

# UNFULFILLED PROMISE

**How Health Care Reforms of the  
1990s Are Failing Community and  
Continuing Care in B.C.**

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**BY DONNA VOGEL, PhD**  
With research assistance from  
Stuart Murray

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## **About the author**

Donna Vogel is a researcher with the Canadian Centre for Policy Alternatives – BC Office. Her area of specialization is the public sector and public services in B.C. She holds a Ph.D. in sociology from the University of British Columbia.

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# Summary

"The [Seaton] Commission views long term care, home care, day care and other assistance to the chronically ill, the frail or the disabled as one of the most critical elements in our health care system. The quality of life of many British Columbians, and the province's ability to contain the overall costs of the system, are intimately tied to this field of health care."<sup>1</sup>

In 1991, the Royal Commission on Health Care and Costs set the agenda for health care reform in British Columbia. Like similar inquiries in other provinces, the Seaton Commission observed that increasing numbers of British Columbians had chronic conditions that could best be cared for at home or in supportive, non-acute care facilities. The goal of health care reform in the 1990s, the commission concluded, should be to shift resources and focus away from crisis intervention and acute illness, toward prevention, early intervention and health promotion. To do so, British Columbia should develop integrated, community-based networks of programs and services – health care that was "closer to home."

"Unfulfilled Promise" poses two central questions:

- **What actually happened in the 1990s regarding health care reform and British Columbians' access to Community and Continuing Care?**
- **What are the implications of these trends for people's health and well-being, and for the future of public health care?**

The study begins by examining Ottawa's cuts to health care funding, which coincided with provincial reform initiatives. It then examines the current state of long term residential care, home care and access to prescription drugs in B.C. Finally, the study profiles the people who are most vulnerable to shortcomings in the Community and Continuing Care sector – and the corporate interests that are moving into the breach.

The study reveals that:

- Inadequate funding and infrastructure for public Community and Continuing Care have created growing gaps between British Columbians' needs and the public services to which they have access.
- This shortage of public CCC services places a rising and unsustainable burden on unpaid caregivers, most of whom are women.

The gaps in public Community and Continuing Care services are creating a two-tier system.

- The gaps in CCC services create opportunities for private firms to enter the health services "market." This is leading to the growth of a two-tier system in B.C., with access to health care increasingly dependent on a person's ability to pay for services out of her/his own pocket.
- The non-profit segment of Community and Continuing Care is undermined both by a lack of public investment and by the encroachment of well-financed transnational corporations. This seriously erodes the traditional capacity of non-profit societies, ethnic and/or religious organizations, and local agencies to develop and deliver community-based services.
- Reduced access to public Community and Continuing Care, with the corresponding growth of for-profit involvement, will inevitably increase the overall costs of public health care.
- In combination, these trends cause undue suffering for some of the most vulnerable members of our society—the frail elderly, people with disabilities and women—and jeopardize the future of universal public health care in B.C.

# 1

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## Chapter 1

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### **The Context of Health Care Reform in the 1990s**

The 1990s were a period of drastic cutbacks in federal support for all social programs. Ottawa's shrinking financial commitment to Medicare was dramatic. As a percentage of provincial/territorial health care costs, the federal cash transfer fell from 19.2 percent in 1989-90 to an historic low of 10.2 percent in 1998-99.<sup>2</sup>

Although Ottawa did transfer more tax points to the provinces, the federal total per capita contribution to health care is still much lower than the peak levels of the mid-1990s.<sup>3</sup> Even with one-time cash increases in 1999-2000 and 2000-01,<sup>4</sup> Ottawa's share of the nation's health care budget remains well below pre-1990 levels. A recent report by the Provincial and Territorial Ministers of Health estimates that, if the federal

transfer had increased since 1994-95 by the same amount as did provincial health care spending, Ottawa's contribution would have been \$8.8 billion higher in 2000-01.<sup>5</sup>

Ottawa's share of the nation's health care budget remains well below pre-1990 levels.

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## Ottawa cuts, provinces react

Provinces faced a huge set of problems: diminishing federal funds, rising health care costs, and growing – and aging – populations. Many simply passed the damage on to their citizens by slashing health care programs. British Columbia opted to absorb some of the federal cut by running a deficit. But with provincial revenues in a slump, and corporate lobby groups in vocal opposition to deficit spending, Victoria came under immense pressure.

As a consequence, the need to control health spending became a top priority in B.C. as throughout Canada. Measured in terms of dollars available for each British Columbian, health spending actually declined throughout much of the 1990s.<sup>6</sup>

## Roadblocks to "closer to home"

The timing couldn't have been worse for policy makers and others who championed health care reforms that shifted the focus from hospital to home.<sup>7</sup>

The aim of these reforms was sound. The 1991 Seaton Commission had uncovered ample evidence that community care based in early intervention and prevention not only produces better health outcomes, but also tended to be less costly than crisis-oriented acute care.

But the dismaying reality of B.C.'s reforms in the 1990s, in part due to federal cuts and sluggish provincial revenues, was the downsizing of acute care without a parallel investment in Community and Continuing Care.

**Hospital funding:** The Seaton Commission recommended hospital downsizing with the proviso that the dollars saved be reallocated to Community and Continuing Care. Despite a substantial decline in hospital utilization in the 1990s, the anticipated savings never materialized.

Measured as days per 1,000 population, hospital stays in B.C. declined by 46 percent from 1991 to 1999.<sup>8</sup> At the same time, spending on acute care continued to grow. From 1996-97 to 1999-2000, funding for acute care grew by 8 percent.<sup>9</sup>

Why were savings from acute care so elusive? A complex array of factors emerge:

- population growth
- increased health care expenditures on elderly people
- inflation
- expensive new technologies
- rising drug costs
- new acute care treatments
- higher patient acuity

All contributed to the failure of hospital downsizing to free up sufficient funds to support B.C.'s intended reforms.

**"Sicker and quicker":** Hospitals reacted to bed closures by reducing the average length of a patient's stay, not by reducing admission rates. The utilization of day surgery also increased. Shorter stays mean that patients are sicker while in hospital and may be sent home before they are fully recovered.

This "sicker and quicker" scenario impacts on both the acute and CCC sectors.

**CCC funding:** Public funding for community-based health services did grow: by 13 percent between 1996-97 and 1999-2000.<sup>10</sup> But the increase did not compensate for the downsizing in acute care and other systemic pressures.

Since the 1990s, British Columbians have been quickly discharged from hospitals into communities that are expected to deliver the next stages of their care. However, CCC services are not always available, nor is the care necessarily covered by Medicare. This growing gap – between what is needed and what is provided – is the root of many disturbing developments in B.C.'s public health care system.

The dismal reality of reforms was the downsizing of acute care without a parallel investment in community-based care.

# 2

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## Chapter 2

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### **The Failure of Reforms: Not Closer to Home**

The Seaton Commission's recipe for reform was that community-based services should be strongly enhanced to serve as the foundation of the entire health care system.

The pillars of Community and Continuing Care would be long term residential care, home care nursing and Home Support, along with an array of services in community clinics. People being cared for in the community would have publicly funded access to prescription drugs and medical equipment, just as they do in hospitals. Taken altogether, these programs would replace more costly interventions (i.e., hospitalization), enable people to stay in their homes when appropriate, and prevent people from becoming sick or sicker.

Today, the vision of *Closer to Home* is overshadowed by a CCC sector that is *more* difficult to access rather than less. This study does not include the year 1999-2000, but widespread reports of recent cuts suggest that the trend towards restricted access in Community and Continuing Care is even greater than the following documentation reveals.

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## Residential care: Not enough beds, not enough options

Residential care refers to services such as long term care (LTC) facilities, supportive housing, assisted living and other arrangements. These services provide health care and support for frail elderly people and people with debilitating and chronic disabilities.

British Columbia has an alarming shortage of publicly funded residential care options. Indeed, the number of long term care beds in our public system declined in the second half of the 1990s. In 1993-94, there were 129 residential care beds per 1000 people over 75 years. By 1998-99, the number had fallen to 106 beds per 1000<sup>11</sup> – an 18 percent drop in capacity over five years.<sup>12</sup>

By 1999, 7,000 seniors were on waitlists for one of B.C.'s 24,707 publicly funded LTC beds.<sup>13</sup> Thousands of new residential care beds are needed, and existing facilities over 30 years old require upgrades or replacement. Current estimates identify a need for at least 6,000 new residential care beds over the next five years, a figure that does not even factor in the aging of our population.

By 1999, 7,000 seniors were on waitlists for one of B.C.'s publicly funded LTC beds.

## Cutting people out

Shortages of both hospital and LTC beds mean that only British Columbians with serious needs are able to access publicly funded residential care. People with less critical needs – those assessed at the Personal Care (PC) and Intermediate Care 1 (IC-1) levels – are usually unable to find a bed.<sup>14</sup> (The same disparity exists for people who need home care, as we will see below.)

Table 1 shows 95 percent fewer people in PC, and 86 percent fewer people in IC-1 between 1990-91 and 1998-99. Other evidence shows that all the new program funding for long term care in the 1990s went to deal with higher levels of acuity<sup>15</sup> and to redress wage inequality between staff in LTC and hospital settings.

British Columbians are burdened by rising user fees in publicly funded facilities.

<b>Table 1: Residential Care Days (in 1000s of days) by Care Level: BC Totals</b>							
<b>Fiscal Year</b>	<b>PC</b>	<b>IC1</b>	<b>IC2</b>	<b>IC3</b>	<b>EC</b>	<b>Total</b>	<b>Utilization Rate/1000 Population</b>
1990/91	4,186	16,392	17,913	16,023	32,450	86,964	2,642
1991/92	3,305	14,530	18,701	17,719	33,819	88,073	2,611
1992/93	2,669	12,834	19,661	18,828	34,421	88,413	2,548
1993/94	1,798	11,275	20,629	20,195	34,687	88,583	2,480
1994/95	1,073	9,317	21,570	21,314	35,690	88,963	2,416
1995/96	609	6,990	23,266	22,325	36,107	89,297	2,360
1996/97	411	4,887	23,714	23,952	36,820	89,783	2,313
1997/98	286	3,343	24,306	25,146	37,215	90,297	2,280
1998/99	207	2,222	23,905	25,985	37,696	90,015	2,251
% change 1990 - 1999	-95%	-86%	33%	62%	16%	4%	-15%

**Source:** CC Warehouse, Summary Tables, September Refresh, 90/91 – 91/92

**Supportive housing – a neglected option:** Long term care institutions should not be the only option within B.C.'s public residential system, though they are today.

Supportive housing is defined as shelter for people with moderate disabilities or needs (usually seniors) that provides "a supportive and social environment that balances autonomy with security."<sup>16</sup> B.C. lags behind other jurisdictions in Canada and Europe in failing to subsidize supportive housing, which is widely regarded as an affordable and desirable option.

**Middle and low-income people abandoned:** The lack of publicly funded residential care options for people with moderate needs has created a significant new "market opportunity" in B.C.: private-pay intermediate care and supportive housing. Yet only a fraction of people needing such support are able to afford private care. For-profit services are simply out of the question for low-income seniors and most people with disabilities. Many middle-income people are also ill-served by shortfalls in public residential care. (See Chapter 3 for more on these issues.)

## Access down, user fees up

Lack of access isn't the only problem. Rising user fees in publicly funded facilities also increases the burden for individual British Columbians.

Until 1993, all patients in residential care paid the same fee, based on a percentage of their public pension (i.e., Old Age Pension/Guaranteed Income Supplement). In 1993, the province introduced a graduated fee schedule from \$23 to \$34 a day, based on a patient's annual income above the OAS/GIS. Since then, the fee has risen to \$25 to \$50 a day.

Among LTC residents, 74 percent are still paying the lowest daily rate – a clear sign of their low incomes (Table 2) The remaining quarter have faced fee hikes as high as 47 percent.

<b>Table 2 : Rates for Publicly Funded Residential Care, 2000</b>		
<b>Annual Income above OAS/GIS (\$)</b>	<b>\$ Per Day</b>	<b>% of Clients</b>
0 - 7,000	\$25.70	74
7,000 - 9,000	\$27.20	4
9,000 - 11,000	\$29.90	4
11,000 - 13,000	\$32.60	3
13,000 - 15,000	\$35.30	3
15,000 - 18,000	\$38.00	3
18,000 - 21,000	\$40.40	2
21,000 - 24,000	\$42.80	2
24,000 - 27,000	\$45.20	1
27,000 - 30,000	\$47.60	1
30,000 or more	\$50.00	3

**Source:** Ministry of Health

**Pay up, or do without:** Finally, there is a growing body of evidence that a two-tier system is developing *within* publicly funded LTC facilities.

Currently, residential patients receive prescription drugs at no additional cost. However, medical equipment such as hearing aids are extra. Systematic data on additional charges is unavailable, but an informal survey of nurses working in LTC facilities revealed a decline in services and supplies offered to residents at no extra personal cost.<sup>17</sup>

What does this mean to residents? Essentials that were formerly covered under the basic user fee – surgical stockings, incontinence products, recreational activities, to name a few – now cost extra. (See Table 3.) Worse still, residents and relatives often report that they must privately pay for *care itself* – from rehabilitation therapy to getting their hair done to help with bathing. Workers in public LTC facilities report

Workers report spending their own money to buy clothing and other supplies for people in their care.

spending their own money to buy clothing and other supplies for people in their care.

These developments point to a disturbing division between “haves” and “have nots” within public residential facilities, a division relating to quality of care and quality of life.

<b>Table 3: Examples of "Additional Costs" in Publicly Funded Residential Care</b>	
<b>Description</b>	<b>Charge</b>
Cablevision	\$8.68/month
Recreation Therapy	\$15.50/month
Happy Hour	\$4.00 each
Special Lunch	\$3.69 each
Shampoo/Set	\$10.00 each
Breakfast Outing	\$7.51 each
Parking	\$6.00/month
<b>Source:</b> Patient statements from two residential care facilities in B.C., 2000.	

## Rationing care in the home

Care shortages and rising care needs are equally evident in home-based programs, another supposed pillar of closer-to-home reforms.

There are two main types of home care (a client may require one or both):

- 1) professional nursing (home care nursing), and
- 2) non-professional personal care and housekeeping (Home Support).

These services can help people to stay in their own homes when they have either acute, chronic or terminal illnesses, or a short or long-term disability.

Home nursing and Home Support are intended to play key roles in enabling the frail elderly and people with disabilities to live independently in the community. Home care nurses (RNs) and Home Support workers also constitute a crucial “early warning” system that can identify and deal with health risks before they become acute health problems.

Eligibility criteria for publicly funded home-based care is set by local health authorities. The actual assessment is performed by continuing care assessors (RNs) and, in some cases, by social workers in the acute care sector. In theory, access to home nursing and Home Support is based on an individual's health needs in a broad sense. But the 1990s

People with relatively low care needs are simply not being served.

saw a marked trend to restrict services to individuals with serious health needs only. A person's entitlement to public home care is now based on a narrow idea of medical risk (usually of hospitalization) rather than on a well-rounded criteria of prevention and health maintenance.

Further, due to regional differences in assessments and availability, some British Columbians are being denied services that were formerly provided to them elsewhere in the province; this effectively restricts their choice of where to live.

## Home care nursing: elusive, exclusive

There are no user fees for home care nursing. But access has been seriously restricted by another factor: inadequate and unstable public funding. In effect, budget-strapped health authorities have tightened up eligibility criteria to the point that people with relatively low care needs are simply not being served. The proof? The number of clients receiving home nursing did not increase at the rate one would expect given hospital downsizing, the sicker-and-quicker phenomenon, and the critical shortage of public residential care. Table 4 shows that the number of people receiving public home nursing grew by only 13 percent since the beginning of the 1990s.

The consistency of cuts across B.C. suggests that budgetary pressure from the health ministry was the cause.

<b>Table 4: Home Nursing Clients</b>	
<b>Fiscal Year</b>	<b>Client Count</b>
1991/1992	32,077
1992/1993	31,718
1993/1994	34,117
1994/1995	32,179
1995/1996	34,648
1996/1997	35,715
1997/1998	36,547
1998/1999	36,284
91/92 – 98/99 % Change	13%
<b>Source:</b> 1991/1992, CC Data Warehouse, April 2000 refresh Other fiscal years, PURRFECT 5.0, CC Data Warehouse, September 1999 refresh	

## Home Support: A genuine crisis

The situation in Home Support is even more worrisome. User fees do apply to Home Support, based on an income test used province-wide. Currently 70 percent of Home Support clients pay no user fees due to their low income. Again, however, publicly funded Home Support falls

far short of demand, and care is being rationed to people with very high needs only. (Please see "Cutting Home Support," *Without Foundation*, Part III, for a more complete picture of the crisis in B.C. Home Support.)

By 1999, local health authorities had all but eliminated care for clients assessed as having less serious needs such as help with cooking, cleaning and laundry. Although eligibility criteria are set at the local level, the consistency of Home Support cuts across B.C. strongly suggests that budgetary pressure from the provincial health ministry was the cause.

Year	PC	IC1	IC2	IC3	EC	Total Hours	Total Grant Funding
1991/92	1,741,067	1,843,857	1,369,319	768,660	1,216,647	6,939,550	\$109,784,324
1992/93	1,735,252	1,893,069	1,483,465	798,653	1,338,978	7,249,417	\$128,292,414
1993/94	1,717,247	1,970,931	1,620,171	909,555	1,537,212	7,755,116	\$140,505,337
1994/95	1,495,674	1,877,356	1,709,177	1,071,748	1,620,054	7,774,009	\$154,364,679
1995/96	911,170	1,610,982	1,850,953	1,164,942	1,663,020	7,201,066	\$160,221,108
1996/97	663,282	1,486,088	2,067,910	1,314,022	1,808,358	7,339,660	\$179,827,388
1997/98	528,527	1,469,849	2,305,650	1,524,171	1,945,984	7,774,181	\$199,841,289
1998/99	380,580	1,369,518	2,386,929	1,664,279	1,980,300	7,781,606	\$200,303,252

**Source:**  
1991/92, CC Data Warehouse, April 2000 refresh  
Other fiscal years, PURRFECT 5.0, CC Data Warehouse, Jan. 2000 refresh

The number of people receiving Home Support in B.C. declined by 19 percent between 1991 and 1999.

Table 5 shows that funding for Home Support increased significantly over the 1990s (in current dollars). But rather than signalling a growing service, the figures reflect the higher acuity of a relatively small number of clients, as well as higher wages for staff. (The government of B.C. pursued a deliberate policy to redress the low wages of women workers in the CCC sector.) The hours of service for people at the two lowest levels of care (PC and IC-1) plummeted by 51 percent in the 1990s.

Table 6 shows that the total number of individuals receiving Home Support in B.C. actually declined by 19 percent between 1991-92 and 1998-99. This, during a time when the number of British Columbians over 70 years and older – the primary users of Home Support – increased by 25 percent.<sup>18</sup>

Even people who are fortunate enough to qualify under the stringent criteria are not home free. Like people in LTC facilities, Home Support and home nursing clients must pay out of their own pockets for numerous services and supplies (e.g., Life Line monitoring services, hearing aids and other medical equipment, physiotherapy and specially designed household equipment). These mounting private costs are yet another barrier to quality, accessible care in the community.

<b>Table 6: Home Support Clients</b>	
<b>Fiscal Year</b>	<b>Clients</b>
1991/92	55,980
1992/93	57,803
1993/94	59,857
1994/95	58,201
1995/96	50,726
1996/97	47,779
1997/98	46,831
1998/99	45,529
91/92 – 98/99 % Change	-19%
<b>Source:</b> 1991/92, CC Data Warehouse, April 2000 refresh Other fiscal years, PURRFECT 5.0, CC Data Warehouse, Jan. 2000 refresh	

## Prescription drugs: Escalating costs, escalating risks

The private expense of prescription drugs presents a final, formidable barrier to accessible, quality care in the community. Rising pharmaceutical costs can be a problem for British Columbians of all ages and abilities, irrespective of whether they require home nursing, Home Support or residential care.

The problem is fundamental. A patient's medication needs are covered by Medicare while she/he is in hospital or in a publicly funded residential care home. If that same patient is in her/his own home, the situation changes abruptly. Full coverage is no longer the case. British Columbians face rising out-of-pocket and private insurance costs for drugs when they are discharged from hospital early, or are forced by LTC waitlists to stay at home (or do so by choice), or simply have a condition that requires medication.

Private spending on prescriptions increased rapidly in the 1990s. Drug costs were the fastest growing component of total public and private health care expenditures everywhere in Canada. In B.C., drug costs rose by almost 60 percent, from \$215.91 per person in 1990 to \$342.50 in 1999.<sup>19</sup>

British Columbia is fortunate to be one of only three provinces with a drug insurance system that covers every resident. But once again, B.C. programs became increasingly restrictive in the 1990s, notably via

substantial increases in user fees for Pharmacare. Pharmacare is comprised of a number of different plans, each with its own eligibility criteria and fee schedule. Private costs take the form of deductibles and co-payment schedules, which vary from plan to plan.<sup>20</sup>

From 1974 until 1987, senior citizens and social assistance recipients in B.C. received 100 percent coverage for prescription costs. In 1987, the province introduced a co-payment scheme that required seniors to pay 75 percent of pharmacists' dispensing fees, up to a maximum of \$125 per year. In 1994, this co-payment was increased to 100 percent, to a yearly maximum of \$200.

**Table 7: Pharmacare Plan E  
(Residents Registered with MSP who are not receiving benefits from another Pharmacare Plan)**

Year	Deductible	Co-payment	Max (\$)
1991	\$375	20%	\$2,000
1992	\$400	20%	\$2,000
1993	\$500	20%	\$2,000
April 1994 – 1998	\$600	30%	\$2,000
April 1998 – Present	\$800	30%	\$2,000

**Source:** Ministry of Health Pharmacare Program

The universal Pharmacare plan, which covers most British Columbians under the age of 65, has both a co-payment scheme and an annual deductible. Table 7 shows that in 1991 the deductible was \$375 per family, after which families were required to pay 20 percent of prescription costs to a maximum annual amount of \$2,000 (including deductible). By the year 2000, the deductible had more than doubled, and the personal co-payment had increased to 30 percent. (Low-income families receiving Medical Services Plan (MSP) premium assistance receive 100 percent coverage from Pharmacare once a \$600 deductible is reached.)

It isn't hard to imagine that a person's health may suffer if she/he is unable to pay these out-of-the-pocket drug costs. A study by Statistics Canada highlights just such a concern. The 1999 study found that low-income people are the least likely to have private insurance. As a consequence, they take less medication than people with higher incomes and those covered by private drug insurance plans, "regardless of the number of chronic diseases individuals had."<sup>21</sup> Over time, the negative implications of rising private drug costs will spread: as people's health status declines, pressures on the public health care system will mount.

Private spending on prescriptions increased rapidly in the 1990s.

# 3

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## Chapter 3

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### Two-Tier Health Care: Hurting Vulnerable People

Community and Continuing Care in the 1990s made a dramatic departure from the role envisioned by the Seaton Commission. Although there were some increases in CCC programs, public investment was far from adequate. Instead of a broad reallocation of closer-to-home resources, health care became *more* crisis oriented in the past decade.

