

Health

# Closer to Home: Concerns and Comments from the Disability Community

submitted to  
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## **Introduction**

The BC Coalition of People with Disabilities would like to thank the Ministry for this opportunity to comment on Closer to Home: The Report of the Royal Commission on Health Care and Costs. The Report speaks to many issues of great importance to people with disabilities and we are encouraged by the Minister's insistence upon consumer input.

The Report reflects many of the concerns raised by the Coalition and other organizations representing people with disabilities. There are many recommendations that point the way to major improvements in our health care system. However, there are serious shortcomings in the philosophy and the particulars of the Report which we draw to your attention in this brief.

We will highlight recommendations from the report that we feel deserve particular attention by Cabinet and will also make additional recommendations for your consideration.

## **Major Points for Review/Discussion**

### **What is Health?**

Much to our surprise, the Report neither defines nor describes what the writers mean by "health". While it states that "many people have adopted the 1984 World Health Organization definition.... and others support the 1986 Ottawa Charter for Health Promotion...", the Commissioners felt it was necessary to "concentrate on ... narrower fields [by excluding 'the social and economic environment']..." (p. iv). It is understandable why the Commission would want to limit its terms of reference, but the lack of a definition for "health" makes the references to it ambiguous if not meaningless.

We wonder how the Ministry can hope to effectively evaluate the need for one program over another or improve methods of service delivery if the goal, i.e. health, is not clearly defined and agreed upon. We also cannot hope to achieve a system of accountability if we don't know what makes us healthy. Nor can we determine which interventions are the most effective and cost-efficient.

Dr. Michael Rachlis, in his Canadian bestseller "Second Opinion - What's Wrong with Canada's Health Care System" sites a hospital president who stated that "a hospital is just about the only 'business' you'll ever find that has no idea what its product--'a healthy patient'--costs to produce" (p.30). This makes sense when we realize that hospitals don't spend time studying health--they deal with illness, disease and injury. **Hospitals, consequently should not set standards for health (Summary, p. 25). Governments must, in consultation with the public, define health and set standards for service and resource provision to attain and maintain it; they must not abdicate from this responsibility.**

The Report's assumption of hospital authority in determining health standards is very disturbing--this encourages a conflict of interest. Hospitals often complain of underfunding--sometimes using scare tactics--and the public and government are held at gunpoint to increase their allowances. It is also true that hospital boards are sometimes occupied by single interest groups who will not necessarily reflect the broader public health interests.

Without knowing what health is and how it is achieved, we will not question a hospital's demand for twenty new incubators for premature babies. We will not ask questions about the health of these twenty women and how many of their premature births could have been prevented by acknowledging their social, educational and economic situations--or by funding interventions more directly related to the cause of their poor health.

The Report recommends support for and coordination of alternative health service delivery groups to "increase the quality of care available at the community level" (B55). But, again, as long as health is ill-defined or defined by institutions that have a vested interest, it will be impossible to make judgements about which therapies or services will help to build a truly holistic health care system. Funding support, through the Medical Services Plan, will continue to be limited by medical model priorities.

This is particularly relevant to people with stable disabilities who are healthy and use alternative therapies to maintain their health. They consider themselves to be "outside" the medical system--both in terms of not being "sick"

and how they achieve their health. We feel that a great deal could be learned about health and cost-effective ways of maintaining it by talking to people with disabilities about how they achieve their health goals.

1. We recommend that the Ministry of Health conduct a small study to learn from healthy people with disabilities how they define and manage their own health.

For the purposes of this brief, we define health as a person's state of physical, mental, emotional and spiritual well-being. Health is a basic, interconnected, and dynamic force in our lives that is influenced by our circumstances, beliefs, culture and social, economic and physical environments. While we understand that it was not the mandate of this Report to deal with the many factors that influence health, we feel it important to state our definition of health at the outset. We also feel strongly that unless a similar holistic definition is adopted by the Ministry of Health that services and programs will not meet the public's health needs.

#### Institutionalization: A Thing of the Past?

There have been tremendous changes in thinking around people with disabilities in the past twenty years and, as with any social change, there is often a lag in comprehension—we use words and concepts before we really understand their ramifications and what they mean in our day-to-day lives. Institutionalization is such a concept.

Most people, including the authors of the Report, say that deinstitutionalization is laudable and that every effort should be made to move people with disabilities into the community into situations that are as independent and client-oriented as possible.

However, institutionalization is not defined by a building, but by a certain mind-set that makes dehumanizing and paternalistic assumptions. People who live in institutions, as well as the people who work in them, develop "institutionalized" ways of perceiving people and solving problems. "De-institutionalization" is therefore a process where all parties must unlearn these ways of thinking.

Because of this institutionalized thinking that still permeates considerations around the disability community, there are mixed messages throughout the Report regarding institutionalization and people with disabilities' ability to manage their own lives. An example of this is the Report's suggestions to appoint case managers and other personnel to oversee and direct health care matters for people with disabilities. This may, in fact, be necessary in some cases, but it is wrong to start from the premise that this management will always be needed.

