FROM SUPPORT TO ISOLATION

THE HIGH COST OF BC'S DECLINING HOME SUPPORT SERVICES

By Marcy Cohen
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and Aleck Ostry

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Summary

Home support is part of a continuum of community- and home-based health services known as continuing care. Home support can include housekeeping, meal preparation, bathing, grooming, and basic medical care functions such as help with medications, catheterization, changing wound dressings, etc.

In addition to providing basic care for people with chronic ailments or disabilities, or those recovering from serious illnesses, home support is a form of preventative health care. Home support functions as an early warning system, helping to identify more serious problems as they emerge, ensuring good nutrition and hygiene, and providing essential social support and contact. Such supports can save the overall health care system a great deal of money by staving off more expensive emergencies and delaying the need for institutional care (i.e. hospital or residential care).

"I feel that it's not right for all these cutbacks because your mental health is as important as your physical health… This is gonna be your home to the day you die. And you have to feel comfortable in the surroundings."
— Home support client

Home support, then, represents the basic supports people need in order to stay at home, but which thousands of frail seniors and people with disabilities cannot afford on their own. In BC, eligibility for publicly-funded home support is income-tested and based on a restrictive definition of individual need. It is not universally available and free to all British Columbians.

Access to publicly-funded home support services for frail seniors and people with disabilities has been decreasing in BC since the mid-1990s. This study examines the decline in the context of wider cuts and restructuring in the province's health care system since 2001. As was documented in the 2005 CCPA study *Continuing Care Renewal or Retreat?*, this restructuring involved reducing access to residential care and home health services at the same time that hospital beds were cut.

The BC Ministry of Health reports that since 2001 it has enhanced both home support (personal care and daily living assistance) and home care (professional nursing). However, the Ministry's own statistics tell a different story. This study analyzes health ministry statistical data for the entire province, and draws on evidence collected by the research team using in-depth interviews with home support clients, workers, and informal caregivers (family members and friends) in the Greater Vancouver area.

Key Findings

Reduced access to publicly-funded home support means frail seniors and people with disabilities are being left without the basic supports needed to monitor their health and postpone or even avoid the need for residential or hospital care.

- Home support is increasingly being used to backstop pressures in acute and residential care, with more medically-oriented services being delivered at home to a smaller number of higher-needs clients.
- Instead of expanding home support services to meet growing demand, the preventive and maintenance functions of home support have been significantly reduced. Fewer seniors are able to access services, and the focus on higher levels of care means fewer and fewer daily living supports (such as meal preparation, housekeeping and social contact) are being provided.
- High demand, inadequate funding, and the shift to higher-needs clients have led to a deterioration in working conditions for home support workers, which in turn has a negative impact on the quality and efficiency of care that clients receive.
- The combination of significant cuts to hospital and residential care beds and reduced access to home support since 2001 contributes to a downward cycle in BC's health care system.

> *"When I first came in, if somebody was palliative we did the [direct] care but we had a whole team behind us to come in and help with it. Now we don't have that team at all."*
> *— Community health worker*

Cuts to Home Support

- The number of clients receiving home support dropped by 24 per cent between 2000/01 and 2004/05; the number of total home support hours dropped by 12 per cent.
- When the growing population of seniors is taken into account, the drop in home support services is even steeper. This occurred even as hospital stays shortened.
- In 1996/97, BC was 17 per cent above the national average in access to home health services (home support and home care combined). By 2002/03, BC had fallen to third lowest in the country, 24 per cent below the national average. Nova Scotia is the only other province that reduced access to home health services during this period.

Two European Examples

Researchers examining the Danish and Swedish eldercare systems found that investing in home support not only improves health status and quality of life for seniors, it is a more efficient way to allocate health care dollars.

Denmark provides a wide range of free, universally available, 24-hour home support services for seniors, including those with limited needs. These services are nationally mandated and administered by municipalities. Municipalities are legally obligated to offer a home visit twice a year to all citizens 75 years and older, in order to find out about potentially unmet care needs in the population and to make sure seniors know about the services available to them.

The Danes were more concerned with the additional costs that would result if seniors did not get help early on than they were with limiting access to home support resources. In contrast, Sweden charges user fees for home support and provides fewer services concentrated at higher care levels. Yet overall eldercare costs are lower in Denmark than they are in Sweden.

The Danish model points to the type of reforms that could be very effective in enhancing the health of BC seniors and people with disabilities while also controlling cost increases in the health care system as a whole.

Fewer Clients, Higher Needs

- Since the late 1990s, and in particular since 2000/01, home support services have shifted dramatically to clients with higher needs, and services have become more narrowly focused on medical tasks. The public system provides less and less daily living services such as meal preparation, shopping, housekeeping, and social contact.

> *"I get a homemaker once a week but…I'm on a very limited budget…I have had to take from my grocery money and either live in the dirt or pay somebody to do it."*
> *— Home support client*

- Between 2000/01 and 2004/05, the number of clients categorized as needing Personal and Intermediate Care 1 (lower needs) dropped by 67 per cent. At the same time, the number of Intermediate Care 3 and Extended Care clients (higher needs) increased by 29 per cent and 22 per cent respectively.
- These changes should have resulted in increased support from nursing professionals. However, between 2000/01 and 2004/05, the number of clients receiving home nursing care decreased by 8 per cent (as a share of the population 75 and older).

Impacts on Working Conditions and Quality of Care

Community health workers (CHWs)—those who provide home support—in the Greater Vancouver area who were interviewed for this study report a serious deterioration in working conditions and the quality of care they are able to deliver. Clients interviewed described similar trends.

- Discontinuity of care: An increased reliance on casual (i.e. non-permanent) staff and irregular and split-shift scheduling mean clients no longer receive care from the same person on a regular basis. This limits the capacity of workers to get to know their clients, monitor changes in their health status, and prevent crises from occurring.

> *"They are taking away any basic humanity from one person to another."*
> *— Community health worker*

- Increased complexity, inadequate support: Increasingly complex and medically-oriented tasks are being delegated to CHWs, but without a corresponding increase in training, professional support, or pay. College training programs for CHWs only minimally cover many of the skills that are now being assigned or delegated to CHWs. Home support agencies that deliver publicly-funded services receive a per diem hourly payment that does not recognize the need for ongoing training and staff development.
- Less time, more medicalized care: CHWs must now deliver more complex care with less time allotted per visit. Many clients and workers report on the perfunctory nature of home support visits and the loss of time for social contact. Many workers report being hard-pressed to complete care in the allotted time.

> *"They have said they have to cut hours and services and you get afraid. How are you going to manage?"*
> *— Home support client*

- Lack of communication and professional coordination: CHWs' first-hand experiences provide them with an understanding of their clients' conditions and situations, yet they have few opportunities to inform their agency of clients' needs. The increased pressure in both home support and home care means supervisors and nurses have less time to provide professional backup and support to CHWs.
- Prevention and maintenance undermined: In reducing access to basic services and cutting hours, the home support system has redefined housekeeping, social visits, emotional support, physical exercise, and nutrition as unrelated to health outcomes, despite the evidence to the contrary.

Vulnerable Clients, Vulnerable Workers

In addition to health policy, the study's findings relate to the economic security of home support workers, clients, and their families.

- Both the people who rely on public home support and the workers who provide it are mostly low-income, economically-vulnerable individuals, mainly women.

"They give you 15 minutes—30 minutes but you actually stay there for 15 minutes—the other 15 minutes is travel time. You know, you come in—'Mrs. So and So—here take your medication' and then 'bye.' That's it."
— Community health worker

- In 2003, 82 per cent of home support clients had pre-tax incomes of less than $15,000 per year. Eighty per cent are 75 or older; 10 per cent are people under 65 with disabilities; 70 per cent are women, most of whom live alone.
- Changing working and employment conditions for CHWs have had a severe impact on their economic security. In 2004, they faced a 4 per cent wage rollback, and agencies have laid off regular staff in favour of hiring casual workers with fewer benefits and fewer hours. Most of the CHWs interviewed were visible minority immigrant women.
- Lack of adequate home support has placed additional pressures on clients' families and friends, some of whom are forced to forgo employment income in order to provide care themselves.

Recommendations for the Provincial Government

- Increase funding for home support to ensure that individuals who require only prevention and maintenance supports (i.e. meal preparation, cleaning, shopping, etc.) to remain in their own homes receive the services they require, and that these services are part of the care provided to all home support clients.
- Increase integration of home support with other health services, including the provision of core funding to home support programs/agencies and better co-ordination with home care and other community health and primary care services.

"I don't have a life…I just want a little peace, a little time for me. But I don't have it… My Mom gets a pension, but it's not very much. I can't leave her, and I can't take her, I can't afford [a taxi]…and I can't take her with me on the bus, it's too much for her."
— Daughter of home support client

- Improve working conditions for community health workers and provide more opportunities for CHWs to have input into care planning, and develop a mechanism to support continuing education.
- Prioritize research on innovative models for home support delivery (both local and international) that are comprehensive, prevention-oriented, and effective in controlling costs within the broader health system.
- Increase transparency and accountability in health care by requiring health authorities to report their continuing care expenditures by category. (Health authorities are currently not required to report this breakdown, making it impossible for the public to know how much is being spent on various services, such as residential care, home support, home care, etc.)
- Establish an independent external review of the full range of continuing care services, with the goal of developing a new plan and approach to the delivery of these services.

Introduction

> *"Home support services are the mainstay in the lives of people with disabilities… More than seeing therapists and shrinks, doctors and blood counts and dialysis… I'm not saying they're not important, but what makes it work, what makes us cope with our lives, is home support service."*
>
> *— Home support client*

Home support is a vital component of a strong overall health care system; it is part of a continuum of care that includes, among other things, home-based services, residential care, physicians' offices, community health centres, hospital-based acute care and emergency care.

Home support refers primarily to personal care and support services that allow people to remain in their own homes. These services include personal assistance (bathing, grooming, etc.), basic nursing tasks (medication administration, simple wound or bowel care), and can include housekeeping and meal preparation. In short, these services represent the basic supports that people need to stay at home, but which thousands of frail seniors and people with disabilities cannot afford on their own.

In addition to providing basic care for people with chronic ailments, disabilities, or recovering from serious illnesses, home support is a form of *preventative* health care. It is preventative in that it functions as an early warning system—the "eyes and ears" of the health care system—helping to identify more serious problems as they emerge, ensuring good nutrition and hygiene, and providing essential social support and contact. As such, a solid home support system can save the overall health care system a great deal of money, by staving off more expensive emergencies and delaying the need for institutional care (i.e. acute and/or residential care). Recent headlines regarding the crisis in BC's emergency rooms are one more reminder of the price paid for a system that inadequately invests in community care (both home based and residential), and thus, cannot free-up acute care beds in a timely manner.

The idea that home health services (i.e. home care and home support) are an important foundation for a reformed health system has been widely acknowledged both in government policy documents and by the public. This idea first gained prominence in Justice Seaton's 1991 BC Royal Commission on Health Care and Costs and is captured by the report's title "Closer to Home." The report emphasizes the benefits of shifting services from acute care crisis intervention to preventive services delivered "closer to home," based on evidence indicating that shifting services in this way will improve health status and control cost increases.[1]

The current provincial government continues to articulate a commitment to this vision. As recently as the fall of 2005, a policy document on aging from BC's Ministry of Health noted that government "must change its focus from an acute care model to a 'health care' model with an increased emphasis on prevention" to reduce overcrowding hospitals and waiting lists for services.[2]

However, the idea of "closer to home" is not simply about shifting from acute crisis intervention to preventive care. It is also about the substitution of home-based care for services previously provided in institutional settings, both acute and long-term care. The 2000 CCPA report *Without Foundation* examined changes to community and continuing health (i.e. mainly residential and home-based care) introduced during the 1990s, and the implications of these changes for frail seniors and people with disabilities. The report documented the disconnect between the rhetoric and the reality of shifting care "closer to home." Although the rhetoric emphasized the benefits of community care, early intervention and prevention, the reality focused more on acute and long term care substitution.[3]

In home support, in particular, there was a dramatic increase in demand. This stemmed primarily from a combination of shorter hospital stays, improvements in technology and surgical techniques, an increase in the population of seniors, and a reduction in the availability of long term care beds (no new beds were brought on stream in the later half of the 1990s). But because funding did not keep pace with this growing demand, particularly after the mid-1990s, eligibility requirements for home support became more restrictive, with access limited to individuals with higher care needs. Those who required only non-personal care services (i.e. meal preparation, housekeeping, shopping and social support) to maintain their health and remain in their homes were increasingly denied access to publicly-funded home support, and access to support services such as meal preparation and cleaning was reduced for people with higher needs.[4]

Overall, the home support system has seen a significant shift toward servicing clients with more acute health care needs. Effectively, the home support system has been used as a less expensive means of propping-up a shrinking long-term and acute care system, rather than as a broadly accessible means of providing health prevention and maintenance. Because home support services are not protected under

The Wider Context

The decline in publicly-funded home support and home care is occurring in the context of wider cuts and restructuring to the overall health care system. While overall health care spending has increased, the number of residential care beds has been in decline, as have the number of acute care beds. As noted in the 2005 CCPA study *Continuing Care: Renewal or Retreat?:*

> *The decision of the provincial government and health authorities to reduce access to residential care and home health services at the same time as they were cutting hospital services has disastrous implications. Frail seniors and people with disabilities, some of BC's most vulnerable citizens, and their families are paying a heavy price for the cuts, which also have a direct impact on all British Columbians, who depend on and pay for our public health system.*

the Canada Health Act, changes in eligibility for services can be implemented through a simple policy directive issued by the Ministry of Health.[5]

For people with disabilities or frail seniors with chronic ailments these changes were very significant. For many of these individuals, it was the basic services—meal preparation, social support, house cleaning—that made it possible for them to retain their independence, manage their day-to-day health challenges, and continue to be involved with family and friends.

Glossary

CONTINUING CARE: Also referred to as home and community care. Continuing care refers to the range of programs, from home health services to residential care, whose objective is to maintain, restore, or improve the health and functioning of frail seniors and people with disabilities. Current programs include home-based services (home support, rehabilitation and home nursing), community-based services (adult day care and respite care), assisted living, and residential care. Each health authority has a continuing care (or home and community care) division. Eligibility for these services is based on an assessment by a continuing care assessor. The assessor determines the type and level of services required, monitors ongoing care, and makes necessary adjustments.

CARE LEVELS: Continuing care services classify individuals by care level. The classification system consists of three groups: personal care, intermediate care, and extended care. Within these groups, intermediate care is divided into levels 1, 2, and 3. The care levels move in progression from the lighter care requirements of personal care, through the intermediate levels, to the heavier care requirement of extended care.

