The time for a National Home Support and Home Care Act is now

BC Coalition of People with Disabilities

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Summary

As BC's cross-disability advocacy organization, the BC Coalition of People with Disabilities (BCCPD) sees every day the hardships caused by reductions in Home Support and Home Care services. People with disabilities or chronic illness and seniors depend on these services to enable them to continue to live in their own homes and participate in their families and communities. Between 1997 and 2002, the number of British Columbians receiving Home Support services dropped by almost 50 percent. As Home Support and Home Care services are reduced, the health of these individuals suffers and the pressure on expensive acute and long term care is increased. A research project conducted by Dr. Marcus Hollander that studied Home Support clients between 1996 and 2001 found that "British Columbians who were cut off from previously available housekeeping support suffered from a 50 percent increase in the death rate and other plummeting health outcomes."

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Coinciding with the reduction in Home Support and Home Care services since the mid-1990s has been the elimination of hospital beds and the closing of institutions, making thousands of people dependent on the underfunded health resources of their communities to provide at-home care. The earlier discharge of hospital patients and the advances in outpatient services have resulted in a complexity and intensity of care that would never have been seen in the home setting a few years ago.

Since the mid-1990s the federal government has moved away from the original vision of a Canadian health system that "is a comprehensive health insurance program which will cover all health services — not just hospital and medical care — but eventually dental care, optometric care, drugs and all the other health services which people require." A truly compre-

hensive health system must include Home Support and Home Care services. However, instead of moving towards a national Home Support and Home Care plan, the federal government has reduced both transfer payments to the provinces for extended health services and the requirement for the provinces to report to the federal Ministry of Health about their delivery of extended health services. In turn, the provinces have cut Home Support and Home Care services to the bone.

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Organization after organization, conference after conference, as well as the Royal Commission on the Future of Health Care in Canada, have called for a national Home Care plan. The BCCPD says the time is now. Canadians need a national Home Support and Home Care Act that is governed by the same principles as the Canada Health Act: Universality, Comprehensiveness, Accessibility, Public Administration, and Portability. A publicly funded, publicly delivered and publicly accountable National Home Support and Home Care Act would:

- *Establish strong national standards for Home Support and Home Care services based on the criteria of the Canada Health Act.*
- *Provide accountability for the delivery of these services. Cost-share with the provinces to ensure stable, adequate funding.*
- *Cover a wide range of community-based services, including home nursing and Home Support services ranging from housekeeping to intense personal care.*
- *Be available to people with disabilities, seniors, family caregivers who require respite, and people with terminal illnesses who wish to die in their homes.*
- *Include provisions for an arms-length appeal*

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mechanism that adheres to the principles of third-party, neutral resolution of disputes.

• Be firmly rooted in the goals of self-determination, citizenship rights and community participation that are cherished by all Canadians.

A National Home Support and Home Care Act is a logical and essential next stage in achieving a truly universal national health care program that values and cares for the well-being of every Canadian.

The time for a National Home Support and Home Care Act is now

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The British Columbia Coalition of People with Disabilities (BCCPD) defines Home Support to mean assistance with personal care, food and nutritional needs, health monitoring, and other services necessary for the activities of daily living, and Home Care to mean nursing services and other professional health services provided in the home to assist with specific medical needs. Home Support services promote health and independence and recognize the essential need for respite for the family caregivers who continue to provide the major portion of at-home care. The range of services provided by Home Support workers includes:

- hygienic needs such as bathing, brushing teeth, and toileting;
- getting out of bed and dressing;
- assistance with activities of daily living, such as shopping, handling mail and personal finances, and taking medication;
- housekeeping, cooking and laundry;
- monitoring health and providing emotional and psychological support; and
- respite for family caregivers.

The rise and fall of Home Support

Home Support in BC was created as a program of the provincial Ministry of Health's new Continuing Care Division in 1980. When health services began being regionalized in 1995, regional health authorities assumed responsibility for the administration of Home Support, although the Ministry continued to fund the program. In some cases, the health authorities contract service agencies (both not-for-profit and for-profit) to provide services in accordance with the assessed needs of a client. In other cases, the health region provides funds directly to clients through the Choice in Supports for Independent Living (CSIL) program and the clients purchase their own services within a contracted framework. User fees, based on a client's ability to pay, are imposed under either option. The specific services and number of hours varies from person to person, based on individual needs determined by an assessor assigned by the local health authority.

