belonging to cultural minorities are placed in institutions that are not sensitive to their needs (Genaille 1998). Institutional reform and improvement, rather than cutbacks, should go hand in hand with building a home care program.

In addition, women's socialization, taking into account cohort effects, should be remembered when analyzing data. Our study found that in both Winnipeg and St. John's, home care recipients unhappy with the level of hours assessed or with other home care issues were expected to lobby politicians and contact the media. Although some older women are strong, vibrant, media-savvy, and turn stereotypes on their heads, many are still, to some degree, products of female socialization at the time they were born and raised. Women born in the earlier part of the 20th century when notions about how women should behave were more restrictive may not feel confident enough to make demands of politicians or reporters. The "squeaky wheel" system of home care does not work well for women.

Service Delivery

Women bear the brunt of the problems with home care delivery

Continuity of care issues, such as high turnover of home care staff and lack of appropriate training for replacement staff, workers not available on short notice, different workers assigned who are unfamiliar with the client's needs, poor communication between agencies, workers and recipients, affect women in the following ways.

- Unpaid caregivers, mainly women, may be helping in gruelling physical tasks, such as transferring a heavy recipient, at the risk of injuring their backs or developing chronic health problems of their own. Many unpaid caregivers are women over 65 caring for their elderly, disabled or ill husbands.

- Home care workers, who are mainly women, are being sent to do tasks for which they have no training, which could result in injury to themselves and the recipients, and in guilt and lowered self-esteem for having caused unnecessary pain.

- Women, who make up the majority of low-income Canadians, are least likely to afford higher agency fees when their publicly funded home care worker is sick and not replaced.

- Workers are being sent into situations that may be dangerous, such as caring for violent mentally ill recipients or convicted sex offenders, whereas what would be more appropriate would be to regularly send in a person with special training who feels comfortable dealing with this type of situation. Women with no special training may be at particular risk of sexual and physical violence.

Lack of adequate respite care affects women in the following ways.

- When fees are attached to respite care, low-income unpaid caregivers, mainly women, may not be able to afford this option.

- Unpaid caregivers, mainly women, may be unable to take vacations, especially when there are no other family members who can take over the care of the recipient. Unpaid caregiving can become a 24 hours per day, seven days per week, 365 days per year unpaid job until the death, recovery or institutionalization of the recipient. This may have a long-term impact on the health and well-being of the caregiver.

Aboriginal home care and the situation of Aboriginal women

Home care has been an issue recently in the transfer of health services from the Medical Services Branch at Health Canada to individual bands. Home care was not taken into account in planning the transfer. Unless bands specifically asked for home care funds at the time of the transfer, the Medical Services Branch tells them to “find the money yourselves” (Dunn 1998).

Aboriginal women and men are affected by early discharge from hospitals even though home care services are not available on most reserves and in remote communities. As well, there are a lot of chronic diseases prevalent in these communities. Home care services are needed to keep people in their communities longer, so they can benefit from family and community support. Now, when their condition deteriorates, they are frequently transferred to urban centres where there are facilities to care for them, necessitating travelling long distances and being cut off from family, community and familiar surroundings (Dunn 1998).

The Métis have no special arrangements with government for health care. They, and non-status Indians, are covered by the same provincial programs as other Canadians (Genaille 1998).

There is a severe shortage of home care and support services for Aboriginal people with HIV/AIDS in urban areas. A high percentage of new cases of HIV infection are Aboriginal people, and half are young women. Some Aboriginal services have been set up in urban areas, such as Feather of Hope in Edmonton (Genaille 1998).

> "Aboriginal women bear unbelievable burdens. Often in remote areas, it is expected that they will perform care activities—for example, women whose children have a chronic chest condition, not unusual for Aboriginal children—are expected to care for these children in the most primitive of housing situations, cold damp, poorly insulated, the worst possible place for these kids. Women are expected to do chest care—pummelling and suction—without support and in some cases without running water."
>
> Connors 1998

There are two significant and unfortunate differences between Aboriginal women and other women in Canada regarding home care: Aboriginal peoples have a far shorter life expectancy, so there are fewer elderly people in these communities who might need home care. The second shocking and unacceptable difference is that giving up employment to perform unpaid caregiving work is not as great a factor for Aboriginal women because there are so few employment opportunities for them and they experience an already high poverty rate (Dunn 1998).