HOME HEALTH SERVICES: These services involve all professional and non-professional health services provided to individuals in their own homes. They include home support, home care and rehabilitation services. The community and home services divisions of the regional health authorities assesses clients' eligibility for publicly-funded home health services. Individuals may also purchase these services privately.

HOME CARE: Home care services are provided by health authorities, which employ professional nurses (i.e. Registered Nurses) to provide services (including post-acute, chronic and palliative care) to individuals in their own homes.

HOME SUPPORT: Home support services are provided by health authorities or contracted agencies, which employ community health workers (CHWs) to provide primarily personal care and support services that assist people to remain in their own homes. Services include personal assistance (e.g. bathing, dressing), basic nursing tasks (e.g. medication administration, simple wound or bowel care), and can include housekeeping and meal preparation.

COMMUNITY HEALTH WORKER/HOME SUPPORT WORKER: These are the front-line workers who provide home support services to clients in their own homes. Until the mid-1990s, these workers were known as 'home makers' or 'home support workers' and had little formal training. Most community health workers today have completed a college program, about six months in duration, that includes training in personal care and support for frail seniors and people with disabilities.

The report updates and expands on *Without Foundation* by focusing on the post-2001 period and the current government strategy for "Continuing Care Renewal." The April 2005 CCPA report *Continuing Care Renewal or Retreat?* documented the broader restructuring of services between 2001 and 2004, including bed closures in both acute and long term care, and the substitution of Assisted Living and home health services for residential care.[7] In documenting these changes, comparisons with other Canadian jurisdictions were used to illustrate their extent and significance. In 2001, BC already had the leanest in-hospital system in the country.[8] And yet from March 2002 to March 2004, additional cuts reduced acute-care capacity by a further 19 per cent. In long-term care the story is even more dramatic: in 2001, BC was near the national average with respect to access to long-term care for seniors aged 75 and over. As a result of long-term care closures, however, by 2004 BC had the lowest access for seniors 75 and over (along with New Brunswick), even taking into account the increases in Assisted Living units.[9]

> The BC Ministry of Health claims that, "Since 2001 home care and home support services have been enhanced in many areas." Yet its own statistics tell a different story.

The goal of this current research is to examine the implications of this broader health restructuring for home support. The Ministry of Health claims that, "Since 2001 home care and home support services have been enhanced in many areas." Yet its own statistics tell a different story.[10] This report includes an analysis of Ministry of Health statistical data for the entire province, as well as qualitative evidence based on interviews with home support clients, workers, and informal caregivers (family members and friends) from the Greater Vancouver area. The report focuses on current pressures within the home support system, within the context of broader health restructuring, including the:

- implications of relocating personal care and medical services, previously offered in long-term and acute care settings, to the individual's own home;
- support (or lack thereof) for workers to provide these more medically-oriented services; and
- implications for continuity of care and monitoring changes in clients' health caused by the removal of support services for activities of daily living (i.e. meal preparation, shopping, cleaning, etc.).

In other words, this report examines in more depth the trends that were beginning to emerge in the *Without Foundation* study and that have accelerated in the post-2001 period. Because of increased demand for home support to serve as a substitute for acute and long-term care, it is not clear that home support can retain its core function of maintenance and prevention. This function is central to the goal of supporting people to live independently in the community, and in preventing or delaying the onset of health crises that could result in admission to a long-term or acute care facility.[11] As a result, policy changes introduced since 2001 may have the opposite effect to those intended; that is, they may further increase pressure on the already over-strained acute and long-term care services, by failing to provide the preventative and maintenance services required to maintain individuals in their own homes.

Home Support as Prevention

> *Home support workers deliver the basics: a washed floor, a clean bathroom, a stocked fridge, a hot meal, laundered sheets and shirts, a safe bath. They perform health care tasks such as changing dressings and urine bags. They provide other essentials, too: a conversation, a watchful eye, a reminder to eat and take a pill, a risk free walk to the store, a touch.*[6]

The decline in home support services, in addition to being a health issue, is also related to issues of economic security. Both the people who rely on public home support and the workers who provide this care are predominantly low-income and economically vulnerable individuals—mainly women. The restrictions to public home support outlined in this report leave people with limited and unsatisfactory options:

- few clients are able to afford to pay for care privately, thus they must either do without, dip into money needed for other essentials, or call upon informal caregiving from friends and family;
- these informal caregivers, in turn, risk losing paid work, and experience the additional stress of juggling employment with family obligations; and
- the workers who provide home support services have increasingly seen their permanent employment made casual, their pay reduced, and their shifts shortened and split.

THIS REPORT IS ORGANIZED INTO THREE SECTIONS. The first section outlines the evolution of the home support system in BC. It is followed by a statistical portrait describing the home support client population, the changes over time in client access to home support, regional differences in the allocation of home support services, and inter-provincial comparisons.

Statistical portraits, however, tell only part of the story. To more fully understand how reduced access in the face of mounting needs affects peoples' real lives, the third section shifts to a qualitative approach, focusing on the implications of these changes from the perspective of the clients, workers and informal caregivers who are the front-line of the home support system. The experiences of these people, often shared in their own words, is compelling and powerful. Their stories reveal a system that is under severe strain, undermining the health and wellbeing of clients, placing undue pressure on caregivers, disrupting continuity of care, reducing hours for clients, and eroding the preventative role of home support in BC.

The Evolution of Home Support: A Brief History

In the decades following the Second World War, home support began in BC as an income-tested, community-based homemaking service under the provincial Department of Rehabilitation and Social Improvement, the department that provided welfare and other services to low-income British Columbians.[12] Eligible clients were ill mothers (primarily low-income single parents) requiring childcare, chronically ill or convalescent adults, and elderly people still capable of some self-care. (Physically disabled people were not eligible for these programs at the time.)

By the late 1960s, BC was a leader in home support with 21 home support workers per 100,000 population compared with a Canadian average of nine.[13] In 1969, BC provided the most rurally accessible services in Canada, with 13 of its 29 home support agencies located in rural communities of less than 10,000 people. From the 1970s through to the late 1980s BC consistently spent the highest proportion of healthcare funds on home care and home support services of any province (Figure 1).[14]

During this time, BC's home support services were strongly oriented toward prevention and maintenance. The preventive and maintenance role of home support workers was achieved through the program's ability to maintain continuity of care—allowing workers to get to know and regularly monitor clients in order to detect functional changes and report at-risk clients for preventive interventions.

When the government introduced the Long Term Care Program in 1978, it included residential care homes as well as home support services. With this shift, home support was officially recognized as a health (rather than welfare) service.[15] In 1980, the government amalgamated the Long Term Care Program (later renamed the Continuing Care Division) with home nursing and physiotherapy and created a single point of entry (i.e. assessment) for clients to all of these services. The single point of entry made it easier for clients to access a range of services, and BC's early leadership in this area was recognized nationally.[16]

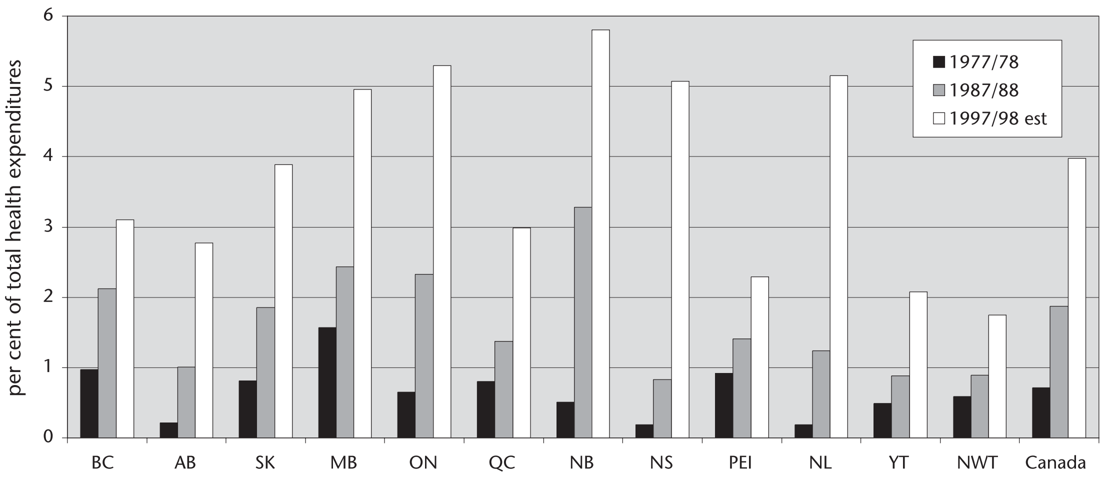
At the time, home support services were "to provide personal assistance with activities of daily living and/or essential household tasks which the client was unable to perform independently."[17] Home support workers could assist with bathing, dressing, nutritional services (meal preparation, grocery shopping, food expiration monitoring), household cleaning, minor household repairs, walks, and transport to medical appointments. The home support program also encouraged home support workers to socialize with their frequently housebound, primarily low-income clients.

As the 1980s unfolded, however, BC's home support programs began to devote an increasing proportion of their budgets to clients with higher care needs. Significant shifts also occurred in the home service client population. Median client age rose from 51 years in 1976 to 77 years in 1988.[18] The number of clients living alone rose from 41.4 per cent in 1976 to 82 per cent in 1988, although the predominance of female clients, roughly 80 per cent, remained unchanged over the 12-year period. These trends were driven by a combination of the aging population, increased female life expectancies relative to males, and the shift to servicing clients with more complex health care needs (i.e. the development of home-based health services as an alternative to institutional care).

In 1991, BC's Royal Commission on Health Care and Costs, chaired by Justice Peter Seaton, recommended regionalizing services and integrating preventative home support and other community health services. The idea was to create a continuum of care that would limit unnecessary hospital and long-term care expenditures.[19] Throughout the 1990s, based on the recommendations of the Commission, the BC government reduced hospital acute care utilization by shortening lengths of stay and shifting from in- to out-patient care.[20] Yet the orderly and integrated transfer of resources to the community, as envisioned by Justice Seaton, did not occur.

In the mid-1990s, the federal government slashed healthcare transfers to the provinces. While the BC government, unlike others across Canada, did not close hospitals, the reduction in federal funding had an impact on the home support sector. As the acute care system released people "quicker and sicker," home support became more focused on post-acute care and less on prevention and maintenance, and in particular experienced cutbacks in the provision of non-personal services (housekeeping, meal

Figure 1: Share of Provincial Expenditures Spent on Home Health Services by Province, 1977/78, 1987/88 and 1997/98



Note: Source data is provided in Appendix D.

Source: Health Canada. 1999.

preparation, social support and shopping) required for low-income frail seniors and people with disabilities to remain at home.[21]

A 1997 report by the BC Association of Community Care (a provincial organization that represented and advocated for non-profit long-term care and home support agencies) highlighted the effects of increasing client acuity on the province's home support system.[22] The report expressed concern about the continued expansion of home support workers' scope of responsibilities. This was occurring as clients' increasingly complex needs required workers to deliver more sophisticated and more medically-oriented services. Mounting supervisory workloads left supervisors less able to support and monitor home support workers, leading to concerns about worker stress and isolation.

When the provincial government first regionalized health services in 1997, the BC Association of Community Care was subsumed under the BC Health Association, which had until that time been the advocacy organization for the acute care sector. Not surprisingly, the larger acute care sector dominated continuing care in its access to resources and its decision-making powers. In 2001, when the government consolidated 52 regional health organizations into six health authorities, the BC Health Association itself was disbanded. In other words, as a result of two successive phases of regionalization, non-profit home support agencies lost the capacity to organize provincially and advocate directly for their members with the provincial government.

At present, all representations to the provincial government are organized through the six mega-health authorities. In terms of the overall budgets of the health authorities, home health services, both home care and home support, are very minor players with limited influence.[23] And as the qualitative study in section three of this report shows, many of the concerns raised in the 1997 report from the BC Association of Community Care—high levels of acuity, reduced supervision, and increased scope of responsibility for workers—have not been addressed to this day.

As the acute care system released people "quicker and sicker," home support became more focused on post-acute care and less on prevention and maintenance.

While BC's health care system increasingly relies on home support as a mainstream health service, many aspects of home support remain unchanged from the 1960s, when it was an adjunct to the welfare system. The funding mechanisms for services and clients are two cases in point. First, health authorities continue, for the most part, to provide funding for home support on an hourly basis for specified services. In other words, home support has not evolved into a globally (i.e. core) funded program integrated with other aspects of community care. Instead, it continues to be a stand-alone service faced with increasing demands to deliver more acute services for each hour of care. As the emphasis on medically-oriented care increases, there is a need for greater integration of home support with other more mainstream health services such as professional nursing and physician care (e.g. to manage care for people with chronic ailments). The implications of the failure to integrate home support with other more mainstream health services is explored in more depth in the third section of this report.

Second, the income-testing of home support clients (e.g. the fact that clients with higher income pay a user fee for services) is another legacy from the past, when home support was an adjunct to the welfare system, and represents a form of "passive privatization" of health services. As medical and personal care services that were fully funded under Medicare in hospitals are shifted to the home and provided by home support workers, costs are transferred to individuals through a user fee based on income. In addition, and probably even more importantly, because it is primarily the medical and personal care dimensions of acute and long term care that have been relocated to the home and NOT the supports for daily living (i.e. meal preparation, housekeeping, etc.), the cost for these supports have shifted to individuals regardless of their income. The implications of this shift in costs to clients and their families, many of whom are low income, are discussed at length in the qualitative findings of this report.

A Statistical Portrait of Clients and Services

Fewer Clients, Higher Needs

This section examines the overall changes since regionalization in clients' access to home support by care level and by health authority, using data from the BC Ministry of Health PURRFECT database.

With the increased reliance on home support to serve as a substitute for long-term and acute care, one would anticipate an increase, over time, in clients with higher needs (i.e., Intermediate Care 3 (IC3) and Extended Care (EC)). The key question is whether the increased demand for home support services for higher-needs clients is being answered with additional services, or instead tightened eligibility that limits access to services for people with more moderate needs (i.e. Personal Care (PC), Intermediate Care 1 and 2 (IC1, IC2)), many of whom require only non-personal services (i.e. meal preparation, housekeeping, shopping, etc.) to maintain their independence.

From Figure 2 the answer is clear: services have shifted dramatically from clients with limited care needs (PC and IC1) to those with higher level needs (IC3 and EC). From 1997/98 to 2004/05 there was an 80 per cent reduction in access for clients with limited care needs, and an increase of 35 and 21 per cent for IC3 and EC clients respectively.