As another example, a key "Strategy for Change" will be to:  
"...appoint Children's Hospital, Queen Alexandra Hospital, Sunny Hill Hospital and the BC Rehabilitation Society GF Strong Centre as the agencies jointly responsible for setting provincial standards and providing consultation to the regions (Report Summary, p. 25).

Where do people with disabilities fit into this recommendation? Where are the numerous skilled, community-based groups of people with disabilities who work the "front lines" as advocates and educators? Again, our input is diminished by the automatic deferral to the "expertise" of people who work within the institutional medical model.

Yet another example on page C160:

"Therefore, the commission recommends that:

16. so far as is practicable, the home care client should have the right to change worker or agency (underlining ours)".

On the surface, this recommendation, and others in a similar vein, seem to support the concept of independence and consumer control. However, rather than starting from a position that assumes the consumer's right to this control, the tone suggests that the consumer should take control only "if practicable". Who determines what "is practicable"? This may seem to be a subtle point, but it undermines our ability to obtain truly self-managed services.

2. We urge the Ministry of Health to review and restate its commitment to deinstitutionalization and independent living for people with disabilities

and to ensure that programs and services are available that will further this commitment.

### Medicalization

An issue that keeps re-emerging in many different guises for people with disabilities is the medicalization of our lives. The medical model still molds the philosophy of health services, particularly in the case of people with disabilities who are still too often inappropriately viewed as "patients" rather than "clients" or "consumers."

One of the many areas where the medical model needs to be challenged is within the delivery of attendant services. Many attendant services agencies make a very clear distinction between "medical" and "non-medical" tasks—and attendants are authorized only to perform the latter. Incredible as it may seem, cutting fingernails is considered a medical procedure. If this regulation is observed, an attendant cannot perform this task—a nurse must be called in.

More significant procedures deemed medical include bowel and bladder routines, giving of medications, suctioning and ventilator care—activities which are part of daily functioning for many British Columbians with disabilities. Once this medical designation is made, these services that can only be performed by licensed, and costly, personnel.

The medical mystique falls away when we realize that people with disabilities who have enough upper body dexterity—including children—are taught to do these tasks themselves. Many consumers consequently argue that the medical designation for the type of tasks described here, independent of the context in which they are performed and the individual they are performed on, is nonsensical, frustrating and expensive. When these procedures are part of the daily life of a person with a stable, ongoing disability, the medical label only serves to maintain an unnecessary and oppressive medical presence in the person's life.

**3. We recommend that the Ministry of Health consult with disabled representatives to change the "medical" designation of certain care procedures**

for persons with stable disabilities who are able to direct these procedures themselves.

#### Home/Attendant Care Services

In general, the recommendations around consumer control and participation reflect some understanding of the issues for people with disabilities. We applaud the Report's support of consumer control and community-based services—these are cornerstones of independence for our communities.

The Report envisions a much more effective and responsive health system via recommendations around:

- consumer participation in planning of programs that effect them
- the need for directing funds to home care vs. institutional care wherever possible
- improved training and remuneration for home support personnel
- quality control standards for care
- clients right to appeal decisions regarding their care

However, there are some critical areas that are not discussed or misrepresent the key issues for people with disabilities.

#### Long Term Care Legislation

An overriding concern is the lack of long term care policy. There is no legislation or regulations governing programs and service delivery—nor is there a definition of what long term care is. This is clearly a serious obstacle to planning health services and programs for people with disabilities. Our recommendations in this section are intended to provide suggestions and thoughts for a new legislative framework.

4. We urge the Ministry of Health to immediately begin the process of drafting long term care legislation in cooperation with concerned community groups.

### **Management of Attendants**

One of the great costs of attendant services is administration. In countless instances where services are provided to people with disabilities, there is a great deal of management overlap in recruiting, hiring and training. While agencies collect a fee for these duties, it is often the consumers requiring the services who are carrying out these tasks. Many people with disabilities will attest to the amount of time we put into finding replacement attendants, training them, and so on.

The clients then receive token "supervision" by attendant agencies so the agencies can claim to have performed their supervisory role. Given the rapid turnover in the attendant field, agencies are no doubt grateful for the countless volunteer hours spent by consumers to manage their own care. However, this is clearly an unfair, ineffective, and costly system. People with disabilities are also reluctant to complain about this situation because they fear losing services.

The Enhanced Consumer Participation Model which has been operating in the City of Vancouver is a case in point. This project merely "legitimizes" the use of people with disabilities' volunteer labour. Clients carry out most of the management of their own attendant services while the Ministry continues to pay the home care agency for "management".

While the Report discusses the merits of consumer-controlled brokerage systems, such as the one presently used by the North Okanagan Handicapped Association, it falls short of directly recommending the implementation of new home care legislation that would ensure consumers' control over their own care. Nor are there any recommendations regarding consumer control of funding for their own services.

**5. We urge the Ministry of Health and the Ministry of Social Services to begin discussions with B.C. Coalition of People with Disabilities and other knowledgeable groups to develop legislation for consumer controlled delivery and management of support services.**



The Report makes commendable recommendations around training for home care personnel to better enable them to work with people with disabilities. However, rather than training the "middle people" around the consumer—attendants, care providers, case managers—we would like to suggest that funds be devoted to training people with disabilities themselves. If people with disabilities—who are the fixed point in a system characterized by transient personnel—learn how to better manage their own care, the system will inevitably run more smoothly.