Discrimination

We live in a society in which prejudices about race, religion, income, gender, sexual orientation, language, background, and body size and appearance still play a factor in interpersonal relations and lead to discrimination against both recipients and workers in all sorts of situations. Perhaps these prejudices and stereotypes are especially prevalent in home care, where the focus is on very personal and intimate services provided in someone's own home.

> "Significantly, too, relatively little research attention has been given to people who do not have children, who do not live in heterosexual partnerships or who do not live in Western, nuclear family forms—in short, who do not fit in with the homogenous picture of 'family care' painted in the LTC [long-term care] policy discourse."
>
> Aronson and Neysmith, 1997

Another factor is stigma about certain diseases and conditions. Some palliative care workers do not feel comfortable working with people living with AIDS. In situations where home and palliative care workers do not have adequate AIDS education, people living with AIDS are poorly served (Baxter 1998).

Home care recipients should never be exposed to workers who will belittle them because of gender or some socio-economic factor. Cultural and other sensitivity should be among the qualities workers are screened for, and additional training provided before they begin their jobs. Workers should never have to put up with abuse from recipients, and should have recourse to be reassigned and emotional support provided where abuse has occurred.

Homophobia

Some families have ostracized members who are gay or lesbian, leaving some gay and lesbian seniors, people with disabilities and those who are ill or incapacitated with few family resources to rely on. They may be subject to home care workers who have discriminatory attitudes toward them. Even if a lesbian has a partner who can care for her, this partner may have a difficult time negotiating with a heterosexually oriented system.

> Hospital and nursing home policies may discriminate against homosexual partners; therefore a successful use of home care services is especially critical for gay and lesbian caregivers. In acute care situations, two ways of ensuring partner access are: through the signing of a release of information form at a hospital or clinic; and, obtaining a duel durable power of attorney, specifying within the agreement that the partner has the power to make medical decisions on the other's behalf in the event of incapacity (Sum Quod Sum Foundation, 1997).

Several participants recommended that training for workers and caregivers should address communication skills and issues of discrimination on the basis of gender, race, age, economic status, size and sexual orientation.

Homophobia not only causes problems for gay and lesbian recipients of home care, but may also work particularly against lesbians in terms of the burden of providing home care for elderly parents. Our society recognizes heterosexual marriages as important relationships to be supported, so home care provision often falls on unmarried daughters.

Lesbian daughters, such as one of our interviewees, are thought of and view themselves as the likely providers of home care within the family, even if they are in fact involved in a relationship. Their relationships are frequently not valued by others, and no thought is given to the stress of providing home care as having an impact on that relationship.

Racism and harassment

Home care recipients and caregivers experience racism in home care services. For example, one disabled woman of colour was told by a home support worker, "as an immigrant you should be grateful that you are here and for the services you receive" (Go 1998). There is often no recourse for caregivers who experience racism at the hands of recipients or vice versa. Anti-racism training is not provided by most home care agencies, and matching recipients to home care workers may happen on an ad hoc basis.

Recipients may be technically in the position of suing the agency under human rights laws, where applicable. However, such cases may take almost a decade to conclude so the client may not live to see the decision, and low-income recipients may not be able to afford legal advice. Such recipients are usually getting the home care services to begin with because they are in some way incapacitated. The onus should not be on vulnerable recipients to ensure they are not victimized by racist workers.

We did not discover any agency harassment policies in the course of our research. On the contrary, we interviewed a recipient harassed by a worker, and her complaint was not taken seriously for some time.

Stigma of "women's work"

Female workers in our study, even those trained as LPNs, mentioned that they felt stigmatized in home care work, because of being a woman and working in a domestic environment. Women found they were treated as menial workers by some clients, their families and agencies, even though they were entrusted with the intimate and professional care of human beings.

Gender differences also persist in the kinds of work female and male home support workers do. Male workers do less homemaking and more personal care.

The impact of isolation on women's ability to organize to improve conditions

Paid home care workers may find it difficult to unionize, due to the isolation of their workplaces. They don't get to know each other, exchange knowledge and experiences or benefit from a colleague's opinion or expertise. This may be more of a problem for home support workers and non-unionized workers.

