



BC Coalition of People with Disabilities
#204-456 West Broadway
Vancouver, BC V5Y 1R3

Our Voice in the Community
www.bccpd.bc.ca
604-875-0188

Home Support Crisis: the faltering heart of continuing care A Community Action Brief

August 2000: Home Support is in critical condition

Aptly described as the heart of British Columbia's continuing care system, Home Support was once a growing service that promoted health, independence and community participation for people with disabilities and seniors. Today, Home Support is a pale shadow of its former self. Wounded by steady, ongoing cutbacks since 1994, Home Support is no longer able to live up to its promise or potential for thousands of people who require the service. Instead, cutbacks are becoming a source of stress, health risks and isolation.

The rapid deterioration of Home Support has been a shock. But even more shocking is the failure of health authorities to respond. Despite proclaimed support for community-based preventative health measures from all levels of government, no one is attending to Home Support as it wastes away. Indeed, a sense of denial about the condition of Home Support permeates discussions when, and if, politicians or health officials publicly acknowledge the issue.

The decline of Home Support creates ripple effects through the entire health care system. In addition to the impact on thousands of British Columbians who require the service, the cutbacks create additional pressure on acute and long-term care services. The trend to reduce services, while the need dramatically increases, will eventually eliminate the viability of Home Support as a major program to provide care in the home instead of hospitals or residential facilities.

In order for Home Support to regain its promise and live up to its potential, governments and regional health authorities must recognize that Home Support requires immediate emergency treatment.

What is Home Support?

Publicly-funded Home Support is what gives meaning to phrases commonly used in health care policy discussions, such as "closer to home", "prevention" and "health promotion".

Home Support provides basic, necessary services that enable people with disabilities, seniors and people with chronic illnesses to live in their own homes and participate more fully in their own communities. Home Support also provides badly-needed respite for family caregivers.

Home Support emerged out of the creation of a Continuing Care Division of the BC Ministry of Health in 1980. Initially, Home Support was administered centrally by the Ministry of Health. Today, with the advent of regionalization, the Ministry continues to finance Home Support, but regional health authorities have assumed responsibility for administration. In some cases, health regions contract with local service agencies (both not-for-profit and for-profit) to meet the assessed needs of a client. In other cases, the health authorities provide funding directly to clients through the



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Choice in Supports for Independent Living (CSIL) program. This program allows clients to purchase their own services within a contracted framework. Under both options, user fees may be imposed based on a client's ability to pay.

The specific services and number of hours vary from person to person, based on individual needs determined by an assessor assigned by the local health authority. The range of services provided by Home Support workers includes:

- bathing, brushing teeth, wiping up after bowel movements and other hygienic needs;
- getting out of bed and dressing;
- assistance with activities of daily living;
- housekeeping, cooking and laundry; and
- monitoring health, and providing emotional and psychological support.

Whatever the level of need, Home Support is the difference between a person's ability to live a healthy, independent life and being forced to choose between institutional care or a home situation that creates strtes stress, poor health outcomes and a loss of independence.

Who uses Home Support?

One of the problems with the delivery of Home Support services is that rigid assessment processes fail to recognize the diversity of clients and their very differing needs.

Most Home Support clients are poor and on fixed incomes, but many are professionals with full-time employment. Some are young, energetic people with disabilities who actively participate in the larger community while others are elderly seniors who want to live safely in their own home. Some are people with chronic illnesses who live with their families. Others are people with cognitive disabilities resulting from traumatic accidents. Some require 24-hour support that involves all facets of their lives; others need only a few hours a month for household chores they can't manage themselves.

Home Support clients are students, professionals, part-time workers, retired people, people looking for work, community volunteers, people who are socially and culturally active, and people who want to live quietly in their homes. Anybody who doesn't require Home Support today may need it tomorrow. Home Support clients do not fit into convenient boxes.

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The benefits of Home Support

When Home Support is able to function as it should, the benefits to both clients and the larger community are numerous.

Studies show that when clients receive the level of service they need, Home Support improves both quality of life and health outcomes. Furthermore, recent research from Saskatchewan (Health Sciences Utilization and Research Commission) indicates that when Home Support service levels



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are too low, the risk of death and the risk of losing independence are both increased.

The benefits of properly-funded Home Support include:

- People with disabilities are enabled to participate in the community and exercise their basic citizenship rights;
- Seniors are able to live in their homes for as long as possible;
- Families and friends receive the respite they need so they can continue to serve as primary caregivers to their loved ones;
- Demand for costly institutional or residential care is reduced because people who want to live in their own home are able to do so;
- Pressure on acute care services is reduced because Home Support promotes health and well-being;
- Families and communities benefit from the presence and participation of seniors and people with disabilities;
- All citizens benefit from the assurance that if they or a loved one require Home Support, it will be available.

The current crisis

Serious cutbacks to Home Support service levels began in 1994.