Given the broader restructuring in the health system since 2001, it is not surprising that this shift has since accelerated. The number of clients with limited needs receiving home support services declined by 40 per cent (from 27,440 to 16,550) between 1997/98 and 2000/01. In the four years since 2000/01, this decline accelerated to 67 per cent (from 16,550 to 5,451). And while access for clients with moderate needs (IC2) increased by 12 per cent from 1997/98 to 2000/01, it declined by approximately 22 per cent in the post-2001 period.

GLOSSARY

CARE LEVELS: Continuing care services classify individuals by care level. The classification system consists of three groups: personal care, intermediate care, and extended care. Within these groups, intermediate care is divided into levels 1, 2, and 3. The care levels move in progression from lighter care requirements of personal care, through the intermediate levels, to the heavier care requirement of extended care.

It is also significant to note that the increase in the number of clients with the highest needs was much less steep than the dramatic decline in the number of clients with more moderate needs.

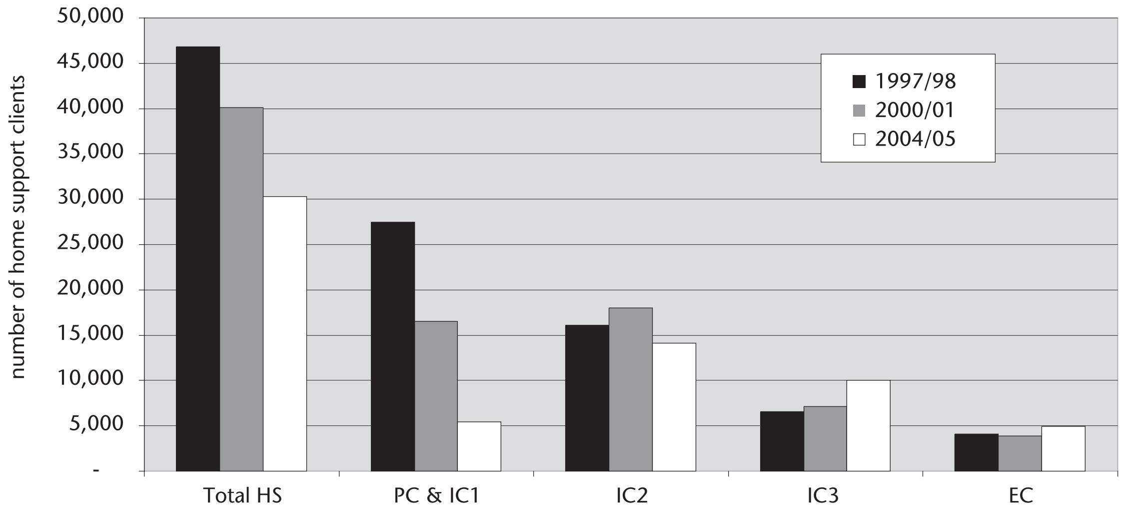
Table 1 takes a longer view of the changes in home support.[24] What is particularly remarkable is the overall reduction in the number of clients with access to home support over the 11 years from 1993/94 to 2004/05, a decline by almost 50 per cent, from 59,857 to 30,323 clients.

This downshift in access occurred while the number of BC seniors age 75+ increased by 47.8 per cent.[25] It is also interesting to note that the largest single-year drop in clients occurred between 1994/95 and 1995/96, the year the federal government dramatically cut transfer payments to the provinces.

Clients with higher needs require more hours of care. As home support shifted to higher-need clients, there were fewer clients receiving more hours of care (Table 1). Thus, hours of care did not decline as rapidly as the number of clients, although there was a reduction in hours as well, particularly since 2000/01, when they declined by 12 per cent.

From 2000/01 to 2003/04, funding for BC's Health Authorities increased by 21 per cent.[26] However, after 2001 the Ministry of Health no longer required health authorities to report their expenditures by

Figure 2: Home Support Clients in BC by Care Level, 1997/98, 2000/01, and 2004/05



Note: For a given year, the total home support client count is less than the sum of the client counts for the four levels. This is because clients receiving more than one level of care in a given year are counted once for each level of care they need, but when counting total home support clients they are only counted once. Source data is provided in Appendix D.

Sources: Ministry of Health PURRFECT database including the following: Data for 1997/98 comes from PURRFECT ver. 7.1, CCASUR ver. 1.30, report date Oct. 26, 2004. Data for 2000/01 comes from PURRFECT ver. 8.1, CCASUR ver. 9i, report date Oct. 21, 2004. Data for 2004/05 comes from PURRFECT ver. 11.1, CCASUR ver. 11.1, report dates March 5-6, 2006.

sector (i.e. acute, long-term care, home support, etc.). Consequently, it is impossible to determine the extent to which expenditures for home health services have increased or decreased relative to institutional care. The reduction in hours and clients suggests, however, that *if* there was a modest increase in funding for home support, it was woefully inadequate, particularly given the overall increase in health authorities' budgets.

There has been some very interesting research, from British Columbia as well as from Denmark and Sweden, examining the cost implications, in both financial and human terms, of the elimination of preventive and maintenance home support for clients with limited needs. In BC, changes in eligibility requirements in the late 1990s, which restricted access to people with limited needs (i.e. PC and IC1 clients who required non-personal care services such as housekeeping, meal preparation, and social support), were not implemented uniformly across the province. This created a natural experiment that allowed Victoria-based researchers Marcus Hollander and Angela Tessaro to compare overall health care expenditures for clients from health units that had implemented the cuts with those that had not.[27] Although there were few differences in the first year following the cuts, the differences in costs increased significantly over time.[28] By the third year, per capita overall health expenditures for clients from the health units that implemented the cuts were $4,095 (or 34 per cent) higher than those from health units that did not reduce home support for those with limited needs. In other words, in health units where basic preventive and maintenance services were cut, clients were significantly more likely to be admitted to long-term residential care and/or use acute and home support services two to three years down the road.

Table 1: Number of Home Support Clients Served in British Columbia by Fiscal Year

Fiscal year	Client count	Hours
1993/1994	59,857	7,755,166
1994/1995	58,201	7,774,009
1995/1996	50,726	7,201,066
1996/1997	47,779	7,339,660
1997/1998	46,831	7,774,179
1998/1999	46,362	7,876,210
1999/2000	42,379	7,459,578
2000/2001	40,086	7,141,624
2001/2002	38,263	7,226,054
2002/2003	34,093	6,646,538
2003/2004	32,046	6,424,922
2004/2005	30,323	6,287,142
93/94 to 00/01 % Change	-33.0%	-7.9%
00/01 to 04/05 % Change	-24.4%	-12.0%

Sources: Ministry of Health databases including the following: 1993/94 to 1996/97 from PURRFECT 5.0, CC Data Warehouse, September 1999 refresh. Data for 1997/98 comes from PURRFECT ver. 7.1, CCASUR ver. 1.30, report date Oct. 26, 2004. Data for 1998/99 to 2000/01 comes from PURRFECT ver. 8.1, CCASUR ver. 9i, report date Oct. 21, 2004. Data for 2003/04 comes from PURRFECT ver. 10.1, CCASUR ver. 10.1, report date May 16, 2005. Data for 2004/05 comes from PURRFECT ver. 11.1, CCASUR ver. 11.1, report dates March 5-6, 2006.

Research comparing the Danish and Swedish eldercare systems resulted in similar findings. Denmark provides more home support for seniors, including seniors with limited needs, and does not charge clients for these services. In contrast, Sweden charges user fees for home support, and provides fewer services, concentrated at higher care levels.[29] And yet, overall eldercare costs are lower in Denmark than they are in Sweden.[30] In discussing these differences, Stockholm University professor Marta Szebehely points out that providing care for people with limited needs does not require very large resources (in Denmark it is only 10 per cent of the home support budget):

> *Yet these small provisions may considerably improve the quality of life for elderly people and may help them to manage at home longer. For a frail wife caring for her even frailer husband a few hours of home care a week may be an important relief, especially if the service system quickly can respond to changes in the couple's situation (his needs increasing or her strength declining).*[31]

This example points to the key role played by home support workers in prevention. They are the "eyes and ears" of the health system, monitoring changes in health status and ensuring continuity of care for clients.

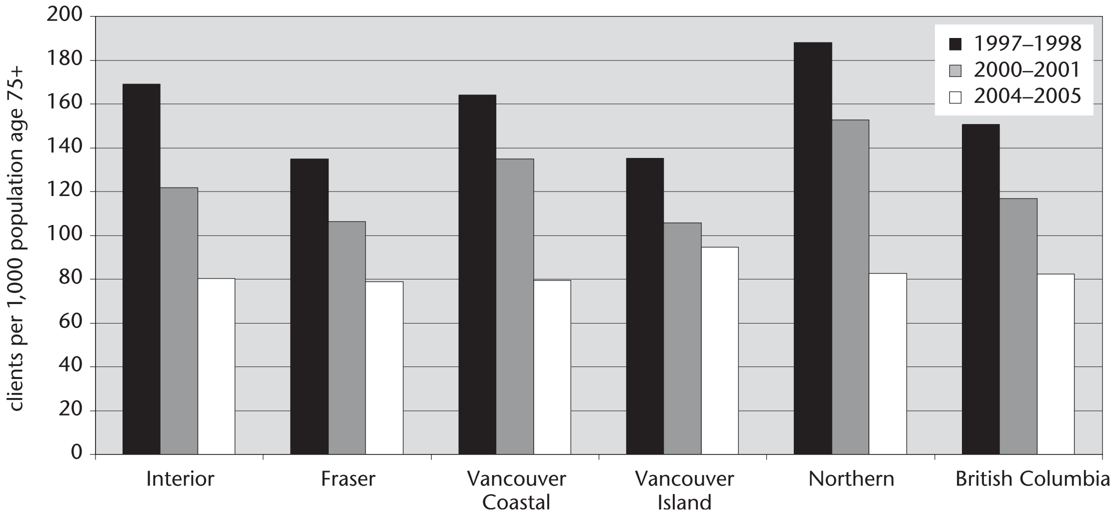
These findings suggest that cuts to home support services for prevention and maintenance may well demonstrate the principle of "penny wise and pound foolish," a point reinforced by the qualitative research presented in the third section of this report.

Decline in Home Support by Health Authority

Figure 3 shows the decline in home support for clients in BC's five regional health authorities. To take into account that the number of older seniors varies from region to region, these numbers are standardized to "clients per 1,000 population 75 years or older."

The decline in the number of clients served was most dramatic in the Northern Health Authority (56 per cent) and least dramatic in the Vancouver Island Health Authority (30 per cent). By 2004/05, the

Figure 3: Home Support Clients per 1,000 Population Age 75+, by Regional Health Authority



Note: Source data is provided in Appendix D.

Source: Ministry of Health, PURRFECT, CCASUR – Cont. Care Age-Standardized Util. Rates. Data for 1997/98 comes from PURRFECT ver. 7.1, CCASUR ver. 1.30 report date December 1, 2005. Data for 2000/01 comes from PURRFECT ver. 8.1, CCASUR ver. 9i, report date December 1, 2005. Data for 2004/05 (and all population data) comes from PURRFECT ver. 11.1, CCASUR ver. 11.1 report date March 6, 2006. Population data used data for first year of the date range (i.e. 1997 population is used for 97-98). These data reflect clients age 75+ per population age 75+.

Vancouver Coastal and Fraser Health Authorities were serving the fewest home support clients per 1,000 population aged 75 or over.

In summary, in the late 1990s, health authorities varied substantially in the number of home support clients they served. By 2004/05, however, all the health authorities served a much lower and more similar (age-adjusted) numbers of clients.

However, when we compare clients and hours at the community level (i.e. the local health areas, see Appendix A), variations both over time and between communities are much larger. Some, although certainly not all, of the variation between local health areas may be explained by differences in the income and health status of the seniors' population, the availability of alternate services, and/or differences between rural/remote and urban communities. Other differences, however, may reflect the strength of community advocacy for these services, historical differences in the application of health authority policies, or reporting errors.

Although a full analysis of the reasons for these differences is beyond the scope of this paper, further research in this area could prove very fruitful. For example, in 2004/05 the community with the greatest number of clients per 1,000 population age 75 and over was Saanich with 184.7 clients, whereas South Okanagan had the lowest with 40 clients per 1,000 population 75 and over. A comparison between communities that focuses on the reasons for the disparities, and an analysis of the impact of these variations on health status and the utilization of other health care resources, could be telling.

> These findings suggest that cuts to home support services for prevention and maintenance may well demonstrate the principle of "penny wise and pound foolish."

Reduced Access to Home Care

In a 2003 Ministry of Health planning document for the Continuing Care Renewal program, the Ministry acknowledged the need to increase access to home-based services to compensate for the reduction in long term care beds.[32] Although the focus of this study is on home support, it is also important to consider changes in home care (i.e. professional nursing care) over the same period. As Table 2 indicates, while the reduction in access to home care services was not as large as for home support—8 per cent compared to 30 per cent—fewer seniors 75 and over were able to access home care in 2004/05 than in 2000/01.

In other words, despite recognition in the 2003 Ministry of Health planning document that more, not fewer, home-based services would be required as the health authorities implemented reductions in

Table 2: BC Home Care and Home Support Clients per 1,000 Population 75+, 1997/98, 2000/01 and 2004/05

	1997/98	2000/01	2004/05	% change 1997/98–2000/01	% change 2000/01–2004/05	% change 1997/98–2004/05
Home care clients per 1,000 seniors 75+	70	65	59	-7%	-8%	-15%
Home support clients per 1,000 seniors 75+	151	117	82	-22%	-30%	-45%

Source: Ministry of Health, PURRFECT, CCASUR – Cont. Care Age-Standardized Util. Rates. Data for 1997/98 comes from PURRFECT ver. 7.1, CCASUR ver. 1.30, report date December 1, 2005. Data for 2000/01 comes from PURRFECT ver. 8.1, CCASUR ver. 9i, report date December 1, 2005. data for 2004/05 comes from PURRFECT ver. 11.1, CCASUR ver 11.1, report date March 6, 2006. Population data used data for first year of the date range (i.e. 1997 population is used for 97-98). These data reflect clients age 75+ per population age 75+.

long-term care, the increase in services has not occurred.[33] This absence points not only to the lack of accountability within the health system, but to pressures on staff in both home care (i.e. registered nurses) and home support (i.e. community health workers) who must cope with ever-increasing demands with limited resources. Moreover, because home support clients have higher, more medically-oriented needs than in the past, there is a need for more, not less, co-ordination, support and backup from home care nurses. This may be very difficult to achieve given the growing demands on home care nurses. These issues are considered in more depth in the qualitative study in the third section of this report.

Inter-Provincial Comparison

Inter-provincial comparison is useful in analyzing whether the restructuring of home care and home support in BC reflects national trends. Although inter-provincial comparisons are not yet available on a yearly basis, the Canadian Institute for Health Information (CIHI) did examine changes in the number of home health clients (i.e. both home care and home support) per 1,000 population (i.e. all ages) over a six year period from 1996/97 to 2002/03 (Table 3).