For family members, it may be intensely draining to be the only adult caring for a relative or friend with Alzheimer disease or other incapacitating illness or condition in isolation. The recipient may also find care in the home isolating, as there is no one around in similar circumstances with whom to share experiences.

The isolation of women as recipients, informal caregivers and paid workers obscures the gender imbalance, and these women may feel they are alone in their situations instead of forming part of a systemic problem that relegates women to low and no wages, and financial insecurity in old age. This isolation impedes them from organizing together to pressure policy makers to change the situation.

> "In 1994, it was estimated that 90% of home care services in Canada were provided by publicly funded home care programs. It is estimated that this ratio has changed since then as more private services are offered to help people who are not eligible for publicly funded home care and for those who wish to complement the public services they are receiving."
>
> CHCA et al. 1998

Privatization does not benefit women

The provision of home care services by private, for-profit agencies is proliferating. A survey of Quebec health professionals and users of services reported a high staff turnover in private home care agencies and differing quality of care (AFEAS 1998). In particular, Quebec's "social economy" policy, which encourages welfare recipients to set themselves up as private care providers is leading to unskilled workers trying to handle situations for which they are not trained (AFEAS 1998).

Some of our interviewees were not opposed to a parallel for-profit home care delivery system, in principle, as long as there are clear controls on who is doing the delivery and what the criteria are, and there are quality indicators, accreditation and standards. However, this is not the way the current privatization of home care is playing itself out, as there are no national standards.

> "These homemakers have very low pay, most of the time don't have benefits, have to go on welfare when they get sick. This system is keeping them poor.... With increasing privatization, when wages get pushed even further down, I don't know how they're going to survive."
>
> Go 1998

Privatization has implications for the quality of care women receive, and for the wages women are paid. Ontario is now leaning toward a "managed competition model" where private agencies are competing with the more established non-profit agencies such as the VON, which is unionized. Private agencies are sending in low bids. "I don't know how they are paying their wages" (Go 1998). This is the last year of a guaranteed minimum wage in Ontario for homemakers ($9.15 per hour) as the provincial government is not committed to continuing the wage guarantee. Next year, advocates are predicting a drastic drop in wages as a result. It is feared that non-profit agencies will not be able to compete, because they are not willing to exploit workers (Go 1998).

> "As a Canadian and an individual, it makes me angry and bitter that profits are coming out of the health system and going to other countries at the expense of our Canadian women and their families."
>
> Roe 1998

The United States is the country with the highest per capita spending as a percentage of the gross domestic product (GDP) on health care in the world, and it is also the country with the highest proportion of private health spending (CMA 1998b). Canada is not only under the pressure of comparison with the U.S. system, but under political pressure from private health companies in the United States to operate in Canada.

The Manitoba privatization experiment shows clearly that private, for-profit health care is simply not cost effective or high quality (Shapiro 1997). Instead of all the resources going into service, some are gleaned as the owner's profit and not used for providing service.

Working Conditions

Wages/hours of work contribute to poverty

Casual hours plus low wages equal poverty for many of the female, home care workers we interviewed. With no career advancement possibilities, no guaranteed access to training, no money to retrain for a better paid occupation, the financial position, particularly of casual home support workers, is frightening. Our findings on home care wages confirm the results of other studies discussed which postulate structural gender inequities in the labour market, based on whether occupations are female dominated and involve "traditionally female roles," such as caregiving.

> *I sometimes feel like I'm running an Irish workhouse.*
>
> President, private home care agency,
> St. John's

Retired VON Executive Director Donna Roe said, "I really believe that nurses wouldn't have achieved the compensation packages and benefits if it hadn't been for unionization" (Roe 1998). Our findings confirm that unionization has a positive effect on the wages and benefits of home care workers.

Gender issues in health and safety

Men are more likely to drive to work than women, while women are more likely to travel to work as a passenger, take public transit or walk (Statistics Canada 1998a).

As most home care recipients are low-income earners, presumably living in low-income neighbourhoods, our interviewees brought up safety issues for female paid caregivers getting to and from the homes of the recipients.