***Growing needs, shrinking care, unequal access.*** If these trends in Community and Continuing Care continue, British Columbians should prepare themselves for a very serious prognosis: A full-blown two-tier sector, with rising burdens for unpaid caregivers. This chapter explores some of the reasons that Community and Continuing Care is susceptible to two-tier forces, and who is most at risk.

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## Two-tier care: Why is this happening?

British Columbians, like other Canadians, expect their health care needs to be covered by Medicare. But the legislative framework for Medicare, the Canada Health Act, is currently deemed to apply only to physician services and acute care in hospitals. This narrow interpretation – and it is just that, *an interpretation* – must be kept in mind when examining the health care reforms of the 1990s.

Community and Continuing Care falls under the category of “extended health services”. There are no regulations in the Canada Health Act that define these services, and so governments are under no strict obligation to provide them. As the average length of a hospital stay declines and an increasing array of medical procedures is performed in day surgery or outpatient clinics, more and more treatment/recovery is occurring in private homes and LTC facilities – in “extended health services.” Once a patient leaves hospital, an increasing portion of the costs of care are being transferred from the public sphere to the private individual and her/his family.

With a constrained CCC sector, people are no longer assured coverage. Thus, health care restructuring has effectively launched a two-tier system in which the care an individual receives depends on her/his ability to “fill in the gaps” by buying private goods and services.

### Private spending on the rise

Private spending on health care was on the rise everywhere in Canada in the 1990s. (Private spending can be by individuals or by private insurance plans, e.g., an employment benefit plan.) The Canadian Institute for Health Information reports that private health care expenditures grew from 25 percent of all health spending in 1990 to 30 percent in 1999. Out-of-pocket health spending increased by 52.5 percent. Most private health care dollars are spent on the services of professionals other than physicians (mainly dental and vision care – 48 percent) and drugs (26 percent).<sup>22</sup> But we are also seeing rising private costs for residential care and services to patients at home.

Canada's public health care system suffered with this increase in private financing. In 2000, Canada ranked a distressing 30th in the World Health Organization's survey of 191 national health systems. Dr. Julio Frenk, a WHO director, noted that Canada's poor showing was due to the erosion of our universal health care system by growing out-of-pocket charges. “Canada with 70 percent of total health care expenditures *being public* is the lowest of the G-7 industrial nations outside the United States,” said Dr. Frenk (emphasis added).<sup>23</sup>

In B.C., the proportion of all health care spending from private sources remained stable at 27 percent in the 1990s. This reflects a

... the costs of care are being transferred from the public sphere to the private individual ...

relatively strong commitment by Victoria to maintain our public system. Similarly, B.C. has provided more public dollars for health services outside physicians' offices and hospitals, compared to many other provinces.

This is particularly true for non-hospital institutional care and "other health spending." In B.C., private spending in these areas, which includes most CCC services, accounted for 14 percent of total expenditures (i.e., public and private spending combined). British Columbians fared much better than Albertans, who paid 22 percent, and Ontarians, who paid 27 percent. Private spending on drugs accounts for 59 percent of total private expenditures in B.C., 69 percent in Alberta, and 71 percent in Ontario.<sup>24</sup>

The situation in B.C. may be less serious than elsewhere, but the growth of out-of-pocket spending is still considerable. On average, individual British Columbians were privately paying \$172 more per year for health care in 1999 than in 1990. Even more worrisome, this figure only represents increased spending by people who are willing and able to pay, directly or through private insurance premiums. What remains unquantified are:

- 1) "under-the-table" expenditures (i.e., private arrangements between a family and hired caregiver), and
- 2) the costs in effort, time, and suffering incurred by people who cannot afford to pay and simply do without treatments and services that are not fully insured by the public system.<sup>25</sup>

Canada's poor showing in WHO's 2000 survey was due to the erosion of Medicare by growing out-of-pocket charges.

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## Greatest needs, fewest personal resources

The barrier of private-pay health care is most overwhelming to the people who are most dependent on Community and Continuing Care: frail, elderly single women, and people with disabilities.

A recent socio-economic and demographic profile of British Columbians who receive residential care or Home Support reveals just how vulnerable they are, and just how little money they can spare – if any.<sup>26</sup> Among the total number of people who applied for public support (subsidies) for these services, 66 percent were women, 66 percent were single, and 90 percent were seniors (1998-99).

Table 8 shows that people who apply for residential care or Home Support are even *more* likely to be living at or near the poverty line than their demographic counterparts in the population at large. Among single seniors who needed subsidies in 1998-99, fully 78 percent of all residential care applicants and 82.2 percent of Home Support applicants had annual incomes below \$20,000.

<b>Table 8: Percent of Subsidy Applicant At or Near the Poverty Line Single Persons Age 65+, 1998/99</b>						
<b>Subsidy</b>	<b>Income Category</b>	<b>Female</b>	<b>Male</b>	<b>Total</b>	<b>Low Income Cutoff (LICO)</b>	<b>Community Size (Population)</b>
Residential	Under \$20,000	78%	70%	76%	\$16,472	500,000+
Home Support	Under \$10,000	71%	63%	69%	\$12,885	Less than 30,000
	Under \$15,000	75%	67%	74%	\$14,468	100,000 to 499,999
	Under \$20,000	83%	77%	82%	\$16,472	500,000+

**Notes:**  
1. Residential Care income data is not reported for finer divisions below \$20,000 per year.  
2. Low income cutoffs are for single persons in 1998, as specified in Poverty Profile 1977, National Council of Welfare, Autumn 1999, Appendix A.  
**Source:** CC Data Warehouse, Information and Analysis Branch of the BC Ministry of Health.

Among disabled applicants for subsidies, 94 percent have incomes under \$10,000.

**Single, female and poor:** Elderly women who rely on publicly funded care are even more vulnerable than elderly men – and single women are in greater need than married couples. In general, single seniors (usually widowed women) are among the poorest members of society. The 1996 Canadian census found that more than 66 percent of single seniors have an income below \$20,000 and almost 50 percent have an income below \$15,000. This compares with a poverty line (i.e., Statistics Canada’s Low Income Cut-Off) of \$17,571 for urban centres in B.C. in 1998.

Among single, female seniors who apply for Home Support subsidies in B.C., 83 percent have incomes below \$20,000, compared with 77 percent of their male counterparts. Women outnumber men by five to one among single subsidy applicants over 85 years old.

**Disabled by poverty:** Most people with significant disabilities are also living on – or over – the poverty edge. Among disabled applicants for residential care and Home Support subsidies, poverty is widespread and extreme. For example, among Home Support subsidy applicants who are disabled and under 65 years, 94 percent have incomes under \$10,000.<sup>27</sup>

### **Out of pocket, out of luck**

Evidently, low-income seniors and people with disabilities will have little if any money to pay for the private care and extra charges now common within LTC facilities. For example, 75 percent of residents in publicly funded residential care pay the minimum daily user fee (\$25.60) – clear evidence of their strained financial circumstances. Add this poverty to the extreme shortage of publicly funded LTC beds, and a serious

problem is apparent. Private care is *not* an option for these elderly people.

A quick survey of some private facilities for B.C. seniors reveals fees that far exceed what most seniors needing care can afford. Table 9 shows the cost of a studio apartment—the most modest unit in these congregate care facilities—ranging from \$1,295/mo (\$15,540/yr) to \$2,590 (\$31,080/yr). This fee includes meals, housekeeping, recreation, laundry, and 24-hour emergency response. By adding up the numerous “extra” charges for day-to-day essentials such as toothpaste, shampoo, lotion, materials for dressing wounds, over-the-counter medicines, personal grooming and recreational activities, the cost of this private residential care would rise by at least 10 percent.

Facility	Location	Corporate Linkage	Studio	One Bedroom
Bevan Lodge	Burnaby	H&T Total Care Services	\$1,295	N/A
Arbutus Manor	Vancouver	Ishtar Seniors Communities	\$1,691	\$3,280
Hawthorn Park	Kelowna	Diversicare Management Services	\$1,750	\$1,950
Douglas House	Victoria	Ishtar Seniors Communities	\$1,865	\$2,055
Hollyburn House	West Vancouver	Lifestyle Retirement Communities/Diversicare Management Services	\$2,590	\$3,360

**Source:** Facility Information (May, 2000).

***It's not fair, it's not smart:*** Analysts at Statistics Canada drew similar conclusions about social inequities at the national level. A 1998 report noted significant disparities based on income and gender in Canadian seniors’ access to Home Support.<sup>28</sup> The study found that low-income and less educated seniors had much higher levels of need and unmet need for personal assistance than those in higher-income households. Further, seniors with lower incomes were more dependent on formal services (in contrast to informal care by family and friends). Not surprisingly, unmet needs were higher among women, especially low-income women.

The authors of the study concluded that, without formal support from the public health care system, the socio-economic gulf would have been wider, and the health status of people without care would have been worse. Their findings serve as a warning to governments and health

Without support from the public health care system, the socio-economic gulf would have been wider.

authorities: Cutting access to public Community and Continuing Care is not only contrary to basic social equality, it will inevitably rebound in costs to the health care system.

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## **The impact on family and friends**

The negative implications of two-tier Community and Continuing Care extend well beyond the patient in need. Also directly affected are the family members and friends who must try to fill the gaps. The vast majority of these informal caregivers are women.

Building on a growing body of research, a new study published by Status of Women Canada found that female relatives are increasingly expected to supplement inadequate public home care services “without pay and at great personal expense in terms of their own health, incomes, benefits, career development and pension accumulation.”<sup>29</sup> The researchers concluded that inadequate funding and lack of public health services are directly contributing to the impoverishment of women.

Who are these informal caregivers? Most are women who work in the paid labour force – and their job performances are being adversely affected by their unpaid caregiving responsibilities. A 1999 Conference Board of Canada study found that caring for aging family and friends is taking a toll on many Canadian workers, including on their ability to function well as employees. According to Judith MacBride-King, author of the study, “these people are more likely than other caregivers to report health problems, lack of time for themselves and too little sleep.”<sup>30</sup>

Caring for aging family and friends is taking a toll on many Canadian workers.

# 4

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## Chapter 4

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### **Privatization: Hurting Health Care**

The gaps in public Community and Continuing Care are creating opportunities for private firms to enter the health services "market." Indeed, British Columbia has attracted the attention of some well-financed transnational corporations. Yet their commercial interests are far removed from the Canadian public's interest in a universally accessible, high quality health care system. Clearly, privatization is at odds with Medicare.

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### **The privatization of residential care**

The critical shortage of accessible LTC facilities is due, in part, to the province's failure to invest in public infrastructure. In the 1990s, B.C.'s capital spending on health facilities fell by almost 50 percent: from 4.3 percent of total health spending in 1990 to 2.3 percent in 1999.<sup>31</sup> Local health authorities have been all but forced to enter into contracts with for-profit providers to meet the needs of their region.

There are no new *publicly owned* facilities being built in B.C. at this time.

The decline must be put in historical context. Faced with an onslaught of negative media about deficits and public spending, the provincial government was reluctant to put more debt on the books. Off-book investments were deemed more politically palatable, and so Victoria opted to fund new LTC developments through the private sector.

Under public-private partnerships (P3), new LTC facilities would be built by private investors. The for-profit company would retain ownership of the buildings and land in exchange for public subsidies for property costs, operating expenses – and investors. The P3 policy means there are no new *publicly owned* facilities being built in B.C. at this time.

Relying on private investors for the capital to build new LTC facilities is one more threat to public health care. In essence, P3 is another name for privatization. And not only does the government's assistance to the corporate sector come at the expense of the non-profit sector, it is also an inefficient and costly response to LTC shortages.

Under P3s, public costs will be higher in the long run. For example, the private sector has steeper borrowing costs than the public sector, an expense that will be passed on to taxpayers. Some regional health authorities see P3s as an additional obstacle to well-coordinated and fiscally responsible services. The alternative to P3s – facilities developed by the non-profit, public sector – eases the way for centralized administration, which translates into lower costs and economies of scale.

Public sector development can also harness the initiative, energy and human resources of non-profit societies such as religious and ethnic organizations. And public sector development uses taxpayer dollars to create *public assets* that become the heritage of all British Columbians, rather than privately owned assets for a privileged few. None of these benefits are forthcoming in a privatized system.

### **Public shortages spur for-profit gains**

Several large firms have been aggressively investing in residential and long term care in B.C. in recent years. The three fastest growing corporations – CPL Long Term Care, CPAC (Care) Holdings, and Ishtar Seniors Communities have seen dramatic revenue gains. (CPAC and Ishtar operate in B.C. only.) From 1998 to 1999, CPL's revenues grew by 15 percent, CPAC's by 29 percent, and Ishtar's by an astounding 102 percent.

<b>Table 10: Long Term Care Corporations Revenues (\$000s) Canadian Operations</b>			
<b>Company Name</b>	<b>Revenues</b>		
	<b>1998</b>	<b>1999</b>	<b>Increase</b>
CPL Long Term Care REIT	\$252,681	\$291,136	15%
CPAC (Care) Holdings Ltd.	\$12,617	\$16,223	29%
Ishtar Seniors Communities Inc.	\$17,456	\$35,247	102%
<b>Source:</b> Annual Reports			

This rapid expansion is cause for concern. Private investors are interested in making profits through what they view as real estate investments, rather than by providing accessible care to every British Columbian in need. For example, Ishtar's 1999 *Annual Report* explicitly states that the corporation's target population is wealthy seniors, "the high-end market ... where values and returns are higher ..."<sup>32</sup>

But the problem with corporate involvement goes beyond the profit motive.

**What will it ultimately cost?** In "The Hidden Costs of Privatization" (*Without Foundation*, Part II), author Michael Rachlis reports that for-profit long term care is of lower quality than non-profit care. His survey of international research also indicates that, although growth in the private sector may initially decrease costs, overall costs for health care are likely to increase over time.

The primary reason for any short-term cost reductions is lower staffing costs in for-profit facilities. For example, non-profit LTC facilities in the U.S. tend to have a more diverse, better trained and better paid staff complement than their for-profit counterparts. Better trained workers provide higher quality care as well as more continuity of care, due to lower staff turnover.

In this regard, B.C. is not directly comparable to the U.S. experience. The unionization of B.C. staff in both for-profit and non-profit facilities has limited the ability of private employers to pay substandard wages. Nevertheless, B.C. has no regulations or monitoring that control *how* private facilities spend the public dollars they receive. Thus, private companies can divert public funds that are intended for staffing to their investors. For-profit facilities in B.C. can also charge their clients "extra" for all manner of goods and services (see Chapter 3), and likewise pass on those revenues to investors. At the very least, there is a serious need for B.C.-specific research into the many ramifications of for-profit long term care.

Private investors are interested in making profits through real estate investments, rather than by providing accessible care to every British Columbian in need.

Inadequate staffing is a known problem in some for-profit homes.

... expect an increase in corporate pressure to weaken the province's regulations governing residential care ...

**Quality of care declines:** International studies also show that for-profit facilities are more likely to be cited for deficiencies in care including too few staff than are non-profits. On this point, the U.S. literature is much more relevant to B.C, which does not have mandatory staffing levels for LTC facilities.

Inadequate staffing is a known problem in some for-profit homes. Several facilities were ordered to close in B.C. in the late 1990s due to poor staffing levels and inadequate care, including lack of nutritional supports and incontinence supplies. The substandard facilities included Trout Lake Manor and Lakeside Place in Vancouver.<sup>33</sup>

**Pressure to lower standards:** Private sector enterprises are strongly affected by public regulations. As a rule, corporations demand a weakening of laws, regulations and enforcement in order to cut costs, increase revenues and raise their stock value. In their 1999 *Annual Report*, for example, CPL Long Term Care warns investors that the company has potential exposure with respect to changes in government laws and regulations related to the LTC sector.<sup>34</sup> The CPL report goes on to note that in the U.S., regulations covering Medicare and Medicaid reimbursement, professional training, certificates of need, licences, financial relationships with physicians, and the dispensing and storage of pharmaceuticals, "could have a 'material adverse effect' " on the company's operations and finances.<sup>35</sup> It is standard practice for health care corporations to make such a statement to avoid shareholder litigation in the U.S.

If for-profit interests continue their aggressive investment in residential care for B.C. seniors, we should expect a corresponding increase in corporate pressure to weaken the province's regulations governing such care.

**Increased regulatory costs, and fraud:** There is also good reason to be concerned about the added public cost of regulating for-profit companies. In the 1990s, U.S. regulators dealt with a spate of improper claims and fraud by some private health care providers. There were cases of fraudulent billings to the U.S. Medicare, Medicaid and other programs. The cost of ensuring compliance with new regulatory standards has added to the already high administrative charges in the U.S. system.

Indeed, the fact that health care is so much more expensive in the U.S. than in Canada 13.5 percent of GDP in the States compared with 9.2 percent in Canada is attributed in part to higher administrative costs.

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## Commercial home care: In whose interests?

Again, few studies exist anywhere that compare the performance/quality of for-profit and public, non-profit home care and Home Support services. And again, the lack of B.C.-specific research is very troubling in light of the growing involvement of for-profit corporations in this area.

The international evidence that we are able to draw upon indicates that, like residential care, for-profit home care is likely to be poorer quality than non-profit care, and is likely to increase overall health care expenditures over time.

In "The Hidden Costs of Privatization," Michael Rachlis notes two U.S. studies that found lower costs in non-profit home care organizations. One study attributed the cost differential to the fact that, because home care was reimbursed on a fee-for-service basis, private suppliers had an incentive to provide more service. The other study found that the cost of for-profit care was higher regardless of the method of payment.

Rachlis notes similar results in comparisons of quality of care. Non-profit home care was rated better, primarily due to the higher incidence of staff turnover and lower levels of staff training in the for-profit sector. Once again, international experience differs in at least one important respect to B.C.'s experience with unionized staff and the limited ability of private Home Support agencies to pay substandard wages and benefits. For this reason, the quality-of-care difficulties relating to high staff turnover may be of less concern in this province.

There are, however, other problems associated with for-profit care that are directly applicable to B.C.:

- Public funding is being diverted to corporate shareholders, many of whom are based outside B.C. or Canada.
- For-profit companies may try to pressure their B.C. clients to buy additional, unnecessary health care services.
- Large companies may make artificially low bids to win local contracts, and then increase their fees after smaller, often non-profit care providers are driven out of the market.<sup>36</sup>

Each of these outcomes is common in the U.S. system.

Large companies make artificially low bids to win local contracts, and then increase their fees after smaller non-profit care providers are driven away.

Fraud in the American home care industry is so prevalent that Washington launched a multimillion dollar investigation in 1995.

**A case of for-profit care:** Today, local health authorities in B.C. contract out the provision of Home Support to a mix of for-profit companies and non-profit organizations. Gentiva, a former subsidiary of Olsten Corporation, is one of the largest for-profit home care agencies operating in B.C.<sup>37</sup>

A 1997 study by the Canadian Centre for Policy Alternatives reported that the U.S. Olsten corporation was charged with submitting fraudulent U.S. Medicare claims in Georgia, New York, Florida and New Mexico, and with failing to carry out physician's instructions in Washington State. In July 1999, Olsten accepted a settlement requiring the corporation to pay US\$61 million and enter into a Corporation Integrity Agreement that obliged the company to properly train staff and prevent fraud.<sup>38</sup>

Olsten also fared poorly in Manitoba in the 1990s. The province contracted out a portion of home care services to the U.S. corporation, a move that drew widespread opposition from health care workers and the public. After a one-year trial period, it was determined that Olsten's services were actually more expensive than publicly delivered care. News of Olsten's legal problem south of the border didn't help, and the government was forced to abandon the privatization project.

The problems with Olsten are not unique. Fraud in the American home care industry is so prevalent that U.S. government launched Operation Restore Trust in 1995, a multimillion dollar investigation spanning five states. As a result of the investigation, Washington declared a moratorium on licensing new home care agencies, identified \$188 million to be paid to the U.S. government and expanded the investigation to other states. Moreover, a 1997 study concluded that for-profit home care added more than \$1 billion to overall U.S. Medicare costs.<sup>39</sup>

## More information, please

As these cases demonstrate, there is a pressing need for research comparing the performance and costs of for-profit corporations and non-profit agencies. In general, British Columbians are in the dark about how for-profit home care affects the overall public health care system. For example:

- How does the use of private services hinder our ability to develop public preventive and early intervention programs?
- How does the lack of multiservice coordination in home care rebound on the acute care sector?

The little evidence that does exist suggests that public funds for home health services should be directed towards non-profit care providers. The upcoming chapter explores some of the benefits of investing in public Community and Continuing Care.

# 5

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## Chapter 5

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### **Fulfill the Promise of an Integrated, Public System**

The de facto rationing of Community and Continuing Care services in British Columbia is incompatible with the Seaton Commission's closer-to-home vision of 1991. Worse, the lack of investment in public Community and Continuing Care means that B.C. is inadvertently encouraging two-tier health care and privatization.

But the problem is more than threats to population well-being and social equality. There is also clear and mounting evidence that inaccessible Community and Continuing Care will actually endanger our public health system. Some of the dangers are very concrete. When British Columbians are unable to receive necessary care in their homes and communities, they risk falling ill more often and more seriously, and ending up in physicians' offices and costly acute care facilities.

Other dangers come in the form of public discouragement and private opportunism. As the personal and public costs of health care climb, and access to community-based care diminishes, we can expect to hear more from corporate lobbyists about our inability to sustain Medicare. And the calls for further privatization will intensify.

## Good care, cost-effective care

Already today, reduced home care services and inadequate LTC resources are leaving some patients with no choice other than to stay in hospital, even though they could be recuperating at home or in lower-level care facilities. Periodic crises in emergency departments can be partially linked to patients who are forced to stay in hospital due to shortages in LTC beds, rehabilitation services and Home Support.

Investment in public CCC services would obviously help relieve these problems. But there is also evidence that community-based services are cost-effective in and of themselves. Table 11 shows the comparative costs of acute, long term care and home care. Clearly, it is more cost effective to use community-based care when it is appropriate to an individual's needs.

<b>Table 11: Estimated 30 Day Cost Per Client</b>		
<b>Acute Hospital</b>	<b>Long Term Care Extended Care Level</b>	<b>Home Support</b>
\$15,540 - \$26,190	\$4,623	\$1,972
<p><b>Note:</b> Long Term Care refers to free-standing care facilities.  <b>Source:</b> Ministry of Health, "Home Support Services, Operation Analysis: Past to Present," 1998.</p>		

A number of studies have examined the comparative costs of home care, focusing on such effects as hospital patient-days saved and related savings to government. A study in the early 1990s by Dr. Nancy Hall found that, among a sample of patients with chronic illnesses in New Westminster, B.C., those who received attention from a visiting home care nurse were 39 percent less likely to have died or to have been placed in a LTC institution than those who received no care.<sup>40</sup> A recent study by researchers at the University of Leicester in Britain found that home care is not only substantially cheaper than hospital care, but that patients treated at home need only half as many days of care as those treated in hospital.<sup>41</sup> A similar study in Saskatchewan concluded that while health outcomes are the same, it costs \$850 more overall to care for recovering patients in hospital than it does to discharge them and provide follow-up home care.<sup>42</sup>

More recently and closer to home, a substudy of the National Evaluation of the Cost-effectiveness of Home Care found that "dollar for dollar, the home care client is the best value to government." Analyzing data from B.C., researcher Marcus Hollander concluded that overall public health care costs for clients in home care range from one half to three quarters of the costs for clients in a facility.<sup>43</sup> Because most

"... dollar for dollar, the home care client is the best value to government ..."  
 — Marcus Hollander

elderly people prefer to stay at home as long as possible, this means home care is good for taxpayers and patients alike *as long as appropriate services are in place*. "[M]ore services and programs need to be designed to keep clients stable and supported at home,"<sup>44</sup> said Hollander, if governments want to reap the benefits of cost-effective home care. It is important to note that Hollander's findings relate to stable clients; less stable clients, he acknowledged, may be better cared for in institutional (i.e., LTC) settings.<sup>45</sup>

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## For the sake of Medicare

In the absence of a solid public infrastructure for Community and Continuing Care, the burden of care – in dollars and unpaid support – is being shifted onto patients, their families and their friends. As a result, the door is being opened ever wider to privatization. With more public and private dollars flowing into private services, Medicare will be at the mercy of an ever-shrinking pool of resources.