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Provision of adequate and appropriate Home Support and Home Care services is challenging. The members of our society in need of these services are as diverse and individual as the rest of us. The majority of Home Support clients are poor and on fixed incomes. A large portion are seniors. But other Home Support clients continue to work full time, with a little help. Home Support clients are young, old and middle-aged. They may be students, professionals, or part-time workers. They may be looking for work or retired. Some enjoy the interaction of social and volunteer activities while others like to live quietly alone or with a few friends and family members. Some need only a few hours of help a month, others require 24-hour care.

Unfortunately, rigid assessment questionnaires and lack of time hinder the assessors' ability to recog-

nize and appreciate the individuality of a client and determine the actual level of need. A hurried interview, coupled with pressure to control costs, can lead an assessor to misinterpret a client's reluctance to discuss difficulties with daily living activities as an absence of need for assistance. These are problems that could be addressed and improved to make administration of the program more responsive to real needs. Unfortunately, what has happened instead is the steady erosion of an essential program because of drastic cuts in funding. This at a time when its services are needed more than ever.

Bleeding Home Support and Home Care dry

Hospital patients are discharged earlier and many are still in need of a complexity and intensity of care that would never have been seen in the home setting a few short years ago.

Between 1997 and 2002, the number of British Columbians receiving Home Support services dropped from 27,871 to 13,938 — a reduction of almost 50 percent. This, when the number of seniors, the largest group in need of Home Support services, has increased by 25 percent. The closing of institutions has returned thousands of people in need of a whole range of services to communities with already inadequate resources. Hospital patients are discharged earlier and many are still in need of a complexity and intensity of care that would never have been seen in the home setting a few short years ago. Advances in medicine and technology have resulted in more outpatient alternatives to hospital care. The complexity of Home Care services has also increased so that Home Care programs provide services to a broad base of clients including those with complex geriatric problems, and oncology and palliative care needs. Home Care also provides health care services to clients with acquired brain injury, paediatric clients, clients experiencing problems with complex wound/ostomy management and continence management. It

is obvious that Home Care is an essential component of a viable, sustainable health care system.

The reduction in hospital beds and the more intensive care required by many clients has increased both the urgent need for Home Support services and the cost of providing those services. Yet, while the 1990s saw hospital-based spending decreased, hospitals beds closed all over the province, and the length of hospital stays decreased by 46 percent, there was no parallel investment in Home Care services. In fact, the number of patients receiving Home Care actually declined by 19 percent during that period. At the same time, clients assessed at the least-acute level of need lost 78 percent of their Home Support hours.

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The dilemma of inadequate Home Support and Home Care services is clear: The need is there; but the commitment to Home Support and Home Care as essential elements of health care, and the funding to deliver the services, is not. Those people who do receive Home Support get fewer hours and fewer services, unless they are assessed as “high risk”. Among the services that have been reduced, or even eliminated, are basic housekeeping, help with shopping, meal preparation, and assistance with bathing. Studies show that inadequate levels of Home Support lead to decreased quality of life, reduced independence, and an increased likelihood of hospitalization or institutionalization. A 2001 research project conducted by Dr. Marcus Hollander that studied Home Support clients between 1996 and 2001, as part of the National Evaluation on the Cost Effectiveness of Home Care, found that “British Columbians who were cut off from previously available housekeeping support suffered from a 50 percent increase in the death rate and other plummeting health outcomes.” Over this same period, 14,500 people lost personal care and Intermediate Care 1 (IC1) was cut back severely.

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At the same time, the increased use of acute and long-term care dramatically increased costs in the health care system. The report of the province's Review of Continuing Care in BC, October 1999, stated that underfunding had reached the point where the "Continuing Care system in BC is not able to satisfy basic demands for service, let alone respond adequately to the need for innovation." The four years since this assessment have seen a further deterioration in both funding and services.

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Deep cuts to Home Support service levels since 1994 have harmed and limited the lives of thousands of British Columbians. The lifeline has become a tightrope with thousands of clients unable to maintain their balance on the razor-thin line of eligibility for the services they need. People with visual impairments struggle to shop and prepare nutritious meals and attend to household chores. Frail seniors fear a fall in the tub or shower while bathing without assistance, and risk injury helping an even frailer spouse in and out of bed and bath. People with disabilities, chronically ill, and seniors denied housekeeping assistance are at serious risk of living in unhygienic, unsafe conditions. Exhausted women wrestle with the responsibility of families, jobs, and the need to care for and act as an advocate for an incapacitated parent or other family member. (In BC, unpaid caregivers provide the majority of at-home services.) Lack of adequate respite for family caregivers brings families to the brink of collapse. People who experience brain injury or other significant disability as a result of illness or accident are unable to return home from institutional care because they cannot get Home Support and Home Care services.

