

Health

New Directions: Disability Communities' Role, One Year Later

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Background

In September of 1993, the BC Coalition of People with Disabilities (BCCPD), in cooperation with BC Association for Community Living and the Canadian Mental Health Association, BC Division, prepared a package called **"New Directions in Health: Disability Communities' Role"**. We intended with this package to provide our members with information on New Directions, what it might mean to people with disabilities, our fears and our hopes, and some suggestions for involvement in this global restructuring of health care in BC.

The BCCPD, and other community groups, had concerns about the New Directions process and substance, but we felt it was in our best interests to participate in whatever ways were open to us. We saw hope in government's acknowledgement that BC health care was in need of reform. We also supported the overall vision and the recommendations of the Royal Commission on Health Care and Costs (often referred to as the Seaton Report) which provided the philosophical framework for moving health care "closer to home." Finally, the health needs of people with disabilities have not been adequately understood or provided for by the present system, so we wanted to be "in on the ground floor" of New Directions.

It is now over a year since the New Directions initiative began and, during this period, we have devoted resources and time to understanding and participating in this process. We have:

- established a BCCPD Health Issues Committee,
- produced a TRANSITION magazine on health concerns,
- attended the Minister's forums on New Directions,
- met with Health Minister Ramsey,
- had numerous meetings with other Ministry of Health staff,
- organized a forum on New Directions in the Vancouver region,
- promoted the representation of BCCPD members on government committees associated with health issues, and
- produced the "New Directions in Health: Disability Communities' Role" package and distributed it to the over 3,000 groups and individuals on our mailing list.

We are better informed because of these efforts and, in this paper, want to share some of our concerns and insights with you.

Where Are We Now?

After the first year of involvement in the New Directions planning, we have reluctantly concluded that our initial concerns about this program were well founded.

The experiences of our staff, volunteers and colleagues indicate that the provincial government has adopted one of the recommendations from the Seaton report—moving health care services “closer to home”—to rationalize the downloading of health care responsibilities from Victoria. Downloading means that the responsibility for health care will be passed on to the local and regional levels while Victoria retains political power and financial control.

In our view, the most important recommendations from the Seaton report have been ignored or adopted in name only—and we have no reason to believe that health care will improve without a change in philosophy. Instead of being driven by the new principles proposed in the Seaton report, the present restructuring seems motivated only by the desire to control spiralling health costs. New Directions may bring services “closer to home”, but if these services are based on the same lack of progressive principles and critiques of effectiveness, why will health care improve or health dollars be better managed?

A devolution of services from Victoria to the regions is not in itself a bad idea. However, Justice Seaton—and the people of BC—never intended that health care restructuring be an end in itself: it was envisioned as a vehicle to carry forward a re-examined, re-prioritized and **re-formed** health care system. Under New Directions restructuring is proceeding without these essential first steps. The changes that we see are dollars-driven vs. consumer-driven. Government is further fragmenting a system that, as Justice Seaton noted, has no guiding vision, no consistent structure and no way to assess itself.

The Seaton report spoke about a better health care system that would:

- look at new ways to develop a health care system that will be progressive,
- focus on health promotion,
- move toward acceptance of alternative therapies and away from reliance on medical monopolies of health dollars, and

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- seriously look at how to make the system responsive to the needs of marginalized people.

But we see little evidence of these goals in the New Directions strategies.

A Comparison of Seaton and New Directions

We should perhaps say here that this provincial government is not obliged to adopt the Royal Commission's recommendations. However, the 300-page report represents a summary and analysis of presentations by hundreds of individuals and groups in this province. While not perfect, the report gives government a unique opportunity to use comprehensive and current information on the state of BC's health care to make substantive changes to the health care system.

A brief look at some key recommendations and comments from the Seaton report will help us to understand how the New Directions plans have strayed from the substance and intent of the Commission report.

First, it is relevant that the Seaton report Summary presents eight key issues for consideration before discussing the movement of health care services to the regions. These eight sections create the springboard from which the following sections address specific areas for change, such as regionalization, rural services, substance abuse, hospitals and services for people with disabilities. These first sections discuss:

- the five principles of medicare and the need to entrench them in legislation to provide a baseline understanding of health care expectations and responsibilities,
- guidelines for development of a better health care system: closer to home; public interest first; community involvement; funding; improving communications within and between Ministries; needed level of education for medical professionals; and, openness of government process,
- the need for health professionals and the public to recognize different roles and responsibilities for health care reform to be possible,
- the need for a Provincial Health Council,
- a call to re-examine the disease vs. health perspective of our health care system, and

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- recommendations for ways to evaluate various health care procedures to see how effective they are.