A small number of wealthy people and corporations may actually welcome the erosion of Medicare, because it provides them with more personal choice and opportunities to make money. For the vast majority of British Columbians, however, a reversal of this trend is crucial to our health and the overall quality of our lives.

Health policy is about making choices. Despite the claims of corporations and neo-liberal politicians during the 1990s, this province does have the resources to provide all citizens with high quality health care. The real question is whether we spend our health care dollars out of our own individual pockets, and accept the inevitable inequities and inefficiencies, or continue to pool our dollars within an integrated public system so that everyone has access to health care, now and in the future.

Revitalizing public health care in British Columbia is obviously a complex task. However, we already know a great deal about what works and what doesn't. Now is the time to act on that knowledge.

***Genuinely closer to home:*** First, we need to revisit the recommendations of the Seaton Commission. To restate the primary directive of *Closer to Home*, health care resources should be committed to a network of integrated CCC services based on prevention, early intervention and community development.

***For the public, by the public:*** Second, we need to stem the tide of privatized health care by bolstering the public, non-profit face of Community and Continuing Care.

Today, non-profit societies, community organizations and local agencies – the traditional providers of CCC services – are starved for stable funding and infrastructure. Public investment in public services can come in many forms: from dedicated program funding for front-line

Do we spend our health care dollars as individuals and accept the inevitable inequities? Or do we pool our dollars within a public system so that everyone has access to care?

services like public Homes Support, to capital funding for non-profit LTC facilities, to subsidies for supportive housing.

***Medicare must cover Community and Continuing Care:***

Third, the province must work with Ottawa to enfold Community and Continuing Care into the public sphere. Ultimately we need a strong legislative framework that guarantees the right to quality health care no matter what the venue: hospital, doctor's offices, community clinic, LTC facility or private home. Provincially, this could mean amending the Continuing Care Act to enshrine the principles of the Canada Health Act. Federally, it could mean expanding the current interpretation of the Canada Health Act to include Community and Continuing Care, or drafting new legislation such as a National Home and Community Care Act.

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## Endnotes

1. *Closer to Home: The Report of the British Columbia Royal Commission on Health Care and Costs* (1991). C-163. Commonly known as the Seaton Commission.
2. Shrinking cash transfers were only part of the federal withdrawal. Traditionally, the federal government gives the provinces a mix of cash transfers and tax points to finance health care. In this period, Ottawa also shifted the mix to favour tax points, which created two problems: 1) Provinces are not obliged to use the tax revenue for health care; and 2) Tax points, unlike cash transfers, give Ottawa no clout in enforcing national standards or spending priorities.
3. Robinson, Sept. 11, 2000.
4. These infusions brought the federal contribution up to 13.2 percent and 13.8 percent, respectively. Provincial and Territorial Ministers of Health (June 2000).
5. Ibid.
6. Real per capita spending declined: i.e., total health expenditures divided by the B.C. population and adjusted for inflation.
7. See *Closer to Home*, (1991), Rachlis and Kushner (1989), and *Blended Care* (1999).
8. Ministry of Health, Population Table, People 24; Statistics Canada, Spring, 1997; Statistics Canada, "Hospital Downsizing" in *Health Reports*, Vol. 8, No. 4 (Catalogue 82-003), Spring 1997.
9. MOH, January 2000. 14.
10. MOH, January 2000. Appendix 4.
11. Ministry of Health, "Continuing Care Residential Planning Model," Oct. 7, 1999. The number of beds, already low, did not keep pace with B.C.'s population growth or with the increasing proportion of British Columbians over the age of 75.
12. Ministry of Health, 1999, *Community for Life*. 2.
13. Government of British Columbia and Statistics Canada, cited in Patricia Chisholm, Jan. 17, 2000. 20.
14. British Columbia is unique in having a single classification system for entry into Community and Continuing Care. A patient's needs are assessed on a five-point scale ranging from the least acute (Personal Care) to most acute (Extended Care).
15. MOH, JAC Secretariat (Jan. 2000), Figure 2.
16. Gnaedinger, i. Supportive housing is sometimes called congregate care.
17. The survey was conducted in May-June 2000 in Vancouver, B.C.
18. B.C. Stats, British Columbia Total Population by Age.
19. CIHI (1999), Tables D.2.10.3 and D.3.10.3.
20. Deductibles are payments by individuals for a prescription, up to a specified amount. Co-payments are payments of a portion of prescription costs. Residents of licensed LTC facilities and private hospitals, medically dependent children, individuals requiring home oxygen and eligible income assistance recipients receive Pharmacare benefits at no personal cost. All other groups have been hit with sharp fee increases.
21. Statistics Canada, (Spring 1999).
22. CIHI (1999), Table D.2.10.2.
23. Kenna K. "Canada No. 30 in health care: world ranking determined by size of user fees." *Toronto Star*. June 21, 2000.
24. CIHI (1999).
25. Thanks to Paul Leduc Browne for pointing out the significance of these unquantifiable private costs.
26. Profiles of residential care and Home Support subsidy applicants was undertaken by researcher Stuart Murray, using data provided by the provincial Ministry of Health.
27. CC Data Warehouse, Information and Analysis Branch of the B.C. Ministry of Health (1998-99 fiscal year).
28. Chen and Wilkins (Summer, 1998). 49.
29. Morris et al., 2000.
30. Conference Board of Canada, November 10, 1999.
31. CIHI (1999), Table D.3.10.2. The actual drop was 46.5 per cent.
32. Ishtar (1999).7.
33. Stewart Bell, "Families Express Doubts about Nursing Homes", *Vancouver Sun*, Aug. 7, 1997.
34. CPL *Annual Report* (1999). 24.
35. Ibid. 25.

- <sup>36</sup> See CCPA-MB (1997) and Shapiro (1997) for a more thorough discussion of, and evidence of, these concerns.
- <sup>37</sup> Gentiva was with Olsten until March 2000. The two other largest corporations delivering Home Support in B.C. are Comcare and Para-Med/Extendicare. The Ontario Health Coalition has profiles of these and other for-profit corporations on their website: [www.web.net/ohc](http://www.web.net/ohc).
- <sup>38</sup> CCPA-MB (1997). See also [www.web.net/ohc](http://www.web.net/ohc).
- <sup>39</sup> Leon, Neuman, and Parente (1997), 3, cited in CCPA-MB (1997), 1.
- <sup>40</sup> Hall, et al., 1992. Quoted in *Blended Care*.
- <sup>41</sup> André Picard, "British report cites advantages of home care", *Globe and Mail*, Dec. 20, 1999, A4.
- <sup>42</sup> "Hospital patients home sooner, cheaper with home care," *A Closer Look*, Health Services Utilization and Research Commission (HSURC), 1998. Summary of the HSURC's *Hospital and Home Care Study* at [sdh.sk.ca/hsurc/nlspring98.htm](http://sdh.sk.ca/hsurc/nlspring98.htm).
- <sup>43</sup> Hollander, 1999.
- <sup>44</sup> Ibid.
- <sup>45</sup> Hollander's research does not take into consideration the possibility that the relative cost-effectiveness of home care could be partially the result of *downloading costs* to patients and families, rather than an actual reduction of costs.

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# CUTTING HOME SUPPORT

From “Closer To Home”  
To “All Alone”

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BY NANCY POLLAK

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## **About the author**

Nancy Pollak is a writer, researcher and editor in Vancouver. She is the author of *Critical Choices*, *Turbulent Times: A Community Workbook on Social Programs*, and a former editor of *Kinesis*.

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## Summary

*"They said, 'No more housework.' They would send someone to help me get in and out of the bathtub – that's what they offered.*

*"But I don't need that. Imagine having a lady to come and do something I can do myself? It seemed like a waste of money, so I said no."  
(Connie, age 100, Vancouver Island)*

When Connie turned down the offer of a bath from her continuing care assessor, she didn't know she was about to lose all her services. Yet at age 100 and living alone, Connie joined the ranks of thousands of people dropped from the Home Support rolls in British Columbia.

She had been receiving two hours of house cleaning every two weeks. Not bad for a centenarian. But evidently too much for health authorities in B.C., where across-the-board cutbacks in 1999 made endangered species of housekeeping and nutritional services.

Most British Columbians would be horrified to learn that a 100-year-old woman – an independent, determined woman who is almost totally blind – had her services cut. Yet most British Columbians don't know what's going on: how drastic the cuts to Home Support, how common Connie's story.

Rather than becoming a solid component of a "closer to home" health reform strategy, Home Support is suffering from a bad case of "home alone."

### What is going on?

Home Support is now virtually unavailable to people who require housekeeping and nutritional services only.<sup>1</sup> Hours of service are significantly reduced for people with somewhat steeper personal care needs. For those with complex or severe health care needs, service is more or less intact.

### Who is being cut?

The victims are elderly people (often very old) and/or people living with a disability or illness. They are usually low-income folks who cannot afford to buy services; 69 percent of single, subsidized Home Support recipients earn less than \$10,000 a year.<sup>2</sup> They often live alone or are themselves caring for an elderly spouse. They are mainly women. (For more details, please see "Unfulfilled Promise", *Without Foundation*, Part I).

They became a target for cutbacks precisely because they didn't seem to need a lot. With the aim of shifting resources to people with more substantial needs, they were re-assessed and judged to need nothing or

much less. Between 1991/92 and 1998/99, people at the lowest level of need lost 51 percent of their Home Support hours.<sup>3</sup> Many believe they were targeted because fragile people living in poverty have few reserves for fighting back.

## How many British Columbians are affected?

Although the hours and dollars allotted to overall home care services have risen, the number of recipients has declined. The most recent statistics show a decline of 19 percent, from 55,980 Home Support clients to 45,529 (between 1991/92 and 1998/99).<sup>4</sup> Some health regions were hit harder than others: Central Vancouver Island Region suffered a 32 percent cut to Home Support clients between 1994 and 1997.<sup>5</sup> During the same period, the elderly portion of B.C.'s population grew by 13 percent,<sup>6</sup> and will continue to grow at a significant rate.<sup>7</sup>

These statistics do not tell the whole story. The number of people affected by reductions in Home Support in 1999/2000 has not yet been tallied. These clients are not the only folks affected. Relatives, friends and neighbours are also hard hit when their loved ones are abandoned by the public system, with serious consequences to *their* health, jobs and family life.

## Who does the cutting?

The decision to reduce Home Support is made by regional health authorities, with local variations in process, timetable and numbers. The decision is always due to budget constraints. While government policies extol the merits of "closer to home" and "client-centered care" and "maintaining seniors in their homes", the real-life needs of some people are deemed no longer affordable to the pinched regional purse.

Regional bodies may have authority, but they lack the funds and legislative infrastructure to deliver home-based services that are stable, comprehensive and public. For this reason, governments in Victoria and Ottawa must share responsibility for depriving people of Home Support.

## What is being lost?

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 or to take a pill, a risk-free walk to the store, a touch.

For many individuals, Home Support is the difference between bearable and unbearable, healthy and unhealthy, safe and unsafe. For British Columbians as a whole, Home Support is supposed to be a preventive service that, in tandem with informal caregivers, helps vulnerable people to stay healthy in their home and involved in their community. It is a vehicle of citizenship and of dignity. When people

"Until recently, I was saying they were eroding our Home Support. Now I would say they are eradicating it." – Sarah, living with a disability, Victoria.

are forced into institutional care, or confined to bed, or under-nourished at home, or too poor to "buy" contact with the outside world, they are surely deprived of their basic human rights.

Finally, Home Support is intended to serve more than individuals in need. It is supposed to act as a buffer against strains on our hospitals, long term care facilities, health personnel and provincial budget. British Columbians would do well to ask if government or health authorities are researching how these cuts to Home Support are affecting acute care and LTC facilities.

Home Support should be an essential tier of a health care system that is preventive, holistic, equitable, universal and coordinated. Yet despite the hard work and commitment of staff, Home Support has become a narrow, unfair, risky and inadvertently costly service.

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# Introduction

This paper examines the implications of cuts to basic Home Support services in British Columbia. It is a case study that addresses the questions:

- **What happens when vulnerable people no longer receive help with meals, grocery shopping and housekeeping?**
- **What happens when their hours of personal care are reduced?**

Care recipients, Home Support staff and other concerned people were asked to describe their personal experiences and to comment on what they saw happening in their communities. (Please see Appendix 6 for research methodology.) Their concerns were organized into five categories, ranging from the personal to the systemic:

1. Damage to the health, safety and well-being of people in need.
2. Pressures on family and friends as informal caregivers.
3. Deterioration of training, teamwork and morale among Home Support staff.
4. Avoidable expenses to other parts of B.C.'s health care system.
5. Growing inequities and threats posed by for-profit service.

## A Home Support primer

Home Support is a fundamental component of community-centred health care, as described in the Seaton Commission's *Closer to Home* report (1991).

In B.C., Home Support is offered at four different levels of care: from Personal Care (PC) to Intermediate Care (IC 1, 2 & 3) and Extended Care (EC). This study focuses on cuts to Home Support at the PC level – specifically, wholesale cuts to nutrition and housekeeping services, and partial cuts to personal care.

## Who uses Home Support?

Most Home Support recipients are elderly people, often living alone and on low income. Many have a degree of dementia or Alzheimer's.

The other major group is people living with physical and/or mental disabilities. This includes people with AIDS, multiple sclerosis, schizophrenia or a cognitive impairment. Some are parents with young children still at home.

Other individuals use short-term Home Support while recovering from an injury or illness. Others are receiving palliative care.

People on Home Support want to receive care in their home for reasons of independence, privacy and comfort.

## **What does a Home Support Worker do?**

Their job duties are extensive and vary according to the client and the worker's training: from personal care (e.g., bathing, dressing, feeding, toilet care, putting to bed, skin care) to nutrition and housekeeping (e.g., shopping, meal preparation, laundry and vacuuming) to health care tasks (e.g., ostomy and catheter care, dressings, respirators, oxygen).

Like other front-line care providers, a Home Support worker has a relationship with her or his clients that is only hinted at in the job description. "Provides socialization and companionship" – in fact, a Home Support worker may be the only person with whom a client has ongoing human contact.

## **How does a person get Home Support?**

Individuals are visited at home by a continuing care assessor who asks about their needs and capabilities, and assesses their risks. Eligibility is based on a written criteria that varies somewhat from region to region. The main considerations are the person's ability to perform "activities of daily living" (ADL), their health status and their risk of hospitalization.

The Home Support worker may be the only person with whom a client has ongoing human contact.

## **What is the role of nurses?**

Registered nurses (RNs) work in Home Support in many positions including continuing care assessors, field supervisors of Home Support (H.S.) workers, discharge planners, case managers and home care nurses. Field supervisors, for example, work closely with H.S. workers on client issues and train workers in health-related tasks.

## **What is the role of physicians?**

Family doctors and other physicians do not have the power to order Home Support for their patients. They can recommend and refer, but the decision to provide services rests with the local health authority.

## **Who employs Home Support workers?**

Home Support workers who perform publicly funded services are employed by three different types of employers:

1. public home care organizations (e.g., operated by a Community Health Council);
2. non-profit agencies (e.g., operated by a charitable society); or
3. for-profit companies (e.g., a private corporation).

Home Support is immensely valuable in enabling people to live independently at home.

Local health authorities contract with one or more types of employers to deliver services.

There is also the CSIL program (Choice in Supports for Independent Living), under which individuals hire their own Home Support worker with funds from the Ministry of Health. Most people using CSIL are living with a disability.

## **Is Home Support covered by B.C.'s health care plan?**

Yes and no. Unlike hospital and physician care, Home Support and other Community and Continuing Care services are not presently covered under the Canada Health Act. Governments are not legally obliged to provide Home Support as an insured and widely accessible health service. As a result, Home Support is vulnerable to cutbacks and privatization.

In B.C., recipients of Home Support pay a user fee based on their income. The vast majority of recipients pay no fee: they are fully subsidized because their income is very low.<sup>8</sup>

## **Is Home Support good value?**

Yes. Home Support is immensely valuable in enabling some people to live independently at home. It is an effective and relatively inexpensive mode of health care for stable clients. A recent B.C. study found that "the overall health costs [for clients on home care] ... range from one-half to three-quarters of the costs for clients in facility care."<sup>9</sup>

# 1

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## Chapter 1

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# Harm to the Health, Safety and Well-Being of People in Need

*"It's now at the point where you probably don't get service if you're 80, 90, and you're blind and you use a walker. If you do, it's maybe for a bath for one hour. That's about it." (H.S. worker, Sechelt)*

*"Not providing housekeeping is like saying, 'We'll make sure your body is still working, but not the rest of your life.' As though people are only their bodies. As though health is only a physical condition." (Sarah, living with a disability, Victoria)*

"[We] assess whether a client has a rash under her breast or in her groin, or a bladder infection, or bruises – all the things we look for on a daily basis."

When cuts to housekeeping and nutrition services occurred, many clients were completely removed from Home Support. The impact on their lives was much more than an unclean home, empty cupboard or missed meal. For many, the loss of Home Support means that nobody comes by to monitor their health and safety, or to offer emotional support.

This blow to basic services is part of a trend to cut vulnerable but apparently stable people. There are total cuts to some, partial cuts to others. Health care staff throughout the province are deeply troubled by disappearing services and falling standards of care. An RN field supervisor in the Kootenays said:

"You keep refining and refining and refining the priority list – and now I'm putting out fires. I am not a bad nurse, but I'm very concerned. I have adhered to [RN] Standards of Practice all of my career, and this is the first time I'm terrified. I'm just waiting for the big lawsuit to happen."

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## Closing the eyes of the community

Home Support workers spend intimate time in the homes of isolated individuals. They see themselves as the eyes and ears of the community. When they are shut out, what goes unseen?

***Deterioration in health status:*** The Home Support worker is often the only person who sees the client from week to week. They are trained to observe and report changes in health and functional status.

"We've got listening skills. We're trained to listen and observe, that's how we pick up on things. But we can't listen anymore. We don't have time." (H.S. worker, Prince George)

"[We] assess whether a client has a rash under her breast or in her groin, or a bladder infection, or bruises – all the things we look for on a daily basis when we're assisting our clients. When you get cut back, you're not able to [find] those things." (H.S. worker, Prince George)

***Unsafe health equipment:*** Home Support workers also check on the condition of health aids and equipment such as wheelchairs, oxygen supplies and bath boards.

"We do a lot of intervention with their safety and the aids they use. One person, his wheelchair was falling apart on him. We don't have time to see that if we're just in and out. It would be so impersonal."  
(H.S. worker, Victoria)

**Unsafe homes:** People on Home Support are usually elderly or disabled, and their homes may not receive regular upkeep. The result? Broken stairs, faulty appliances, bad wiring and snowy steps.

"You go in and observe the situation. You see the burnt frying pan or boiled kettle or burnt towels. What scares me the most is their stove. They want to be independent enough to warm that cup of tea. These are things we could be doing for them." (H.S. worker, Prince George)

**Medication errors:** Elderly people and mental health clients are no longer reminded to take their medications, and to take them properly.

"I had a lady who had been in hospital. She's palliative care – she got the usual two weeks when you're coming out of hospital. She's got a brain tumour. Her memory is lousy. I reported that she was overdosing on her sedatives – she was taking about 10 or 12, she was only supposed to be taking 2 a day." (H.S. worker, Parksville)

**Loss of emotional and social support:** Home Support workers offer a brief chat, an act of kindness – the simple human contact without which a person's spirits fail.

"Putting a little make-up on an 80-year-old woman, or taking her to see the flowers – this gives her a reason to live." (H.S. worker, Squamish)

"You walk in that door, you say good morning. And you see that client who looks so grey, and you think, 'Oh gads, is today the day?' And an hour later, one short hour later – it's absolutely amazing – they've got colour.

"I've stopped and thought, 'Did I imagine this?' They have colour in their cheeks and they're smiling. An altogether different person. To take that measly hour away is just devastating." (H.S. worker, Sechelt)

**Loss of confidantes:** Some elderly people will talk to their Home Support worker about problems they are reluctant to discuss with relatives: from the relatively minor but health-related (skin rashes) to the profound (thoughts about dying).

"They've always talked to us more than they've talked to their family members." (H.S. worker, Prince George)

"You see the burnt frying pan or boiled kettle or burnt towels."

"They talk about dying. It's important that they do that. And they can't do that with their family because they get, 'Oh, don't talk that way, Mom!'" (H.S. worker, Smithers)

**Loss of an advocate and community resource:** Home Support workers will often speak up for their client, who may be hesitant to disclose their actual condition to other professionals. They also bring information about the outside world.

"[Without Home Support] nobody is there as an advocate for the client who will not say, 'I need to have assistance in and out of the tub, I need to have my meals cooked, I'm sorry but I have a bladder problem and I need to have my laundry done twice a week!'" (H.S. worker, Smithers)

"We're there to plug them into other resources. We're supposed to be the repository of community resources for our clients. But how much time do we have to really do it? And if we're not there [anymore]?" (H.S. worker, Vancouver)

**Financial problems:** Home Support workers see bills piling up and financial matters left unattended. They've heard stories of people losing their homes or failing to pay taxes.

"Their money management is not as good, or their medication management. They need reminders. You see the bills stacked up there, obviously not paid." (H.S. worker, Parksville)

"Many seniors are beginning to feel anxiety, stress and even depression as they feared losing their home if they could not maintain it." (Louise FitzGerald, researcher, Greater Trail Community Health Council)<sup>10</sup>

**Abuse and exploitation:** Some people are vulnerable to abuse by family members or to financial exploitation by relatives or 'friends.' Others are concerned that they will be forced to deal with private cleaning agencies, which may not be as trustworthy as a public agency.<sup>11</sup>

"You need time and patience to deal with some clients. I can see the frustrations arise, the physical and mental abuse arise. The burden on families is intense." (H.S. worker, Victoria)

"We had one person who got a friend to do their shopping, and that person took their money and they never did get their groceries." (H.S. worker, Smithers)

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# Nutrition: Nothing much for dinner

Good nutrition is important at every age, but can be elusive for elderly people even under the best of circumstances. Researchers have documented the prevalence of malnourishment among older people. One Ottawa study found that 15 percent of women over 65 were suffering from malnutrition when admitted to hospital; another 44 percent were at moderate risk.<sup>12</sup>

Nutrition is also a potentially costly issue for individuals and the health care system itself. A balanced diet plays a role in disease processes: accelerated aging may be related to deficiencies in certain vitamins and minerals,<sup>13</sup> and diet seems "to play a protective role in Alzheimer disease."<sup>14</sup>

Eliminating hot meal preparation is like telling elderly people not to eat. Like other isolated people, they benefit from someone fixing a meal, serving it and saying a friendly 'now eat up.' They also benefit from being taken shopping: choosing the foods they prefer, getting out of the house.

