

Health

# "New Directions" in Health: Disability Communities' Role

prepared by  
BC Coalition of People with Disabilities  
204-456 W. Broadway  
Vancouver, BC V5Y 1R3  
(604) 875-0188

Nancy

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## What Does "New Directions" Mean for Me?

As an advocate or a person with a disability, what are your hopes about health care in BC?

- That people with mental illnesses will no longer encounter resistance in neighbourhoods where group homes are proposed?
- That, as a parent of a child with a disability, you will not have to send your child to an institution for care because the Ministry of Health will provide money for you to care for him or her at home?
- That people with a mental handicap will receive the health supports they need to enable them to live in their communities.

If you are concerned about issues like these, you have an opportunity right now to speak out and become involved. As you may know, the Ministry of Health (MOH) has launched a "New Directions" campaign which claims to be a top-to-bottom reorganization of the way health services will be managed and delivered in this province.

The general purpose of these changes is to "decentralize", or spread out, the responsibility for health care from the government to the twenty-one health care regions of BC through Community Health Councils and Regional Health Boards.

**The philosophy and the details of how health dollars will be spent and managed throughout BC are being decided now—and people with disabilities need to be in on these decisions.**

Other documents in this "New Directions: Disability Communities Role" package describe the structure, goals and priorities of the New Directions plan. We hope in this paper to convince you that your participation is essential. Here are a couple of key reasons:

- First, advocates and people with disabilities all over the province have worked hard to raise public and political

awareness about our health concerns. Now, when new plans are being made about how health dollars will be spent, people with disabilities have to make sure that our needs and our recommendations for change stay on the table.

**If we don't participate, our issues could be pushed down the list of priorities.**

- Second, the MOH has adopted new language to describe its concept of "partnerships" in health. For example, the Ministry, in the New Directions documents, discusses the social, environmental and economic contributors to health.

It will be a very positive step if the MOH incorporates this understanding into its philosophy to support broad-based programs and to convince other government ministries and departments to "buy in" to this philosophy.

**However, we fear it is more likely that the MOH has adopted this language to prepare us for cutbacks. The Ministry may be saying, "Health isn't only our responsibility, we shouldn't have to pay for everything."**

The new language used in these documents also emphasizes the importance of *relationships* in health. Again, this acknowledgement is a double-edged sword. Will it mean that government will provide financial and other support to families and friends who provide care for people with disabilities? Or will it mean placing the burden and/or blame upon families and communities to care for people with disabilities whether or not support resources are made available?

**Advocates and people with disabilities need to be involved in the planning stages of these changes. We need to make sure that the MOH does not shirk its responsibilities for health before other governing bodies, organizations and individuals have even begun to consider *their* responsibilities.**

- Third, at a recent meeting with Ministry officials, we were disturbed to learn that the regions may not have much discretion in how they spend their money. This is because the key funding decisions will be made centrally by MOH. These are: the core services that each region must provide, the funding formula for each region (which includes funding for core services and identified regional needs), the fees that the regions must pay to providers and doctors' fee for service.

**We are therefore very concerned that the regions will have little money left after meeting core requirements—money that is supposed to be spent on services that the region has defined as important.**

## Here's the Good News

The New Directions train is in motion and we need to be on it. So, rather than being discouraged, let's look at some of the positive aspects of this situation:

- Whether the reasons are ours or not, the MOH has agreed that the health system needs help. This is a time of change and we can do our best to use this state of transition and openness to our advantage.
- This is an opportunity to challenge the medical model of service delivery for people with disabilities. This model affects everyone, but, perhaps even more so, people with disabilities. We believe that people with disabilities' expectations have expanded and matured in regard to health.

By bringing more holistic, preventative ideas about health to the table, we can have an impact on broadening choices for people with disabilities and, hopefully, elevating our collective quality of life.

- By saying "yes" to this process, we can be in "on the ground floor". Some of the issues being decided are the

funding formula for regional budgets and core services that will be consistent province-wide. If we voice our opinions now, we'll have a better chance of controlling the prioritization and progress of our issues.

- The New Directions process could be an opportunity for the disability communities to discover common goals and to develop a cross-disability lobbying voice on health. We can develop allies and learn from each other's strategies and goals.
- Advocates and people with disabilities who become involved will also be in a position to educate themselves and other people with disabilities on how health dollars are spent. It will be useful, for example, to know how doctors' fee schedules are assessed and reviewed, and what the role is of pharmaceutical companies in Pharmacare policy decisions.