Since 1994, the number of British Columbians who receive Home Support has declined by almost 20 per cent. Most people who still receive Home Support now get fewer hours and reduced service if they are not deemed to be "high risk". Housekeeping has been virtually eliminated, while meal preparation, assistance with shopping and other "low priority" services are in steep decline.

Health regions may argue that they are not actually cutting back on Home Support. Indeed, for the most part, regions have actually increased the dollars they spend on Home Support. But those increased dollars have not come close to meeting the increased need. The resulting consequences on the delivery of Home Support are numerous.

Underfunding

Despite dramatically increased need, fewer people are benefiting from public spending on Home Support. As the population ages and more people acquire disabling conditions, there are more people who need Home Support. At the same time, a greater proportion of those people have very intensive needs. Furthermore, costs per hour of Home Support have increased, in part because of the more intensive care required by many clients.

Instead of increasing funds accordingly, health authorities have decided to make the people who require Home Support pay the price for increased need and higher costs. In October 1999, the final report of the province's Review of Continuing Care in BC noted that underfunding has 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."



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Inadequate assessments

Increased workloads mean that staff have less time to do their jobs. Assessments and reassessments are frequently hurried and inadequate. In fact, the assessment of need for this essential service is often made without a face-to-face interview. Rigid assessment questionnaires do a poor job of assessing people's actual levels of need. People are often reluctant to say that they have difficulty cooking or cleaning for themselves, that they are losing control of their bladder or bowels, or that they lose track of whether or not they've taken their medication. It is easy for assessors who are short of time and under pressure to control costs to misinterpret a client's reluctance to complain for the absence of need. This endangers the people receiving care and opens caseworkers and their employer to tragic and liability-prone situations.

Lack of portability

As the individual regions grapple to contain Home Support costs, the administration of Home Support varies from region to region. Although the Ministry of Health's Continuing Care Policy Manual stipulates that Home Support is supposed to be portable, in reality clients find it difficult or impossible to retain their level of Home Support when they move into another region. This is a common experience for people from outlying regions who require treatment or rehabilitation in Vancouver. Although they may qualify for Home Support in the Lower Mainland, when they return to their home region they find they cannot obtain the same level of Home Support.

Lack of continuity

For most people who receive Home Support, staff continuity is very important. This unique, day-to-day relationship develops over time and is often a central component in the client's care, well-being and sense of safety.

Because of the personal nature of Home Support, many clients find the need to repeatedly adjust to new workers very frustrating. For those seniors or people with disabilities who have some form of cognitive impairment, this can be especially distressing. Regrettably, one of the ways regions have tried to control costs is by "streamlining" Home Support workers adjusting workloads to cut down on workers' travel time, rather than maintaining client/worker connections. This has greatly disrupted the lives of many Home Support clients. Furthermore, the increased use of private, for-profit companies has often resulted in reduced continuity.

Over-worked, over-stressed staff

Home Support workers also strongly feel the impact of service cuts. Many workers find they are unable to do an adequate job in the amount of time they are assigned. Home Support workers often put in extra hours, with no compensation, because they care about clients whose needs are not being met. Not only do workers have more clients, but in many cases the worker's travel time is deducted from the hours allotted to each client. Workers commonly experience days that are spent rushing from home to home, doing the best they can with too few hours. As stated in the final report of the Review on Continuing Care in BC, the "overall increase in care needs of clients makes it much more difficult for staff to manage their already large caseloads. While both the



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number of clients needing the highest levels of care and the complexity of the care itself have increased, there has not been an increase in staff."

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Loss of skilled staff

Health regions are trying to cut costs by servicing more clients with fewer staff. This creates a situation where the number of Home Support workers declines in relation to the demand for service. This is creating a highly stressful environment for workers in which burn-out is becoming commonplace. With less opportunity to work and increased pressures, many Home Support workers are moving into other occupations. The longer it takes for governments and health authorities to restore Home Support services to 1994 levels, the fewer skilled, experienced staff there will be to meet the need.

Ever-present stress in the lives of Home Support recipients

In the current atmosphere of relentless cost-cutting, the term "reassessment" has come to mean "cutback". Home Support recipients are under great stress due to the ever-looming threat that their hours may be cut. And it seems impossible to acquire certainty. Cutbacks can happen any time, even to those who have already been reassessed. In the CSIL program, many recipients must sign vague, open-ended contracts devoid of any guarantees about funding or service levels. They are told they must sign the contract to get any funding, but they must be prepared for reassessment that could change the terms of their service.

The absence of arms-length appeal mechanisms

The stress caused by the constant threat of cutbacks is worsened by the absence of fair, arms-length appeal mechanisms. Some regions have no appeal mechanism at all, while others have structures that in no way adhere to the principles of third-party, neutral resolution of disputes. Most advocates strongly suspect that the absence of appeal mechanisms is another symptom of cost-cutting. Neutral appeal bodies would no doubt be horrified by many of the cases they would hear. Health authorities who are trying to save money don't want to see cutbacks reversed.