Clients are often told to use Meals on Wheels when they are cut. Although this program plays an important role in the community and manifests the goodwill of many volunteers, few people can thrive on a diet of Meals on Wheels. Servings are not necessarily palatable or diverse (a lot of bland pasta and hamburger). Meals are not always delivered at appropriate times or even daily, and may frequently be left uneaten.

**Many elderly people need encouragement to eat:** Their taste buds have faded, their appetites are low, their enjoyment scant. They're bored with food. Researchers know that "food can become tasteless and unappetizing for [elderly people] as a result of declining taste and smell perception."<sup>15</sup>

"If you have no incentive to get up, take that Meals on Wheels out of the fridge and put it into a pan or a warming oven, you're going to lay in bed and waste away." (H.S. worker, Prince George)

"A lot of people are blind or depressed. They just don't look in their fridge. Stuff could crawl out of there. They're not eating. All they eat is tea and toast, tea and toast, tea and toast." (H.S. worker, Parksville)

**People need food that is easy to eat:** This is especially true for elderly people and people with disabilities. Delivered meals often have peas, green beans or corn, which fall off the fork and roll around the floor: not only uneaten, but a safety/hygiene problem.

"A lot of people are blind or depressed. They just don't look in their fridge."

"I can't pick up a pot of boiling water. I can't [cut with] a knife, can't slice or chop food. I guess the baby carrots, the ones without skins, are an option.

"Meals on Wheels aren't in microwave containers. If I remember, I ask [the volunteer driver] to transfer the food to a container I can microwave. If I remember. They deliver lunch at 10:30 in the morning." (Lorna, living with MS, Victoria)

"Meals on Wheels comes in and puts his meal on the counter. When his niece goes there [after work], it's ice cold. Another worker was asked to clean out the fridge ... there were 14 soups and 10 dinners that she threw in the garbage because none of them are dated." (H.S. worker, Prince George.)

***Eliminating grocery shopping affects nutrition and the pocket book:*** Elderly people often need help just making out a grocery list. Blind or sight-impaired people can't read labels or see what's in their fridge or cupboard. They can't easily do their own shopping – so they don't.

Most clients can't afford taxis or delivery fees. This forces them to shop in more expensive local 'convenience' stores or to not shop at all.

"One client was blind. We took her shopping once a week, around the store, read the labels. When you come home you put the [products] away so she knows where they are, what's in them, how to use them. But that was cut off. She was told that she could get a taxi; we don't have stores that deliver." (H.S. worker, Sechelt)

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## Hygiene: Nowhere to go but down

When housekeeping services are cut, the result is predictable: a home with unclean floors, bathroom, fridge and stove, and piles of unwashed dishes and laundry. But housekeeping cuts are also directly related to safety, personal hygiene, health hazards and depression.

***Arthritic and elderly:*** Many fragile people have bad arthritis or cannot bend over. Due to old age or disability, they may be unable to mop floors, pick up wet towels, carry laundry, open doors, scrub burnt pots, etc. This leads to unsafe living conditions and deteriorating spirits.

"There are several people in the building that could use just general help ... Someone to go in and do their vacuuming. They're so full of arthritis, they can't even move. You can't even touch them or they cringe in pain.

"They can't get into the washers and dryers ... But they can't get no [Home Support] hours at all." (H.S. worker, Prince George)

"The cutbacks in cleaning – that's important because it's a safety issue. They can't bend over, or they break a glass, or their eye sight goes, or nobody checks the fridge." (H.S. worker, Prince George)

**"The Bath" – A spurious criterion:** Today, the minimum criterion to qualify for Home Support is needing help with your bath. This leads to dangerous inequities. As an RN in Trail said, "You have to get naked before you get help."

For example, people with serious cognitive or mental health problems may be disqualified from Home Support if they can still bathe themselves. Many elderly people will not acknowledge they can no longer safely bathe themselves (especially men): they simply pretend they can. And then they will not let their relatives bathe them because of embarrassment or pride.

"I can't morally or ethically tell people they can't get help unless they agree first to be bathed." (RN, Smithers)

"The 1st client was ... denied housecleaning services; however, she was offered 1 hour a week for bathing. She stated that she does not require bathing assistance, she requires housecleaning assistance." (Louise FitzGerald, student researcher, GTCHC)<sup>16</sup>

**Unmonitored while bathing themselves:** In the past, Home Support workers would do housekeeping and meal preparation while the elderly person bathed, in case he or she had a problem. With the worker gone, people are at risk from bathing alone, or at risk because they aren't bathing enough.

"You find that a lot of these people maybe say they can bathe themselves but they're not actually bathing themselves. They're sponging themselves out of a sink. Sponging because they're so sore they can't get into a bathtub. They can't stand in a tub and have a shower. It drains them. It's exhausting when you live in pain like that – constantly, all the time." (H.S. worker, Prince George)

**Dirty homes are unhealthy and depressing:** Most people can picture how quickly an untended home will fall into disarray. It isn't just humans that suffer: pets are neglected or allowed to run wild, creating further health hazards.

"People ... with respiratory problems: They're now living in homes that are dirty. It's not a healthy situation." (H.S. worker, Prince George)

"You have to get naked before you get help."

"They're sitting in a dirty, untidy house, which they're not used to, and that bothers them. It certainly bothers me, to walk out of that place and not leave them in a clean house." (H.S. worker, Smithers)

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## Declining services: Some overarching themes

People with decreased hours of service are also suffering. A person's daily needs don't diminish just because their hours are cut. They still require the same number of meals and baths, the same amount of housework and human contact.

***Continuity of care is lost:*** This is especially hard on people with dementia and/or mental health problems. In fact, everyone prefers a regular worker(s). In the wake of cutbacks and amalgamation of Home Support agencies, clients may see many different workers – up to 20 a month.

"What a nightmare. Sometimes I see 14 different people a week. I need physiotherapy but I'm often sent a worker who has not been trained. Frustrated doesn't cover it. Stress plus MS equals an attack. Extra stress makes my health deteriorate." (Lorna, living with MS, Victoria)

"People are only getting service every two weeks instead of every week. They don't seem to be able to always get the same [worker], and they spend so much time just explaining where things go or putting things back in place. It's hard on them because many of them have some dementia." (Mervin, a senior, Sechelt)

"When we have a lack of continuity, when we have a system that doesn't cause cohesion but causes separateness and isolation, that pulls people apart ... it doesn't help the clients." (RN, Fraser Valley)

***Inadequate care and rushed clients:*** Along with across-the-board cuts, other shortfalls exist. Morning care may not start until 10 a.m. Weekend care is often nonexistent. Visits by a Home Support worker are further apart and shorter. How could a client not be rushed when their worker is on a treadmill of 15-minute or 30-minute visits?

"We did more hours on essential services during the 1995/96 strike than we do now." (H.S. worker, Howe Sound)

"They're no longer a person, they're an object. They're not getting proper service. You're not giving them proper time with the bath." (H.S. worker, Prince George)

"I had one woman say the other day, 'Well, you really don't have time to make me a proper meal, just give me a sandwich.' Now, should they have to say that? Should they feel so burdened to you?" (H.S. worker, Smithers)

**Clients are fearful:** They're afraid of further cuts and afraid to speak honestly about their needs. Fear levels are so high that complaining about inadequate service is almost out of the question.

"Since the cutbacks, the stress and the tension and the fear amongst the clients is much, much more. As hard as I try not to push on to them that I am hurrying – and you have to hurry – it rubs off on them." (H.S. worker, Smithers)

"In September [1999], when cuts took effect, some people didn't sleep for three or four days, the emotional impact of the change was so great. People are living in fear of speaking up, of losing whatever services they have." (Mervin, a senior, Sechelt)

"Personal support is not a medical issue. It's a health issue in the deepest sense."

**Self-sufficiency is thwarted:** When people are denied services, the deeper societal benefits of Home Support – of fostering self sufficiency and interdependency – are lost. These benefits are of inestimable value to individuals and to British Columbians as a whole, and withholding them is literally costly. Home Support can, for example, make the difference between a person being employable or not, of being educated or not.

"Personal support is not a medical issue. It's a health issue in the deepest sense. It's a human rights issue ... Home Support enabled me to minimize the wear-and-tear on my body, which enabled me to go to school." (Sarah, living with a disability, Victoria)

# 2

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## Chapter 2

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# Pressures on Family Caregivers

*"I know a woman up here who is dealing with breast cancer herself. Her father lives down in the Kootenays, and he's just had surgery. They sent him home but he can't do anything: can't bend, can't do this. And he can't get any Home Support."*

*"And now she's all stressed out [thinking] ... 'I'm going to have to go down there and look after him because his place is getting to be a mess, and the neighbours are phoning.' Plus she's got two kids here and a husband" (H.S. worker, Smithers).*

*"Families chose to look after their own – always have, always will. It's a myth that we don't care for our elders ... It's documented that families only access services when care needs become more complex." (Lorna Hillman, Family Caregivers' Network Society, Victoria)*

Family and friends are the cornerstone of home-based care in Canada. The World Health Organization notes that, around the world, between 75 and 85 percent of the care received by seniors is from informal caregivers. In Canada most of that work is by "wives, daughters and daughters-in-law,"<sup>17</sup> with husbands and sons also contributing.

Cuts to Home Support are hurting these unpaid caregivers. The few hours of grocery shopping, house cleaning and meal preparation provided by a Home Support worker often made the difference between amangeable and unmanageable workload for relatives and friends.

This is more than the oft-told story of the adult child torn between caring for her children and husband, helping her aging parent and holding down a job. This is also the deep scarring of:

- elders who suffer loss of dignity and feel a burden;
- adult children who experience terrible guilt, burn out or fall ill themselves; and
- kids who lose part of their childhood because their family is turned upside-down with caring for an aging or disabled relative.

There is no shortage of British Columbians willing to care for their loved ones. What is lacking is a broad public commitment to support their efforts. Sweden, for example, offers flexible work arrangements for employees caring for elderly relatives. In contrast, B.C. offers the romance of a 'caring community', with little infrastructure to enable real people to really care. The result? Neglected patients, overworked families and new business opportunities for private companies.

***Home Support was never a substitute for family support:***

Home Support workers do not relieve family caregivers of their responsibilities, they provide support. And often that support is so the family caregiver can provide enhanced care – or simply keep going.

"The family is the regular, the live-in home support. You're supporting their support. And you want the family to stay healthy." (H.S. worker, Vancouver)

"The kids are running in after they've finished their day's work, grabbing a grocery list, the next night they go and get some of the groceries for the parents, drop them off. They don't have time to stay because they've been at work all day. So the client feels guilty because

"My daughter is 75. She's not doing very well herself."

here's their rushed child, trying to get home." (H.S. worker, Prince George)

**Taking advantage of the "capable caregiver":** Home Support services are often denied if the assessor concludes there is a capable caregiver in the home or living nearby. These caregivers are spouses, relatives, neighbours or friends. In the case of spouses, they are frequently very elderly and frail themselves (usually women) and may be just as wounded by the loss of service as the official client.

"My daughter is 75. She's not doing very well herself. She takes me shopping when she can." (Connie, age 100, Vancouver Island).

"There may be family, but they have a life - working, children ... And God forbid if my parents ever needed the help because I couldn't provide it. The expectation on the family is far too great. (H.S. worker, Squamish).

**Respite care in desperately short supply:** Even before cuts to Home Support, informal caregivers were often stretched to the limit and in dire need of respite of any duration. A recent B.C. study found that, "for many caregivers, respite is minimal and their days are characterized by eternal vigilance ... [they] always have the care receiver on their mind."<sup>18</sup>

The need for respite is very real. Studies show that health problems are common among people who care for someone with dementia; depression is twice as common for the caregiver of a dementia patient than for other patients.<sup>19</sup>

"Family members are looking for that one-hour break, please and thank you. Because that's all we're in there for – 50 minutes – and they run downstairs and put their feet up on the couch because they're got the other 23 hours to deal with." (RN, Trail)

**Increasing absenteeism, lower productivity:** As they try to fill the gaps left by Home Support, family caregivers are under duress: missing work, coming in late, even quitting their jobs.

"Employers underestimate what is involved in the care of adults. It's not like looking after children, who have to do what they're told. Adults don't. Caring for an adult, negotiating with them, respecting their dignity, dealing with their far-more volatile health needs – employers don't understand how much is involved." (Lorna Hillman, FCNS)

"The relatives become clients themselves." (H.S. worker, Parksville)

"Employers underestimate what is involved in the care of adults."

***Strained relations, depression and worse:*** When Home

Support services disappear, adult children may ask their parents to move in with them. This is especially true in low-income families when room is available. Yet most parents don't want to live with their adult children or be overly dependent on them.

The Greater Trail survey noted the "Potential for experiencing helplessness, anger, frustration, negative self-perception because seniors are having to ask family members or friends for even more support. Many seniors believe they are burdening their families because their 'children' are in their fifties and sixties, and are dealing with their own health issues."<sup>20</sup>

"It can really strain the relationships. The family isn't prepared for the major transition. The move is incredibly stressful when you're elderly. The elderly person loses their social network. They become depressed, and the family can't handle it." (Lorna Hillman, FCNS)

"That client is probably very humiliated by having their [adult] child bathing them. They lose so much dignity." (H.S. worker, Victoria)

# 3

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## Chapter 3

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### Deterioration of Training, Teamwork and Morale

*"You aren't as productive, and you're not as good an employee when you're under a lot of stress and being rushed and rushing the client. It's just a vicious circle. It rubs off on you. You're definitely not communicating." (H.S. worker, Prince George)*

*"There's no added education [for Home Support workers] or funding to deal with higher acuity. We've got all these people going home with tubes and all sorts of stuff, and Home Support workers are attempting, without supervision, to deal with them." (RN, Trail)*

*"Pity the last client on your list." (H.S. worker, Vancouver)*

Cuts to housekeeping and nutrition are part of a trend to shift Home Support resources from low-needs clients to high-needs clients. The trend is clear. Between 1991/92 and 1998/99, the number of Home Support hours assigned to people at the Personal Care (PC) level declined by 78 percent. During the same period, the hours assigned to people at the top two levels of care (Intermediate Care 3 and Extended Care) increased by 183 percent.<sup>21</sup>

Cutbacks to housekeeping and nutrition clients did not mean a decline in workload. "We never saw those people to begin with, one RN observed. "[Cuts] didn't make any difference to workload – it kept increasing."

Greater acuity is now a hallmark of home care clients. People leave hospital quicker and sicker, and require intense amounts of care. Others are unable to move into long term care homes or supportive housing due to a scarcity of resources.

Acuity. Workload. And, in some regions, restructuring or amalgamation of care providers. These factors have created a crisis in morale for Home Support staff: a crisis about delivering quality services and supporting every person in need.

"Every day, it's like being on an acute floor."

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## Increased workload

**Most clients have greater acuity:** Although the number of people receiving Home Support has dropped dramatically, the number of hours of service increased by about 12 percent between 1991/91 and 1998/99.<sup>22</sup> This increase reflects the greater needs of a much smaller number of patients.

"Clients are being discharged from hospital much more acutely ill. The expectations of those workers in the homes to deal with these issues has vastly increased from when I started five years ago." (RN, Penticton)

"We are discharging to community all these short-term hours, routinely. Every day, it's like being on an acute floor. You're setting up in the home [but] only for a finite period of time. We do all the palliative – I'm training four or five palliatives constantly, which change moment by moment. I personally have 12 EC clients in the community. I also work hands-on nursing at a group home, which is all extended care, for six people. Well excuse me, I'm not getting my assessments done, or my reviews of delegations of task."<sup>23</sup> (RN, Trail)

"You can't rush them. It's really hard on these old people."

**Same needs but less service:** Reductions in personal care service are commonplace. For many clients, their one-hour morning visit became a 30-minute bath, and their 30-minute evening visit became a 15-minute dash.

Reductions were not based on diminishing needs but on diminished Home Support budgets. The effect? Clients feel shortchanged and rushed. Workers too are placed in a terrible position, trying to provide the same quality of care in much less time.

"If your [client has] a rough day getting up in the morning, then, bang, their 15 minutes are gone. You just can't do it. You can't say, 'I'll leave you with one shoe on today.'

"You can't rush them. It's really hard on these old people. They've got heart problems. They get mad at you. It stresses them out. Put them under more stress and then they don't relax. And they feel so guilty about having you there to help. They say, 'Oh I'm sorry I didn't do this before you came.'" (H.S. worker, Prince George)

"I do 8 to 10 client visits in an 8-hour day. Some are 15-minute visits: might be eye drops, foot care and breakfast in 15 minutes. And that's outrageous, because that client was getting 30 minutes before for eye drops, foot care and breakfast, and he's been cut to 15 minutes." (H.S. worker, Prince George)

**Travel time: Robbing the client, straining the worker:** Travel time used to be separate from the client's time; today it is subtracted from the client's time. Now a one-hour visit may be just 15 minutes long – to do what used to require two hours.

"We're expected to do almost the same amount of work, bathing and stuff, in less time. And then throw our travel time in there – it's taken off the client. And 10 minutes out of 30 is different than 10 minutes out of 60." (H.S. worker, Smithers)

**Too many hours, too few minutes:** Some Home Support workers keep up a dizzying pace, with more clients in a day than hours of work. Others are coping with a 10-hour window: they work steadily in the morning and evenings, with a patch of 'blank stuff' in the middle of the day. The overall effect is exhaustion.

"Some days you go to 8 people for seven hours. Seven hours of work, 8 clients." (H.S. worker, Smithers)

"We're not as alert and fresh as before. You work like crazy the first half of the day, then you go back and you aren't in very good shape." (H.S. worker, Sechelt)

"I do a lot of muttering under my breath." (H.S. worker, Squamish)

**Restructuring = structural problems:** In 1999, the Simon Fraser Health Region deleted the position of Home Support Nursing Supervisor (field supervisor) and transferred the function to other Continuing Care personnel. Many home care nurses, supervisors and managers are highly critical of this move, citing concerns about workload, chaotic communication and deterioration of their ability to fulfill RNABC Standards of Practice.<sup>24</sup>

"With home care nurses [now doing] what field supervisors used to do, they are not immediately accessible. Home Support workers have been told by the clinical resource nurse not to call anybody unless it's a delegation of task issue. So the Home Support workers are left in the houses to make decisions on their own, with a client who may be having a medical problem." (RN, Burnaby)

"Field supervisors advocate for Home Support workers. Without the supervisor there, a lot goes by the wayside: making sure they're in a safe place; educating them; making sure their call-ins are followed up on. There's no one who's really doing that now." (RN, Burnaby)

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## Teamwork and training: Good theory, haphazard practice

Home Support workers report good support from nurses and field supervisors, when it's available – and huge frustrations when it's not. RNs are similarly upset about their inability to promptly and fully respond to Home Support workers' needs for training and problem solving.

Field supervisors talk about their respect for Home Support workers. Goodwill among staff can be considerable but goodwill is not enough. Crushing workloads, staff shortages and cutbacks have displaced the principles of teamwork and continuous training.

**Lip service to "team concept":** Everyone throughout the health care system – administrators, care providers and clients alike – agrees that people are best served by an integrated, team approach to care. Yet teamwork is more theory than practice. "As much as they talk about 'the team' in the literature," said an RN in Burnaby, "there is absolutely nothing making a true effort for a team context."

"We have an RN creating a care plan with really good input, and using a case manager and whomever [else] is involved, trying to round them all up to develop a care plan ... but we've forgotten an integral part: the Home Support workers. They're so important." (RN, Trail)

"I would run faster and harder, I'd work overtime, I'd work though my lunch."

"You can go in [to a home] for five years and know somebody very, very well. And all of a sudden an assessor spends 20 minutes and, hey, they know this person. But they've never once asked us. That hurts sometimes." (H.S. worker, Prince George)

**Greater acuity calls for more training:** But who has the time? Home Support workers and RNs talk about the need to upgrade skills in the face of sicker clients with more complex needs. The training is not forthcoming. On top of this, delegations of tasks may not be reviewed as frequently as is necessary and desirable (please see endnote 23 for an explanation of this term).

"There's been a huge increase in the numbers of delegations in the past year because of higher acuity and earlier discharges. We have not reviewed delegations in the community in 16 months. We start [the workers], we get everybody initially trained, we make sure that they're competently performing at that moment.

"I used to be able to [review my delegations regularly]. Up until a year and a half ago I did this. I would run faster and harder, I'd work overtime, I'd work though my lunch. I'm still doing all of that stuff; however, the acuity has gone up so quickly." (RN, Trail)

**Good support, if you can find it:** Home Support workers are isolated: from one another, from their supervisors, from the home care team. Some isolation relates to the nature of their work in private homes. But some is the result of their exclusion from meetings and decision-making processes about clients. Restructuring and heavy workloads do not help. The elimination of the field supervisor position in the Simon Fraser Region exacerbates the isolation of workers, as does short staffing in other regions.

"Home Support workers are very isolated. Often times they might not see a supervisor or any other member of the staff for a whole day, or a week, or a month. They never get to share information." (RN, Chilliwack)

"The direction we should be going is team meetings, where Home Support workers are on the same footing as nurses, social workers and everyone, in formulating the care plan for the clients." (H.S. worker, Vancouver)

"Home Support workers don't know who to report to in the absence of field supervisors – they can't be reporting to six different home care nurses. They're voicing their concerns." (RN, Burnaby)

"We have two field supervisors carrying the work of three. If a supervisor has to go out to see a client, there's only one left [in the office]. The 80-odd Home Support workers are getting frustrated – they can't get through." (RN, Penticton)

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## Morale: How low can we go?

**Caring deeply, yet unable to care well:** Home Support staff are more than committed – they are often very special individuals. How many people can go into a stranger's home, provide intimate care and leave some hope behind? Yet cutbacks, uncertainty and client distress have eaten away at staff's ability to feel good about their work.

"I want to go home from work feeling I've really accomplished something. But your mind never turns off. We're all wearing thin. We're burned out." (RN, Penticton)

"It's not that [the workers] don't like their job. They just cannot handle the cutbacks ... seeing the clients deteriorating, not being able to do anything about it. The morale is horrific." (H.S. worker, Prince George)

"I want to be able to do whatever is necessary – I don't mean paint the ceiling, I mean to do whatever is necessary to leave the client in a comfortable place. A safe environment." (H.S. worker, Smithers)

"We have two field supervisors carrying the work of three. "

**We're losing good workers:** Some regions (e.g., Nanaimo, Okanagan) have shortages of Home Support workers. The reasons are plentiful: poor working conditions (hours of work, workload, lack of support); low morale (insecurity, lack of consultation or respect, inability to serve clients well); inability to make a decent living (cuts in hours of work); and no time for family and social needs.

