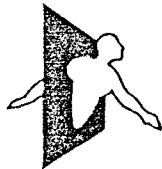


Health

submission to the  
**Royal Commission on  
Health Care and Costs**

by

**B.C. Coalition of People with Disabilities**



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October 1990

ROYAL COMMISSION ON HEALTH CARE AND COSTS

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Introduction

People with disabilities have made major advances in the last two decades. In the past twenty years we have seen the development and refinement of important concepts such as independent living and consumer participation. Advances which have improved the quality of life for many individuals living with disabilities have been made with regard to housing, transportation, employment and service delivery.

Our Coalition represents people with a wide range of disabilities working towards a common goal of increased control over our lives along with integration and participation in our communities. Our members include people with physical, visual, hearing, learning, psychiatric and mental disabilities. In recent years we have begun to examine and recognize issues relating to HIV/AIDS as a disability.

Today, people with disabilities are being integrated into the community. The specter of a lifetime of institutionalization and powerlessness has been reduced for many people with physical and mental impairments. However, much remains to be done to improve the ability of our members to live lives of dignity and choice. This submission to the Royal Commission on Health Care and Costs is intended to promote the principle of consumer participation as a means of ensuring that people with disabilities live our lives in homes where personal control is optimized and assured.

We urge the commission to examine and understand the concept of consumer participation and propose recommendations which will support and enhance the development of this principle. The BC Coalition of People with Disabilities believes that consumer participation in the health care system is an issue the commission must address as it develops a vision for health care in the 1990s. This principle serves to improve personal decision making, enhance human rights and ensure dignity and community integration.

By consumer participation we mean that health care consumers be recognized as active participants in our care. For too long, consumers have been ignored by service delivery systems based on the medical model. These systems, built on the assumption that experts know best, harm people with disabilities when administrative concerns take precedence over the concerns of the individual client. Systems based on the principle of consumer participation can ensure that the needs of the consumer are represented at all levels of decision making. Proposals which foster the development of consumer controlled service delivery systems are one way of recognizing the principle of consumer participation. As well, consumer participation can be advanced by the appointment of consumer representatives to decision making and advisory bodies.

Although we strongly support the continued development and implementation of deinstitutionalization, community living and consumer participation, we do not see the adoption of these principles as an excuse for governments to abdicate their responsibilities. In recent years we have seen cases where governments have attempted to empty institutions without providing the necessary community support.

For example, people with psychiatric disabilities have been placed into communities which do not contain adequate support systems. Many have found themselves with inadequate or non-existent housing or have been reinstitutionalized in the prison system. The BCCPD hopes that cases such as this will provide needed lessons as we seek to develop and enhance the basic principles of the disabled movement in the 1990s.

As well, we cannot talk about goals such as community integration without referring to the abysmal financial position of people living with disabilities. Any report which seeks to look at the health concerns of people with disabilities must address the fact that the lack of social support and employment opportunities are an extremely effective barrier against consumer participation.

The BCCPD wishes to bring to the attention of the commission three issues which will update the health care system for the nineties:

I — The need for increased consumer control of all aspects of service delivery.

The Coalition believes it is time for consumers to be recognized as equal partners in health care delivery. For too long, decisions have been made for us rather than with us. People with disabilities have been made to fit into service delivery programs and models rather than being recognized as active and responsible participants in the development of care systems which meet our needs.

Consumers lack control in service delivery when systems are based on models which exclude direct consumer participation. We will use some examples to discuss some of our concerns regarding the current state of consumer participation for people with disabilities.

**Example #1: Consumers caught between over-lapping jurisdictions** - Three disabled adults living in a long-term care facility require new wheelchairs. Previously, the Ministry of Social Services and Housing has provided funding for personal mobility aids. This time, MSSH has denied the request. "The Director of GAIN has deemed the responsibility for the purchase/repair of wheelchairs for residents of a residential facility rests with the Ministry of Health which funds such facilities."

The position of the Continuing Care Division is that only equipment for the general use of all residents is provided by the Ministry of Health. "If medical equipment is needed on a continual basis for residents' personal daily use, the cost remains the responsibility of each resident."

The outcome of this is that the consumers are denied financial assistance to obtain a wheelchair. No one has stated they are not entitled to new wheelchairs. Rather, the problem is a lack of willingness to accept responsibility by each ministry.

Cases such as this which involve jurisdictional disputes and lack of communication between ministries harm only the consumer. We argue that if consumer participation were a cornerstone of the long-term care system, cases such as this could be resolved quickly and efficiently.

**Example #2: Consumers lack control over scheduling of care attendants** - People who work (but who still need financial support to pay for attendant care) may have trouble scheduling attendants during hours when they need them. The consumer must adapt to to the schedules of the homemaking agencies.

These two examples suggest that the ability of people with disabilities to live productive and fulfilling lives may be hampered by current service delivery models. Alternative systems are being developed which place much more control in the hands of the consumer.

For example, systems based on the brokerage model enable the consumer to have a say in the hiring and training of caregivers. The consumer may establish the times and hours that the caregiver works (within the framework of an assessment by long term care).

This idea is not completely new in British Columbia. In Vernon, for example, six members of the North Okanagan Handicapped Association receive home-care services through a unique consumer controlled service delivery system. After receiving an assessment of the number of hours per month of care required, the consumer has direct input into the hiring and firing of staff. The consumer also negotiates and establishes the scheduling of the individual caregivers.

The system is administered by an administration office that provides support for consumers. The board of directors of the organization is also consumer controlled. Although, the service exists for only six people, the NOHA model provides a good example of the kind of service we would like to see accessible to many more British Columbians.