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Everywhere, women carry the burden of inadequate and unattainable Home Care and Home Support services: Women, especially elderly women,

make up the largest group of Home Support and Home Care services users. Women make up 95 percent of both paid and unpaid Home Support caregivers. All have suffered from the cutbacks in funding and services.

A national problem

Dr. Hollander's national research project concluded that: "If Home Care is integrated with long term care as a part of a broader system of continuing care, it has the potential of making Canada's health care system more cost-effective." The project found that in terms of cost to the government, Home Care costs less than residential care for all levels of care and that savings are even greater when Home Care clients are helped to maintain a stable health condition.

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The Hollander project reinforced national studies that year after year have described Home Care and other community-based health services as the foundation and future of Canada's universal health care system. In 1997, after consultations across the country, the National Forum on Health declared that Home Care should be considered an integral component of publicly funded medicare services. The following year, the National Conference on Home Care said it again.

Yet, during the 1990s, private spending on health care increased by 50 percent and a study by the Dialogue on Health Reform reported that half the increase in private spending came from shifting services covered under the Canada Health Act to the home where they were not subject to the funding requirements of the Act. In 2000, the World Health organization's survey of 191 national health systems ranked Canada 30th based on the erosion of our universal health care system by out-of-pocket costs.

In 2001, leading Home Care experts participating in the Centres of Excellence for Women's Health conference in Charlottetown signed a Declaration that stated, in part: "Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life without discrimination as to gender, ability, age, physical location, sexual orientation, socioeconomic and family status or ethnocultural origin. The right to care is a fundamental human right."

An absence of vision and courage

The establishment of universal access to hospital and medical care was just the first stage of a truly comprehensive health system.

Former Saskatchewan premier Tommy Douglas had a vision for a health system that "is a comprehensive health insurance program which will cover all health services — not just hospital and medical care — but eventually dental care, optometric care, drugs and all the other health services which people require." He recognized that the establishment of universal access to hospital and medical care was just the first stage of a truly comprehensive health system. Canada, unfortunately, has yet to attain such a system.

In 1996, the Canada Health and Social Transfer (CHST) combined federal cash contributions to social assistance, post-secondary education and health into a single block transfer — and cut the amount by $7 billion. The federal share of health funds had already declined from 33 percent in 1977 to 22 percent in 1994. In 1998, the Canadian Medical Association estimated that "using the pre-CHST percentage distributions, the federal government's current cash allocation to health care stands at roughly $5.0 billion, or 7% of total health expenditures."

The federal government further distanced itself from the health care of Canadians by the repeal in 1995 of Section 6 of the Canada Health Act. This

removed any obligation on the part of the federal government to provide funds specifically for extended health services. It also removed the requirement for the provinces to report to the federal Ministry of Health about their delivery of extended health services. The Act defines extended health services as nursing home intermediate care services, adult residential care services, Home Care services, and ambulatory (outpatient) health care services. At the time that Section 6 was repealed, the federal government was providing about $51.32 per capita specifically to extended health services, about 10 percent of its total health contribution that year. The repeal of Section 6 eliminated both federal financial support for extended health services and any accountability by the provinces regarding the extended health services they provide their citizens.

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In response to the reduction in both federal transfer funds and accountability, many provincial governments embarked on programs of “health care reform” which entailed moving services out of the hospital sector and into the community without providing an adequate infrastructure and funding to deliver the services. With no accountability to the principles of the Canada Health Act or the federal government in the delivery of extended health care services, provincial governments have been free to slash Home Support and Home Care services to the bone and transfer the costs of care, equipment and drugs provided in the hospital setting to the sick, disabled and elderly at home.

The time is now

There have been enough research papers, conferences, forums and federal commissions, all calling for a national Home Care program. The 2002 report of the Royal Commission on the Future of Health Care

in Canada (Romanow Commission) recommended that a “national platform for Home Care services” (along with diagnostic services, pharmacare, and a mechanism for accountability) be included in the Canada Health Act. It further recommended that certain aspects of a national Home Care program be implemented immediately. Eighteen months later, the recommendations of the Romanow Commission, with input from Canadians across the nation, have not been acted on.