"Home Support workers are leaving to work in facilities where they enjoy a regular schedule and a supervisor on the floor. They are not having to make inappropriate judgement calls or call the shots [from a client's home]." (RN, Penticton)

"In our area, we've had posting after posting for Case Managers, but nobody wants that damn job." (RN, Trail)

"A long term care assessor quit because there was so much pressure on her to cut, cut, cut. She lived in a small community, and she was seen as a bad person. It will be hard to fill this position." (RN, Smithers)

"A long term care assessor quit because there was so much pressure on her to cut, cut, cut."

**Insecurity breeds danger:** Many Home Support workers have had their hours reduced or fragmented. As a result, they may find themselves competing with one another for hours. The result? Stress and increased occupational risks. The situation is harmful to clients too.

"Some Home Support workers won't report difficulties [with a client] because they're afraid of being taken off the client. You run the risk of hurting yourself instead." (H.S. worker, Victoria)

"Cutbacks there have been so severe, so severe, we have so many displaced workers now in that area, it's incredible." (H.S. worker, Kootenays)

**Conflict, betrayal and disrespect:** A strained system leads to strained relationships. Discharge planners have to "beg for hours for people going home" from continuing care assessors, who are in turn pressured by their managers to reduce hours. Some HS workers are put in the terrible position of explaining cuts to their clients – an especially galling predicament because workers are never consulted, even though they are intimately aware of a client's actual needs.

In general, frontline staff feel disregarded by administrators and decision makers. They are neither consulted about changes, nor can they predict when the changes will stop.

"There is such animosity between schedulers and Home Support workers due to the cuts, they don't even want to be in the same area." (H.S. worker, Squamish)

"You know who's stuck dealing with cuts? Us ... The first the client knows [anything] is when the agency, the scheduler, calls up and says, 'We've changed your schedule ... your hours were cut back.' The schedulers get [the anger], the Home Support worker gets it too." (H.S. worker, Vancouver)

"We're left hanging out to dry with these cuts. Who made the cuts? Continuing Care made the cuts. We horrible case managers made the cuts. Yet we were told from above to make the cuts. Believe me, I didn't get too many Christmas cards last year." (RN, Chilliwack)

"Up in our area there's going to be a lot of changes coming through, but we won't know what they are until they happen because nobody consults anybody. And every Community Health Council is fighting. It's quite dysfunctional. Things will happen and then they'll let us know. It's quite unfortunate that it happens this way." (RN, Smithers)

# 4

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## Chapter 4

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# Avoidable Costs to B.C.'s Health Care System

*"There's a lady who lives in this complex where I see another lady with MS. She was always turned down for Home Support, Period. She's 90 years old. She got up on a chair to change a light bulb and she fell. Broke her hip. Now she's getting Home Support four times a day.*

*"If they'd let her have somebody for an hour a week, for a bath, to say 'Hi, how're you doing?' she'd probably be okay." (H.S. worker, Parksville)*

*"My 91-year-old who wants to die at home – he's hearing from the nurse that the hospital's waiting there, that maybe he should be in the hospital. But he wants to stay at home." (H.S. worker, Vancouver).*

*"This is a Back Trade industry: My back for your back." (H.S. worker, Squamish)*

Home support is good value. It can embody principles of interdependency and social solidarity by supporting people to live at home and participate in their community. It can enable a person to die in their own bed. It can foster a preventive, holistic model of health care that involves individuals, relatives and neighbours.

And it can save money.

Part I of *Without Foundation* – "Unfulfilled Promise" – outlines the potential fiscal benefits for British Columbia. For example, research shows that supporting stable elderly people at home is more cost effective than caring for them in residential facilities. Home Support can, and does, ease the pressure on primary, acute and long term care resources. However, to fully reap these benefits, researchers advise that "more services and programs need to be designed to keep clients stable and supported at home."<sup>25</sup>

Home Support appears to be moving in the opposite direction in B.C. The province is in reactive mode, trying to cope with shortfalls in acute and long term care resources. And in a truly vicious circle, gaps in Home Support are reverberating in hospitals and long term care homes, which must deal with the injuries, illnesses and heightened fragility of neglected people.

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## What about prevention?

A basic goal of Home Support is prevention, delivered under the banner of surveillance, safety and support. Cutbacks have signalled a tacit abandonment of this goal. In some regions, Home Support is now based on a narrow criteria of risk avoidance, in which risk equals imminent hospitalization. The Capital Health Region's new Priority Screening tool for long term care services reflects this constricted model.

Such criteria are a far cry from traditional Home Support values of maintaining people in their homes and fostering independence. A narrow approach is certainly not what the Seaton Commission advocated with its closer-to-home ethos.

The truth is, many people who appear to be managing their "activities of daily living" do so only *because* they are visited by a Home Support worker once a week.

"Homemakers do an incredible job. Because of homemaking, and only because of it, I have not had to be hospitalized. I had their support. I knew if they were coming, I would be able to continue my day and could just manage. They were my sole support." (Vickie, a mental health client, Vancouver)

"What bothers me is that the [new] screening tool is for elderly people and people with chronic illnesses. The whole basis is whether you're at risk for needing hospitalization, for acute care. Then you'll get service. But people with disabilities are not sick. They are not necessarily at risk

"Because of homemaking, and only because of it, I have not had to be hospitalized."

for hospitalization. So the re-assessment method now being used is clearly not appropriate." (Lorna Hillman, FCNS, Victoria)

"One of my mental health clients is in his sixties. He says, 'Oh I'm so glad – I was so depressed but I knew you were coming so I knew I had to keep going. You're my lifeline.' We've all heard that. They look forward to you, it gets them up in the morning." (H.S. worker, Victoria)

**Stress and isolation are health hazards:** Isolated and fragile people may not be sick, but being denied the brief companionship and help of a Home Support worker can make them sick. The Greater Trail report noted "Potential for feelings of anxiety, stress and/or depression because seniors do understand ... they may be putting themselves at physical risk while performing certain aspects of housework and yet they feel pressured to maintain their home for fear of losing it."<sup>26</sup>

"Sometimes all an elderly person needs is two hours a week, to reduce their stress and anxiety. And that's what we're seeing with the cuts. Not that they need 'cleaning' but that they're anxious." (RN, Penticton)

"The system for elderly people is so focused on dementia, yet depression among the elderly is rampant. We've got more people calling up about how depressed their elderly parent is, more than about dementia. And what does depression lead to? Poor nutrition, suicide, drug addictions ..." (Lorna Hillman, FCNS)

"I think of the 90-year-old man who says to me, 'You know what I need. You know what I need.' And he perks up and he smiles because he knows he's got the support." (H.S. worker, Vancouver)

"Sometimes all an elderly person needs is two hours a week, to reduce their stress and anxiety."

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## We want to take you higher?

The cost benefits of Home Support relate to the number of hours and type of care a person requires. Beyond a certain level, institutional care is more economical and practicable, given the current organization of our social and health care systems. Thus, a built-in tension exists between the legitimate desire of people to live at home, especially younger people with disabilities, and the system's ability to afford and deliver services in homes. It is a Rights vs. Costs issue, one of many in our health care system.

But cuts to basic Home Support have meant that people end up in facilities prematurely and in emergency wards unnecessarily. It's common sense: the 'invisible' dirty home, uneaten meal, depressed spirit and minor ailment will inevitably burst into view, either as a health crisis or an untimely decline.

**Short-term crises:** These arise from lack of basic care, monitoring and support with daily living.

"The only choice I have is to let my home go dirty. If I have to do [heavy house work], I will have to kill the pain. If I am forced to be up more than I want, I have to take more medication, which makes my hands tremble. I'm not always steady – I can fall." (Dora, living with a disability, Victoria)

"House cleaning is now totally gone ... it's only a matter of time before those people are very ill, have an accident. And they won't [be needing] Home Support then because they're going to be in hospital or in extended care." (H.S. worker, Prince George)

"The system creates more hospital use: We see emergency visits by people who aren't getting the Home Support they need." (Lorna Hillman, FCNS)

**Institutionalization:** This is a contradictory area. B.C. has a serious shortage of long term care beds. This alone puts pressure on health authorities to maintain people in their homes as long as possible. Elderly or disabled people may eventually need to move into a facility, yet there is anecdotal evidence that some people are moving sooner due to avoidable health crises or a sheer lack of services.

"We can't get hours to go in and give him meals at night. Getting meal prep hours for clients is almost impossible ... What's going to happen is he's going to end up in the hospital, in Simon Fraser Lodge or Parkside Lodge. He needs a nutritious meal and some encouragement to eat it." (H.S. worker, Prince George)

"We have people who have been moved from their homes to lodges and facilities very shortly after being cut off services because they couldn't manage. One lady had a fall and broke her hip trying to do something that health care workers used to do for her." (H.S. worker, Prince George)

"The system creates *more* hospital use: We see emergency visits by people who aren't getting the Home Support they need."

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# Injured workers, damaged relatives

Cutbacks in Home Support are creating other dents in the provincial budget, including Workers' Compensation claims for injured Home Support workers and health costs incurred by overwhelmed family caregivers.

**Too hard, too fast, too bad:** Home Support workers are getting hurt on the job at an alarming rate. Between 1993 and 1998, the Total Time-Loss Claim Rate for Home Support workers averaged 12.4 percent, compared with a 7.4 percent average throughout the health care system as a whole.<sup>27</sup>

These injuries are related to cutbacks: to shorter (rushed) visits, longer days and clients with more complex needs. Home Support workers find themselves taking more risks – for example, lifting or transferring a heavy client – because support and back-up are not readily available. The result: numerous back injuries, broken wrists, falls, accidents on icy stairs and sidewalks ...

"Our WCB rates are huge – they're just 'boom', every year we're going up another increment. Home Support workers are going faster and harder, with higher injury rates, more time on the road." (RN, Trail)

"Girls run out of the house trying to get to their next job, fall on the ice. It happens all the time. You're constantly rushing, never able to be safe with yourself." (H.S. worker, Prince George)

"WCB has targeted our agency as a problematic injury place. We used to be exemplary." (H.S. worker, Parksville)

**Grinding down the family:** Informal caregivers are also paying the price. Many relatives are overtaxed and exhausted. This stress influences the quality of care they can provide and will eventually rebound on the health care system. One Canadian study found that people who care for dementia patients at home have almost twice as many chronic health problems as people who care for non-dementia patients.<sup>28</sup>

"Medication use is huge among women family caregivers: anti-depressants, sleeping pills – just to keep it all together." (Lorna Hillman, Family Caregivers' Network Society)

"WCB has targeted our agency as a problematic injury place. We used to be exemplary."

# 5

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## Chapter 5

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### **Growing Inequities, Growing Threat of For-Profit Services**

*"Now I pay a woman to come and clean every second Wednesday. Can I afford this? Well, I've had to cut out fruit. It's too expensive." (Connie, age 100, Vancouver Island)*

*"In my area, Oak Bay/Gordon Head, most clients who had cuts can afford to make the difference up. But we do have a lot of mental health [clients], a lot of whom are physically challenged. That's another story." (H.S. worker, Victoria)*

Home support is in the same precarious position as other health services that lie outside Medicare's umbrella: neither public provision nor universal coverage are guaranteed.

Even if public Home Support were widely available, the needs of at-home patients have never been fully covered. From wheelchairs to medication, from physiotherapy to nutritional supplements, individuals

are more or less responsible for their own essentials. Home care may get you out of the hospital, but you'll be giving up one of the hospital's greatest assets: the meeting of your daily needs.

Home Support services have always been income tested, with wealthy clients paying full fees and other clients paying partial (or no) fee.<sup>29</sup> Home Support service can also be purchased privately from companies and individuals, by those able and willing to pay.

In short, home care is riddled with disparities. And these disparities attract commercial interests that are eager to fill the gaps in service. The Home Support market is considered a handsome business opportunity for private firms, especially U.S. home care corporations. There is no hard data on the size of the private-payment market, but the dollars are considerable.

Home Support *is* a two-tier system. British Columbians should be very concerned, because evidence points to growing inequalities among our citizens, amid growing threats to our public health care system.

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## Whose cutback can't be bought back?

Public provision of Home Support softens the divide between those who can afford and those who cannot afford private care. But with wholesale cuts and radical reductions in services, the divide is now sharper and deeper.

When people were cut off housekeeping and nutritional services, they were often given a list of private companies that sell the services they lost. The Ministry of Health's own statistics could have predicted the majority response: Buying services was out of the question.

***Elderly, single, female, poor:*** These four words describe the majority of Home Support clients.<sup>30</sup> They have no private income, and no other supports.

"I work in the East Side of Vancouver. I've seen clients cut back to twice a month. A lot of these clients are elderly, the majority are women. From their generation a lot of them were stay-at-home moms who never earned much money. So come their retirement, all they have is the OAP. They don't have big pensions so they can't afford ... to pay for it themselves. Things get worse in their house. Their health starts to decline." (H.S. worker, Vancouver)

"The majority of people didn't [buy services] because they didn't have the financial wherewithal. Some had some monies. It was hard for them, they had to cut back in other places ... their food, on doing things, going out. But most didn't." (H.S. worker, Smithers)

"A lot of them were stay-at-home moms who never earned much money. So come their retirement, all they have is the OAP."

**Psst, wanna buy an old lady's house?** By virtue of their class and generation, some clients are house-rich and cash-poor. A woman may have bought her home many decades ago while married; the house may be worth plenty today, but she is widowed and subsisting on a bare-bones Old Age Pension and GIS.

Health administrators sometimes accuse these people of "asset hoarding," a term used to morally justify cutting Home Support services. Expecting a person to sell her home to purchase her basic needs is discrimination on the basis of class: If you've got a lot, you can keep a lot; but if you've got a little, you could lose it all.

"This one lady who got cut ... she has a house on the waterfront. Bought the land years ago for \$4,500. She's on a fixed income."  
(Mervin, a senior, Sechelt)

**Young, disabled and profoundly cut off:** People with disabilities are also reeling from cutbacks, and unable to pay the difference. The depth of poverty is staggering among disabled Home Support subsidy applicants under 65 years: over 90 percent have annual incomes below \$10,000.<sup>31</sup>

For this community, loss of services is more than a blow to body and spirit – it's an attack on their basic rights as citizens.

"It's hard to get at the people who are badly affected. . . . It's hard to get information..."

"What gets missed is the reality that, for people with disabilities between 18 and 65, Home Support is key to our independence. Yet the authorities see it as a health care service only. They don't recognize that they have any responsibility to help to foster our independence or our citizenship: our ability to work, to have a life, to participate in the community." (Sarah, living with a disability, Victoria)

"It's hard to get at the people who are badly affected. Are they getting what they need? Are they in a state of neglect? In a hospital, at least there's a record. You don't know what's happening to a person when they're in the community. It's hard to get information, even harder under regionalization." (Christine, B.C. Coalition of People with Disabilities, Vancouver)

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## At a loss for going home

The inequalities cited above are magnified by another inequality: The huge gap between the goods and services patients receive in a facility and what they receive at home.

Under Medicare, people in hospital are covered for drugs, medical supplies, aids, equipment, therapies, dietary needs, etc. But once they go home, access to these things becomes a wholly individual matter. Age, pensions, status with social services, personal wealth, location, family, ability to speak English – all these factors influence whether a person has

the leverage, money or right to get what they need. The situation is neither fair nor farsighted.

***It all Depends:*** The number of goods and services not covered under home care is far too lengthy to list here. Suffice to say the range is vast, from low-tech items such as standing poles, bath chairs and boards, eating aids, commodes and pill crushers, to expensive pharmaceuticals and colostomy supplies, to wheelchairs (about \$3,000) and ventilators (up to \$13,000).

Even the most basic needs – a dry bed, a clean body – are beyond the financial reach of many people.

"I have a couple of clients who are incontinent and wear Depends. We all know how much those Depends cost. What happens is, they let the time they wear them stretch out – 'They're only a little bit wet.' Because if they have to buy a lot of them, they won't be able to buy food." (H.S. worker, Vancouver)

"Bed pads – those rubber sheets you put across the mattress on every hospital bed. If you have an incontinent client, the pads mean that the sheets don't get wet and you don't have to change the bedding every day. Or do laundry every day." (H.S. worker, Prince George)

"If they have to buy a lot of [Depends], they won't be able to buy food."

***Overburdened volunteers:*** Volunteers and free-loan health aids are important to Home Support clients and their families. These goods and services play a valuable support role in the community, but are not designed to be full-fledged proxies for quality public health care. It is dishonest to tell clients, after a cutback, to get what they need from volunteers, just as it is inappropriate to expect volunteers to replace trained and supervised workers.

The problems are numerous:

- Many smaller communities have no Friendly Phone Call, Friendly Visitor or Volunteer Driver programs.
- Meals on Wheels and similar food services are limited in their capacity to meet the nutritional needs of fragile people (please see Chapter 1), and cannot play the monitoring and social support role of a Home Support worker.
- Volunteers come and go. This lack of continuity can be very stressful for clients who need time to build trust and communicate needs.
- The Red Cross cannot always keep up with the demand for home care supplies in heavily populated areas. These items may be available for free, but not freely available.
- Burnout is a reality in this sector, too. In the words of one RN, "Volunteers are being maxed out."

Privatization goes hand-in-glove with fragmentation, and fragmentation is both inefficient and expensive.

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## Fragmentation: Undermining regionalization

The problem isn't just that some people can buy services and other people cannot. Private housekeeping and meal preparation may cover a person's baseline needs, but private care will isolate that person. When we cancel the public Home Support worker, we cancel our capacity to monitor a client's well-being and connect him/her to a network of community services. The preventive potential of Home Support is lost.

In this way privatization undermines a key goal of regionalization: integrated, community-based, preventive health care services. Privatization goes hand-in-glove with fragmentation, and fragmentation is both inefficient and expensive.

Home Support has many imperfections, all the more glaring because the *promise* of Home Support is so excellent. This study is about defects caused by skewed priorities, shortsighted policies and insensitive practices. The underlying principles of publicly funded Home Support services are sound.

Yet cutbacks are thwarting that promise by encouraging the growth of for-profit providers, and hence further fragmentation. Again, hard data about this growth needs to be gathered.<sup>32</sup> There is, however, anecdotal evidence that when public services are unable to meet demand or conform to budgetary restraints, the private sector gets a boost.

Continuing care managers can contract services from both non-profit and for-profit suppliers. With cutbacks, some public, non-profit agencies cannot offer the skilled personnel needed, forcing case managers to use for-profit suppliers. Restructuring is also making some regional Home Support services inefficient, which again makes the private supplier more desirable.

"It's been my experience that the [non-profit] Home Support agency can't provide for the acuity of care anymore, so we're having to go for [people from] for-profit. The non-profit Home Support agency just doesn't have the LPNs or RNs, and with the acuity we're having to bypass our normal provider of care." (RN, Chilliwack)

"New clients are being referred to private agencies because we don't have field supervisors readily available to assess the client. Our home care nurse will eventually do the assessment, but [in the meantime] the client gets service from the private agency. There's no continuity of care." (RN, Burnaby)

"In the Northwest, most communities have only one non-profit agency. The Community Health Services Society in Terrace, I've heard, is going to set the Home Support rates regardless of [union] contracts.

If the Home Support agencies aren't happy with the rates or the mileage or anything, they'll encourage for-profit agencies to come in. And that's scary because most Home Support agencies are able to provide the service.

"It's one thing if an agency can't provide [the services] and is looking at overtime. But it's another thing if the agency can provide it yet is being [undercut] ..." (RN, Smithers)

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## Appendix 1

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### What People Are Saying about

## Harm to the Health, Safety and Well-Being of People in Need

"I know a couple, both pushing 90, both in bad shape ... they're down to 1.25 hours ..."

- "I know a couple, both pushing 90, both in bad shape. She's got emphysema and needs oxygen constantly – she's in a wheelchair. He's got major heart problems. They were getting 3.5 hours a day [spread over] four visits a day. Now they're down to 1.25 hours, three times a day: half an hour in the morning, half an hour for lunch, and fifteen minutes to get them both into bed. That was pretty drastic." (H.S. worker, Parksville)

- "I have another lady, she's 90-some-odd years old. When her husband was alive, they received 4 hours a day: 2 hours in the morning, 2 in the evening. You did everything: bathing, laundry, shopping, anything that was needed of you. When her husband passed away, those hours continued for a short period of time, then the cuts came and she was reduced to 3 hours a day and now she's running at 2.5.

"She gets 1.5 hour in the morning and 1 hour in the evening to get her ready for bed. Now you were bathing her, shopping, doing her physio ... she had a stroke so she's [partially] paralyzed. She's wheelchair bound, she's in an apartment that's wheelchair accessible. But she spends that whole day by herself. Her only contact is that Home Support worker." (H.S. worker, Squamish)

- "I had a 60-year-old man. He lost his wife about six months ago to cancer. He had a stroke – his left side is paralyzed – and a skin condition, so his hair needs to be washed every day.

"We were going in for an hour every day, washing his hair and making his lunch and doing his supper in advance so he could warm it in the microwave. He was also getting 1.5 hours once a week for a bath and laundry, changing his bed.

"And it's been cut to nothing. Nothing.

"The assessor brought one of those boards you get from a medical supply place, with spikes in it, so you can put a piece of meat or something on it and cut with one hand. She said, 'Here, you can do that. Or you can order Meals on Wheels or Chef on the Run. If you try hard you can wash your hair with one hand.'

"He was really upset. He said, 'How can you do that to me?' And she said, 'You were supposed to be cut off a long time ago. You're only on your wife's assessment. You should have been cut off six months ago.'" (H.S. worker, Sechelt)

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## Emotional and social support

- "When you come to one that's having a bad day or whatever, the first thing I think is, 'Now that's me there. If I sat in this chair, never seeing anybody but Home Support workers, in pain, how would I feel?' Wouldn't you be miserable too? So if you can make them smile ..." (H.S. worker, Smithers)
- "You need human contact, you need to keep your house organized, you need someone who is empathetic, you need someone who knows your child. These people are the glue that keeps things happening." (Vickie, a mental health client, Vancouver)
- "That age group, the 80 and 90-year-old people - they don't throw stuff away. They don't ask their neighbours to do anything. They don't ask their family to do anything. One of my clients said, 'If you think I'm asking my family to do this, you're crazy. I'm going without putting those stockings on.'" (H.S worker, Sechelt)
- "A lot of those outlying areas, where people live a long way from town – [H.S. workers] used to be able to take those people, to take them into town to get their groceries, a social event. I mean, this health care worker would be the only contact this person had in the outside world." (H.S. worker, Prince George)

"It takes you a long time to get the trust of people with mental health problems."

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## Nutrition and shopping

- "A lot of them are just bored. They're bored with their diet, bored with the food. They look for the Home Support worker to come and get creative in their kitchen. Especially with seniors who've been eating all their lives. They're sedentary, they don't care. Or they're on special diets." (H.S. worker, Victoria)

"[The Community Health Council] is trying to organize seniors to do volunteer shopping [for other seniors], but unless you take someone with you, you can't know what they want - everyone has their preferences, their favourites.