> "Home care workers deserve to work in clean and safe environments. They should be well paid with benefits including pensions. The federal and provincial governments are off-loading health care from a well-paid, predominantly women, workforce to a low-wage predominantly women workforce."
>
> NUPGE 1998

There are also health and safety issues on the job. Unskilled workers and untrained, unpaid caregivers might unknowingly spread disease. They may not know how to sterilize properly the environment or protect themselves. The stress of the nature of the work itself may increase the possibility of error due to heavy workload, fatigue, lack of information and sometimes inadequate training. In addition, balancing work and family responsibilities, especially with irregular shifts and job insecurity, may take its toll on the physical and mental health of home care workers. As we've seen, it is women who tend to do unpaid housework and family care, so many home care workers leave their low-paid job to do a similar job with no pay in their own homes.

With limits on the number of hours of service, deprofessionalization and the private hiring of untrained caregivers, heavy lifting may be a part of the work expected of someone hired to do home support and attendant care. Without training in the proper handling of incapacitated individuals, paid and unpaid caregivers may sustain back and other injuries. Women tend to have less upper body strength than men, so training may be especially important. If a privately hired or an informal, unpaid caregiver sustains such an injury on the job, there is no workers' compensation or formal sick leave.

Women are subject to violence

Recipients of home care could be taken advantage of financially, or physically and verbally abused by paid or unpaid caregivers. Their isolation in the home may shield the abuser from ever being caught. As well, nursing and health care work are occupations prone to very high rates of physical assault by the recipients of their care, as well as to sexual harassment and verbal abuse.

In British Columbia, New Brunswick and Saskatchewan where studies were performed, most nurses had experienced physical abuse on the job, primarily from patients (Canadian Panel on Violence Against Women 1993). Home care workers may be particularly vulnerable as they do not have colleagues around who can help them. Likewise, a number of home care workers we interviewed mentioned they had to deal with violent recipients.

The effects of such violence include fear, trauma, job turnover, absenteeism and disability claims resulting from stress (Rogers 1998a). Rogers calls on policy makers to develop educational and managerial strategies, including risk assessment and prevention measures.

Deprofessionalization of services

Just as in our case studies in Manitoba and in Newfoundland and Labrador, unpaid family caregivers in Quebec said they were often asked to perform medical procedures they felt unqualified to do, such as changing colostomy bags, inserting catheters, giving injections or clearing a blockage in an instrument (AFEAS 1998). This pan-Canadian reliance on unpaid, untrained people to perform medical care tasks has profound implications for the quality of care given to recipients, as well as for the stress and pressure on family caregivers. If they make a mistake leading to the injury or death of their loved one, they may never forgive themselves. It is unfair to put people in that position, in a country in which medical care is supposed to be accessible and free.

> “Family members are seen to choose to fulfil natural commitments to relatives in need. As a result, women’s unpaid caring work comes into view only when it breaks down or threatens to do so. Community based services are provided to buttress and sustain family carers, not to substitute for them.”
>
> Aronson and Neysmith 1997

Our study found that deprofessionalization of home care work is a problem and that it is contributing both to a lower standard of care for the mainly female recipients of publicly funded care and to the impoverishment of women as paid and unpaid caregivers.

The Burden of Costs

There is a widespread perception that home care is cheaper than hospital or institutional care. Home care, done properly, is not necessarily cheaper. It’s only cheaper because it is inadequate and people (women) are not receiving the care they need (Armstrong and Armstrong 1996).

Policy developers may view home care as setting up inexpensive, mini-hospitals in the home. However, homes are not hospitals. They are not sterile environments. They do not have a wealth of medical expertise at their fingertips. They are, by and large, not equipped to handle someone who is ill or disabled without major, costly renovations. Once a home is renovated this way, its ability to be sold on the market later may be reduced, imposing a double financial burden on the family—first to make the modifications, then to lose money as the house depreciates in value.

In some jurisdictions, home care nursing services are covered, while homemaking services require fees even if the recipient is unable to clean her own environment—a service which would be provided free in hospital (CHCA et al. 1998).

Our findings indicate that the increasing use of fees and tighter eligibility requirements which are driving people in need of home care to purchase services, appear to be a part of a national trend (NUPGE 1998). Because of women’s lower average income, they are least able to afford this. Eligibility requirements may include means testing of family income in some provinces, even if the potential home care recipient has no access or control over family income.

The ability to cope with home care's associated costs varies not only by gender, but by other characteristics.

> Those with more resources, by virtue of class, race or age, will be better able to offset the costs of caring, whether by purchasing private help or by being able to negotiate public resources from a more privileged position (Aronson and Neysmith 1997).