Nova Scotia is the only province other than BC to have reduced access to home health services over this period. In 1996/97, BC was 17 per cent above the national average; by 2002/03, it had fallen to the third lowest in the country, 24 per cent below the national average.

This inter-provincial comparison suggests that the choices made in BC, in relation to home health restructuring, were not standard across the country. Different choices were possible and would have been preferable, particularly given the evidence of the benefits of preventative and maintenance care in improving health status and controlling overall health expenditures.

Table 3: Number of Home Care and Home Support Clients per 1,000 Population, by Province, in 1996/97 and 2002/03

	1996/97	2002/03	Per cent difference from 1996/97 to 2002/03
Nova Scotia	19	12	-34.7
British Columbia	27	19	-30.0
Saskatchewan	27	28	+3.0
Alberta	24	26	+7.1
Manitoba	26	29	+12.3
Ontario	28	34	+21.8
Yukon	11	14	+30.9
New Brunswick	33	45	+37.3
NWT	10	37	+274.0
PEI	21	Missing	
Quebec	38	Missing	
Canada	23	25	+6.5

Notes: Data missing in 2002/03 for Quebec and PEI. Data from 2002/03 converted from a rate per 100,000 to per 1,000 in order to compare with 1996/97 data.

Source: Ostry, 2006.

Profile of Home Support Clients in BC

This section focuses on specific characteristics of the clients who use home support services in BC—their ages, gender and income levels. The analysis is based on data from the Ministry of Health Continuing Care Database for 1993, 1998 and 2003.[34]

In 2003, 80 per cent of home support clients were 75 or older, and 10 per cent are people under 65 with disabilities (see Appendix B). Approximately 70 per cent are women, most of whom live alone.

The analysis confirms that both single seniors aged 65 and over (Table 4) and people with disabilities have very low incomes. In 2003, 82 per cent had annual pre-tax incomes of less than $15,000 (in 2000 dollars). These income levels are below Statistics Canada's pre-tax Low Income Cut-Off (LICO) for individuals living in a town of between 30,000 and 99,999 people.[35]

In other words, the majority of clients in the home support system are poor elderly women whose only resources are the Guaranteed Income Supplement and Old Age Security benefit. These women tend to live alone, are often isolated, and are almost completely reliant on the subsidized home support services they receive.

> The majority of clients are poor elderly women whose only resources are the Guaranteed Income Supplement and Old Age Security benefit. These women tend to live alone, are often isolated, and are almost completely reliant on the subsidized home support services they receive.

Not surprisingly, when we compared our estimates of home support clients' incomes with those for BC's entire population over age 65 (as measured in the year 2000 using Census data), the home support population was considerably poorer (see Table 5). For example, in 2003, 82 per cent of home support clients over age 65 earned pre-tax incomes of $15,000 or less, while only 53.9 per cent of BC's seniors overall had incomes this low.

Moreover, despite common misperceptions about "wealthy seniors," it cannot be assumed that most seniors have untapped wealth that can be drawn upon to pay privately for home support. Amongst all BC seniors age 65 and older, the median total wealth in 1999 was $203,201.[36] It can reasonably be assumed that this mostly represents the value of housing for which mortgages are paid off. Therefore the wealth of seniors is not large enough to constitute extra money for home support costs, unless it is society's view that seniors should be expected to take out second mortgages to pay for home support.

Table 4: Income Distribution of Single Home Support Clients Aged 65 and Over

Pre-tax income (expressed as dollars in the year 2000)	Per cent of home support clients		
	1993	1998	2003
Under $15,000	79.5%	80.6%	82.0%
$15,000 – $29,999	15.8%	13.9%	12.1%
$30,000 – $49,999	3.7%	3.9%	4.5%
$50,000 and over	1.0%	1.5%	1.4%

Source: Continuing Care Data Warehouse data file provided on October 20, 2005 by the UBC Centre for Health Services and Policy Research (CHSPR). The methodology for converting CHSPR data into income categories comparable to Census data is available from the authors on request. This table describes home support clients in British Columbia for singles aged 65+ for both men and women. All income figures are pre-tax.

Finally, it is important to note that people with disabilities who receive home support (but who are under age 65) also have very low incomes (see Appendix C). In 2003, 82 per cent had an annual income of $15,000 or less. This suggests that, like frail seniors who access home support services, the vast majority of people with disabilities are also on fixed incomes and can ill afford to pay for these services privately. The cuts in assistance with tasks such as meal preparation, cleaning, and shopping, may be particularly difficult for this population.

The fact that home support is income-tested rather than universal, and therefore serves a very low income and marginalized population with little political clout, may partly explain why the dramatic cuts to this sector have received so little attention in the media and in policy debates.

Table 5: Comparison of Pre-Tax Income of Home Support Clients and 2000 BC Census Population (Single Seniors 65 +)

Pre-tax income (2000 dollars)	Home support clients			2000 Census
	1993	1998	2003	
Under $15,000	79.5 %	80.6 %	82.0 %	53.9 %
$15,000 – $29,999	15.8 %	13.9 %	12.1 %	23.1 %
$30,000 – $49,999	3.7 %	3.9 %	4.5 %	15.9 %
$50,000 and over	1.0 %	1.5 %	1.4 %	7.0 %

Source: Authors’ calculations using the Continuing Care Data Warehouse data file provided on October 20, 2005 by the UBC Centre for Health Services and Policy Research (CHSPR), and the Statistics Canada 2001 Census. The methodology for converting CHSPR data into income categories comparable to Census data is available from the authors on request.

Qualitative Findings

The Impact of Home Support Cuts on Clients, Workers and Families in Greater Vancouver

A number of questions emerged in the historical and statistical discussion requiring further investigation through a more qualitative methodology. For example, to understand the implications of the shift away from the preventative and maintenance role of home support, it is important to examine issues such as continuity of care, the role of community health workers (CHWs) in monitoring and reporting changes in clients' health status, and the impact on clients' health and wellbeing when basic services such as meal preparation and shopping are withdrawn.

At the same time, with the increased emphasis on acute and long-term care substitution and on medically-oriented care in the home, it is also necessary to investigate issues such as training for CHWs, co-ordination and support from supervisors and registered nurses, and assistance for informal caregivers.

The following qualitative component of this study examines these concerns from the perspective of the community health workers, clients and informal caregivers (family members and friends) who are on the front lines of the system. The study focused on Greater Vancouver, featuring home support services provided in the Vancouver and Richmond delivery areas of the Vancouver Coastal Health Authority (VCHA).[37] As is demonstrated here, the lack of sufficient funding for home support impacts the economic security, health and wellbeing of workers, clients and their informal caregivers in a multitude of ways.

Because the configuration of services may vary from community to community, it cannot be assumed that these findings are reflective of the situation across the province. It is worth noting, however, that the general pattern of changes in the number of home support clients and the hours of care delivered in the VCHA is similar to the province as a whole (Figure 3). At the same time, it is important to acknowledge that this study does not include individuals who are no longer eligible for home support, nor does it deal with issues of frail seniors and people with disabilities living in rural and remote communities.

To provide some historical background for the qualitative study the research team reviewed policy documents and conducted interviews with home support managers, supervisors, schedulers, and home care nurses in Richmond and Vancouver.[38] This background is reported first, followed by a description of the methodology for the qualitative study.

Background to the Qualitative Study

Health delivery areas have restructured their home support services in a variety of ways. In the 1990s services in the Vancouver home support system were delivered through 10 externally-contracted agencies, reduced to five (two for-profit, three not-for-profit) in the late 1990s. Within the health care system, clients are referred to these agencies by various health professionals, including case managers, home care nurses, occupational therapists, and physiotherapists as well as hospital discharge coordinators, emergency and palliative social workers, and geriatric outreach program staff.[39] The agencies are responsible for scheduling coordination between CHWs and clients, CHW supervision and training, and quality assurance.

While Vancouver reduced the number of home support agencies from 10 to five, it did not attempt to integrate home support with home care, and continues to have different reporting structures for each. As a result, managers responsible for these two services have few opportunities for direct communication and co-ordination.[40] This finding raised concerns among the research team, given the increased acuity of home support clients and the requirement for more, not less, co-ordination with professional nursing to ensure good quality care. These concerns are further explored in the qualitative findings to follow.

Vancouver's restructuring is just one possible approach to creating localized geographies of home support across a region of widely differing client populations. Richmond Health Services has chosen to internalize its previously externally-contracted home support services. In the process, it has created an in-house home support delivery model.

Prior to 2001, Richmond contracted with two external home support agencies, one for-profit and the other not-for-profit. In 2001, it absorbed the non-profit agency and gave notice to the for-profit agency that its contract would not be renewed. In 2002, Richmond's newly consolidated home support services moved into Richmond Hospital, where long-term care case management, home care nursing, and home

GLOSSARY

COMMUNITY HEALTH WORKER/HOME SUPPORT WORKER: These are the front-line workers who provide home support services to clients in their own homes. Until the mid-1990s, these workers were known as 'home makers' or 'home support workers' and had little formal training. Most Community Health Workers today have completed a college program, about six months in duration, that includes training in personal care and support for frail seniors and people with disabilities.

care rehabilitation were already housed. Richmond appointed a manager to oversee both home care nursing and home support and, at the same time, eliminated office staff, reduced the supervisory team to two RN supervisors for 225 CHWs, and cut roughly 1,000 clients from the system.[41]

Home support services in Richmond are still reeling from this combination of cutbacks and restructuring. This more centralized structure was again reconfigured in 2004 as Richmond added an additional supervisor and began to implement a decentralized model of 'cluster care' based on existing long-term care facilities.[42] Richmond is developing 'campuses of care' around the four existing intermediate care facilities and one extended care facility.

While our background interviews suggest Vancouver and Richmond home support structures differ, the basic roles of workers and managers are surprisingly similar. Using standardized assessment tools, case managers assess clients' eligibility for gaining access to services through a single entry system. Case managers are key personnel, as they control the amount and type of resources allocated to a client. And the problems of higher levels of client acuity, the difficulty in gaining access to professional nursing support, and providing preventive care were common to both.

> In 2002, Richmond eliminated office staff, reduced the supervisory team to two RN supervisors for 225 CHWs, and cut roughly 1,000 clients from the system.

Qualitative Methodology

The qualitative study of clients, informal caregivers and workers is based on focus groups and individual interviews that allowed participants to discuss issues in response to open-ended questions. We conducted a total of 10 focus groups and three individual interviews. Sixty-five individuals participated in the study. The research included 26 workers in four focus groups (supplemented with a demographic survey of the participants), 36 clients and three informal caregivers.[43]

The research team selected participants primarily through a purposive sampling design to reflect a wide range of the types of home support provided and the diversity of those who receive care in Greater Vancouver.[44] Because of sampling problems in Richmond, we included a client focus group in the neighbouring suburb of Surrey, which allowed us to broaden our range of client characteristics regarding race and ethnicity.[45] Participants were recruited through workplaces/residences, unions, and agencies. Union stewards selected CHWs randomly, whenever possible, from union seniority lists, and otherwise selected workers to reflect a broad spectrum of experience.[46] Several agencies that provide services for people with disabilities, seniors, immigrants, and individuals with low incomes put us in contact with home support recipients and informal caregivers. While the research team was able, with the help of agencies and unions, to recruit a wide range of workers and clients, we had difficulty locating informal caregivers. Because of their caring responsibilities, they may not have had the time to take part in the study and/or they may have had difficulty making arrangements for substitute care.

A researcher conducted all the focus groups and interviews between November 2004 and April 2005 at community centres, agency offices, residential buildings, or individuals' homes. An interpreter assisted the researcher with a South Asian client focus group. The transcripts of the taped focus groups and interviews were completed in July 2005.

Profile of Participants

The clients/patients who participated in the study had a variety of acute, chronic medical conditions and/or disabilities such as crushed discs, Alzheimer's disease, arthritis, osteoporosis, diabetes, Parkinson's disease, knee replacement, and cancer. Many had multiple health problems. Several clients lived with spouses who had a variety of health problems themselves. Some used wheelchairs.

Clients lived in a variety of types of housing (e.g., cooperative housing, group homes, subsidized housing, apartment buildings, senior facilities, and houses). Sixty-four per cent were women; 36 per cent were men. These proportions are close to the overall pattern in BC of home support clients/patients (i.e., 68.5 per cent women; 31.5 per cent men in 2003).[47]

All but one of the CHWs were women. Nine were Canadian-born, and 17 were foreign-born (e.g., from the Philippines, Indonesia, India and China). The languages they spoke at home included English, Dutch/Indonesian, Hindi, Punjabi, Tagalog, and Rotuman. Several had completed high school either in Canada or another country. Six had a university undergraduate degree and/or graduate degree from a country other than Canada. Over half had obtained a health-related community college diploma in Canada (long-term care, community nursing aide, or community health worker). Many of the workers had other health care training, including midwifery, cardiopulmonary resuscitation (CPR), care for adults, medical

Table 6: Personal and Employment Characteristics of Community Health Workers Interviewed

Gender	Female	25
	Male	1
Age	Range	36 – 58
Education	No high school diploma	1
	High school diploma	9
	Post-secondary diploma	14
	University degree (non-Canadian)	6
Children	Children	13
	No children	8
Weekly hours	Range	7 – 40
Country of origin	Canadian-born	9
	Foreign-born	17
Language at home	English only	8
	Non-English	11
	No response	2
Marital and Family status	Married/common-law	15
	Separated/divorced/widowed	5
	Never married	1
	Single parent	3
Gross Annual income	Range	$18,000 – 36,000
	Median	$28,000
Hourly wage	Range	$15.00 – 18.50

health support, home care aid, home support attendance program, long-term care aide, St. John Ambulance course, and nursing attendant (see Table 6 for a profile of CHWs in the study[48]).

The majority of workers were in their 40s. Most were married or lived in a common-law relationship, and had children; several were single parents. Some workers were caring for non-work related, dependent adults who either lived with them or close by; two workers were responsible for looking after more than one adult. The majority earned around $18 an hour and the average (median) reported gross income per year of $28,000. Most had a combined household net income of $37,000 per year or less, which is 14 per cent or more below the median BC family income in 2003 (median income in 2003 was $42,800).[49]

The workers had provided home support services for between two and 25 years; about half had worked in this sector for 10 years or more. Four worked in cluster care (i.e. they carried a caseload for a certain number of clients living in close proximity); 22 worked in traditional home support.[50] Most CHWs worked over 30 hours per week. The majority provided care for 10 or more clients on average each week. Over half worked for a health authority, the rest for non-profit agencies. All those interviewed were unionized.