Also, legislation will be changed to ensure that "lay representatives constitute at least one-third of all professional governance bodies." These will be significant vehicles for people with disabilities to broaden our understanding of health care issues and to present our issues.

- This process also offers us an opportunity to stand firm as *advocacy groups* or *special interest groups*. Both terms are being used in a negative way these days. First, people with disabilities are not a small group; eighteen per cent is a significant part of the population. Second, both terms mean that a group of people have come together because a system isn't working. So, by definition, we have a right to challenge the system because our needs and capacities are not being recognized by it. Third, all special interest groups are not created equal and they are different from *vested* interests. We are challenging the system because people's needs and rights are not being met; our "profit" is in people, not in dollars.

## ...And the Bad News...

In addition, to these positive reasons for people with disabilities' involvement, there are, of course some negative ones:

- The effort we have put in to educating the health bureaucracies about disability issues will need to be repeated at the regional levels because priorities will be largely locally defined.
- There are many powerful vested interests operating within the health system. If people with disabilities are not represented in these crucial early days, we can be certain that the interests of other groups and for-profit players will displace ours.
- Members of Community Health Councils will be both appointed and elected. Advocates know from experience that officials appointed by government are often chosen for their proven records of support for the status quo. We must be watchful and realistic about government's commitment to change; our presence is needed on the Councils to challenge the resistance that may well be hidden behind the propaganda of change.
- People with disabilities have fought for innovation and creativity in health services, and for consumer control over them. In the new planning process, all services will be "up for grabs". We need to be involved on the boards and councils to define the services we need and to prevent backsliding into traditional medical-model-only programs and services.
- The MOH is using words like "streamlining" and "removing duplication of services". We are concerned this will translate into the removal of *choice*. Part of the education process around our health needs has been an emphasis on the importance of choice in achieving and maintaining personal health, and also in providing diversity to meet our needs.

If, for example, three different groups have formed in a community to meet housing needs, this may be because each group has different needs. We will need to work from the inside to challenge the "one wheelchair fits all" mentality.

- MOH will define core services and programs that will be funded and given priority in every region. This will be a crucial area for people with disabilities to have input. We want to be part of establishing a minimum level of programs and services for people with disabilities.

To use the group home example again, we want to avoid a situation where a region could bend to community pressure to deny requests for a home by giving its funds elsewhere.

## Conclusion

Much of the language used in the New Directions propaganda reflects a progressive understanding of what health is and how it can be improved and maintained. **However, as advocates, it would be very foolish to believe that these words will in turn be reflected in action if we do not guide the process.**

As advocates, we may feel some cynicism about how systemic changes happen or don't happen. However, the hard truth is that while our participation in this planning process doesn't guarantee we will be heard, our absence pretty much guarantees that we *won't*.

As an advocate or a person with a disability, you need to become involved in the New Directions planning if:

- you want to be part of shaping a health system that redesigns our current medical model concept of health,
- you want to ensure that a "shared responsibility" for health does not mean downloading responsibilities meant for the MOH,

- you want to be part of developing health priorities for your region and your community,
- you believe, as the New Directions material states, that people who have more control over their health become more healthy—and that this ultimately means saving dollars,
- you believe that cutting services to groups like people with disabilities is not the only way to cut health spending, and/or
- you want to hold the government to its promises of consumers consultation, input and control of health in this province.

We need to make government live up to its words. Government has recognized that changes are needed in the health system—let's make sure that they're our changes.

## What Can I Do?

The most important things we can do are to educate ourselves on "New Directions" and to get involved. There are many ways that people with disabilities and advocates can influence what will happen in health care in B.C.

The sheet in this package called, "What Can I Do?", will give you some concrete suggestions. These suggestions are being used now by people with disabilities around the province. Read it and share the information with your friends and colleagues. ≈



## What Can I Do?

It's important not to become discouraged and to remember that we *can* affect the health care we receive in BC. This sheet is an "Action Plan" that provides some concrete suggestions on how to get information, to share it and to take action based on your priorities. Overall, you and/or your group will need to:

- define your issues around disability and community-based health care, and
- set priorities and make recommendations to address changing health care needs.