"Or they send someone to cook a meal and all there is one potato because no one has done the shopping." (Mervin, a senior, Sechelt)
- "Meal on Wheels – It's another step in taking away somebody's independence, because now I no longer can make a decision on what

I eat. I live in my own home, but I gotta eat what's brought. You try to stay out of a facility but ..." (H.S. worker, Smithers)

- "I had a client who had some surgery, and she came home and was getting Meals on Wheels seven days a week for the first two weeks. They brought her meals Monday, Wednesday and Friday. They would bring her a hot meal for Monday, a cold meal pre-wrapped for Tuesday. Wednesday would come a hot meal as well as a cold meal for Thursday. Friday she would get a hot meal and two cold meals for Saturday and Sunday." (H.S. worker, Prince George)
- "If your eye sight's going, and sometimes when you buy chemicals in bulk, you can get confused. Some people put their [cooking] oil right beside their cleansers, their ammonia. They could start cooking with window cleaner. And their sense of smell is going." (H.S. worker, Prince George)

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## Personal and household hygiene

"Can you imagine if you're incontinent and you're allowed a bath twice a week."

- "Can you imagine if you're incontinent and you're allowed a bath twice a week, is all. Do you want to be told you can't have a bath?" (H.S. worker, Prince George)
- "When you bathe them, you don't have time to rub the water between their toes or massage oil into their backs, which is part of preventing skin breakdown." (H.S. worker, Smithers)
- "If they had an hour for a bath it's down to half an hour. That's to dunk them in a tub. You've got a lady with a walker and you're going in there in the morning expecting to get her out of bed, to the bathroom, in the tub and dressed in half an hour. It's not possible." (H.S. worker, Prince George)
- "I have one client who at one point was a seven-day service client. She is bedridden, lives alone, wears diapers - she's incontinent. She was cut to three days a week. I would go in and the laundry would be piled. Before you would even walk in the door, there would be a smell of urine and feces - it would just hit you.  
"Eventually, after complaining and complaining and complaining, one assessor said, 'Well, she drinks, so she's not going to get any more [help].' Finally, another assessor agreed to put more hours in ... back to seven days.  
"It was terrible. People in her building were complaining." (H.S. worker, Vancouver)

- "I can see their personal hygiene going downhill, definitely. I just dealt with one mental health client who had scabies. I had to treat him. He can't do it himself." (H.S. worker, Victoria)
- "I've lived with rheumatoid arthritis for 20 years ... I didn't look into the continuing care system at first. But after emergency surgery, the LTC assessor gave me two hours every two weeks.  
 "I lived in a duplex. She [the worker] would do my laundry, vacuuming, washing the floors, changing the bed linen, generally tidy up. Then out of the blue in 1994, I was cut.  
 "With rheumatoid arthritis, apart from the pain and stiffness, you're dealing with fatigue. If I vacuum, I run the risk of stirring up my condition. I may have to take the whole next day off just because I vacuumed." (Suzy, Victoria)
- "There are absolutely no cleaning hours coming in whatsoever in Prince George." (H.S. worker, Prince George)
- "In the bathroom: towels fall on the floor, bathroom rugs, unclean toilets, towels and face clothes being re-used week after week after week because they can't do the laundry." (H.S. worker, Prince George)

"They get to be clean in a dirty house."

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## Monitoring and advocating

- "Maybe they've got an in-grown toenail that's bleeding, and you have to phone the podiatrist to make an appointment. You've got cutbacks, you can't do it.  
 "Is that client capable of doing it? Is that client capable of saying to their family member, 'I need to go to the podiatrist, my foot is bleeding.' They won't. They will not phone their family members because they know their children and all those people have busy lives." (H.S. worker, Prince George)
- "[Without us] their meds could go downhill. It's automatic – we ask them if they've taken their meds." (H.S. worker, Victoria)

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## Appendix 2

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### What People Are Saying about

### Pressures on Family Caregivers

- "It's not only the client that you end up dealing with, it's the family, too. They're there when you're with the client quite often. And they have concerns, they have problems. It's not just the client." (H.S. worker, Victoria)
- "With the cuts to housekeeping in Prince George, the family members are having to pick that up – going with the clients to the doctors' appointments and things along that line. And the family members are having to book time off from work to take their mother or father or a handicapped person to the doctor instead of Carefree coming and the Home Support worker riding in Carefree to the doctor's office. Just for a general checkup.  
"The client is very cognizant of what they need to tell the doctor, but they need assistance with the wheelchair, through doors and things like that. So family members are having to book time off work to do that.  
"Or it's not being done at all. Because 'I don't want to bother my kids.' Or the kids just plain say, 'Sorry I don't have the time.' ... And here, these people are sitting at home, and they need to go to the doctor. They need to get their groceries purchased.  
"And we can't do [shopping and appointments] anymore, not for the average client." (H.S. worker, Prince George)

**Wanda:** Wanda, age 85, lives on Vancouver Island with her 88-year-old husband. They have mobility problems. She's had both knees replaced and needs a new hip; her husband is in a wheelchair. They used to get two hours of cleaning once a week, but were totally cut in December 1999. ("Thank you very much, it was a nice Christmas present," says Wanda.) No one told her anything about how to appeal the decision.

Wanda is determined to keep her husband at home, even though he has some signs of dementia.

"It's a big worry for me to keep my house clean. I can't vacuum anymore, I can't reach high up for things. If I wasn't entitled, why did they put me on [the service] in the first place?"

- "There's a lot of people out there who don't have family. They have nobody but the Home Support worker. They're the only person they ever see. You go there once a week, that's the only person they see.  
 "And there are people that have relatives, and some are able to help and some are too busy to help. This day and age, both people have to work to raise a family. And then there's people who have relatives who couldn't care less.  
 "And then due to the economy we've got people whose family is forced into leaving their community and their loved ones behind, who do not want to go with them. They have to leave because they need a job ... They have to go where the job is." (H.S. worker, Smithers)

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## It's not just relatives

- "I just had a lady who passed away on me last week. This lady was incontinent ... had absolutely no feeling left in her rectum. She could be walking along and the stool would fall out of her ... She was totally incontinent.  
 "She had baths twice a week. No care on the weekends. We went in three times a week, two was for baths and one was for cleaning. And meal care in the morning only. We went in and made her cream of wheat.  
 "In the building where she lived, the residents were going in and making her lunch. They were going in and making her dinner. We weren't given the hours, the residents were taking care of her.  
 "One of the ladies taking care of her is also one of my clients, a general cleaning client. She gets service one hour every two weeks. She's got heart problems. And she just spent six weeks in the hospital with pneumonia. And here she is, traipsing down from the fifth floor to the second floor, making soup for this lady, going to the hospital with this lady, going to the doctor with this lady ...  
 "The [neighbour] lady could have had another heart attack and ended up back in the hospital trying to care of the [first] lady. It got to a point where she felt guilty if she went out shopping or anything because she didn't know what was going to happen. She was worried at night about the other lady. Would she fall out of bed? Would she fall in the bathroom? Would she step in this stool that's on the floor and fall and hit her head? And stuff like that. It was wearing on both of them.  
 "It's not so much about cutbacks but about no increases."  
 (H.S. worker, Prince George)

"With the cuts to housekeeping in Prince George, the family members are having to pick that up – going with the clients to the doctors' appointments ... And the family members are having to book time off from work."

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## Appendix 3

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### What People Are Saying about

## Deterioration of Morale, Teamwork and Training

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### Workload

- "I have an 85-year-old lady, she's had a quadruple heart operation. She's diabetic, she's now got blood clots in her legs. She's awaiting massive surgery. She was cut. She was getting an hour twice a day, five days a week. They cut it back to 1 hour twice a week and 1.5 hours once a week: 3.5 hours a week from 10 hours. She was pretty upset.

"I reassured her that we'd be able to do all the same things. So we're doing the 10 hours now into the 3.5 hours. The workload has gone up. She seems to have adjusted all right but only because we were assuring her we'd get it all done." (H.S. worker, Parksville).

- "I don't have the patience and tolerance I used to have." (H.S. worker, Vancouver).
- "One of the biggest things that has happened in our areas is a *huge* increase in one-hour placements, which actually means a 45-minute spot, because we are a huge geographical area, 430 square miles. What we're looking at is high mileage and large amounts of time going from client A to B. If they're one-hour placements and you've got a ten-hour block, you're maybe going to nine clients. We've got mileage for a two-week period for Home Support workers that's 600 km, 700 km – that's not unusual. (RN, Trail)
- "You have to have travel time, 10 minutes for a client. I have a client I have to put Attends on. He has a beautiful lift. We were first going in there for an hour [but it was cut to half an hour]. It takes you 40 minutes by the time you get him up, move him off the bed, body mechanics, very important. You can't rush this guy, he's got a hip replacement. His second one.  
"Think about it: You get there at 8 o'clock, you get to take 10 minutes off of that client to go to your next client, he's only getting 20 minutes. It takes me 40 minutes. I don't care because I

work from 8 to 8:30 [with him] and I don't start again til 9 and I've got half an hour [between visits]. I don't want to rush this client. He says, 'Shawna, you're the only one who puts a pillow between my knees.' The other girls just pull his legs over the side.

"He's 69, about 6'2", 200 pounds. He has MS. His wife is totally burnt out. The wife does everything. She can no longer do it because of her arthritis. He's heading for the lodge." (H.S. worker, Prince George).

- "If that client were in a facility or hospital setting, there's no way in this world it would be one person doing [the lift], it would be two." (H.S. worker, Prince George)

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## Restructuring

- "It's like a giant filtering system. You've got the Home Support workers, hundreds of calls, and we're filtering. That's what a Home Support [field] supervisor does: filters. And then I weed out and problem solve some of it, and refer to the case manager those things that are important, giving her by far a less bulky package of things she has to deal with. And she in turn will deal with all of those issues because she is the hub, the person with access to all the information. She'll get back to me with a response.  
"But if you take away a hunk of it – whether it's because we're running around because we don't have time or whether we've deleted positions – then all of a sudden there's this big black hole. And client-centred care is gone." (RN, Trail)

"You're still doing twice as much work in half the time. Because you want to give them everything you gave them before."

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## Teamwork and training

- "The team concept of Home Support workers and RNs in developing care – it's gone by the wayside. In the old days, when we had a five-week month, they used to sneak hours every once and a while for care planning with *a team* of Home Support workers who were going into a client for years, like a quadriplegic. We all sat at a table for 40 minutes, we could all do things routinely, the same, take the best out of everybody, feel like a team.  
"Now we're a four-week month and nobody has time. Now we'd have to ask for an override, for extra time [to have such a meeting] and it's not given." (RN, Trail)
- "[We want] team meetings for workers who work with a heavy care client." (H.S. worker, Smithers)
- "All I want to see out of all of this is us working as a team again. It's taken a lot of personal effort from all of us to maintain relationships

between case management and Home Support. I don't want to go back to the place where I started eight years ago where I wasn't a 'real' nurse. I brought 28 years of expertise to my job [and] the case manager at the time said, 'You're not a real nurse if you're working for Home Support.' I know Home Support nurses who have done astronomical things." (RN, Trail)

- "The nurse that we deal with in the cluster care [supportive housing] system where I work, they're constantly telling us how well we do. It's different out in the community, where you don't really have the contact [and] you're isolated. They talk about how the cluster care program could never work without us, the ability to be so flexible." (H.S. worker, Prince George)

- "My employer is attempting to do on-site, away from the client, group delegation-of-task training, to save money. So far I've dug in my heels. I've had argument after argument, I've gone out and done on-site training when I've been told I'm not allowed to ...

"I feel so very alone sometimes [isolated from other RNs doing Home Support work] especially when you're being cut and cut, thinner and thinner. You can't even see the horizon anymore. They do not want us talking together. I've been told by my supervisor: 'You will not phone Nelson. You will not phone any agency without my permission.'" (RN, Trail)

- "We need scheduled meetings among the workers." (H.S. worker, Prince George)

- "The new WCB regulations regarding workers' safety are also having an impact. The field supervisor is responsible for ensuring the worker is working in a safe environment. We can go in and do an initial visit on the home. But if we don't get back for a year, as supervisor – lots can happen in a year. Dangers like an electrical short on a light switch, violent family members, snowy and icy stairs ...

"Our workers work at night. They're going out into the tunnies, isolated areas, with no means of communication, no way to communicate to the supervisor on call that their car has broken or they're in a crisis situation." (RN, Penticton)

- "We do [delegation of task] but not well. We do it to get it in the home and up and running, but we don't have the time to do follow-up to make sure it's being done [properly]." (RN, Penticton)

"We do [delegation of task] but not well ... we don't have the time to do follow-up ..."

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## Morale

- "I love Home Support out of all the jobs I've ever done. I've done really technical, ICU, heart, [but] this is my all-time favourite. It's the people contact. You're really working with a group of people to make something work for someone who really needs it. Otherwise that person in the community is not going to get it. And it's the longevity of the contact - people I've known since I started. Mentoring to the Home Support workers, knowing those Home Support workers for so long and so intimately, because we're working so closely.

"I know clients intimately because they share. As you've got your hand on the door knob, they're sharing big time. And I know Home Support workers because I've known them so long; and because of the stress and angst of the job, they share very quickly. It's a real history, watching the evolution." (RN, Nanaimo).

- "I want more time. To make them more comfortable, to have them tidy and clean when I leave." (H.S. worker, Smithers).
- "You're crisis managing all the time. There's no self reward when you're going home thinking, 'Jeez I forgot to do this,' and you're leaving voice messages for this worker because you forgot to do it at the office." (RN, Penticton)
- "I want to get rid of one word in my vocabulary: reprioritization. I'm so sick of it. Why do it in the first place if you have to redo it every day? What used to be important five minutes ago ceases to be important at all anymore because now you have something even bigger and now it's gone." (RN, Trail)
- "It's the rumour mill – we're the last to know [about changes]. The rumour mill is running rampant, and we hear about these changes coming down ..." (RN, Smithers)
- "Continuing Care doesn't know either. Even our region coordinator for Continuing Care is constantly blindsided. She'll take information, she'll think she's got it together, then she'll get a memo with incredible change. And it's very hurtful, painful. Because she's trying to lead a staff, to build camaraderie and confidence, and we're constantly being blindsided." (RN, Chilliwack)

"Morale is really low for everyone working in the system: the lack of communication, the lack of direction."

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## Appendix 4

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### What People Are Saying about

## Avoidable Costs to B.C.'s Health Care System

- "I had a client who is close to 90. I didn't help her with her shower, but I would be there while she had it. I did the housekeeping for her. She lived in a log house by herself, fed the birds – she was a really neat little lady. I knew she was just hanging on by a thread. It was just a matter of time before I would be helping her with her shower and stuff. I had her for a few years.

"And they cut her off, totally cut out. A short time later she had a stroke. She's in hospital now, and then she's heading for the lodge." (H.S. worker, Smithers)

- "There was one who was not quite so lucky. She was one of my clients. She was mid-90s. She used a walker, she was on oxygen. We went in about three times a week. On one day somebody did some of her housework because she had breathing problems, and you have to keep her house kind of dust-free, and did her laundry, did some shopping. She was very, very frail. We were bathing her and weighing her and trying to make her eat.

"When Continuing Care came along and told her they were going to cut her hours, she went into a terrible depression. It was just terrible to see someone go from managing okay and living with the fact that you're 95 and you've outlived everybody, to [becoming] very shaky – into her bed, getting worse and worse. We ended up going there from three times a week to twice a day, seven days a week. They hadn't even done it [the cuts] yet – this was just telling her.

"So of course they didn't do the cuts. But this person never really recovered from that. And I know that eventually she would have died anyway, and she died. But we were very, very upset about this whole thing." (H.S. worker, Sechelt)

- "I have a client who I work with once a week. She has a bath. And she had a rash in her groin. Now, her granddaughter comes up from the Lower Mainland every Sunday night and stays til Wednesday. She sleeps there two nights a week. The granddaughter did not even know she had the rash.

"I saw the rash when we were doing her personal care, got some corn starch for it, showed her how to apply the cornstarch, and the next week the rash was gone. Otherwise she would have had to go to the doctor and get a prescription. But she wouldn't tell her granddaughter that.

"With the cutbacks, we just don't have the time to give them that sort of care." (H.S. worker, Prince George)

- "I went to a client – he only lives two blocks from the building I live in. They sent me in for an hour and fifteen minutes. This gentleman is in his late 80s. He's had a stroke. He won't get out of bed for anyone. He won't eat. He's incontinent, but he has no pads. Different workers come in two times a day, seven days a week. They give him morning care, to get him up and feed him breakfast (he won't eat). They bring him Meals on Wheels and he refuses to eat.

"I went in. His niece was there, trying to get him out of bed. And the odour was horrific. He did get up, ate a little, had a glass of juice and some coffee.

"I talked to one of his workers yesterday. His family has come up from Williams Lake and they just tore a strip off of her [the worker] because he's lost almost 100 pounds, and they're accusing the agency and the workers of not feeding him." (H.S. worker, Prince George).

- "I have a 96-year-old woman and she is really being stressed by the cuts. She's still got a fair amount of hours for her personal care, but not for cleaning and stuff like that. She's feeling more of a burden. The only relative she has is a niece who brings her meals on the weekend because we're only there to get her up in the morning.

"She lives in fear. She does not want to go in the hospital. I don't know how many times she's been in the hospital since I've been working there – four times. If they keep her more than three days, she's right out of it. She hallucinates so bad. One time I stayed overnight with her when she came home. By 8 o'clock the next morning, she was pretty well out of it. She hallucinates from the medications in the hospital.

"She's one of the healthiest eaters I've ever seen." (H.S. worker, Smithers)

- "I'd like to know how [the cuts] have increased doctor's visits, or admissions to hospitals, or mental health visits. We had a huge component of mental health clients, psychogeriatric and adult. I see a whole lot of this stuff anecdotally. That's why we're speaking in general terms, because all of us are so busy. I'm sorry, I'm responsible for 200 people!" (RN, Trail)

"They cut her off, totally cut out. A short time later she had a stroke. She's in hospital now, and then she's heading for the lodge."

"I'd like to know how [the cuts] have increased doctor's visits, or admissions to hospitals, or mental health visits."

- "I have one client I've been seeing for a long time. She's got MS, she's in her 50s, she's wheelchair bound. I go in there every morning, Monday to Friday, and, say "Hi, how are you doing?" She was in tears.

"She was told she would only get 4 hours a day and would have to be placed in an institution. This is someone who is mentally with it, her only problem is she is disabled with MS. She would have to be uprooted from her home.

"I got her to write a letter to the newspaper, it'll give you an idea. She'd get 6 hours a day; she was cut .5 hour at her meal time – that's only because her doctor intervened and said [to the assessors], 'You're going to have to answer to her health because it's going to go right down.'

The woman wrote, "It's been drawn to my attention that I, personally, could be faced with having to be placed in the extended care unit of the Gorge Road hospital for seven days a month, to cut back on the hours I am presently receiving from my Home Support workers. I would have to pay \$25 a day – goodness knows where I'm going to get that money – and I assume the government would have to make up the difference. "

"She wasn't eating, her health had gone down quite drastically, she was weak. So I phoned the doctor after three days of this and within a week he had the decision kind of reversed. It was ridiculous.

"She said to me, 'Deanna, if I have to go back to that Gorge again' – she was in there for a seizure for about three months – 'I will give up. I do not want to go there.' It was so emotional, terrible. For the rest of her family too." (H.S. worker, Victoria)

**Dora:** Dora is a 67-year-old woman who lives alone on her OAP. She has degenerative disk disease and must spend most of her time either reclining or semi-reclining; her wheelchair has a semi-reclining function. "I've had seven spinal surgeries," she says. Dora can walk short distances: "My doctor tells me to walk to avoid osteoporosis."

She was diagnosed with fibromyalgia in 1997 and with chronic tendonitis ("from using my wheelchair") in 1999.

When Dora first had the disease, she took regular pain killers, then moved to morphine; when morphine no longer eased the pain, her physician put her on Dilaudid. "When I am doing anything weight-bearing, the pain starts up."

Dora has been on Home Support since 1991, fully subsidized because of her low income. She received three hours a week for laundry and house cleaning. She hadn't been assessed since 1996.

In May 2000, the assessor visited her ("she saw me walking – I can walk 10 steps in my apartment and then sit down") and, at the end of the visit, informed her that all her hours were being cut.

"I just sat there and bawled," says Dora. "There was no negotiation. She didn't say, 'Could you manage with one hour less?' And there is no appeal."

Dora can't afford to hire help. "The only choice I have is to let my home go dirty. If I have to do [heavy house work], I will have to kill the pain. If I am forced to be up more than I want, I have to take more medication, which makes my hands tremble. I'm not always steady – I can fall." Dilaudid is a drug with known side effects. "Too much Dilaudid is not good for my body."

Dora is trying to appeal the decision, despite the lack of a formal appeal mechanism in the CHR. She's devastated by the cut, and angry too. "People with disabilities often don't have the energy to fight."

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## Appendix 5

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### What People Are Saying about

## Growing Inequities, Growing Threat of For-Profit Services

- "My biggest complaint is, it's a little drop in the bucket for these old people who brought us where we are [today]. A lot of those clients can't afford to hire a private person. They never worked for a Canada Pension, they're on Old Age Pension. And some of them are renting." (H.S. worker, Smithers)
- "The greatest impact is on low-income people, especially low-income women. That's who is most affected by the cuts ... Cuts mean that the family either needs to pay for it themselves or do it themselves. Or it doesn't get done." (Lorna Hillman, Family Caregivers' Network Society, Victoria)
- "Certainly the expense has gone up for them. I'd like to think that what we [home care nurses] used to do was: visit, help do some problem solving in the house – not make a diagnosis but go through what the patient might need at this time, what we could get the family to do, etc. I think the costs are definitely up for clients." (RN, Burnaby)
- "I've got one woman who won't change her Depends very often because of the price of them. I try to tell her the importance of having a change so she doesn't get a bladder infection, but she says, 'They cost so much I can't afford them, I'll have to wear them a little longer.' And she limits herself to about two a day, and she should be changing them way more. You get rashes, skin breakdowns, sores, bladder infections." (H.S. worker, Smithers)
- "When I worked in Nanaimo it was sort of a horror story to get any kind of aids for these people because there were so many people and not enough supplies.  
"I had a very overweight woman. She'd had a stroke, didn't have the use of her left side. She had a son living with her, the son was an alcoholic and a drug user. But because the son was living in the house, the assessor said she doesn't get very many hours because the

son is capable of looking after her. Of course, the son didn't look after her.

"She had no service on the weekends, she has no bath chair, no bath board, nothing to hold onto. She had a commode, and she'd sit at the kitchen table and the commode would sit right beside her in the kitchen, and all weekend long, she would use that commode. And of course the son did nothing. And everyone hated Monday morning because we would come in Monday morning and it would be overflowing.

"There were no pads bought for her because it was a cost issue. She was on some medications – she wasn't 65 yet – and she was at the point where she was only taking them once every second day – it was either that or food. She did end up in the hospital. She had ulcers, and sores, bladder infection, you name it. She did pass away. But with the proper care it wouldn't have happened, it wouldn't have happened." (H.S. worker, Smithers)

- "It used to be that the client had an hour of service and the travel time was on top of that hour. Not anymore. That changed a long time ago. But if the client is paying for home support privately, they get the full hour of service." (H.S. worker, Prince George)
- "... Home Support workers are left in the houses to make decisions on their own, with a client who may be having a medical problem. And the Home Support worker is saying, 'Well this isn't right – I'll call an ambulance.' And the client says, 'No, I'm not going to the hospital, I'm not paying \$40 just to be sent home again' – which happens all the time." (RN, Burnaby)
- "If you go back to those twenty-four provisions that came from Continuing Care in Victoria, when it was all about client-centered care – all these agencies had to adhere to these rules ...  
"And now there's all of those things in place ... but we don't have the money. And we're just going to go for – whatever – and we're going to forget about that 'crap'. That worries me." (RN, Trail)

"Cuts mean that the family either needs to pay for it themselves or do it themselves. Or it doesn't get done."