The next sections discuss the key findings from the focus groups and interviews with clients, workers, and informal caregivers. Despite the diversity of their health delivery areas and forms of home support, the participants had, as a result of the broad system changes, similar experiences. As the most vulnerable in the health care system, the clients, workers, and informal caregivers were struggling with reduced resources and worsening conditions that make the provision of quality services increasingly difficult.

Continuity/Discontinuity of Care

> *"They've laid off too many permanent staff, (now) we're always getting different people…because it's a different person, my rapport doesn't grow that far. I have to completely explain everything."*
>
> *— Home support client*

In BC, home support includes a mandate to provide preventive care. When CHWs have regular and daily contact with clients, they can assess whether clients' conditions are changing and arrange for assistance before serious health crises occur. Such a preventive mandate, however, requires continuity of the service provider.

Considerable research evidence shows that high staff turnover leads to poor quality of care and that staff continuity improves outcomes in long-term care, home care and home support.[51] In a study of home care clients, workers, and physicians whose patients use home support, researchers found that continuity of care involves many attributes and is best ensured by both effective communication strategies and consistent personnel.[52] The authors suggest that "while good continuity of care cannot assure good outcomes in every case, it can optimize care by organizing home health care delivery around the individual's needs and ensuring that we intelligently use our increasingly scarce family and health-care resources."[53] They concluded that consistency of personnel is necessary to ensure that service providers have the appropriate knowledge and skills, make accurate ongoing observations, have rapport with the client, and maintain good working relationships with other service providers.[54]

In our study, we found that inconsistency in home support provision is becoming the norm. In particular the shift from a permanent to casual workforce was making it more difficult for CHWs to provide continuity of care. For example, in 1998 one Vancouver agency employed 63 per cent of its CHWs in full-time positions, plus 27 per cent in casual, and 11 per cent in part-time positions. By 2001, a similar proportion was full-time, but casuals had risen to 37 per cent, and none were part-time. In 2005, less than half (47 per cent) of the CHWs were full-time; over 53 per cent were casuals.[55] In another agency, in 2005, 58 per cent were full-time and 42 per cent were casual workers.[56] The high proportion of casual workers suggests that many clients are not receiving care from a consistent provider and the quality of their care may be at risk.

While the growing casualization of CHWs has important implications for the quality of the services delivered, it is just one part of the larger trends in home support that are reducing consistent contact between CHWs and their clients. All the clients in our study wanted to have a regular CHW they could trust, understand and get to know, but few were able to count on the same person to provide care. Many clients felt uncertain when different workers came into their homes. One client noted, *"They keep changing people. You got a stranger."* Another said, "*I've had different workers in my home...Three months, three different workers…. It's very uncomfortable*." Clients talked about their discomfort, but also their confusion: "*They send somebody else…. They are hard for me to talk to them, and very hard for them to understand me."* Without an ongoing relationship, it is difficult for clients (many of whom have physical and/or mental impairments, and do not speak the same language as the CHW) to make their needs known.

All the clients in our study wanted to have a regular CHW they could trust, understand and get to know, but few were able to count on the same person to provide care.

Staff discontinuity can also lead to scheduling mishaps and irregularities that may also have serious implications for a client's care. One client reported "(In) *the afternoon*, (the CHW) *never came*, (I had) *nothing to drink, nothing to eat*." Such irregularities add further to client confusion. "*They try to juggle me, like, show up at a different time,"* one said. *"I get confused."* Since the BC home support system increasingly serves a very elderly and frail population with acute mental and physical health conditions, discontinuity of care may have significant negative implications.

Several CHWs attributed the problems of discontinuity to the cuts in home support. As one worker put it, "*We used to have an ongoing schedule…you could have a schedule for three weeks, but since the health (care) cuts they have to juggle the schedules a lot of times, so you just get a call that day. They don't book anything 24 hours before*." Such irregular scheduling creates difficulties for workers in organizing their lives and for clients in ensuring they receive consistent care that is responsive to their needs.

As one worker explained, "*The policy is that we do not own the clients, we only own the hours*." In other words, health authorities do not place a high priority on scheduling services to ensure that CHWs provide continuity of care.

Scheduling

In BC almost all home support providers (whether in-house or externally contracted) use Procura, a computerized software package, to enter care plans and schedule services. In Vancouver, supervisors set up schedules, whereas in Richmond this is done by schedulers. Schedulers have diverse backgrounds, from extensive experience in home support, professional training as a RN or LPN, to almost no training at all.

In using Procura software, those responsible for scheduling provide workers with printed schedules, and in some cases leave scheduled changes on workers' voice-mail systems. Schedulers are often the first and only agency contact for CHWs and such contact may be reduced to voice-mail, which alerts the scheduler when workers have retrieved their messages. This scheduling and communication system provides little opportunity for CHWs to give input into schedules or to accommodate clients' needs, let alone provide regular feedback about their clients to the agency.

Even if the home support system adheres to its regular schedule with clients, it does not provide flexible or emergency backup care. Those who live alone—which is the majority of home support clients in BC (69.3 per cent of the women; 43.9 per cent of the men, see Appendix B)—are especially vulnerable when accidents occur. As one worker commented, "(A client) *was sitting in a wheelchair and he fell down and the next day I went to work and he told me, 'yesterday I fall and I had a nap on the carpet for a few hours until somebody could come'—just pee everywhere*." If clients require help outside of scheduled hours, they must contact the home support agency and not their CHW. This absence of backup support does not facilitate a CHW role in providing ongoing care and/or in monitoring changes in clients' conditions.

Split Shifts

Care discontinuity has become normalized as split shifts become more common. Due to health authority cutbacks in hours of care and the decision to reduce assistance for basic services such as cleaning, shopping, and meal preparation, workers are increasingly forced to work split shifts. As one worker indicated, the interrupted schedules are "*the biggest changes for the group of us—there is no more work in the middle of the day—we don't do cleaning in the afternoon, so we are just going in between three and six at night to make sure people eat and get their medication.*" CHWs in regularized positions must be available for work within a 10-hour window. They often work split shifts—in the mornings and then again in the early evenings.

Moreover, instead of organizing care in a two-hour block, CHWs now often must provide care within one hour. *"The minimum hours per client before was two hours, because it included personal care and tidying up,"* one worker noted. "*But because the government cut down the hours—removed the cleaning…they reduce it to one hour just to give them a bath.*"

Split shifts can be challenging for workers. During this unpaid time, some travel home and back, while others find a midday second commute too costly or time-consuming. Many workers were frustrated. As one noted, *"Having nothing to do in the middle of the day, going back for the supper shifts—it's really frustrating. I have nine years' seniority. You feel like you are starting a new job, like you're the rookie again."* Many found the interrupted schedules extremely stressful. As one worker put it, "*I have 8 to 9, 9 to 10, 10 to ll, ll to 1 and then I stop and go back at 3 to 6…it's bang, bang, bang, stop and then go back and give six medications. Sometimes…if you start from the morning stressed it seems like the whole day is stress.*"

According to another, the split shifts are destroying workers' quality of life: "*We have some workers that come in and work like hell for four hours, then they tell them come back four hours later for half an hour to give medication…They are just trying, I think, to choke the lives out of us. Get us to leave, right?"*

The split shifts add to the challenges of balancing work and family obligations. Changes to employment standards law in 2002 mean that shifts can now be as short as two hours (whereas the previous minimum call-out period was four hours).[57]

> The scheduling and communication system provides little opportunity for CHWs to give input into schedules or to accommodate clients' needs, let alone provide regular feedback about their clients to the agency.

Taken together, these changes in working conditions for staff—the casualization of the workforce, the split shifts, the uncertainty of scheduling, and the lack of back-up in case of emergencies—have undercut the continuity of care that is so important to clients and the quality of care they receive. These changes have also undercut optimal use of health resources for preventive care and increased the likelihood of costly and avoidable health expenditures down the road.

Increased Complexity of Care Needs

Inadequate Training and Support

> *"I had a client that has dystonia[58] and I was getting very flustered because I just didn't understand it…It took me three RNs to find the information for me to properly understand it…it dragged out for almost three more weeks of total frustration."*
>
> *—Community health worker*

As outlined in the historical and statistical sections of this study, hospital stays have been shortened and patients return home still in need of medical-oriented care. With growing caseloads of high-need patients, home care Registered Nurses (traditionally responsible for the medical care of clients in their homes) increasingly delegate or assign home support staff to undertake, in some cases, fairly complex medical tasks. A common portrayal of home support is that it provides "personal assistance with daily activities, such as bathing, dressing and grooming." This portrayal—included in a recent Ministry of Health document—does not acknowledge the major shift in CHWs' medical responsibilities and need for improved training, professional support, and pay structures.[59] As one CHW put it, "*I never thought as a health care worker I would ever, ever do a bowel stimulation. That should have absolutely nothing to do with us, but because of the cutbacks...*"

Table 7 illustrates the dramatic rise over a seven-year period in the number of medical services in the Vancouver Coastal Health Authority that home care Registered Nurses delegate or assign to CHWs. In

Table 7: Revised VCHA Personal Assistance Guidelines

Task description	1995	2002
Clients capable of directing their own care		
Managing condom and in-dwelling catheter care	Delegable	Assignable
Administering routine care medications (patches, suppositories, nebulizers, eye- and eardrops)	Delegable	Assignable
Ostomy care	Delegable	Assignable
Applying supportive garments	Delegable	Assignable
Assisting with prosthetic or orthotic devices	Delegable	Assignable
Applying electrodes for transcutaneous nerve stimulation	Delegable	Assignable
Symptom monitoring (reporting vital signs, falls, incontinence, behavioral changes, and cardiovascular disease and diabetic symptoms)	Delegable	Assignable
Clients incapable of directing their own care		
Simple wound dressing changes	N/A	Delegable
Complex lifts/transfers for clients with no volitional movement below the neck	N/A	Delegable
Medication side-effects monitoring	N/A	Delegable
Treating fecal impaction	N/A	Delegable
Tracheostomy care	N/A	Delegable
Insulin administration	N/A	Delegable
Assisting with therapeutic exercise routines	N/A	Delegable

Source: Personal Assistance Guidelines (VCHA, 2002) *assigning* a task, a nurse expects the CHW to provide this service for all their clients as the need arises. When a home care nurse *delegates* a service, she or he sends a delegation letter to a home support supervisor requesting the transfer of a specific medical task to a CHW for a specific client. Initiating the transfer of authority from home care to home support for these medical tasks is often a cumbersome, complex, and time-consuming process.

Home care nurses, who are legally responsible for training CHWs to perform the delegated medical function for a specific client, may train the worker in the client's home or, as is frequently the case with medications, by telephone. Workers usually receive telephone training for tasks that agencies have already included in their worker orientation (medications, urinary drainage, etc.). In the past this training was provided in the client's home by an RN who would assess the client and review the task and requirements with the CHW.

As the BC government introduced health reform initiatives in the early 1990s, it also established a Health Labour Adjustment Agency (HLAA) to support workforce adjustment, including training. In the mid-1990s, in response to the growing acuity of home support clients, the HLAA provided courses for home support workers (who had little formal training) to upgrade their skills to the level of a CHW. However, in 2001, the newly-elected provincial government discontinued the HLAA.

Currently, public college training programs for CHWs (which have been standardized provincially) only minimally cover many of the skills that are now assigned or delegated to CHWs. In 2001, a review of the curriculum used in BC public post-secondary institutions to train CHWs recommended that the program be updated to reflect the increased skills required in the field.[60] The provincial government, however, did not provide the funding to support the updating of the curriculum for the public colleges. At the same time, because many employers are concerned that training provided in private colleges (where there are no common standards) may be even less adequate, many are reluctant to hire graduates from these programs.[61]

The home support agencies/programs have few mechanisms in place to support CHWs to upgrade their skills. Agencies/programs receive a per diem hourly payment for specified services (as opposed to core funding). This method of payment—a legacy from the 1960s—does not take into account the need for ongoing training and staff development. As a result, CHWs may not get the training they require as more and more nursing tasks are transferred to them.

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Loss of Professional Coordination

> *"When I first came in, if somebody was palliative we did the (direct) care, but we had a whole team behind us to come in and help with it. Now we don't have that team at all."*
>
> *— Community health worker*

As outlined in the Scheduling section above, CHWs primarily report observations about their clients to their agency supervisors or schedulers through telephone and voice mail. They have few opportunities to meet face-to-face with supervisors to discuss their clients or to participate in case conferences where issues can be identified and appropriate strategies developed. The increased pressure in both home support and home care to provide higher levels of care with fewer resources means that home support supervisors and home care nurses have less time to provide professional backup and support to CHWs.

Many workers reported concern for this loss of backup and professional support. In Vancouver, nursing supervisors at the home support agencies are responsible for 35 to 45 CHWs. In Richmond, three supervisors, along with the help of schedulers, handle approximately 65 workers.[62]

As a result, CHWs are making more independent decisions and judgment calls that previously would have involved far greater professional oversight. As one worker suggested, "*When there was funding, there were a few* (nurses) *that all they did was go around to every client, update, see what's going on, where the family was at*." As this worker indicated, there is now too much pressure on the already overworked nurses. "*That is why everything really is falling apart because….we've only got three (nurses) out of 210 workers*."

As nurses have had to restrict contact with clients, they have been relegated to a gate-keeping function. Several clients indicated that the only time an assessor took an interest in home support services was for the purpose of cutting them back. One said: "*They only check up on us to be re-evaluated.*"

A worker talked about communicating with a supervisor to ensure that a palliative client was following a nurse's directions. "*Of course the nurse did her role, provided the nutritional guidelines for the patient, but when it comes to how well the patient is absorbing it, or the compliance, it is zero. And this is a palliative case*." With less professional contact and coordination, follow-up care is suffering.

Reduced Communication

Workers' first-hand experiences provide them with greater understanding of clients' conditions and situations, yet they have few opportunities to inform their agency of clients' needs. A worker noted, "*They only see paper, they never relate paper to faces*." Even when workers were able to report their clients' conditions to the office, additional help may not be available. One worker talked about a client, paralyzed and on oxygen, who received most of her care from a husband who had frequent heart attacks. "*Even if we report, 'Do you know that so and so's husband is in the hospital?,' they don't have backup*." While it may be desirable to have an efficient system with little waste, it is not desirable to have a system that has so little 'give' that additional resources are unavailable to deal with emergencies and unanticipated needs.

> Workers' first-hand experiences provide them with greater understanding of clients' conditions and situations, yet they have few opportunities to inform their agency of clients' needs.