Taken as a whole, these sections make some basic statements:

- Health care reform depends upon both an entrenchment of medicare's basic principles, and on a commitment to defining our expanding understanding of health and the range of medical and alternative means to achieve it.
- We need to know what works and what doesn't in order to spend health care dollars efficiently.
- The health care system should be driven by the public's health care needs, not the traditional vested interests of health professionals and institutions.
- An independent body is needed to ensure the above principles are upheld.

Provincial Health Council

We believe that one of the most important recommendations of the Seaton report is the establishment of a Provincial Health Council (PHC). This Council was seen as a necessary body to remedy the lack of structure, purpose and accountability of the existing health care system. According to the report, the Council "should be able to oversee the total health care system and be able to review the policies, plans and programs of the Ministry of Health, or any other public or private body whose actions affect the health of British Columbians...It must be completely independent of the government, the Ministry of Health and the health care industry."

The recommendation to form a Provincial Health Council appears in early New Directions literature, but the idea quietly died in the legislature. The New Directions policies and plans are going ahead without a PHC which would have served to:

- focus efforts to define a health care philosophy that reflects the public's broadening understanding of health,
- ensure independent evaluation of plans as they are implemented, and
- develop standards to ensure a common high level of health care throughout the province and to guide the establishment of the Regional Health Boards.

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At the time of writing, the development of the Regional Health Board (RHB) system is well underway and the Boards have no philosophical support (other than the five principles of medicare) to guide the planning and priorities for their regions. According to Planning for Core Services and Standards in British Columbia (November 1993), the Ministry of Health will manage a province-wide information network to assist the Boards and Community Health Councils. But information is not the same as principles; the restructuring we see is not anchored in the principles of reform.

The lack of a PHC is a serious gap in the New Directions strategy and, most likely, not an accidental one. If there is no independent body to establish and monitor a philosophy and standards, the government cannot be accused of not adhering to them.

Core Services and Standards

Two other key components in the reform strategy are core services and standards. Our understanding of these New Directions concepts has been that the Ministry of Health, in consultation with the community, would establish core services and standards which each region would be obliged to provide. These services would then be augmented by particular services or programs identified as priorities in each region.

However, the core process as we have come to understand it over the past year will not provide a baseline of services and standards to ensure equal health care services. In its Planning for Core Services and Standards report, the Ministry of Health states that core services will be defined centrally *and* by the regions. What do core services then mean? We need a clear definition of core services and consensus from British Columbians on what they consider core services.

So far, it appears that the Ministry of Health is hoping to download as much responsibility as possible to the regions. If this happens, different consumer groups, medical institutions and professionals, will be competing for the same dollars—and consumer groups will inevitably lose out. The core guidelines thus far are very vague and show only that “high tech”, institutional services (like dialysis and transplant services) will be centrally managed.

Core services will also be based on existing services as a “starting point” because they “reflect present public priorities for health services”. However, Justice Seaton reported that much of the health care system does

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not reflect public health interests or the range of health options. Rather, it perpetuates medical-model priorities that have developed largely unquestioned over the past decades. We need to incorporate the wealth of ideas and criticisms presented to the Seaton commission on how core services should be developed.

The process of defining which health care services will be considered core has been happening behind closed doors by a committee composed of Ministry of Health staff. The only public input into core services has been the community workshops and a two-page survey in a Ministry booklet. There is also an "advisory" committee established by the Deputy Minister of Health comprised of 35 representatives from different provincial organizations—mostly professionals vs. consumers. Included on the committee are pharmacists, the Association of Caregivers, the Nurses' Union, Health Services Division, Hospital Employees' Union, the dismantled Premiers' Advisory Council for Persons with Disabilities, BC Association for Community Living and BCCPD. Our contacts on this committee tell us that their recommendations and advice to date have not been adopted.

As advocates for change in health care, our priority lies with consumers. We do not wish to be put in the position of threatening jobs (in the way that environmentalists are accused of being insensitive to loggers' jobs). However, as Justice Seaton suggested, we need to re-evaluate how we spend our dollars on health care personnel. The Seaton report found that 97% of the Ministry of Health budget went to institutional care, medical services and Pharmacare. Less than 1.5% was spent on programs such as health promotion, public health nursing, nutrition or speech and hearing programs.