There have been enough federal proposals and promises and federal/provincial bickerings about jurisdiction. When then Health Minister Alan Rock proposed a 50-50 cost shared Home Care program in the Spring of 2000, several provincial governments rejected what they termed federal incursion into provincial jurisdiction, and the federal government backed off. In February 2003, former prime minister Jean Chretien negotiated an accord whereby first ministries agreed to ensure timely access to care, cover drug costs, set up a national Home Care program, and provide accountability for health spending. The ensuing year has seen no progress on the commitments made in what was hailed as a historic accord, and the current prime minister Paul Martin has announced his intention to negotiate a new plan with the provinces.

Now is the time for leadership and action by the elected government of Canada on behalf of all Canadians.

As BC’s cross-disability advocacy organization, the BCCPD says that the time for talk is long past. Now is the time for leadership and action by the elected government of Canada on behalf of all Canadians.

Yes to a National Home Support and Home Care Act

Hospital and physician care in Canada, which fall under the Canada Health Act, together make up less than half of the total health care expenditures.

Canadians are justly proud and protective of our system of publicly funded, publicly accountable health care. Yet, hospital and physician care in Canada, which fall under the Canada Health Act, together make up less than half of the total health care expenditures. The increasing emphasis on community care and drugs means that more and more of total health care services are not covered by the Canada Health Act. At the same time the provincial governments' share of total health spending has declined from 71 percent in 1975 to 64 percent in 1998, while the private sector share has increased to 30 percent. Most Canadians agree with Commissioner Romanow that "It is a perversion of Canadian values to accept a system where money — rather than need — determines who gets access to care."

Canada needs a comprehensive national strategy for Home Care that brings stability, national standards and appropriate funding for the services that help ensure people with disabilities and chronic illnesses and seniors can live independent lives in their homes and communities. The current hodge-podge of programs across the country is inadequate and rapidly deteriorating as provinces cut spending to deal with fiscal shortfalls. The result is catastrophic, both for the health of those who require Home Care and for the overall health care system as it experiences increased pressure on costly acute and long-term care.

Canadians need a national Home Support and Home Care Act that is governed by the same principles as the Canada Health Act:

<u>Universality</u>

Home Support and Home Care services must

be universally accessible to all individuals and families in all communities across Canada.

Comprehensiveness

Everyone in all areas of Canada has the right to quality Home Support and Home Care, whether those services are provided in a hospital, institution or home setting.

Accessibility

All Canadians are entitled to reasonable access to health care services, including Home Support and Home Care services, unimpeded by user charges or extra billing. A two-tiered system incorporating private, for-profit health care, always hits hardest at those with the lowest incomes and creates a society where health care is more available to those who can afford to pay for it. People with disabilities are disproportionately poor and their health will suffer from increased fees and privatization. The principle of public health care must be expanded to include all health services that are provided in the home and the community.

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Public administration

Provinces must administer and operate comprehensive health plans, which include Home Support and Home Care services, on a publicly funded, non-profit basis. The shifting of previously-funded services to the private sector undermines public administration. This leads to inefficiencies and higher costs as well as erecting barriers to coordination across the health care system.

Portability

The protection of portability of health care services, including Home Support and Home Care services must be reinforced. Portability is compromised when programs and services vary between provinces and within provinces from one region to another. In

BC, the administration of Home Support varies from region to region, making it difficult or impossible for clients to retain their level of Home Support when they move to another region. This is a common experience for people from outlying regions who require treatment or rehabilitation in the Lower Mainland and can't obtain the same level of Home Support when they return home.

The BCCPD proposes a publicly funded, publicly delivered and publicly accountable National Home Support and Home Care Act that would:

The federal government must restore its financial commitment to Canada's health care system.

- *Establish strong national standards for Home Support and Home Care services based on the criteria of the Canada Health Act.* Currently, funding, eligibility, criteria and services covered, as well as delivery structures, vary from location to location. The federal government must restore its financial commitment to Canada's health care system and this commitment must include national standards for Home Support and Home Care services that are delivered to people in every area of the country.