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## Appendix 6

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### Methodology

This case study is based on information from a variety of sources.

**Personal interviews:** In April, May and June 2000, telephone interviews were conducted with individuals who were cut off Home Support or had their hours reduced. Other interviews were with people who work with seniors and people with disabilities, as volunteers or paid staff.

Interviews included seniors and people with disabilities on the Sunshine Coast, Vancouver Island and Vancouver. Organizations contacted included the B.C. Coalition of People with Disabilities, the Home Support Action Group, the Kettle Friendship Society, the Sechelt Senior Citizens Association, Greater Trail Home Support, B.C. Old Age Pensioners, the Family Caregivers' Association of B.C., and the Canadian Mental Health Association.

Also reviewed was a video by Flora Stokes entitled "Faces of Seniors," which comprises interviews with six Smithers area residents whose Home Support was cut.

**Group interviews:** In March and April 2000, face-to-face interviews were conducted with Home Support staff.

Fourteen Home Support workers participated in group interviews. Their experience in the field ranges from a minimum of 5 years to a maximum of 21 years. Geographically, they work in Smithers, Squamish, Vancouver, Victoria, Prince George, Nanaimo, Sechelt and Parksville. Their employers are public agencies, non-profit societies and private companies. They are members of three different unions: B.C. Government Employees' Union, Hospital Employees' Union, and United Food and Commercial Workers.

Seven Registered Nurses from the Community and Continuing Care sector also met for a group interview. Their positions range from Home Support field supervisor to case manager, home care nurse, discharge planner and care coordinator. They have been in these particular positions between two and seven years, with many more years nursing experience in other areas. Geographically, they work in Smithers, Nanaimo, Victoria, Trail, Burnaby, Penticton and Chilliwack. They are members of the B.C. Nurses' Union.

**Media and published reports:** Information was gathered from B.C. newspaper articles on local reactions to Home Support cuts.

Newspapers included *The Daily Times* (Trail), *The Interior News* (Smithers), *Maple Ridge/Pitt Meadows News*, *Campbell River Mirror*, *The Chilliwack Progress*, *Times Colonist* and *Vancouver Sun*.

Reports, newsletters and academic studies on a variety of issues were referenced; these are cited in the endnotes.

*Please note:* With the exception of individuals who spoke on behalf of an organization, names have been changed to protect the confidentiality of interviewees.

# Endnotes

1. At the insistence of concerned citizens and Home Support staff, the Greater Trail Community Health Council did a face-to-face survey of clients who were cut off basic Home Support earlier in 2000. The report, entitled "Impact of housecleaning services reductions" (June 5, 2000) is a snapshot of the situation: arbitrary cuts, lack of a clear appeal process, and huge stresses on seniors and families.
2. Table 8, "Unfulfilled Promise," *Without Foundation*, Part I.
3. Ibid. Table 5.
4. Ibid. Table 7.
5. Ministry of Health, Home Support Analysis, 1998. Quoted in BCGEU's "Facts: The frightening trend to cut needed Home Support services in the Capital Region."
6. BCGEU's "Facts: The frightening trend to cut needed Home Support services in the Capital Region."
7. Gideon Rosenbluth, "Seniors and poverty" presentation, Seniors Summit, October 30, 1999. In 1999, 12.8 percent of B.C.'s population was over 65. By 2019, this group will represent 17 percent of British Columbians, including a doubling of people over 85. As well, the rate of dementia doubles every year after age 65. By 2009, B.C. will have 16,500 more cases of dementia than in 1999.
8. Table 8, "Unfulfilled Promise," *Without Foundation*, Part I.
9. Hollander, Marcus. "A comparative cost analysis of home care and residential care services (project newsletter)." A substudy of the National Evaluation of the Cost-Effectiveness of Home Care. November 1999. 1. Dr. Hollander writes: "The central finding of this study was that given two clients with the same level of needs, the best value to government comes from supporting the client at home. Since most elderly clients prefer to stay at home for as long as possible ... this means it is good for both governments and clients if services are there to enable them to stay at home."
10. FitzGerald is the author of the report, "Impact of housecleaning services reductions" (Greater Trail Community Health Council, June 5, 2000). She is quoted from *Trail Daily Times*, June 21, 2000.
11. Ibid.
12. Azad N., et al. "Nutrition survey in an elderly population following admission to a tertiary care hospital." *CMAJ* 161(5):511-5. 1999 Sept. 7.
13. Richard, MJ and AM Roussel. "Micronutrients and ageing: intakes and requirements." *Proceedings of the Nutrition Society*. 58(3):573-8, 1999
14. Nourhashemi, F. et al. "Alzheimer disease: protective factors." *American Journal of Clinical Nutrition*. 71(2):643S-649S, 2000 Feb.
15. Winkler, S., et al. "Depressed taste and smell in geriatric patients." *Journal of the American Dental Association*. 130(12):1759-65, 1999 Dec.
16. Greater Trail Community Health Council. "Impact of housecleaning services reductions." June 5, 2000.
17. Morris, M. et al (CRIAOW). "The changing nature of home care and its impact on women's vulnerability to poverty." Ottawa: Status of Women Canada, November 1999, 18. A 1995 study by the Caregivers Association of B.C. showed that two-thirds of family caregivers are middle-aged people (average age 54), half of whom are working fulltime outside the home; the majority are women. The study was published by Centre on Aging (University of Victoria).
18. Hillman, L. and Neena Chappell. "Stolen moments: Getting a break when you're a caregiver." Centre on Aging (University of Victoria). January 2000. iii.
19. Canadian Study of Health and Aging Working Group. "Patterns of caring for people with dementia in Canada." *Canadian Journal on Aging*. 13(1994):470-487.
20. Greater Trail Community Health Council. "Impact of housecleaning services reductions." June 5, 2000.
21. The hours for PC dropped from 1,741,067 hours in 1991/92 to 380,580 in 1998/99. Table 5, "Unfulfilled Promise," *Without Foundation*, Part I.
22. Ibid. In 1991/92, Home Support services at all levels of care were 6,939,550 hours; in 1998/99, the number of hours was 7,781,606.
23. "Delegations of task" refers to the training/supervising an RN gives a Home Support worker to enable them to perform Level II health tasks, such as ostomy and catheter care, changing dressings, bowel care, etc. Also known as "transfer of function."

24. "Who supports Home Support? A perspective on Home Support Services in the Simon Fraser Health Region," June 1999. This paper was written by concerned Continuing Care staff in the region.
25. Hollander, Marcus. "A comparative cost analysis of home care and residential care services (project newsletter)." A substudy of the National Evaluation of the Cost-Effectiveness of Home Care. Ottawa: Health Canada. November 1999. 2.
26. Greater Trail Community Health Council. "Impact of housecleaning services reductions." June 5, 2000.
27. Occupational Health and Safety Agency for Healthcare (OHSAH). Time-Loss Claim Rate refers to the number of injury claims accepted by WCB relative to the number of workers in the sector. The Home Support figure is based on statistics from 60 unionized Home Support agencies that are members of the Health Employers Association of B.C.
28. Canadian Study of Health and Aging Working Group. "Patterns of caring for people with dementia in Canada." *Canadian Journal on Aging*. 13(1994):470-487. The mean number was 2.6 chronic health problems among family caregivers of at-home dementia patients, compared to 1.8 among other caregivers.
29. Low income and poverty are endemic among Home Support subsidy applicants. See Table 8, "Unfulfilled Promise," *Without Foundation*, Part I.
30. For a thorough account of Canadian women's experiences in the home care field, see "The changing nature of home care and its impact on women's vulnerability to poverty," by Marika Morris et al. Status of Women Canada (CRIA) November 1999.
31. Table 8, "Unfulfilled Promise," *Without Foundation*, Part I.
32. There is a startling lack of research into the implications of privatization in the CCC sector; please see recommendation 3 in the Summary, *Without Foundation*.

# **THE HIDDEN COSTS OF PRIVATIZATION**

**An International Comparison  
of Community and Continuing Care**

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**BY MICHAEL M. RACHLIS, MD, MSc, FRCPC**

*Without Foundation, Part II*  
November 2000

## **About the author**

Michael Rachlis is a Toronto-based health policy analyst. He received his MD from the University of Manitoba and completed his MSc and specialty training in community medicine at McMaster University. He holds part-time associate professor appointments in the Department of Clinical Epidemiology and Biostatistics at McMaster and the Department of Health Administration at the University of Toronto.

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I am, of course, responsible for the contents, opinions and any errors contained in this report.

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# 1

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## Chapter 1

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### Setting the Stage

Health care is near the top of every nation's public policy concerns. Within the larger debate, one key issue is how we should apportion roles to the public and private sectors. After 100 years of grappling with this issue, Canadians have considerable experience to guide us.

We also have the experience of our southern neighbours. For almost 50 years, a natural experiment in health care *financing* has been unfolding in North America. Until the 1950s, Canada and the United States had very similar health care systems. Canada then choose to institute universal, publicly funded coverage for most hospital and medical care.<sup>1</sup> The United States choose publicly funded coverage for the worst health risks only: seniors, people with certain chronic illnesses and people on social assistance.

What can be learned from this experiment in public versus private health care financing? The answer is clear: An overall comparison shows that Canada's approach is superior in both costs and quality.

Canada's public financing of health care leads to lower costs and better outcomes.

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## For-profit care: Lower quality, higher costs

Until 1971, both countries spent a little more than 7 percent of their economies (or GDP) on health care. By 1997 Canada was spending 9 percent and the U.S. was spending 13.5 percent (Anderson 1999). Almost half of the difference is due to much higher administrative charges in the U.S. system (Woolhandler 1993, 1996). Overall Canadians have far better access to health care than Americans. Fully 43 million Americans have no health insurance, and tens of millions others lack adequate coverage for serious illnesses (Consumers Union 2000). As a result, 500,000 Americans declare bankruptcy every year due to their health care bills (Wordsworth 2000).

Our better coverage also comes in the form of more doctors' visits (Welch 1996) and hospital days (Redelmeier 1993). We even consume more of certain high technology services such as bone marrow transplants (Silberman 1994). Finally, Canadian outcomes are as good or better than those in the U.S. for most services, including cancer treatment (Gorey 1997, Keller 1997).

In short, Canada's public financing of health care leads to lower costs and better outcomes.

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## The question of "who delivers?"

Canadians are quite clear about their support for public financing of health care. There are, however, disagreements about the relative merits of non-profit versus for-profit *delivery* of care.

Historically, there has been little for-profit delivery of acute care services in this country. But Canada does have a mix of non-profit and for-profit organizations delivering Community and Continuing Care services such as home care and long term residential care. Many provinces, notably Ontario, are increasing the proportion of these services delivered by for-profit companies. The debate intensified in 2000 with Alberta's Bill 11, which allows for-profit hospitals to deliver publicly funded services. A minority of Canadians support privately funded for-profit health care, but they are a powerful and persistent minority. The arguments behind their oft-repeated claim are twofold:<sup>2</sup>

- the belief that a parallel private system will relieve the strain on our public system and reduce waitlists; and
- the faith that for-profit companies have market-style efficiencies that public and non-profit care providers cannot match.

In fact, the reverse is true. International research shows that moving acute care to for-profit hospitals is generally associated with decreased quality and access, and increased costs. Several recent population-level studies from the U.S. are particularly informative:<sup>3</sup>

- Himmelstein et al. (1999) concluded that for-profit U.S. health maintenance organizations (HMO) rated lower than not-for-profit HMOs on all 14 quality indicators measured by the National Committee for Quality Assurance. Their study covered 329 HMOs representing 56 percent of all United States HMO enrollees. The authors estimated that there would be an extra 5,925 breast cancer deaths annually in the United States if all HMOs were for-profit.
- Garg et al. (1999) investigated all dialysis centres in the United States. The study concluded that patients receiving care at for-profit facilities had 20 percent higher death rates and were 26 percent less likely to be placed on a waitlist for renal transplantation than those attending not-for-profit centres.
- Woolhandler (1997) analyzed 1994 data from all 5,201 acute care hospitals in the U.S. They found that for-profit hospitals were 25 percent more expensive per case than public facilities. Private not-for-profit hospitals were in the middle. Higher administrative charges in commercial facilities accounted for 53 percent of the difference in cost between public and for-profit hospital care. These administrative costs were also increasing much faster in for-profit facilities.
- Silverman (1999) used data from the entire U.S. Medicare program, which insures people 65 years and older, and found that health spending was higher and increasing faster in communities where all beds were for-profit compared with communities where all beds were non-profit. Spending was growing fastest in those communities that had converted all their beds to for-profit care during the study period; conversely, spending fell the most in those communities that had converted all their beds to non-profit care.

**For-profit delivery tends to decrease access and quality while raising costs.**

The evidence of these studies is especially compelling due to the scope of populations examined and costs considered. For example, Silverman (1999) studied an aspect of the entire Medicare program, and hence people at every socio-economic level and with every health status. He also considered *overall* health spending in communities, not merely the costs associated with a particular venue. The private/public split in health care lends itself to distortions along many lines (i.e., divisions on the basis of socio-economic and health status). Population-level studies offset such distortions by being broad rather than narrow.

## **Two-tier health care: More pressure, not less**

The argument for a parallel private system that reduces pressures on the public system – the "escape valve" theory – is also unsupported by the international evidence.<sup>4</sup> Indeed, two-tier care has proven to be a drain on the public health system, which is forced to handle the majority of people's needs but with fewer resources.

In this instance, the Australian and British experience are instructive due to similarities between their systems and ours. Like our country, Australia and Great Britain provide public health insurance to all citizens, albeit with variations in delivery structures and physicians' status. Unlike Canada, both nations allow private, for-profit health care based on an individual's ability (and willingness) to pay for services.<sup>5</sup> This mixing of private/public health care – in which the same physician may work in both systems, and/or the same hospital may deliver both publicly insured and private-pay care – has yielded some disturbing results.

Evidence from Australia and Great Britain shows that private hospitals do not pick up the critical overflow from public hospitals – most, for instance, do not even have emergency departments – nor do they relieve surgical waitlists. The reasons are economic, and the economics are for-profit.

**Skimming the cream:** "Rather than serving more patients," writes Thomas Walkom, who studied the Australian experience in 2000, "private hospitals find it more profitable to perform more procedures on the relatively small number of Australians who can afford their services."<sup>6</sup> The favoured procedures are the more expensive and least troublesome ones; private care providers make a point of generating a market for this preferred economic activity.

Health economists call this "cream skimming," and it is a common phenomenon in both Australia and Great Britain. Cream skimming means that the private system pursues the high-end market with its high profit margins: lucrative, fast-turnaround procedures such as heart bypasses, cataract removals and joint replacements. Protracted and complicated health care services that have unpredictable profit margins – e.g., care for disabilities, traumatic injuries or chronic diseases such as diabetes – are left to the public system.

**Health care is no ordinary market:** It is often assumed that for-profit companies can wring efficiencies by eliminating unnecessary production costs. However, Silverman's work (1999) and economic theory in general strongly suggest that for-profits will find it much easier to expand revenues (e.g., cream skimming) than to decrease costs. Evans (2000) further notes that commercial enterprises tend to find it more profitable to select healthier clients, deny needed care and sell questionably appropriate services than to improve efficiency.

Canadian research has consistently concluded that health care is not a normal market good.<sup>7</sup> For example, patients cannot behave like ordinary "consumers" because they lack knowledge about medical procedures, practitioners' skills, risks, choices, etc. This asymmetry of information between patients and care providers prevents the consumer (patient) from being well informed, a key factor for the establishment of a market.

**A drain, not a boost:** The effects of cream skimming and two-tier health care are much too numerous to recount here. Suffice to say that many researchers in Great Britain and Australia observe that the public system inevitably suffers from the presence of a parallel private system, and the private system fundamentally depends on a weakened public system to thrive. A 1997 study by the Institute of Fiscal Studies reported that Britons who have private health insurance are reluctant to support increased spending on public health care. As a result, the public system becomes starved of resources, forcing even more people to buy private coverage.<sup>8</sup>

Closer to home, Calgary offers a vivid example of what happens when for-profit health care – in this case, cataract surgery – vies with public care. Intense competition among private eye-surgery firms has created a perverse situation, according to Taft and Steward (2000), in which "although they have the most eye surgeons in Alberta, Calgarians face the longest waiting lists [in the province] ... at least for those seeking surgery under medicare." Calgarians also face "the highest fees for [private] cataract surgery."

Private hospitals do not pick up the critical overflow from public hospitals, nor do they relieve surgical waitlists.

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## What about Community and Continuing Care?

The evidence from U.S. acute care literature is strong: For-profit delivery is not a wise policy direction. Similarly, the Australian and British experience should warn Canadians away from permitting two-tier care within our publicly funded system. The following chapters will offer evidence that the growth of for-profit Community and Continuing Care is also undesirable.

### Research method and overview of literature

This study investigated the impact of for-profit delivery via a search of scientific literature and through contacts with experts in the field.

The database of the U.S. National Library of Medicine was searched for peer-reviewed, comparative studies of for-profit versus non-profit long term residential care and home care. The studies chosen examine quality of care, financial and/or other societal outcomes, and were published after 1980. References were traced, and published authors

were contacted for additional studies. The published literature was also searched for review articles and editorials.

The literature search yielded 43 peer-reviewed, comparative studies of long term care facilities, and 9 peer-reviewed, comparative studies of home care services.<sup>9</sup> The quality of the studies is quite variable (see Chapter 3). Two studies are from Canada, 46 from the U.S. and 4 from other jurisdictions.

It is important to note that the U.S. studies typically controlled for socio-economic status by using percentage of Medicaid patients and percentage of private-pay patients as independent variables.<sup>10</sup> Thus, when differences were detected between the performance of non-profit and for-profit services, the differences were *not* due to socio-economic disparities in the residents/clients being served (for example, poorer and less healthy people in non-profit facilities).

As well as the literature search, interviews were conducted with experts in Canada, the United States, the United Kingdom, Australia and New Zealand.

# 2

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## Chapter 2

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### **Delivering Care, Delivering Profits: What Happens?**

This study examines international research literature that compares the performance of for-profit and non-profit Community and Continuing Care service providers. The two areas of interest were long term care (LTC) facilities, commonly known as nursing homes, and home care services. The impact of for-profit health care delivery was assessed with respect to costs, quality of care and societal benefits such as volunteer involvement and community development.

The findings, summarized in Table 1, are quite clear. When long term residential care and home care are delivered by for-profit companies:

- public health care costs increase
- private spending on health care rises
- patient outcomes are worse
- staff turnover increases
- patients and families are less satisfied
- broader societal benefits decline

<b>Table 1: Impact of For-profit Services on Community and Continuing Care</b>	
<b>For-profit Long Term Care Facilities</b>	<b>For-profit Home Care Services</b>
<b>Health care costs</b> Government costs: <i>Reduced initially, then may well increase</i> Overall costs: <i>Likely to increase</i>	<b>Health care costs</b> Government costs: <i>Likely to increase</i> Overall costs: <i>Likely to increase</i>
<b>Quality of care</b> Patient outcomes: <i>Worse</i> Staff turnover: <i>Increased</i>	<b>Quality of care</b> Patient outcomes: <i>Worse</i> Patient/family satisfaction: <i>Worse</i> Staff turnover: <i>Increased</i>
<b>Societal benefits</b> Continuing education: <i>Decreased</i> Volunteers: <i>Likely decreased</i> Civil society: <i>Likely decreased</i>	<b>Societal benefits</b> Continuing education: <i>Decreased</i> Volunteers: <i>Likely decreased</i> Civil society: <i>Likely decreased</i>

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## Long term residential care

The following findings are gleaned from a review of 43 peer-reviewed, comparative studies of long term residential care (see Chapter 1 for a more thorough description of the studies).

### Quality of care: Higher or equal in non-profits

Overall, the literature found that non-profit LTC facilities provided higher or equal quality of care than for-profit facilities. There were very few examples of for-profits providing better quality of care.<sup>11</sup>

Thirty-nine studies considered quality of care. Quality can be defined according to 1) structure of care; 2) process of care, and 3) patient outcome (Donabedian 1968).<sup>12</sup> In all three categories, non-profit care was better than for-profit.

**Structure of care:** "Structure of care" refers to the quality of the physical building as well as to staffing issues (e.g., staffing levels, mix, skills and turnover) and funding.

Four studies investigated physical plant and environmental characteristics of LTC facilities. All found in favour of non-profits.

Nyman (1988) found that non-profit institutions had better room maintenance and plant maintenance. Lemke (1989) and Gardiner (1999) found that patients in non-profits had more control over their physical environment. Greene (1981) found that non-profits spent more on food than for-profit institutions.

The literature shows that non-profit institutions tend to have more staff and a higher skilled staff mix than for-profits (see Costs, below). Non-profits also tend to provide higher wages and benefits. These positive workplace features, combined with staff's greater involvement in the development of care-plans, are associated with lower turnover. Residents of LTC homes appreciate staff continuity because their relationship with workers involves intimate personal tasks. Not surprisingly, staff continuity has been found to improve outcomes in long term care (Cohen-Mansfield 1997, Spector 1991), primary health care (Wasson 1984) and home care wound management (Turner 1994).

Four studies reported on staff turnover. All found that non-profits have lower turnover rates (ANA 1991, Banaszak-Holl 1996, Rosko 1995, Spector 1991). Studies of personnel turnover indicate that turnover can be reduced through better wages and benefits, and through the involvement of lower paid workers (e.g., nursing aides) in care planning and continuing education. Non-profit homes tend to offer their workers these benefits more than for-profits. Administrators also have higher turnover rates in for-profit homes (ANA 1991), a factor that can lead to poorer quality of care for residents.

Staff continuity is known to improve outcomes in long term care ... Four studies found that non-profits have lower turnover rates.

**Process of care:** "Process of care" includes what is done to patients/residents such as physical and mental examinations, lab tests and prescribed treatments.

One way to assess the quality of care processes in a LTC facility is to assess the use of "advanced directives."<sup>13</sup> These directives can improve quality because they link the provision of care to a resident/family's preferences and values. Castle (1998D) reported that non-profit nursing homes were more likely than for-profits to complete living wills and "do not resuscitate orders" for their clients after the implementation of the U.S. Patient Self-determination Act. Significantly, the completion of advance directives is associated with having more staff.

Castle (1997-8B) reported that non-profit nursing homes were more likely to have pain management programs but less likely to have specialized hospice programs than for-profits. Castle (1998B) reported inconsistent differences between non-profit and for-profit homes regarding the provision of mental health services.<sup>14</sup> Castle (1999A) found that for-profit homes were more likely to use anti-psychotic drugs (although not anti-anxiety or anti-depressant medication), while Castle (1999B) found no difference in psychotropic drug use between the two types of facilities.