There is also no mechanism by which we can regulate how many doctors or specialists are trained in BC, or how these positions relate to our health care needs. Because the present system analyzes what we need from the top down and can't analyze specifically what works and what doesn't, we just keep pouring dollars into the same medical model system.

The Seaton report concluded that we need to devise mechanisms to evaluate how programs and services affect our health, and we need to spend more on illness prevention. And this evaluation needs strong input from consumers to be meaningful and to help us redefine "core" services.

The definition of core services is perhaps the most significant piece in the New Directions plan. Core services will spell out what each British Columbian can expect in health care services, no matter where they live. Health services for people with disabilities cannot be left to each region; they

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must be centrally defined in consultation with people with disabilities.

We need a process for comprehensive public input into the development of core services. It is not good enough for government to seek only the advice of health care professionals, and to tell the public what has been decided after the fact. In many cases, these professionals simply do not reflect the best interests of the public or broadening definitions of health.

Consumer Involvement

We have also become very disillusioned about the way government views the role of the voluntary sector. Over the past year, we have seen volunteers from BCCPD and many other groups enter the New Directions consultation process in good faith. The benefits of our efforts are much less clear.

It appears that the government equates consumer involvement with the presence of a person with a disability on a committee. This is a start, but real consumer involvement means knowing that consumers are the experts on their own needs, actively soliciting their input, listening to what they have to say and looking at ways to meet the identified needs and shortfalls. To date, we have little indication that the Ministry of Health has grasped the importance and complexity of health issues for people with disabilities.

The language used in New Directions—"closer to home", "democratization of health care", "consumer control"—does not reflect the reality of the process. We think that one of two possibilities is playing out: that the use of this language is only an attempt to distract us from the fiscal downloading that is the real "new direction". Or, that government simply does not know how to create the reality that the language represents.

A case in point is the Disability Framework. Over the past weeks, we've been attempting to find out about this Framework which is one of the 38 priorities mentioned in the New Directions materials and in various meetings with Ministry personnel. In response to our first enquiries, we became aware that, even though BCCPD is listed as the contact group for the Framework, there was no intention to consult with us directly. Previously submitted written materials from BCCPD and the Premier's Advisory Council would be used to define the Framework's priorities. However, we have now learned (in late August) that there is no Disability Framework and that several key disability areas are targetted for investigation and planning. There is no coordinating entity in place, or a process to ensure consumer guidance.

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These latest developments are discouraging. We urge you to work with us to press Ministry officials for answers on how they plan to include people with disabilities' health needs in New Directions.

Conclusion & Suggestions for Action

The restructuring of health care in BC is going ahead, with or without our support. We feel that as community advocates our role has changed: now we must speak out about what is lacking in this process in hope of raising public awareness around these issues. If we can garner public and community support for how we think the New Directions process needs to change, perhaps together we can convince government as well.

We will therefore be advocating for a slowing down of the New Directions reorganization until the following concerns have been addressed.

- **A consultative process to develop guiding principles and standards for health care, and evaluation mechanisms.** Even though the Provincial Health Council was dropped, we can attempt to fill this role ourselves. At every meeting, forum and in the media, bring up the fact that the restructuring is going ahead without a real reform agenda. Push for a public process to define what we want from our health care system.
- **Mobilizing of consumer groups** concerned with health care at local, regional and provincial levels.
- **Public Input into Core Services and Standards.** As it is, people with disabilities' health needs are marginalized. Services need to respond to the needs of consumers and be standardized centrally so we are assured of quality care in any region. We must push for a public process to clearly and comprehensively define basic health care services for the whole province. These must be in place as a fundamental step toward developing regional health formulas.
- **Core committees with strong consumer involvement** to be established on our key issues, as discussed on the Fact Sheets included in this package.

We need to look back to the Seaton report and use its progressive ideas to energize and focus our lobbying. The way New Directions is going, we will have exactly the same health care system we have always had—only the

management will be "closer to home" and government will be less accountable. **Restructuring does not equal reform.**

Without real reform, the deeply rooted assumptions of our health care system will remain unchallenged: health professionals' authority to decide health priorities; the costly emphasis on "curing" disease and high tech solutions vs. health promotion and illness prevention; and, a reluctance to examine the efficacy of alternative health services which could promote health and decrease spending on traditional health services.

The enclosed fact sheets provide summaries of the key areas around which the BCCPD will focus its efforts, as well as contact people for each issue (more fact sheets will be developed in coming months). We hope this paper will be of help to you in your lobbying efforts; please keep us informed of your experiences and progress.