We therefore make the following recommendations:

6. We recommend that people with disabilities be given a choice in administration of their attendant services by the establishment of two systems: a) a brokerage system whereby a middle person is designated to manage the client's financial and organizational matters, and b) individualized funding to flow to the person with a disability to manage their own services. The responsibility for services and accountability for funding would therefore rest with the individual.

7. We recommend that resources and opportunities, for example bursaries or courses, be made available for people with disabilities who wish to learn skills in business management, assertive self-representation, payroll, training skills, and so on to better enable them to manage their health care services.

Some final thoughts on attendant care:

- As already stated, the transience of attendants is a major issue for people with disabilities—it is not unusual to have four, five, or even more attendants in the same year with all the retraining and reorientation that this involves. We therefore commend the Report's acknowledgement of higher wages as a necessary incentive for more stable employment patterns—this is a very important piece of the puzzle. However, we reiterate our position that another part of the puzzle will be funding for the consumers to better enable them to manage the vagaries of using attendants for their personal care.

- The following recommendation from the Report is critical: to "evaluate the criteria for establishing care levels to ensure that the current

hours of home support provided in the community are sufficient for independent living and flexible enough to accommodate the disabled person's education and employment" (C54). Through our years of experience as advocates, we have heard too many accounts of how limited care hours or limitations on where attendants can work (i.e. only in the home) have a devastating effect on people with disabilities' attempts to carve out an independent life.

8. We urge the Ministry of Health to make the evaluation of home care levels for people with disabilities a priority with a view to supporting the consumer's educational and employment needs (including "volunteer" employment). These care levels will be attached to the person vs. a location, i.e. services must not be restricted to the person's home.

#### Registry of Individuals with Disabilities

"Therefore, the commission recommends that:

...the Ministry of Health...b. develop and maintain a Registry of Individuals with Disabilities through the Vital Statistics Division and the Child and Youth Secretariat, to assist in the development of long range plans and to monitor the changing needs of the population..." (C46).

This recommendation is of great concern to the Coalition and raises the following questions:

- How would this Registry be compiled?
- Would it be voluntary or not?
- If it is voluntary and therefore not comprehensive, will it be of any use?
- If it is involuntary, how can this be justified?
- Who will have access to the Registry and for what purposes?
- What benefit will it be to the disability community?

It is unclear why information from the Health and Limitation Survey of Statistics Canada would not be sufficient for long range planning and monitoring of needs. This data is anonymous and people with disabilities, for good reason, would be wary of a system that denied their privacy in the interests of long term planning or research.

In addition, there are several experienced and reputable disability organizations in this province which could provide data on the changing needs of their members.

**9. We recommend that the Ministry of Health investigate methods for reviewing existing data on people with disabilities rather than creating a government-run Registry of Individuals with Disabilities.**

### **HIV/AIDS**

Along with many AIDS organizations, we were shocked that the Report's AIDS section seemed to disregard much of the research and experience coming out of the AIDS community. We support the criticisms and recommendations made to the Minister by the Vancouver Persons with AIDS Society in their letter of December 16, 1991.

We applaud the Minister's subsequent action to reopen the information-gathering process and rework the AIDS Chapter. This openness, combined with the experience of people with AIDS, will no doubt result in recommendations that will speak to the crucial needs of the public and PWAs.

### **Women with Disabilities**

The experience of women with disabilities in relation to attaining and maintaining health, as well as their interactions with health care systems, are markedly different than the experiences of men with disabilities. Consequently, the Report's general lack of acknowledgement of women's health issues concerns women with disabilities. Service provision that assumes the same health problems for men and women simply will not meet the health needs of women.

Women with disabilities continue to be perceived as asexual in a world that is only beginning to overcome its association of disability with dependance, illness and childish helplessness. These misconceptions contribute to the fact that women with disabilities are at a disproportionately high risk for physical and sexual abuse, inside and outside institutions. Opportunities to report the abuse, to stop it and to receive experienced therapeutic counselling and

supportive recovery are not yet available to women with disabilities (see DAWN Canada report, "Meeting our Needs").

There are many issues unique to women with disabilities; they—and their children—are particularly vulnerable to a variety of health concerns in a system that lags behind in addressing their health needs.

10. We recommend that the Ministry of Health consult with DAWN Canada (as per their report "Meeting our Needs") and women's health organizations to ensure that the health needs of women with disabilities receive equal attention.

### **Conclusion**

We feel that "Closer to Home" has provided a basis for significant improvements to our health care system. However, it contains serious philosophical and practical flaws that must be addressed before plans are made to implement its recommendations. The recommendations we have presented here suggest ways to meet our needs in addition to cutting costs and streamlining systems.

We hope that the Ministry staff and Cabinet will make every effort to ensure that the very considerable efforts made by all parties to date—and in this review process—will not be wasted. The hardest tasks still lie before us: to bring creative and practical ideas to the table, and to persist through the inevitable difficulties until we have the best possible health care system for all British Columbians. •