One benefit of consumer controlled brokerage systems is that consumers become empowered to have a direct say in the decision making which affects their lives. As well, administration costs can be lowered. In the case of NOHA, the lowered administration costs result in higher wages for the caregivers. This results in better quality employees and less problems with turn-over.

Long-term care systems based on the brokerage model have been instituted in Alberta, Ontario and many other jurisdictions. Examples of similar systems which operate on a larger scale exist in cities such as Thunder Bay, Ontario and Winnipeg, Manitoba. We propose that the Commission review the brokerage model as a basis for providing service.

Another example of a consumer controlled service system is the Creek View 202 Project. This a housing project where ventilator dependent quadraplegics have received financing to build and live in a shared house that provides all necessary services.

Such consumer controlled systems do not appear to cost additional money once established. In fact, substantial savings in administration costs may be one benefit of consumer controlled service delivery. We suggest that the money saved not be used to cut-back funding but to pass on savings to people with disabilities in the form of expanded service and increased wages for caregivers.

An additional specific problem is that people with disabilities experience too much red tape when they attempt to access equipment. The Commission should examine ways to streamline access to equipment and develop models of direct service provision. An example of this model is used by the Hemophilia Society to provide equipment and training to hemophiliacs in British Columbia. Such systems must provide access, training and support in the case of equipment breakdown.

We recommend:

- 1) The Royal Commission on Health Care and Costs strongly support the principle of increased consumer participation as an important health care goal for the 1990s.
- 2) The Royal Commission on Health Care and Costs review the brokerage model and alternative care systems based on consumer participation as a basis for long-term care service delivery.
- 3) The Royal Commission on Health Care and Costs recommend that the provincial government provide direct funding for pilot projects which will develop alternatives to existing medical and rehabilitative models.
- 4) The Royal Commission on Health Care and Costs examine models which provide direct access to equipment for people with disabilities.

## II - Legislation and policies governing long-term care are inadequate or non-existent.

It will take a long time to fully implement consumer control in service delivery. An immediate concern is that existing legislation, policies and guidelines may work against the goals of consumer participation.

The current legislation and policies governing long term care contain important gaps which need to be addressed. Again, we will provide examples of cases which highlight existing deficiencies in current legislation and policies.

*Example #3: A man living independently who suffers a short term injury is denied the home support he needs* - A man with cerebral palsy who has been living and working successfully in the community for the last seven years injured his finger in a fall. During his hospitalization the wound became infected which caused severe complications - to the point where amputation of the finger was seriously considered. The complications intensified the cerebral palsy symptoms which in turn created a need for more physical assistance. When he was released from the hospital his short-term condition required substantially more hours of support than was available through the long-term care system.

Although, he received a great deal of support from family and friends, his short-term requirement for attendant care resulted in ongoing negotiations with his service provider and the local health unit. The expectation seemed to be that it was up to this person's mother to provide the care which could not be met by Long-Term Care.

Eventually, this man was encouraged to consider moving from the apartment he has maintained for the last seven years into an institution or care facility. His finger is now much better. However, the emotional scars caused by meeting systemic problems at a time when he was least able to deal with them have yet to heal.

*Example #4: A women forced to pay for the additional care she needs -*

Another case involves a women with advanced Multiple Sclerosis. Like many of our members, she is determined to live in and contribute to the community. Her condition requires six hours per day of attendant care. She is currently only receiving three hours per day because a number of home support agencies have been unable to find trained staff. She is paying out of her pocket for the additional care she needs on an income of \$700 per month. There is no mechanism to provide compensation for this expense. Again, Long Term Care has worked to place this individual in an institution or care facility.

This case highlights how what might seem a small policy barrier can result in a major personal crisis. We believe long-term care policy must facilitate and not hinder the transition of people such as this into the community.

New legislation governing long-term care must be drafted with consumer input. At a minimum, legislation must ensure:

1. A minimum standard of service. All service must be based on standards which are clearly spelled out in legislation.
2. A minimum level of service. All people with disabilities must be guaranteed a service that allows them to live and work independently.
3. A fair and accessible appeal mechanism. An appeals mechanism such as that used by the Ministry of Social Services and Housing must be implemented in order to adjudicate contentious cases.

An appeal mechanism can be very important, for example, in cases which prevent consumers from having access to wheel chairs and other essential equipment because of jurisdictional disputes between the Ministry of Health and the Ministry of Social Services and Housing.

As well, it is important that guidelines provide clear statements about the rights and responsibilities of consumers.

We recommend:

- 5) The Royal Commission on Health Care and Costs propose enabling legislation governing long-term care which ensures a minimum standard of service, a minimum level of service, and an appeal mechanism.
- 6) The proposed enabling legislation be accompanied by policies, regulations and guidelines (developed with consumer representation and input) which ensure consumer control and participation.

**IV — The need to recognize and address the impact of HIV/AIDS on the health care system.**

The BCCPD has concluded that people HIV/AIDS must be included in our efforts to ensure dignity and protection from discrimination for all people whose lives are affected by the social response to physical, psychological and medical conditions. We have also concluded that education about HIV/AIDS is necessary for members of all of our groups.

To this end we are developing education materials which are accessible members of our communities. As well, we have produced materials relating to social and political aspects of HIV/AIDS as a disability.

We have included as an appendix, our submission to the provincial AIDS strategy. We would ask commission members to study this document and its relevance to the development of programs to decrease the spread of HIV/AIDS and to fight the social issues connected with this disability.

**We recommend the Royal Commission on Health Care and Costs study the BCCPD submission to the Provincial AIDS Strategy and recognize HIV/AIDS as a disability issue.**