When women have to give up jobs and pension benefits or promotions, or move to part-time paid work to care for relatives at little or no immediate cost to the state, the long-term social and economic costs of this unfair burden on women are not taken into account.

Lack of paid employment or low pay means fewer or no taxes collected. Lack of adequate pension benefits means an eventual high cost to the state. If a teacher making $35,000 per year quits her job to provide homemaking and other services for a relative that might be provided by someone else for $18,000 or less, this may not result in a net savings for the state over time. The costs in terms of lost taxes, higher public pension layout and higher costs of health care due to the caregiver developing ill health have never been calculated.

Canadians have a sense of entitlement to health care and do not expect to be bankrupted by it. Both home care recipients and caregivers may have paid taxes all their lives, presumably, in part, to pay for Canada's medicare system (Aronson and Neysmith 1997).

> "There is a major problem here [in home care] in that the burden of costs, and also human costs, is being shouldered by the front line women, whether they are family caregivers or workers in the field."
>
> Go 1998

Public versus private costs

Some provinces and territories cover prescription drug costs for home care recipients, others do not. Some cover only the drugs related to the illness or condition for which home care is needed, and not for other illnesses and conditions which are also present, even though if hospitalized, these drugs would also be covered. Some provinces and territories supply equipment needed for the home care recipient. Others rely on individuals and their families to buy equipment and make costly renovations to the home to accommodate a sick or disabled person (CHCA et al. 1998).

Expenses such as special meals, extra cleaning supplies for a sterile environment and rent or mortgage payments are not covered at public expense. If the individual were hospitalized, she or he would not have to pay for food, cleaners or cleaning supplies, or overhead. Home care may prove to be a short-term savings to the state, as many costs of hospitalization or institutionalization are passed on to sick, elderly or disabled individuals and their families.

Home care, in its current form, may also prove to be a part of the undoing of publicly funded medicare in Canada, as it now represents, in most parts of the country, an offloading of costs from the public to the private purse. In the end, the taxpayer pays for medical costs through taxes, privately or a combination of both. When medical costs are publicly funded through taxes, it ensures access to those who cannot afford to pay out of pocket. Tax deductions for medical costs are irrelevant to people whose income is so low they do not pay taxes. Deductions do not provide the necessary funds for medical and other supplies up front when they are needed. Low-income people in Canada today no longer have the same access to medical care that higher income people do, because many expenses are no longer publicly funded (Khatter 1998). And, as we frequently point out, women make up the majority of Canada’s poor.

According to the most recent Organization for Economic Cooperation and Development (OECD) data on health care financing, Canada’s public and private health expenditures as a percentage of GDP is 9.3, ranking Canada fifth among the OECD countries. However, public health expenditures alone as a percentage of GDP is 6.4, ranking Canada ninth. The public portion of total health expenditures in Canada is 68.7%, ranking Canada 23rd among 28 OECD countries. Even in countries with fewer economic resources than Canada, such as Poland and the Czech Republic, over 90% of health expenditures are covered by the public purse (CMA 1998b).

Our study confirmed that not only are home care recipients and unpaid caregivers paying for medical and associated costs, but sometimes the home care worker does too, for a low-income client who can’t afford it. Essentially, governments are saving money and low-income women are paying, paying and paying.

Unpaid women caregivers described how “professionals expected them to appreciate the limits of public resources but to overlook the limits of their own” (Aronson and Neysmith 1997). Our study, unfortunately, confirms this finding.

What to do about the costs to unpaid caregivers

Shirley Masuda (1998), in her focus groups with women with disabilities in every province and territory of Canada, recommended that family caregivers be paid. Sheila Genaille, president of the Métis National Council of Women, also suggests that caregivers be remunerated. She suggests that there should be training programs available for informal caregivers so they can turn caregiving into a paying job (Genaille 1998).

Some of our national interviewees said informal caregivers should not be paid, because it would entrench women in this role, and women will be pressured more than ever to provide care.

As discussed in the literature review, the Nova Scotia Life Support Program provides paid compensation to informal caregivers, most of whom are young women living with the care recipient in rural areas where home care services are scarce (Keefe and Fancey 1997). The researchers found that those who received compensation worked 30 to 40 hours per week on caregiving activities for an average of $88 per week.