The above factors create a situation that is in direct opposition to the original intent of Home Support. Instead of promoting health and well-being in the home and away from institutions, the system is all too often delivering stress and despair, and eroding hard-won advances in independent living for seniors and people with disabilities.

Impact of the crisis

Advocates, agencies, friends and families frequently encounter situations that would horrify most British Columbians.

These include situations where:

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-The absence of Home Support prevents active, resourceful people with disabilities from participating in or contributing to society. Instead, people are confined to their homes because they can't get the assistance they need when they need it for dressing, cleaning, bathing and other necessities.

-Very elderly single women (in their 90s or even 100s) are cut off Home Support entirely. A woman in this situation is at serious risk of living in an unhygienic, unsafe home due to lack of cleaning, suffering from malnutrition because she doesn't eat proper meals and injuring herself by performing chores she should not attempt.

-Respite is not provided to a very elderly person who is providing care to a spouse with intensive health needs. The caregiver's own health suffers from stress, lack of time to meet their own needs and the absence of support for household chores that they now find difficult or impossible.

-People who experience brain injury or other significant disability as a result of accident or illness are unable to return home from institutional care because they cannot get Home Support.

-Low-income people with disabilities are forced to choose between paying for house cleaning out of their already-inadequate food budget or living in an unsanitary house.

-Families who do not receive any or adequate respite are on the brink of collapse from the pressure of providing constant care to an elderly family member or relative with a disability while trying to maintain their jobs or education.

Response to the crisis

Public outcry against the dismantling of Home Support is starting to grow as conditions reach the breaking point.

The impact of Home Support cutbacks is felt province-wide by thousands of British Columbians and public awareness is increasing. Growing numbers of people are angered and astonished that Home Support which provides better quality of life, preventative health measures and cost-effectiveness is the target of cutbacks instead of enhancement.

It appears that the biggest problem is that no one is willing to play a leadership role. Regional health authorities say they simply don't have enough money to adequately fund Home Support, and deny there is a serious problem. Provincial politicians say that regional health authorities have enough money but choose not to spend it on Home Support. They also point to the billions of dollars cut from federal transfer payments as the primary cause of underfunding. The federal government says it's up to the provinces to spend health dollars more effectively. Federal Health Minister Alan Rock recently decided to back away from his commitment to establish a national plan for providing health services in the home.

The net effect of these positions is a frustrating combination of denial about the extent of the crisis and finger-pointing about who is at fault. Meanwhile, nothing gets done and the quality of life for thousands of people who depend on Home Support continues to decline.



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Action Plan

It is essential for the provincial government to play a lead role in restoring and enhancing Home Support.

It is time for finger-pointing and denial to stop, and real leadership to start. All levels of government and the health authorities have important roles to play, but ultimately it is the provincial government that establishes province-wide priorities and sets standards for the provision of essential health services.

The crisis requires both immediate action to stop the cutbacks and restore services, and prompt follow-up steps to protect and enhance Home Support so that it can live up to its promise and potential.

Immediate steps

The provincial government and health authorities must acknowledge that cutbacks to Home Support are causing thousands of British Columbians to suffer increased health risks, isolation and loss of independence.

The provincial government must direct the health regions to immediately halt further cutbacks to Home Support service levels.

The provincial government must work with health regions to restore service levels to 1994 levels.

The provincial government must work with Home Support users and regional health authorities to establish a province-wide, arms-length appeal mechanism for people who dispute their Home Support assessments. Appeal boards must include strong representation from people with disabilities and seniors.

Next steps

The province must establish adequate and stable funding for Home Support in a protected envelope.

The province must ensure the portability of Home Support by attaching funding to the individual. This would allow the recipient to carry the level of service they need with them when they change locations within the province.

The BC government must strengthen provincial guidelines for Home Support so that the service is delivered fairly and evenly in each region of province.



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The province must ensure that Home Support is a universal program by eliminating user fees and stemming privatization.

CSIL contracts must be improved to provide clients with a committed level of funding and services for the course of the contract.

Health authorities must ensure that assessment is independent of budget management, and that cost-cutting is not an implicit or explicit part of an assessor's job description.

Health authorities must replace medical-model assessment tools with holistic personal support plans based on independent living principles.

Ongoing steps

The province should continue to speak out for a nation-wide plan to provide health care services in the home.

The provincial government must ensure that Home Support clients, families and workers are directly involved in follow-up to the final report of the Review of Continuing Care in BC.

Clients must be directly involved as full participants in all decisions that affect their lives. This includes making improvements to the continuing care system so it can strengthen and grow to meet the population's changing needs.

The crisis in Home Support is escalating while countless lives are harmed and limited, families are stressed to the breaking point, skilled workers are lost from the system and British Columbians are losing faith in their health care system. It is critical for government and health authorities to respond now, before even more damage is done.

It's time to end the denial and attend to this urgent need.

Send a support letter now!

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