In addition, as continuity of care becomes disrupted, communication books placed in clients' homes are often the only link through which different CHWs serving a client can communicate with each other. A worker explained the importance of such coordination: "(You) *might be a morning worker and there is a night worker. So there might be a concern and you will read the communication book and maybe you will want to talk to the other worker and say 'Have you noticed this?'—and then we coordinate it to be able to take it further because everyone is agreeing there are things we are seeing*." Yet, the time to write reports, a vital part of maintaining coordination of care, has declined. One worker said, "*We used to* (write reports), *before the changes, before the cuts and everything*." Because of reduced time for home support visits, CHWs have few opportunities to make observations about their clients' health, let alone to record them for another worker.

The multicultural nature of the workforce and client base in both Richmond and Vancouver exacerbates communication and coordination difficulties. For example, 80 per cent of CHWs in Richmond are born in other countries, and the client base represents numerous ethnicities speaking a range of languages.[63] At present, in many areas of the Lower Mainland, workers' skills, cultural understanding and language abilities often do not match those of their clients. More attention and research needs to be focused on this issue to better support both clients and workers.

Less Time per Client, More Medicalized Care

> *"Well, they come, they give me a sponge bath, they get me all dressed from head to toe. And then I have to get my blood pressure done, and then I have to get my insulin done. I take my own medication…And then they also get me into a wheelchair…. Then that is it, then they go home, the time is up."*
>
> *— Home support client*

While home support services have become more focused on clients with higher needs, time with each client is often very restricted. As a result, home support work has become more intensified and more narrowly focused on medical and personal care tasks. As a worker noted, they used to see a client "*three times a week or twice a week for two hours—it was busy, but now, it's an hour for one visit a week*." Another commented on clients who need assistance with medication administration. *"They give you 15 minutes—30 minutes, but you actually stay there for 15 minutes—the other 15 minutes is travel time. You know, you come in—'Mrs. So and So—here take your medication and then—bye.' That's it*." Many clients and workers reported on the perfunctory nature of home support visits and how workers rushed from one client to another. As one worker put it, *"My hours look okay on the computer, about 25 hours a week, but the actual day, the human part is crazy."*

Many workers are so tightly scheduled that they do not have enough time to travel between clients. As one worker indicated, *"They wanted me to go from Steveston to Queensborough in 15 minutes. For five hours with an Alzheimer's client. I was happy to do it. I said I can't make it in 15 minutes! Well, we'll give you a half hour break for your lunch. Hello! We are not in an airplane."* As a result they often had inadequate time for their 'breaks' or 'lunch' and had to fit them in while driving between clients.

Reduced hours per visit have lessened CHWs' ability to provide for their clients' needs, monitor health changes, or ensure that clients are taking medication or eating properly. The lack of time for monitoring clients' health can also result in workers feeling stressed or uncertain about their job. A participant said, "(I feel) *insecure* (about my job*)…. Before I was happy with what I was doing…I had more time. They talked to us."* Without ongoing communication with their clients, workers face many difficulties in interpreting their needs.

In addition, reduced time for visits results in distressed clients, which can have a spillover effect on how clients treat workers. According to a worker, "(Clients) *feel like they have been robbed of the time…—we just go in—okay, medications, you come undress, dress, bath, dress again—wipe the bathroom. Time sheet signed; off you go*." As a result of the cuts in hours, some clients were especially frustrated if their CHW arrived late. One client said, "*Only an hour. When they come, they come 10 minutes late. They leave 15 minutes early. We get less hours. If they go early, they should come on time*."

Workers reported that they often had to leave clients knowing they were not giving the care their clients required. One remarked, *"I have a client that walks from his room to the bathroom—20 minutes—I was looking at the time—I said, 'Oh my lord, what happens when he reaches the bathroom.'"* Another said, *"Think about what that client is going through…a worker will come in, fix a lunch, set it down, and walk away."* She used the example of a person with multiple sclerosis who can't really feed her/himself, but who is left without help. "*We're losing out,"* she said. *"It's worse and worse and we are paying and the people that we are supposed to take care of are paying."*

In the end workers were often hard-pressed to complete the care in the allotted time. Time pressures in home support all but ensure that the care will be perfunctory, placing inordinate stress on both workers and clients.

Undermining of Preventive Care and Social Support

> *"They're not allowed to make your breakfast for you. And they say 'Look, I'll put you on a boiled egg, but I'm not supposed to'… It was so horrendous that the homemakers feel sorry 'Okay, don't tell anybody if I boil you some soup, and sorry we can't go to the store for you,' there is nobody to go to the store."*
>
> *— Home support client*

As the previous section illustrates, services increasingly target people with higher, more complex care needs. Yet, most clients need a broad range of supports for their daily living, not just narrowly-defined medical and personal care. As the statistical profile of home support clients showed, the vast majority have low incomes and are 75 or older. Many are frail elderly women living alone; some are younger people with severe disabilities.

Most clients, therefore, require support with basic housekeeping, shopping and/or meal preparation. In reducing non-personal care services and cutting hours, the home support system has redefined housekeeping, social visits, emotional support, physical out-of-door exercise, and nutrition as unrelated to health.

In reducing non-personal care services and cutting hours, the home support system has redefined housekeeping, social visits, emotional support, physical out-of-door exercise, and nutrition as unrelated to health.

Many studies, however, show the benefits of these basic services in preventive care. For example, research identifies that good nutrition is essential for primary prevention, and that choosing food to meet dietary needs is an important part of chronic care management or secondary prevention. Well-nourished seniors have "lower morbidity and mortality, fewer medical complications and diseases, faster wound healing, and fewer infections."[64] They tend to spend fewer days in hospital when hospitalized. Malnourished seniors, on the other hand, experience "decreased quality of life, decreased independence, declines in overall health status, increased use of health-care resources, and increased morbidity and mortality."[65] Barriers to good nutrition among seniors include: physical difficulties of shopping, preparing food and eating many foods; economic difficulties of a fixed income that limit the seniors' ability to purchase sufficient quantities of healthy food; and social dimensions (e.g., adjusting to eating alone after years of cooking for and sharing meals with family members).[66]

Furthermore, studies suggest that seniors who have higher levels of social support (including good relations with family, friends, or formal institutions) are more likely to have improved morbidity and mortality outcomes than those with lower levels of social support.[67] If individuals are socially isolated and suffer from loneliness, they are vulnerable to depression.[68] If clients suffer from mental illness, their overall health suffers.

Most of the workers disagree with the recent shift in priorities: they believe that basic services like meal preparation and housekeeping are essential to physical health and mental well-being. Many were concerned, for example, with the poor hygienic state of their clients' homes. As one noted, *"I was at a client's yesterday whose bed hadn't been changed since the service had been cut and I was only there to bathe her."* If a client was incontinent, had disabilities, or was frail, it was unlikely they could maintain a clean home without help. One participant said, *"I feel that it's not right for all these cutbacks because your mental health is as important as your physical health…This is gonna be your home to the day you die. And you have to feel comfortable in the surroundings."* Yet, CHWs had little leeway to provide services that would ensure clients' comfort.

In the focus groups, CHWs talked about how they now often observe their clients' health deteriorating because of loss of these basic supports. As one worker put it, "*It's so bad if you think about it, if you see that stuff—you will have a heart break.*" To compensate, many CHWs provided daily care by 'bending the rules.' Several participants discussed how CHWs were "not supposed to cook" for clients, but helped with meal preparation anyway.

Just as importantly, before the cuts many workers were able to combine housekeeping and meal preparation with social visits. *"When household cleaning was included and companionship was included, I think clients were happier,"* one noted. *"They were getting what they wanted."* Many CHWs lamented that they were no longer able to establish a personal relationship with clients with whom they could provide some of the fundamentals of social support. By being told to *"'go do somebody in 15 minutes,'"* a worker recounted, "*they are taking away any basic humanity from one person to another.*" Many CHWs indicated that the ability to socialize with clients was what had made the job worthwhile, allowed them to exercise their skills, and added a significant dimension of care for clients.

While from a systems perspective it is clear that preventive care and social supports are no longer a priority, it is equally clear that the workers and clients' experience reinforce the research findings.

Impact on Clients and Informal Caregivers

This study found that when CHWs could not provide essential services for daily living, clients were left to struggle on their own, pay for additional services, seek informal help, or do without. Some have fought for more hours; most are growing more distrustful of the home support system and feel abandoned by it.

Fighting for Hours, Doing Without, or Paying Privately

> *"I'm not able to do (housework) myself, but pay for this myself—I can't afford to do that."*
>
> *— Home support client*

While many clients required more care than they received, few were able to afford to pay for care privately. One client, for example, could pay for services only by using grocery money. "*I get a homemaker once a week, but the other stuff… and I'm on a very limited budget…I have had to take from my grocery money and either live in the dirt or pay somebody to do it.*"

The CHWs were also concerned about their clients' inability to pay for services. One talked about a client "*who sits in a wheelchair pushing the vacuum.*" And another noted that even when clients can afford to hire someone for services, they have less protection. "*You are left with seniors who are so desperate that they look at ads in the papers, hire unethical people, they hire people who are unlike us—we have a criminal record check and have a history behind us with our job—we are bonded.*"

Rather than paying for care privately, some families and clients were successful in advocating for the care they needed; others were not. As one client said, "*When I got out of the hospital…I went and got on the ringer, they tried every way to not give it to me, until it finally came down to my doctor saying, 'Enough of this crap.' You know, she pulls some weight.*" But, as another client noted, doctors are not always able to ensure that their patients receive adequate hours. "*My doctor's even tried to call there too, and it just seems my home care worker says, 'They're only going to give you two hours a month.*"

Family members sometimes help clients to fight for more hours. A client commented, "*I only had the one shower* (a week) *for a long time, and my daughter kept phoning and phoning…She tried and tried. In the* *end, she went to the hospital, to her* (the case manager's) *office and waited for her…Anyway, I get* (a shower) *now twice a week."*

Despite the fact that 80 per cent of clients are 75 or older, are in ill health, and are frail or disabled, few get help with their non-personal care needs.[69] Many are simply doing without. As one participant noted, "*It's my hands, my fingers are so numb. I keep breaking things and I cannot do the vacuuming*." Another client now using a wheelchair pointed out, "*Before when I had home care, they would come in and do vacuuming and laundry and everything. Now it's just personal care."*

Informal Caregivers

> *"My daughter has two children, small ones. The other one is a nurse. She has different schedules: nights and days. So the only person who can come is my son…Sometimes (he) is in China. If I ask my daughter, well you know, 'I have my kids, how can you ask me that?' I cannot say anything, but who else can I ask?"*
>
> *— Home support client*

British Columbians who require assistance to remain at home are increasingly being forced to rely on family and friends. When clients rely on this informal help, they must often depend on people who already have their own responsibilities, problems, and uncertain circumstances. Informal caregivers may also have their own health care challenges. "*We shouldn't feel that if we get sick, get very, very sick and we're in our apartments by ourselves, there's no way we can get a temporary homemaker for that,"* one client said. *"We have to hope that a friend will come and help you. You're supposed to rely on your friends. But your friends could be sick too."*

When clients rely on this informal help, they must often depend on people who already have their own responsibilities, problems, and uncertain circumstances. Informal caregivers may also have their own health care challenges.

Some clients who lived with spouses indicated that they could manage only because of their spouse's help. However, spouses who provide care may themselves be frail. "*My husband's going in for a cancer operation,"* one client explained. *"And I won't have him there to help me with the food and everything. And I'm just wondering what to do*." Moreover, people caring for a family member can themselves develop severe health problems, particularly when caregivers are also frail seniors. A participant who cares for her husband said, "*He needs me every five or 10 minutes to turn him around. And because of that, both my hands are gone, damaged*."

Many clients relied on a spouse, parents, or children who had other responsibilities. A participant said, "*I have my daughter, but sometimes she has a 10-hour day. I mean, when she does get her weekends off, she's got her own things she's got to do. She's always telling me, 'I'll be there mom, I'll be there,' but I don't want to bother her*." Several had no family members they could call on.

Friends and neighbours can be helpful, but as one client indicated that help is often very limited. "*I do have a couple of friends who, don't help me, but if I need something from the store, I have somebody that I can call*." Some organizations and volunteers provide assistance to some home support clients, but again that help is limited. "*Volunteers make such a difference…They make all the difference in my world*," a client noted, but added, "*It seems to be harder to get volunteers now…Everyone seems to have that same trend now. Busy, busy*." Several workers commented that many of their clients have no one they can rely on to help with daily chores.

Impact on Informal Caregivers

> *"I don't have a life…I just want a little peace, a little time for me. But I don't have it…My Mom gets a pension, but it's not very much. I can't leave her, and I can't take her, I can't afford (a taxi)… and I can't take her with me on the bus, it's too much for her."*
>
> *— Daughter of home support client*

While the home support system depends on family members or friends to provide primary care, they may not be available. If they are able to help, they often lack adequate support for themselves and for their care recipient who may have very high needs.[70] One woman in the study was providing "total care" to her sister with a brain injury, who was not able to stand, was incontinent, and needed a patient-lift to take her into and out of bed. Another woman was looking after her mother who has severe osteoarthritis, was unable to walk without aid, and had Alzheimer's disease. A young man was looking after a friend with spondylosis, and fibromyalgia, which affected all her limbs and included incontinence; the client also had severe recurring depression.

An unpaid caregiver's employment can limit the care they are able to provide. As one young man who provided care for a friend said, "*Sometimes, I can say, 'Every Friday, I'll be there.' … Some weeks, it doesn't work out at all…and that's the time that I'm really concerned*." Because of the high level of care involved, one woman who cared for her mother had lost her job and both were living on a very limited income. Several studies suggest that informal caregivers often have to reduce their hours of work or quit their jobs altogether to provide adequate care, which places an enormous economic strain on the family.[71] Female caregivers, in particular, indicate that the care has repercussions for their employment.[72]

One young woman receiving support from a friend talked about the "big changes" as a result of home support cuts and the fear and intimidation that she experienced in asking for help. She also noted, "*It was very depressing; home support services are the mainstay in the lives of people with disabilities. You know, more than seeing therapists and shrinks, doctors and blood counts and dialysis, none of those things, I'm not saying they're not important, but what makes it work, what makes us cope with our lives is home support service*." She found that home support, which could make such a difference in helping with her daily living routine, was very hard to come by.