In Scandinavia, caregivers are given actual wages and receive employment benefits such as pensions and vacations. However, since home care is seen by policy developers as a cost-cutting measure, it is unlikely that any compensation program set up in Canada would come close to reimbursing women for the actual value of the caregiving work they do. We do not know whether those Nova Scotia caregivers would work just as many hours without the compensation and simply have a tougher time, financially, without the program.

A number of our national interviewees expressed opinions both for and against reimbursing caregivers through the tax system. Some cited the failure of the federal Caregiver Tax Credit to make any difference at all in the lives of women. Some felt the tax system was an inadequate and inappropriate way to deal with the entrenched problem of women's caregiving role and its resulting erosion of women's financial security. Others thought it was better than nothing.

Remuneration of informal caregivers is an important area of study and one in which viable recommendations are urgently needed to begin to make economic equality a reality for women.

Gender-Based Analysis Guidelines

This portion of the paper provides advice for policy makers on how to apply federal gender-analysis guidelines to home care policy development. The six steps of policy development outlined in the guidelines are identifying the issue, defining desired/anticipated outcomes, information gathering, development and analysis of options, communication and evaluation. The specific gender analysis questions to be considered are reprinted in Appendix B.

Identifying the Issue

The first step examines whether both women's and men's experiences are used in identifying home care issues, whether the diversity of the population and different needs are taken into account in identifying issues and whether government objectives of gender equality are considered.

For example, in this study, the researchers were guided by the issues raised by both male and female authors in the literature review in constructing the regional interview questions. We asked these questions of both female and male stakeholders, in roughly the same proportions as their representation in the population of home care recipients, paid workers and unpaid caregivers. Both women and men were involved in identifying their experiences with home care and their recommendations. The interview questions for the policy portion of this study were based on the questions listed in a speech by federal Minister of Health, Allan Rock, at the March 1998 National Conference on Home Care.

We addressed diversity in several ways—by ensuring that one of our study sites has a substantial immigrant, visible minority and Aboriginal population (Winnipeg), and the other (the St. John's region) has urban and rural areas. Our questionnaires tracked the gender, language and ethnicity of respondents. By the very nature of the home care user population, people with disabilities, seniors and low-income people were well represented. As well, we ensured that organizations representing disadvantaged groups were interviewed in the policy portion of the study.

For governments at any level, this step is clear. Consult affected groups about their perspectives on how an existing policy is problematic, or what is important to them in a new policy. Write down gender equality commitments and make them a measurable part of the policy goals. Too often, governments may "consult" in name only, but not act on the recommendations of those most affected by the policy.

Defining Desired/Anticipated Outcomes

This step answers the question, what does the government want to achieve with a home care policy? Governments have to develop ways to measure policy outcomes that take gender into account. This would involve making specific commitments within the goals of a policy, for example, some of the following.

- "There will be no increase in informal caregiving hours as a result of this policy." This would involve measuring the number of hours per week of caregiving work family members perform before and after the new home care policy.

- "There will be no difference in terms of cost to individuals and families in choosing or being assigned to home care rather than hospital or institutional care." This would involve tracking expenses related to caregiving that were not paid before.

- "Wages and working conditions will be improved, to raise the playing field for this largely female work force." This would involve tracking wages and working conditions in the home care industry, and bringing in policies and legislation as necessary to ensure wages do not fall nor working conditions decline.

Although this sounds like a lot of work, it is an essential part of evidence-based decision making. Currently, decisions are being made regarding the structure and operation of home care programs that do not collect or take into account the evidence on these issues.

Our literature review reveals that racism is an issue in home care (Neysmith and Aronson 1997). Our study points to an underuse of home care services by Aboriginal peoples, an issue that should be tracked and explored. By definition, home care involves three vulnerable and sometimes overlapping groups of people—people with disabilities, seniors and others in medical need. Most home care users and home support workers are low-income earners, so income is certainly a factor in home care policy outcomes. In our study, we also took sexual orientation into account. We recommend that all government studies specifically look at these various factors when conducting or funding studies on home care policy development and outcomes.