All U.S. nursing homes are inspected annually by federal inspectors. Three studies investigated the relationship between citations of

deficiencies by federal inspectors and ownership status. All three found that non-profit institutions were less likely to be cited for deficiencies than for-profits (Holmes 1996, Castle 2000, Harrington 2000B).

**Patient outcomes:** One Canadian study reported on patient outcomes in Manitoba's continuing care system (Shapiro 1995). Shapiro investigated the likelihood of a resident being admitted to hospital for eight conditions that are sensitive to the care provided by a LTC institution. She found that residents in non-profits had lower admission rates for four conditions (dehydration, pneumonia, falls and fractures) and similar rates for the other four (anemia, urinary tract infection, gangrene, and decubitus or skin ulcers) compared with residents in for-profit facilities.

Five other studies looked at decubitus ulcers. Two found lower rates in non-profits (Aaronson 1994, Mukamel 1997) while three found no difference (Mukamel 2000, Rosko 1995, Spector and Fortinsky 1998). It might be that the overall rate of decubitus ulcers was too low in the Manitoba study for Shapiro to have found a true difference.

The use of restraints on residents is increasingly seen as an indicator of poor quality care (Castle 2000). Restraints are usually intended to protect patients whose poor judgement might expose them to danger. However, restraints are also associated with increased incidence of accidents and fractures, and with lower quality of life. Four studies reported on the use of restraints by ownership status. Two found lower use in non-profits (Castle 1998C, Mukamel 1997); the other two found no difference (Aaronson 1994, Rosko 1995).<sup>15</sup> In a study of all U.S. federal certified nursing homes, Castle (1998C) concluded that non-profits were much more likely to be restraint free. In another study, Castle (2000) concluded that non-profit nursing homes were less likely to be cited by federal investigators for deficiencies in the use of restraints.

Mukamel (1997) found that non-profits had higher rates of dehydration, but cautioned that this indicator probably isn't valid because it fails to distinguish between poor care (e.g., failure to ensure adequate fluid intake in a disabled, cognitively impaired patient) and serendipity (e.g., rapid fluid loss due to acute illness). This was the only case in the retrieved literature in which for-profit homes had better results on a morbid quality indicator.

Spector and Seldon (1998) studied all U.S. nursing homes with a 1987 data set and found that residents in non-profit nursing homes were statistically significantly less likely to develop an infection than residents in for-profit facilities. Davis (1993) investigated Kentucky nursing homes using a quality index composed of rates of decubitus ulcers, urethral catheterization, use of restraints, chemical restraints and drug errors. He found that non-profits had statistically significantly better performance on the overall index.<sup>16</sup>

Intrator (1999) investigated 253 nursing homes in 10 states, looking at LTC facility characteristics that are associated with hospitalization.

Non-profit LTC institutions were less likely to be cited for deficiencies than for-profits.

A Manitoba study found that residents in non-profit facilities had lower hospital admission rates for pneumonia, falls, dehydration and fractures than residents in for-profit facilities.

She found no statistical differences in the hospitalization rates of residents in for-profit and non-profit institutions. She did find that increased physician involvement and the use of so-called "physician extenders" (e.g., nurse practitioners) did decrease hospitalization rates. Non-profits were more likely to have higher physician involvement and physician extenders than for-profits.

**A note about mortality:** Mortality is often considered the 'gold standard' of quality for acute care services. But mortality is not a particularly useful indicator for long term residential care because most recipients are very elderly: their prime concern is quality of life, not necessarily life extension. Another issue is that a resident's death will be reported as occurring outside the LTC facility if the person was transferred to hospital prior to death. Conversely, the presence of palliative care services might bias an institution to having more deaths than others (Spector 1991).<sup>17</sup>

## Costs: An incomplete picture

Fourteen studies reported on costs. Thirteen found that for-profit care cost less per patient day than non-profit care, while the remaining one detected no difference in costs. However, these findings have a built-in limitation: no study reported on overall health care costs, but dealt with patient care costs for the institution only. In effect, we do not have the critical wide-angle view of LTC costs.

**The importance of overall costs:** The lack of data on overall costs is very significant because residents of LTC institutions have high utilization of hospitals, medical care and pharmaceuticals. Less care or poor quality care within a LTC facility can translate into higher costs in other parts of the health care system. Unfortunately, none of these studies tracked these other expenses.

Further, for-profit companies could attract business by reducing the costs of certain kinds of care while increasing prices for other kinds. For example, a private LTC facility could reduce its advertised per diem rate but then charge a fee for managing medications.

Although their per diem rates may be lower, for-profits appear to transfer costs to other parts of the health care system. The best guidance on this matter comes from population-level studies such as Silverman et al. (1999), which conclude that the greater the penetration of for-profit services into a community, the greater the overall health care costs.

**Better staff mix and pay:** The literature showed that the main reason for lower costs in for-profit residential care was lower staffing costs. Ten of twelve studies that investigated staffing found that staffing costs were higher at non-profit institutions; the other two studies saw no

Non-profits spent more on nursing care and less on overall administration.

difference. All three studies that reported on wages and benefits found higher remuneration at non-profit institutions (Gertler 1994, Hughes 1993, Rosko 1995).

Six of seven studies that looked into staff mix found a richer, better-trained combination of staff in non-profits;<sup>18</sup> the other study detected no difference (Harrington 2000A). These studies found that non-profits used more hours of licensed nurses, physicians and physician extenders. Non-profits also spent more on staff training.

Two Canadian non-peer-reviewed reports supported these conclusions. A study by the Ontario Association of Non-Profit Homes and Services for Seniors found that Ontario non-profit institutions had higher expenditures per patient day than for-profit homes (OANHSS 1997). Significantly, the non-profits spent more on nursing care and less on overall administration. A 1995 OANHSS study showed that the mainly non-profit municipal homes for the aged paid higher wages and benefits than Ontario's mainly for-profit nursing homes.

The importance of staffing is underscored by the fact that the Clinton administration recommended new staffing rules for nursing homes that receive federal funding (Pear 2000).

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## Home care: A neglected area of study

There is a paucity of research into the relative merits of non-profit and for-profit home care. This gap is lamentable given the importance of home care nursing and home support services to the growing number of people who depend on community-based care.

The following findings are based on nine peer-reviewed, comparative studies of home care services.

### Quality of care: Higher or equal in non-profits

The scant literature in this area indicated higher or equal quality of care from non-profit home care agencies compared with for-profit companies.

**Structure of care:** Three studies reported on the structure of care; all found in favour of non-profit services (Hollander 1994, Schmid 1993A, 1993B). As mentioned previously, high staff turnover leads to poorer quality of care. Hollander (1994) reported that annual homemaker turnover was lower in British Columbia's non-profit home care agencies than in for-profit agencies: 37 percent compared with 50 percent.

The researcher reported lower absenteeism and fewer complaints about non-profit staff.

Schmid (1993A) reported lower annual turnover in Israeli non-profit home care agencies (13 percent compared with 23 percent).

Schmid also reported lower absenteeism and fewer complaints about non-profit staff. Non-profit administrators were more likely to monitor their staff and make "surprise visits" to clients' homes. Schmid (1993B) found that Israeli non-profits provided better fringe benefits and more in-service training than their for-profit counterparts.

**Process of care:** Only one study reported on process of care. Shuster (1991) interviewed nurses with for-profit and non-profit home nursing agencies and concluded that their time allocation was similar.

**Patient outcomes:** Only one study reported on outcomes. Schmid (1993c) interviewed clients of Israeli for-profit and non-profit home care agencies. He concluded that clients of non-profit agencies were more satisfied with their care. Clients of non-profits rated these agencies as adapting better to working in clients' homes.

## **Costs: Lower in non-profit agencies**

Three studies compared costs between for-profit and non-profit home care agencies. All concluded that non-profits have lower costs. Williams (1994) used data from interviews with a U.S. nationally representative sample of 921 home care patients. He found that for-profits had higher costs than private non-profits, which in turn had higher costs than public agencies. Overall, Williams concluded that similar patients accrued four times the charges from for-profit firms than they did from public home care agencies. The cost difference was due to increased numbers of visits from for-profit home care staff. At the time, home care was reimbursed on a fee-per-visit basis, so there was an incentive to provide more intensive and longer servicing.

Schlenker (1995) investigated the costs of home care services delivered by capitated organizations (health maintenance organizations) and fee-for-service organizations. He concluded that regardless of payment modality, for-profits had higher costs. Leon (1997) concluded that comparable U.S. home care patients had 31 percent higher costs when for-profit firms provided the care.

To date there have been no peer-reviewed, published studies on Canadian home care costs. However, there is indirect evidence that for-profit care is more expensive. In 1997, the Manitoba government attempted to contract out 25 percent of Winnipeg's home care services to the for-profit sector (Krueger 1997, Shapiro 1997). Thirty for-profit firms displayed interest in the contract, but only the U.S.-based home-care giant Olsten made an application. Awarded the contract, Olsten withdrew in under a year after determining they could not make money while being paid at the public sector level.

Similar patients accrued four times the charges from for-profit firms than they did from public home care agencies.

**Pressure on clients:** Another cost consideration relates to how individual home care clients can be pressured by for-profit providers to buy additional services. Bruce Vladeck, then director of the Health Care Financing Administration, which administers the U.S. Medicare Program, testified before a U.S. senate committee on this problem:

The 'invisibility' of the home health setting invites profiteers to prey on disabled elderly patients who may often be isolated, uninformed and lacking the support of friends and family. We are finding continuous problems with unnecessary home health services. In home health settings the physical isolation of the beneficiary is often an open invitation to unethical providers seeking ways to provide care based on financial incentives, rather than care that is actually needed.<sup>19</sup>

There are anecdotal reports of Canadian home care recipients being pressured in this manner (Shapiro 1997).

There may be other pressures on the horizon, too. Fuller (2000) noted that Dynacare Health Group and Comcare Canada have formed Danapharm Clinical Research Inc. (DCRI) to oversee a variety of services for pharmaceutical companies. These services include recruiting patients for clinical trials. In its promotional materials DCRI says: "Our parent companies, Comcare Canada Ltd. and Dynacare Health Group Inc. provide DCRI with easy access to community-based home health."<sup>20</sup> This convergence could be an example of how for-profit health care companies find it easier to enhance profits by expanding revenues than by controlling costs (Evans 2000).

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## **A comparison of societal benefits**

In the provision of LTC and home care, the non-profit sector contributes more overall societal benefits than the for-profit sector. These benefits relate to "externalities" such as research, education and training, integration of care, use of volunteers and reduced regulatory costs.

## **A positive contribution by non-profits**

The term "externalities" refers to costs of production that do not directly accrue to the producer or consumer of goods and services. Evans (1984) described externalities in this manner:

One person or organization's behaviour may affect others, independent of any voluntary transaction ... [M]y failure to wear seatbelts increases your taxes to pay my hospital bills. Conversely my beautiful garden not only gives you pleasure, but raises your property value. Insofar as my behaviour fails to take account of such effects, because others have no way to induce me to respond to their preferences, I will (from a

society-wide perspective) over- (under) indulge in activities with negative (positive) externalities.

Economic theory suggests that for-profit companies, in pursuit of their own economic interest, would be more likely to engage in activities with negative, rather than positive externalities. For example, it is often less expensive for "dirty" industries to release their pollutants into the environment than to pay for pollution reduction. The social costs of environmental degradation can include human health problems, loss of land for other uses (e.g., agriculture) or simply a deteriorating quality of life. If a company decides to act conscientiously, it may be run out of business if its competitors forego environmental controls and hence have lower costs and cheaper products. It is exactly this dynamic that has led to greater environmental regulation in the past 30 years.

In a similar fashion, for-profit health care organizations have an incentive to avoid costs of production wherever they can, even if their actions raise costs for other individuals, institutions or society as a whole. Thus, we can expect commercial health providers to underspend on such externalities as research, education, community coordination and volunteer development.

Indeed, research shows that for-profit companies contribute less and spend less on social benefits than their non-profit counterparts.

**Research, education and training:** For-profit firms are much less likely than non-profits to provide continuing education and training to their staff.<sup>21</sup> This in turn puts pressure on the public sector and individual workers, who in effect subsidize for-profit companies by providing/paying for educational resources. The lack of investment in workers also has implications for patients. As noted earlier, continuing education is correlated with staff turnover rates and, hence, with quality of care.

**Integration and coordination of care:** Another externality is community planning for integrated care. Community and Continuing Care is provided by a diverse array of public, non-profit and for-profit agencies, even in provinces with regional health authorities. There is a critical need to coordinate these organizations and to create integrated community networks. Efficiency and cost-effectiveness are not the only goals: coordinated care is also better for patients and workers.

Banaszak-Holl (1998) examined the development of community care networks in the U.S. and concluded that non-profit agencies were central for planning networks and coordinating referrals. Rather than contributing to multi-service coordination, for-profit care tends to exacerbate the isolation of patients from community networks.

We can expect for-profit companies to underspend on research, education, community coordination and volunteer development.

**Making the most of volunteers:** Volunteers are extremely important to Canada

Canada's public health care system. Over one million Canadians volunteer in health care organizations, providing millions of hours of unpaid labour (Volunteer Canada 1998). A U.S. study estimated that volunteer time in hospitals equaled 8 percent of the paid workforce hours (Wolff 1993).

There is no peer-reviewed study that compares volunteers in long term care or home care by ownership. Wolff studied volunteers in Wisconsin hospitals. She found that among the 55 percent of people who had a preference, 99 percent preferred to volunteer at non-profit organizations and 1 percent preferred for-profits. The question must be asked: If Canadian health care becomes increasingly privatized, will we forfeit the goodwill and efforts of the volunteers who play such an essential role in CCC?

**Fraud and the cost of regulation:** Fraud has never been documented as a serious problem in Canada's health care system. However, the U.S. system is plagued by fraud and improper claims submission. The world's largest health company, Columbia/HCA, owns approximately 400 hospitals and has annual revenues in excess of US\$20 billion. Since 1997, Columbia has been under investigation by the U.S. Justice Department for fraudulent billings to Medicare, Medicaid and other federal programs. In May 2000, Columbia and the Justice Department announced a tentative US\$745 million partial settlement for alleged fraud committed by the company's hospitals, laboratories and home care agencies (Brinkerhoff 2000, Eichenwald 1997).

Fraud also led the U.S. government to place a moratorium on licensing new home care agencies for their Medicare program in 1997. Although U.S. non-profits have been found guilty of improper claims submissions (Pear 2000), the main offenders are for-profit firms and individual providers. There are signs that new U.S. regulatory efforts may be reducing fraud and improper submissions (Thornton 1999). However, this comes with a considerable increase in non-patient-related costs to ensure compliance with the new standards (Cantone 1999, Eiland 1999). Fraud and the regulatory fallout add to already heavy administrative charges within the U.S. health care system. In essence, money that could be spent on patient care is diverted to regulate the private sector.

Of course, non-profit care also requires regulation. However, the costs of setting standards, monitoring and enforcement are lower for services provided by a public body or non-profit organization (regional health authority, religious denomination or community group) than for services operating within a complex economic environment of mixed public/private financing and marketplace competitiveness.

If Canadian health care becomes increasingly privatized, will we forfeit the goodwill of volunteers?

Money that could be spent on patient care in the U.S. is diverted to regulate the private sector.

# 3

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## Chapter 3

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### **Profitization: What We Need to Know Next**

This study is the most comprehensive Canadian endeavour to review comparisons of non-profit and for-profit delivery of Community and Continuing Care. As we saw in Chapter 2, the findings are clearly in favour of non-profit care. However, this study also uncovered serious gaps in what is known.

The privatization – and profitization – of Community and Continuing Care are extremely significant trends that will impact on Canada's entire public health care system. The Canadian people, care providers and policy makers need to be fully informed about how for-profit services will affect the quality and availability of non-profit health care. Canadians also deserve to be made aware of the overall implications of for-profit health care.

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## Wanted: Stronger and better focused research

The literature that was surveyed for this study has some limitations. The majority of the 52 peer-reviewed studies are from the United States; only two are Canadian. Although U.S. literature is not completely transferable to Canada, it nevertheless bears serious analysis and study: both countries have mixed public/private funding for LTC and home care, as well as mixed delivery. That said, comparative Canadian research would be valuable.

Another limitation is the rather weak design of most of the comparative studies. (Other limitations, notably the failure to capture overall health care costs, are noted in Chapter 2.) Almost all the investigators used retrospective (cross-sectional) methods. There are few prospective (chronological) studies.<sup>22</sup> Cross-sectional studies generally provide less valid results than other research designs (Sackett 1991). The investigators generally used multivariate statistical methods to isolate the impact of independent variables. These methods have a limited ability to deal with complicated chains of causation.<sup>23</sup>

### What works best?

Better statistical methods would improve the validity of these cross-sectional studies, but it would be preferable to have stronger research designs initially. There is a critical need for research that compares the health outcomes of similar populations in non-profit and for-profit care settings, over time. This kind of prospective study would offer the most useful insights into differences in quality, costs and other factors.

For example, it should be reasonably easy to replicate West's (1983) cohort study in which patients were followed chronologically upon admission to a variety of Dallas-area nursing homes. In most provinces, current protocols for admission to an LTC institution gives the institution relatively little choice about who they admit. Residents are now prospectively assessed for dependency. These assessments are primarily used for administrative purposes, but they could also be used to control for entry case-mix. A chronological study of initially comparable residents living in different kinds of institutions would be very valuable.

### Specific quality indicators

Community and Continuing Care is a fundamental component of our health care system that will continue to grow. It is essential that we develop standard quality indicators specific to the sector; otherwise, researchers will be unable to assess what is working well, or analyze why.

We need research that compares the health outcomes of similar groups of people in non-profit and for-profit care settings, over time.

Quality indicators for other sectors do not necessarily apply to Community and Continuing Care. As noted in Chapter 2, mortality is typically the gold standard indicator in acute care (e.g., cancer and heart disease); however, many residents of LTC institutions are more concerned about quality of life than mere survival. Hospitalization is another case in point. A hospital admission may represent good care or bad care for a CCC client, depending on the circumstances.

The U.S. system is developing indicators for quality that track outcomes based on administrative data. Canada must also develop reliable and valid indicators to measure the performance of CCC services. These indicators could deal with factors such as hospital re-admission rates, use of restraints, medication use, etc.

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## **Social cohesion: A benefit we could lose**

The debate about non-profit and for-profit Community and Continuing Care is not simply about quality, costs and community coordination. There are also questions about Canadian society itself. Health care is a key part of our national identity. We like to consider ourselves a caring people. Canadians need to ask: What are the civic benefits that flow from the altruism expressed in a public and non-profit health care system, from the knowledge that one's society cares for all its citizens, including the most vulnerable?

Policy makers in many countries are increasingly concerned about the civicness of contemporary societies. Connections between individuals and community organizations are known to play a crucial role in knitting citizens together (Putnam 1993). In his study of Italy's regions, Putnam observed that regions with greater civicness developed more effective government services (e.g., day care centres, health clinics), which further reinforced their civic spirit.

Research shows that non-profit health services attract more volunteers, play the major role in planning local networks, and provide more support for research and education. Canada has a long tradition of community-based, volunteer-supported health services. Public and non-profit health care is a social asset that we created and share together. It would be more than a shame if we neglected and lost this bastion of our society.

**Public and non-profit health care is a social asset that we created together. It would be more than a shame if we neglected and lost this bastion of Canadian society.**

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# Endnotes

1. Ottawa implemented national hospital insurance in 1957; all provinces had public medical insurance by 1971.
2. Hasan 1996, Leslie 2000.
3. Population-level studies are especially informative because they compare a whole group of people with defined characteristics with another whole group with the same characteristics, but separated by time or geography. For example, a population-level study might compare all B.C. women over 65 with diabetes with all Nova Scotia women over 65 with diabetes.
4. In Canada, the Canadian Alliance party is promoting the escape valve theory as justification for a two-tier health care system.
5. The framers of Australia and Great Britain's public health insurance plans yielded to tremendous political pressure from medical specialists in allowing the private system to operate alongside the public one.
6. Walkom, Thomas. "Fixing health care: The hard lessons from Down Under – Two-tier pain: Costly lesson in frustration," *Toronto Star*, March 20, 2000.
7. For example, the 1964 Royal Commission on Health Services and the National Forum on Health, which reported in 1997.
8. The 1997 report is entitled *Private Health Insurance and the State of National Health Service*. Cited in Jane Coutts, "Private care no cure, British say," *Globe and Mail*, June 24, 1997. A1.
9. Most of these studies are cross-sectional in nature and use multivariate statistical methods to investigate associations between ownership and financial, quality and other outcomes. A cross-sectional study compares two different types of care providers – non-profit and for-profit – at the same point in time (as distinct from a prospective study, which compares two phenomenon over time).
10. The U.S. Medicaid program provides coverage to people meeting certain low-income criteria.
11. Most studies relied upon structure and process indicators, and few reported on actual patient outcomes. Traditionally, literature about health care quality focuses on structure and process; more recently it has begun to highlight the importance of outcomes. However, outcomes comparisons are methodologically more difficult to complete.
12. Donabedian's framework proposes that appropriate structures lead to appropriate care processes, which then lead to better patient outcomes.
13. Advanced directives offer older people and their families an opportunity to chose the level of intervention that they wish before a life-threatening illness develops.
14. The raw data showed increases in mental health evaluations and treatments in non-profits, but analysis by logistic regression showed inconsistent direction of differences according to such factors as size, chain status and certification.
15. Aaronson and Rosko both used the same database; therefore, their work could be considered as one study.
16. Davis did not disaggregate the index for separate analysis of its components.
17. Mortality is an unreliable quality indicator in Community and Continuing Care. In some cases a death might represent poor quality care, while in others it might represent good quality care. The literature indicates a mixed picture for mortality in LTC institutions by ownership. West (1983) conducted one of the few cohort studies in this comparative literature. She followed residents after they had been admitted to Dallas-area nursing homes and found that non-profits had strikingly lower seven-month mortality rates than for-profits (15 percent versus 46 percent). Spector and Seldon (1998) and Castle (1997-8A) also found a reduced risk of death for residents of non-profits. However, Spector (1991) and Zinn (1993) found higher death rates in non-profits, and four studies found no difference in death rates including a Manitoba study conducted by Evelyn Shapiro (Bell 1990, Shapiro 1995, Castle 1997, Mukamel 2000).
18. Cohen 1996, Elwell 1984, Gertler 1994, Harrington 1998, Harrington 2000B, West 1983.
19. Vladeck 1997. The testimony occurred on June 26, 1997.
20. Found at <http://www.centerwatch.com/provider/prv24.htm>
21. Cohen 1996, Elwell 1984, Gertler 1994, Harrington 1998, Harrington 2000B, West 1983.
22. There are few cohort studies and no randomized trials.
23. For example, the literature shows that non-profit services tend to have more staff and a richer staff mix with more expensive personnel. If a study investigates the impact of various factors on quality (e.g., preventable hospital admissions) and controls for staffing, then the relationship between ownership and quality might be obscured. This conclusion would be fair if there were

no causal relationship between non-profit status and increased staffing. However, non-profit ownership seems directly linked to higher quality staffing. This methodological problem is sometimes referred to as "overcontrolling."

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