In expecting families to provide most of the care that clients require, the home support system overlooks many complications:

- It assumes that family members are readily available to help (e.g., they live nearby, their circumstances don't change, they are able to combine caregiving with other responsibilities such as paid work and caring for other family members);
- It assumes that family members who provide help require neither substantial respite nor financial support;
- It neglects the possible ways in which clients are vulnerable when they are forced to be dependent on their families;
- It ignores the implications of the fact that women, many of whom have other responsibilities, generally are the primary caregivers; and
- It overlooks the disparities between those with a variety of resources (e.g., spouses or family members who can help) and those without them, placing the latter in particularly vulnerable positions in which they must rely on an increasingly resource-poor health sector.[73]

Growing Distrust and Feelings of Abandonment

Participants reported that declining and out-of-reach home support services were leaving many distrustful and afraid that services would be cut further. *"They have said they have to cut hours and services and you get afraid,"* said one participant. *"How are you going to manage?"* Even if clients were told that home support personal services would never be cut, many felt insecure about future services. One client said, *"Government decided that…personal care services should get a priority. So it is protected…. So your personal services will never be cut…. (But) you know that their word doesn't mean anything."*

Some regarded the cuts in hours as a broken social contract. "*In our days we worked and we contributed for this health care,"* a client commented. *"If we don't get proper help, attention, hospital, home support or whatever, what is the point? Where is the tax? Health is the most important thing.*" Several clients felt abandoned. One said, "*They make us feel like we're not important….We shouldn't feel depressed; we shouldn't feel not needed.*"

Impact on Community Health Workers

> *"There was (this promise of) this wonderful scheme, you could get what you need in your home, but instead of doing that, they're cutting back, and it's almost like they'd rather we die… They send you home and if you die, it's one less senior to take care of…They sent me home I think after three days. I was confused, the toilet hadn't been fixed with whatever you need to sit on the toilet, I couldn't get into bed because I had my knee staples in my leg. I was alone, all that day, all that night until the next day when I managed to make a phone call."*
>
> *— Home support client*

Changing working environments and employment conditions have had a severe impact on community health workers' economic security, satisfaction with their work, and control over their lives. As job pressures have increased, workers have lost ground economically. In 2004, they were faced with a 4 per cent wage rollback. As well, agencies have laid off regular workers and sometimes hired them back as casual workers with fewer benefits and hours. A worker noted, *"Just before our contracts came due, what they did was they laid off people all over the place—and offered them jobs to come back as a casual—no benefits!"* According to another participant, employers are taking advantage of government restructuring. *"Because of the government changes and also our employer—they are taking advantage… they are putting so much pressure on us and on the clients too."*

Much of the burden of addressing the shortfall of the home support system falls on the shoulders of workers. Studies indicate that care providers who are caught between commitments to organizational rules and to their clients' best interests risk over-extension and exploitation that results in tiredness, frustration, and low morale.[74]

Clearly, the CHWs in our study were over-extended. They provided extra services that were not part of their mandate, while knowing that their clients need more. When asked how satisfied they were with the kinds of services they were able to deliver, several CHWs in a focus group responded "*No*" in unison: "*It's not enough—not enough*," a worker said. "*I think most of us do a little extra*," said another. "*I make their meal—I don't care—if they need lunch, I make them lunch,*" one added. "*Just out of sheer compassion*," another emphasized.

But as their clients are becoming more depressed and distrustful, CHWs face more difficulties in their work. A participant said, "*(Clients) are getting depressed more*." Another said, "*Most of the clients won't trust us because of the hours that they give to us. They won't trust that you can do your right job or your work.*" As a result of their deteriorating working conditions, CHWs have become more anxious about not being able to provide good quality care and they are becoming more concerned about their own future. A worker commented, "*(Clients) are scared! …In fact even for my client who is getting regular care, she is still apprehensive—like what about next year*?" Another said, "*I think just that it's frightening that first of all I see myself….They are just old—which we will be one day and if we don't put something in place it's going to be even worse*."

The added pressures in their work lives were bound to have repercussions on their lives as a whole. The vast majority of CHW interviewed were women who had family obligations, most had children and several were caring for adult dependents. After a long day, according to a worker, *"Sometimes I get too tired, I guess too stressed out from work. We would like to have some time for ourselves besides just spending all the time on family."* Indeed, it is very difficult for CHWs to find a balance between their demanding work and family obligations. As another said, "*It's hard for the family to understand what I have been trying to do all day and they want more attention too."*

Working conditions in home support, such as increased job instability, lower wages, increased workloads, inadequate coordination and professional support, and insufficient time for basic care, are a potent mixture that can lead to stress-related health problems.[75] Added to their stress and vulnerability is the fact that most of the CHWs we interviewed were visible minority immigrant women. Though they may have educational credentials from other countries, they count for little in Canada.[76] As visible minority immigrant women, they are precariously positioned at the margins of the formal economy and have few alternate employment prospects.

Changing working environments and employment conditions have had a severe impact on community health workers' economic security, satisfaction with their work, and control over their lives.

Paradoxically, the shift to more medically-oriented care has occurred simultaneously with the erosion of working conditions, employment security and income levels for community health workers. CHWs are still expected to provide some of the basic care required to maintain clients in their homes and to prevent the deterioration of their health. And yet their working conditions prohibit the effective provision of this care. As a result, not only do both the workers and clients suffer, but the health system as a whole is put under more pressure to respond to health crises that could have been prevented in the first place.

Conclusion

The promise of the Seaton Commission to shift care "closer to home" is, in one sense at least, a reality: home support is, more than ever before, providing mainstream health services for client populations that would, in the past, have been hospitalized or in long term care. What has not occurred is the transfer of resources to ensure that this care is adequately delivered, comprehensive, and focused on prevention.

And why is it that home support has fared so poorly in the competition for health resources? In part it is because the funding mechanism for home support agencies remains fundamentally the same as it was in the 1960s, when home support was an adjunct to the welfare system, and in part because home support has few powerful advocates. When health services were regionalized, the BC Continuing Care Association, the provincial advocacy organization that represented the interests of this sector to the provincial government, was disbanded. There is now no provincial organization advocating for non-profit, community-based health services at the provincial level.

To make this point more concretely: home support is and has always been an income-tested program serving the most marginalized sectors of our communities. The clients who receive these services—primarily low-income, frail seniors and people with disabilities—are a very vulnerable and powerless group. And the workers who provide the direct care have little influence in comparison to the more powerful professional groups in the health system.

As a result, the home support services that are so essential to so many people seldom make headlines. And yet the problems that we do hear about—the seniors backed up in emergency and lining the hospital hallways—may be traceable back to the cutbacks in home support services, the lack of professional back-up and co-ordination, and the discontinuity of care. The research discussed in this study by Hollander and Tessaro in BC, and from Sweden and Denmark, suggests very clearly that this is the case. Simply put, the failure to adequately invest in home support and home care represents a classic false economy—we are paying dearly in more costly health care services.

Before turning to recommendations, it is useful to briefly describe a promising alternative approach—the Danish elder care model and home support system. Unlike BC's, the Danish system is not income-tested, but rather, is universally-funded, focused on prevention, and yet very cost-effective.[77] The Danish reforms began in the 1980s with a move away from traditional reliance on nursing home care and towards a more integrated community-based model that supports people to live in their homes or in purpose-built seniors' housing. All seniors—regardless of the type of dwelling they occupy—have access to 24-hour home support services, a seniors' community health centre, and rehabilitation.[78] Staff from nursing homes who went from being residential care to home support workers were guaranteed job security and wage levels equivalent to what they received in their nursing home jobs. Clients, in turn, were promised the same level of health services (i.e. medication coverage, supplies and support, and personal care services) regardless of where they lived (i.e., at home, in purpose-built seniors' housing, or in an institution). The services were nationally mandated, administered by municipalities, and provided for considerable opportunities for citizens' input.

In 1998 the Danish government introduced national legislation obligating all municipalities to offer a home visit twice a year to all citizens 75 years and older.[79] The purpose of the home visit is to inform the elderly person about the services available and to inform the local authority about potentially unmet care needs in the population. The decision to introduce the legislation stemmed from research findings "in a local Danish study showing that small amounts of help may have a preventive effect by postponing institutionalisation."[80]

In other word, the Danes were more concerned with the additional costs that would result if seniors did *not* get help early on than they were with limiting access to home care resources. It is an interesting contrast to the situation in BC and points to the type of reforms that could be very effective in enhancing the health of BC's seniors and people with disabilities, and in controlling cost increases in the health system as a whole.

Recommendations

A number of recommendations for the provincial government emerge from this research:

- Increase funding to ensure that those individuals who require only prevention and maintenance services (i.e. meal preparation, cleaning, shopping, etc.) to maintain their health in their own homes receive the services they require, and that these services are part of the care provided to all clients in receipt of home support;
- Increase integration of home support with other health services including the provision of core funding to home support programs/agencies and better co-ordination with home care and other community health and primary care services;
- Enhance recognition of the role of community health workers, by improving the working conditions (i.e., creating more full-time permanent jobs and eliminating split shifts), providing more opportunities for CHWs to have input into care planning, and developing a mechanism to support continuing education;

- Prioritize research and reporting on innovative models for home support delivery (both local and international) that are comprehensive, prevention-oriented, and effective in controlling costs within the broader health system; and
- Increase transparency and accountability in health care by requiring health authorities to report expenditures on continuing care services by category. (Health authorities are currently not required to report this breakdown, making it impossible for the public to know how much is being spent on various services, such as residential care, home support, home care, etc.)

As we recommended in *Continuing Care: Renewal or Retreat?*, the provincial government should establish an independent external review of continuing care services (i.e. home and community care) with the goal of developing a new plan and approach to the delivery of these services. This report adds weight to the importance of this recommendation. Such a review needs to begin its work immediately.

Appendix A: Home Support Care by Local Health Authority, Clients Age 75+ (all care levels)

Local Health Authority	Clients/1,000 Population Age 75+			Hours/1,000 Population Age 75+		
	2000/01	2004/05	% Change	2000/01	2004/05	% Change
Interior Health Authority						
100 Mile House	266.8	95.4	-64.2%	37,867	16,244	-57.1%
Armstrong-Spallumcheen	139.1	102.7	-26.1%	20,003	15,559	-22.2%
Arrow Lakes	112.3	72.9	-35.1%	16,286	14,782	-9.2%
Cariboo-Chilcotin	205.2	98.6	-52.0%	31,564	27,364	-13.3%
Castlegar	207.2	125.4	-39.5%	35,394	30,590	-13.6%
Central Okanagan	105.3	80.7	-23.4%	14,120	11,837	-16.2%
Cranbrook	185.4	95.0	-48.8%	25,307	16,660	-34.2%
Creston	160.0	97.7	-39.0%	30,945	21,281	-31.2%
Enderby	216.4	90.2	-58.3%	30,658	13,576	-55.7%
Fernie	148.5	115.0	-22.5%	18,363	25,927	41.2%
Golden	90.6	78.4	-13.4%	15,766	20,459	29.8%
Grand Forks	189.4	111.8	-41.0%	31,051	20,766	-33.1%
Kamloops	114.8	79.6	-30.6%	14,043	12,375	-11.9%
Keremeos	137.9	94.2	-31.7%	17,690	13,755	-22.2%
Kettle Valley	169.7	104.5	-38.4%	28,298	19,448	-31.3%
Kimberley	155.0	96.2	-37.9%	25,941	18,853	-27.3%
Kootenay Lake	189.9	49.1	-74.1%	33,220	6,809	-79.5%
Lillooet	105.0	67.3	-35.9%	10,407	14,848	42.7%
Merritt	138.5	109.8	-20.7%	12,370	10,778	-12.9%
Nelson	141.3	103.6	-26.7%	28,690	23,066	-19.6%
North Thompson	151.7	124.4	-18.0%	16,572	16,266	-1.8%
Penticton	97.9	61.4	-37.3%	14,925	12,044	-19.3%
Princeton	177.2	106.0	-40.2%	44,571	33,001	-26.0%
Revelstoke	158.9	107.1	-32.6%	26,012	21,382	-17.8%
Salmon Arm	127.3	77.1	-39.5%	18,837	10,405	-44.8%
South Cariboo	131.3	95.4	-27.3%	15,857	16,844	6.2%
Southern Okanagan	53.0	40.5	-23.7%	9,848	7,427	-24.6%
Summerland	89.3	61.8	-30.7%	17,164	11,008	-35.9%
Trail	106.4	78.7	-26.0%	16,837	10,324	-38.7%
Vernon	130.6	79.3	-39.3%	14,723	9,868	-33.0%
Windermere	131.4	81.8	-37.8%	20,478	20,651	0.8%
Fraser Health Authority						
Abbotsford	111.2	98.4	-11.6%	17,758	17,066	-3.9%
Agassiz-Harrison	48.5	70.7	45.6%	5,375	11,846	120.4%
Burnaby	103.7	77.0	-25.8%	19,060	17,061	-10.5%
Chilliwack	122.4	119.9	-2.1%	22,399	25,460	13.7%
Coquitlam	99.2	66.3	-33.1%	17,787	10,619	-40.3%
Delta	103.6	53.5	-48.4%	12,570	9,251	-26.4%
Hope	126.5	105.3	-16.7%	22,177	18,053	-18.6%
Langley	117.8	67.7	-42.5%	15,980	12,509	-21.7%
Maple Ridge	81.0	68.4	-15.6%	17,265	11,174	-35.3%
Mission	145.0	146.7	1.2%	28,033	37,369	33.3%
New Westminster	118.1	80.1	-32.2%	21,659	15,744	-27.3%
South Surrey/White Rock	104.6	76.6	-26.8%	11,438	11,105	-2.9%
Surrey	106.0	79.4	-25.1%	19,448	15,895	-18.3%