Some people believe that when policies are gender neutral, they are not discriminatory toward either gender. However, one must not only take overt gender bias into account, but also the social and economic structural gender differences that can lead a policy to be implicitly gender biased. For example, whenever income is a factor, gender is a factor, as women make up a majority of the poor. Whenever one is discussing roles that are particularly expected of women or of men, and caregiving is associated primarily with women, policies may have a disproportionate impact on that gender group.

Information Gathering

This is the policy research stage. The guidelines provide useful suggestions to ensure that information collected is disaggregated by gender to allow for a comparison between women and men, the inclusion of women's perspectives in the collection of primary and secondary research, and the importance of consultation with women's organizations about policy issues.

For example, in our literature review, we looked for gender-disaggregated data for home care recipients, paid workers and informal caregivers, and found information about paid workers the most difficult to obtain. Instead of giving up on it, we collected this information ourselves from agencies in Winnipeg and St. John's, and also extrapolated from national data on gender breakdowns in the health professions. As well, we consulted with women's organizations and health care researchers who incorporate a gender perspective in their work (see Appendix A). We conducted a literature review, and paid particular attention to studies mentioning gender and diversity. We conducted primary research with affected groups. Some members of our research team are women with direct experience with home care.

Development and Analysis of Options

In this step, policy options are formulated and thought is given to each one about the possible impact of the option on women and on men, given gender differences in income, industries, attitudes and so on. We have developed and analyzed the options we present in our conclusion and recommendations.

Communication

This step in the gender-analysis process occurs after the policy is formulated, and focusses on the communication or "selling" of a policy, both internally within the department and externally to Cabinet, the media, the public and stakeholders. The potential gender impact of the recommended policy options is disclosed.

The best way to ensure the policy is well received is to work in partnership with stakeholders throughout. This also includes working in partnership with women's, health, visible minority, Aboriginal, low-income, immigrant and ecumenical organizations, groups representing people with disabilities, unions and employers, and building broad-based grass-roots public support.

Evaluation

Evaluation and the flexibility to correct problems are essential to any good program, home care included. To ensure that a program is in keeping with government commitments to equality between women and men, it is important that equality concerns are incorporated into evaluation criteria in a measurable way. It is also important that evaluation data be analyzed by persons who are knowledgeable about gender issues, and that data be made available to women's organizations, with an invitation to participate in the evaluation process.
Examples of indicators would be tracking information by gender concerning recipients, paid

providers and their wages and benefits, informal caregivers and their number of hours of home care work as well as the costs of home care to them, including lost wages and pension benefits. Indicators would then be matched to targets for the home care program on an annual or other regular basis, and the results published and made available.

Summary

Home care, certainly in the two provinces we looked at and in the literature we reviewed, 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, with their own money and with their health and well-being. As such, the home care programs we looked at are structurally unfair to women.

Respite care and the tiny federal Caregiver Tax Credit may be cited as examples of government attempts to make peace with unpaid caregivers. However, the credit is so small and eligibility so tight that it is primarily symbolic, whereas respite care is inadequate to meet the needs of the caregivers we interviewed. These are primarily programs on paper, rather than actions to address the structural inequality that makes women vulnerable to poverty because of their unpaid and underpaid caregiving roles. They are small efforts to help women cope with these roles, not to challenge the idea that women, as paid and unpaid caregivers and home care recipients, should subsidize the state by paying a high price (both monetary and non-monetary) for the health and support services known as home care.

One way to ensure these issues are considered is to have recipients, caregivers and home care workers at the drawing table in the policy-making process. Women over 65 form the majority of home care users. Yet their experiences and voices are seldom heard.

> While rather ostentatiously invited to participate in narrowed, consultative policy-making processes, elderly people’s voices are seldom included in decision making about the actual design and operation of resources that are provided to respond to their needs (Aronson and Neysmith 1997).

Women under 65 with disabilities consitute another significant user group of home care services, and most home care users are in the two lowest income quintiles. Low-income people and people with disabilities should be consulted in the design of a home care program, or in potential changes in policy. As well, other groups have special needs when it comes to home care and other services—Aboriginal women, immigrant and visible minority women, lesbians. If governments don’t ask these groups the questions, and really listen to and incorporate their suggestions, governments won’t get the answers they need to form a coherent, inclusive policy or program that does not disadvantage any group.

In conclusion, our analysis found that in too many ways, current home care policies and practices are, in fact, contributing to the impoverishment of women.