- *Provide accountability for the delivery of these services.* The Romanow Commission confirmed that the Canadian public is willing to spend more on health care but they want to make sure that more money buys real improvement to their national health care. Accountability means that both provincial and federal governments are accountable to the Canadian people to assure quality health care service and value for taxpayers' dollars. Accountability must tie national standards and objectives to national funding. Canadians expect that their tax dollars pay for national funding to assure common standards of quality health care service and access to all citizens.

• *Cost-share with the provinces to ensure stable, adequate funding.* An effective Home Support and Home Care plan requires federal leadership and cost-sharing with the provinces. The drastic underfunding by the federal government and the demand by provinces for "flexibility" has resulted in different definitions of public health care across the country. Federal funds targeted for Home Support and Home Care services with accountability to national standards and objectives are needed to ensure quality service and value for money.

• *Cover a wide range of community-based services, including home nursing and Home Support services ranging from housekeeping to intense personal care.* Studies show that when people receive the levels of services they need, Home Support and Home Care improves both quality of life and health outcomes. And this contributes to a more efficient and sustainable health care system.

The majority of caregivers are family members. Many are women who are also juggling domestic and work responsibilities. And many are elderly women caring for elderly spouses.

• *Be available to people with disabilities, seniors, family caregivers who require respite, and people with terminal illnesses who wish to die in their homes.* The majority of caregivers are family members. Many are women who are also juggling domestic and work responsibilities. And many are elderly women caring for elderly spouses. Respite is essential if they are to maintain their own health.

• *Include provisions for an arms-length appeal mechanism that adheres to the principles of third-party, neutral resolution of disputes.* Recipients of Home Support and Home Care services must have the ability to appeal reduction or denial of services and they must be assured that the appeal procedure is accessible and fair.

• *Be firmly rooted in the goals of self-determination, citizenship rights and community participation that are cherished by all Canadians.* The absence

of Home Support programs prevents active, resourceful people with disabilities from participating in or contributing to society.

A National Home Support and Home Care Act is a logical and essential next stage in achieving a truly universal national health care program that values and cares for the well-being of every Canadian.

Conclusion

A National Home Support and Home Care Act is key to providing all Canadians with better, cost-effective health care.

A National Home Support and Home Care Act is key to providing all Canadians with better, cost-effective health care. These measures are not only beneficial from a cost/benefit standpoint, they are essential for cementing the link between citizenship and health care. Any further delay in establishing a national Home Support and Home Care Act increases the hardships already inflicted on disabled, chronically ill and senior members of our society who need Home Support and Home Care services.

The time for talk is past. The time for action is now.

Resources

Home Support Crisis. The faltering heart of continuing care
A Community Action Brief prepared by BCCPD.
August 2000.

Submission to the Romanow Commission on the Future of Health Care in Canada
BCCPD. December 2001.

National Evaluation of Cost-Effectiveness of Home Care
An integrated program of 15 studies conducted across Canada and funded by the Health Transition Fund, Health Canada.
Dr. Marcus Hollander. November 2002.

Paying for keeps: Securing the future of public health care
A series by Armine Yalnizyan
Number 2. December 16, 2002.
Accountability: Why strings need to be attached to health care dollars

Background Briefing: The Canadian Health Care System
Benedict Irvine and Shannon Ferguson, based on a report by Stephan Pollard commissioned by Civitas in 2002.

Lies Told to the Sick and Weak
Donna Vogel, PhD. November 2000.
Research for Canadian Centre for Policy Alternatives, BC Office.

Home Care Information
Canadian Home Care Association 2002.
http://www.cndhomecare.on.ca/info

What happened to the National Health Care Program?

Donna Vogel. November 2000.
Women and Home Care
The National Coordinating Group on Health Care Reform and Women
2002.

National Home Care Act
Council of Canadians with Disabilities
Election 2000: Election Monitor: No. 11, November 22, 2000.

Home Support
Risky Living: Home alone with no support
BCGEU 2002.

The Evidence Is In ... It's Time to Act on Homecare
Pat Armstrong
The Canadian Women's Health Network
network magazine, Spring/Summer 2002, Volume 5, Number 2/3
http://www.cwhn.ca/network-reseau/

Why Having a National Home Care Program is a Women's Issue
Jean Ann Lowry
The Canadian Women's Health Network
network magazine, Spring/Summer 2002, Volume 5, Number 2/3
http://www.cwhn.ca/network-reseau/

Hard-won 2003 health accord close to stalling, says health council head
Victoria Times-Colonist, April 21, 2004.