Local Health Authority Name	Clients/1,000 Population Age 75+			Hours/1,000 Population Age 75+		
	2000/01	2004/05	% Change	2000/01	2004/05	% Change
Vancouver Coastal Health Authority						
Bella Coola Valley	180.0	156.0	-13.4%	36,110	34,463	-4.6%
Central Coast	n/a	n/a	n/a	n/a	n/a	n/a
Howe Sound	170.5	109.2	-36.0%	22,549	19,921	-11.7%
North Vancouver	123.7	66.9	-45.9%	18,117	14,596	-19.4%
Powell River	121.3	108.2	-10.8%	24,954	25,086	0.5%
Richmond	122.1	51.6	-57.7%	18,878	10,288	-45.5%
Sunshine Coast	91.1	86.0	-5.5%	18,190	18,054	-0.7%
Vancouver – City Centre	174.3	111.1	-36.3%	25,553	15,537	-39.2%
Vancouver – Downtown Eastside	295.7	160.7	-45.7%	37,106	21,807	-41.2%
Vancouver – Midtown	181.7	83.3	-54.1%	20,063	12,266	-38.9%
Vancouver – North East	143.1	83.5	-41.6%	21,405	16,568	-22.6%
Vancouver – South	119.9	80.4	-33.0%	17,929	14,165	-21.0%
Vancouver – Westside	155.2	78.1	-49.7%	24,457	13,377	-45.3%
West Vancouver-Bowen Island	98.9	51.7	-47.8%	19,806	13,076	-34.0%
Vancouver Island Health Authority						
Alberni	112.0	87.6	-21.8%	17,355	18,095	4.3%
Campbell River	164.1	122.5	-25.3%	40,351	29,891	-25.9%
Courtenay	97.4	89.3	-8.3%	22,249	21,689	-2.5%
Cowichan	124.8	98.6	-21.0%	24,050	22,115	-8.0%
Greater Victoria	100.1	80.3	-19.9%	15,263	16,986	11.3%
Gulf Islands	90.0	76.0	-15.6%	17,465	25,841	48.0%
Ladysmith	110.7	91.4	-17.4%	22,813	16,920	-25.8%
Lake Cowichan	71.9	2.5	-96.5%	9,018	139	-98.5%
Nanaimo	97.6	77.5	-20.5%	17,983	15,072	-16.2%
Qualicum	91.5	66.2	-27.7%	18,124	13,279	-26.7%
Saanich	163.8	184.7	12.8%	33,438	35,193	5.2%
Sooke	97.6	123.2	26.3%	23,792	28,930	21.6%
Vancouver Island North	253.4	136.1	-46.3%	88,984	43,882	-50.7%
Vancouver Island West	n/a	n/a	n/a	n/a	n/a	n/a
Northern Health Authority						
Burns Lake	198.6	126.1	-36.5%	40,799	43,049	5.5%
Fort Nelson	75.5	36.6	-51.5%	6,368	6,372	0.1%
Kitimat	66.7	55.2	-17.1%	10,365	19,083	84.1%
Nechako	172.9	84.0	-51.4%	34,655	17,982	-48.1%
Nisga'a	n/a	n/a	n/a	n/a	n/a	n/a
Peace River North	180.8	57.8	-68.0%	14,108	7,159	-49.3%
Peace River South	191.2	105.4	-44.9%	23,868	18,837	-21.1%
Prince George	169.0	74.8	-55.7%	18,941	9,183	-51.5%
Prince Rupert	101.2	140.9	39.3%	15,456	26,797	73.4%
Queen Charlotte	53.8	147.9	174.7%	11,927	46,601	290.7%
Quesnel	178.0	65.6	-63.2%	25,421	14,494	-43.0%
Smithers	144.7	125.0	-13.6%	25,898	46,802	80.7%
Snow Country	47.6	90.9	90.9%	14,429	3,000	-79.2%
Stikine	n/a	n/a	n/a	n/a	n/a	n/a
Telegraph Creek	n/a	n/a	n/a	n/a	n/a	n/a
Terrace	90.7	81.3	-10.4%	19,257	21,416	11.2%
Upper Skeena	86.3	55.9	-35.2%	14,820	6,757	-54.4%
British Columbia	116.9	82.3	-29.6%	19,465	16,023	-17.7%

APPENDIX A

Notes:

Age 75+ refers to the age of both the clients and the underlying population size to which the number of clients is being compared.

Please note that Local Health Authority data is not as robust as data for larger areas, because there can be discrepancies in the way data is reported, irregularities in the relationships between jurisdictions, and errors due to the way addresses are coded. In several communities, there is home care provided, but the care is not provided through the channels that are typical of the rest of the province (i.e. the care is provided by local communities or First Nations band councils). For this reason, we have listed several communities as "n/a" because the true level of care is unclear. For some additional small communities for which data is reported, the data from PURRFECT may be flawed due to the irregularities noted above.

Source: PURRFECT Version 11.1, CCASUR Version 11.1, report date April 13, 2006.

Appendix B: Distribution of Home Support Clients by Gender, Single Female, and Age

Table B1: Distribution of Home Support Clients by Gender

Year	Female	Male	Both sexes	Female % of total
1993	42,369	17,741	60,110	70.5%
1998	32,668	13,656	46,324	70.5%
2003	19,738	9,077	28,815	68.5%

Table B2: Single Females as a Percent of Total Home Support Clients

Year	Single females	Total clients	Single females as a % of total
1993	30,742	60,110	51.1%
1998	23,732	46,324	51.2%
2003	13,678	28,815	47.5%

Table B3: Distribution of Home Support Clients by Age

Year	<65	65-74	75-84	85+	65+	75+
1993	8.5%	16.6%	40.2%	34.7%	91.5%	74.9%
1998	9.3%	11.7%	37.0%	42.0%	90.7%	79.0%
2003	9.5%	10.0%	34.7%	45.7%	90.5%	80.4%

Source: Authors' calculations using Continuing Care Data Warehouse data file provided on October 20, 2005 by the UBC Centre for Health Services and Policy Research (CHSPR).

Appendix C: Income Distribution of Single Home Support Clients Under Age 65

Income (2000 real)	Home Support Patients		
	1993	1998	2003
Under $15,000	80.3%	81.0%	82.2%
$15,000 – $29,999	15.1%	13.5%	11.5%
$30,000 – $49,999	3.5%	4.1%	4.9%
$50,000 and over	1.0%	1.4%	1.3%

Source: Continuing Care Data Warehouse data file provided on October 20, 2005 by the UBC Centre for Health Services and Policy Research (CHSPR). The methodology for converting CHSPR data into income categories comparable to Census data is available from the authors on request. This table describes home support clients in British Columbia for singles under age 65 for both men and women. Income figures are pre-tax.

Appendix D: Source Data for Figures 1, 2 and 3

Data for Figure 1: Share of Provincial Expenditures Spent on Home Health Services by Province

	1977/78	1987/88	1997/98 est
British Columbia	0.97	2.12	3.1
Alberta	0.21	1.01	2.77
Saskatchewan	0.81	1.85	3.89
Manitoba	1.57	2.43	4.96
Ontario	0.65	2.33	5.3
Quebec	0.8	1.37	2.99
New Brunswick	0.51	3.28	5.8
Nova Scotia	0.19	0.83	5.07
Prince Edward Island	0.92	1.41	2.29
Newfoundland	0.19	1.24	5.15
Yukon Territory	0.49	0.88	2.08
Northwest Territories	0.59	0.89	1.75
Canada	0.71	1.87	3.98

Source: Health Canada. 1999.

Date for Figure 2: Home Support Clients in BC by Care Level, 1997/98, 2000/01, and 2004/05

	Total	PC & IC1	IC2	IC3	EC
Home support clients 1997/98	46,831	27,440	16,103	6,541	4,095
Home support clients 2000/01	40,086	16,550	18,025	7,150	3,854
Home support clients 2004/05	30,323	5,451	14,112	10,055	4,963

Note: For a given year, the total home support client count is less than the sum of the client counts for the four levels. This is because clients receiving more than one level of care in a given year are counted once for each level of care they need, but when counting total home support clients they are only counted once.

Sources: Ministry of Health PURRFECT database including the following: Data for 1997/98 comes from PURRFECT ver. 7.1, CCASUR ver. 1.30, report date Oct. 26, 2004. Data for 2000/01 comes from PURRFECT ver. 8.1, CCASUR ver. 9i, report date Oct. 21, 2004. Data for 2004/05 comes from PURRFECT ver. 11.1, CCASUR ver. 11.1, report dates March 5-6, 2006.

Data for Figure 3: Number of Home Support Clients per 1,000 Population Age 75+, by Health Authority

	Clients Per 1,000 Population 75+		
	1997-1998	2000-2001	2004-2005
Interior	169.2	121.7	80.2
Fraser	134.8	106.2	78.9
Vancouver Coastal	164.1	134.9	79.4
Vancouver Island	135.3	105.7	94.7
Northern	187.9	152.8	82.7
British Columbia	150.6	116.9	82.3

Source: Ministry of Health, PURRFECT, CCASUR - Cont. Care Age-Standardized Util. Rates. Data for 1997/98 comes from PURRFECT ver. 7.1, CCASUR ver. 1.30 report date December 1, 2005. Data for 2000/01 comes from PURRFECT ver. 8.1, CCASUR ver. 9i, report date December 1, 2005. Data for 2004/05 (and all population data) comes from PURRFECT ver. 11.1, CCASUR ver. 11.1 report date March 6, 2006. Population data used data for first year of the date range (i.e. 1997 population is used for 97-98). These data reflect clients age 75+ per population age 75+.

Notes

[1] Seaton et al., 1991.

[2] BC Ministry of Health, 2005b, p. 4.

[3] Vogel et al., 2000.

[4] Ibid., pp. 86-141.

[5] Hollander and Tessaro, 2001, p. 3.

[6] Vogel et al., 2000.

[7] Cohen et al., 2005.

[8] Ibid., p. 15

[9] Ibid., p. 21.

[10] BC Ministry of Health, 2005a.

[11] Hollander and Tessaro, 2001, p. i.

[12] Canadian Council on Social Development, 1971.

[13] Ibid.

[14] Cohen et al., 2005, p. 27.

[15] Health Insurance Directorate and Branch, 1985.

[16] Burke, 1999.

[17] Ibid.

[18] Wyatt Company, 1989.

[19] Seaton et al., 1991.

[20] Vogel et al., 2000, p. 8. Measured as days per 1,000 population, hospital stays in BC declined by 46 per cent over the 1990s.

[21] Ibid., pp. 31-32.

[22] BC Association of Community Care, 1997.

[23] In 2000–01, the last year for which the Ministry of Health provides a breakdown of expenditures by home health services (i.e. home support, home care nursing, and physiotherapy), only 10 per cent of the regional budgets—0.46 billion in a budget of 4.6 billion—went to all home health services. From the Schedule A, Regional Programs, Ministry of Health Services, Total Funding to Health Authorities, 2001-02, as of Update 2.

[24] Table 1 numbers are also from PURRFECT data base. However, PURRFECT is not available by care level and health authority prior to 1997/98.

[25] Authors' calculations based on Statistics Canada data provided on the BC Stats website, as shown at www.bcstats.gov.bc.ca/data/pop/pop/project/bctab6.asp.

[26] Cohen et al., 2005, Appendix 13, p. 44.

[27] Hollander and Tessaro, 2001.

[28] Ibid., p. iii.

[29] Szebehely, 2005, pp. 16-17.

[30] Nososco, 2004.

[31] Szebehely, 2005, p. 17.

[32] BC Ministry of Health. 2003.

[33] Ibid.

[34] Permission to access the Ministry Continuing Care Database was obtained through the University of British Columbia's Centre for Health Services and Policy Research and the BC Ministry of Health. The Ministry of Health Continuing Care database uses data reflecting a calendar year, whereas PURRFECT uses a fiscal year. Therefore, major differences in the two data sources will generally be the result of different time periods covered by the two separate cuts from the same database.

[35] For single individuals in 2000, living in cities with populations over 500,000, the before-tax LICO was $18,525. The LICO is less for smaller cities. For example, it was $15,856 for cities with populations of 30,000 to 99,999.

[36] Kerstetter. 2003. p. 49.

[37] The Vancouver Coastal Health Authority also includes the North Shore/Coastal Garibaldi Health Service Delivery Area.

[38] These background interviews were conducted in the spring and fall of 2004.

[39] Vancouver Coastal Health Authority, 2002.

[40] Hughes et al., 2005.

[41] Ibid.

[42] Ibid.

[43] Thirty-three clients in five focus groups, two clients in individual interviews, two informal caregivers and a care recipient in a focus group, and a caregiver in an individual interview.

[44] By focusing on Vancouver (a major city) and Richmond (a suburb) delivery areas, we sought to include contrasting cases of organizational forms, delivery systems, and population characteristics.

[45] In Vancouver, we talked to two groups of workers and three groups of clients. In Richmond, we talked to two groups of workers and one group of clients. To broaden worker and client experience, one of the worker focus groups in Richmond was composed specifically of foreign-born workers, and one of the client focus groups took place in a facility in downtown Vancouver, with a predominantly male clientele. To expand the variation of clients (and because we had difficulty recruiting clients in Richmond), we added a fifth group of clients that was based in Surrey and lived in a facility for predominantly South Asian elderly. In addition, we interviewed two individual clients in Vancouver to include participants who were more isolated and homebound. Finally, we interviewed three informal caregivers living in a variety of locations (Vancouver, West Vancouver, and Burnaby).

[46] Some workers declined to participate in the study because they did not have time, or their work took place in the evening at the time of the focus group, or they were concerned that their agency might look unfavourably upon their participation.

[47] Appendix B.

[48] Twenty-six CHWs participated in focus groups. Twenty-one responded to the questionnaire.

[49] 2003 medium income $42,800 nominal 2003 dollars, the most current year for which data is available. Statistics Canada, Cansim Table 202-0411.

[50] In traditional home support models, agencies employ Community Health Workers to provide care to individual clients for a set number of hours per week. In providing the care, the worker travels from client to client. Cluster care usually takes place in high-density living situations, such as apartment buildings with a high proportion of elderly residents.

[51] Rachlis, 2000.

[52] Woodward et al., 2004, pp. 177-92.

[53] Ibid., p. 191.

[54] Ibid.

[55] Data from a union employee list.

[56] Ibid.

[57] See Fairey, 2005.

[58] Dystonia is a neurological disorder that causes a lack of muscle control.

[59] BC Ministry of Health, 2005a, p. 5.

[60] Ferguson, 2001. This report recommends funding for curriculum updates.

[61] Berman and Shah, 2003. In this report a number of respondents indicated a strong preference to hire graduates from public college home support programs. They identified gaps in course content in private colleges in both theory and practice and pointed to a lack of familiarity with the different programs being offered by private colleges.

[62] Hughes et al., 2005.

[63] Ibid.

[64] Dewolfe and Millan, 2003, p. 16.

[65] Ibid.

[66] Bartali et al., 2003; Keller and McKenzie, 2003; Lee and Frongillo, 2001; Pierce et al., 2002; Brunt et al., 1999.

[67] Temkin-Greener et al., 2004.

[68] Adams et al., 2004.

[69] Appendix B, Table AII.3

[70] A recent survey found that "only about one in five care providers get help when they need a break" (Stobert and Cranswick, 2004, p. 4).

[71] Morris, 2004.

[72] Cranswick, 1997.

[73] Brotman, 2002. The author discusses how home care fails to support 'ethnic families.'

[74] Aronson, 2000.

[75] Denton et al., 2002. In their analysis of survey data for home care workers (including 'visiting homemakers'), these researchers found that organizational change, fear of job loss, heavy workloads, and lack of organizational and peer support led to increased job stress.

[76] Li, 2003. Li discusses the devaluation of immigrants' educational credentials.

[77] Stuart and Weinrich, 2001. These authors conclude that the Danish system is at least as cost-effective as the U.S., but provides much better coverage. Comparison with Sweden suggest similar findings (see note 29 above).

[78] Wagner, 2004.

[79] Szebehely, 2005, p. 17.

[80] Ibid.

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