You may also want to:

- develop a *regional* consumer strategy to address the concerns of people with disabilities, and
- explore potential partnerships and creative approaches to health care reform.

## *One Step at a Time*

- Contact the New Directions line at the Ministry of Health and ask to receive all New Directions documents and to be on their mailing list. **Call 1-356-6500.**
  - **Request funding to put on a workshop** for people with disabilities and groups in your community. Some communities have already received funding from their local steering committee, the Ministry of Social Services and/or local governments. If you plan a workshop, don't forget to ask businesses for in-kind donations such as pens, booklets or snacks to help keep expenses down.
  - **Become informed.** Attend community meetings, workshops, public forums, seminars and conferences on the New Directions plans. Provide input and advocate for the changes you believe are necessary.
  - **Define your issues.** Develop your own vision of community-based health care. Where are the gaps in service provision? How can the needs of people with disabilities best be addressed? Who needs to have this information and how should it be delivered?
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## New Directions/Health Reform: Some Background

In February 1993, the Ministry of Health announced its plan to reform health care in British Columbia. "New Directions", as this plan is called, starts with a broad definition of health which recognizes that adequate income, secure housing, employment opportunities and social support all affect people's health. New Directions focuses on bringing health care and decision-making about how health dollars are spent closer to the community.

In order to give people more say in how health dollars are spent, the Ministry is developing Community Health Councils and Regional Health Boards throughout the province. There are twenty-one regions which will each have a Regional Health Board. These regions have then been organized into 6 larger regions: Vancouver, Burnaby/Richmond/North Shore, North, Vancouver Island/Coast, Thompson/Okanagan/Kootenay, and Fraser Valley.

### Community Health Councils

Community Health Councils will make decisions about how local health dollars are spent. For the start-up phase of New Directions, the Minister will appoint Council members (the start-up phase is usually referred to as a two or three-year period). After this time, one-third of the council will be elected by the community, one-third will be chosen by the Minister of Health and one-third will be chosen from elected bodies, such as the school board or municipal councils.

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## Regional Health Boards

Because some health services are provided regionally rather than locally, Regional Health Boards will be set up to direct how regional health dollars are spent and how local health dollars are distributed. Members of these boards will include representatives from Community Health Councils, as well as people appointed by the Minister of Health.

## Ministry of Health

The Ministry of Health will still identify services that must be provided (core services) and standards which must be met by each Community Health Council and Regional Health Board.

## What is Happening Now

The Ministry of Health hopes to have these councils and boards up and running by 1996. In order to do this, the Minister has named six Regional Executive Directors to help communities start this process (the Directors' names and numbers are listed on the "Structures and Functions" sheet).

Interim Planning Groups (sometimes called Steering Committees) are now being set up in communities across B.C. These groups are beginning to develop local health plans which will set out how New Directions will work in each community. ≈

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## Structures and Functions

### Ministry of Health

#### Role

- establish a Provincial Health Council
- define core services and standards
- allocate \$ to Regional Health Boards
- plan and fund tertiary care services
- appoint members of the Community Health Councils (see box below)

### Regional Health Boards

#### Structure

- 21 regions in B.C. (existing health unit boundaries)
- representatives from Community Health Councils and Ministry of Health appointees
- Ministry of Health is developing guidelines for membership and structure

#### Role:

- take on the roles of the Regional Hospital Districts and the Union Boards of Health
- regional health planning and service coordination
- eventually allocate regional health budgets
- may vary from board to board

### Community Health Councils

#### Structure

- members of Community Health Councils will be appointed by the Ministry of Health until 1996; after this time:
- 1/3 elected by the public; 1/3 appointed by the Ministry of Health; 1/3 appointed from elected bodies (ie: school boards, municipal councils)

#### Role:

- plan and coordinate local health services
  - eventually manage services and allocate health resources within the community
  - may vary from council to council
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## Process Underway

### Interim Planning Group or Steering Committee

#### Structure

- interested individuals, health care providers and local government officials
- focus on including people who are often not included in this type of planning (e.g. people with disabilities)
- focus away from single issue lobby groups

#### Role:

- develop a community health plan outlining how people will be chosen for health councils and boards, how the council should get input from the community (governance issues) and how health services will be managed, and coordinated in the community

### Regional Executive Directors

#### Structure

- six executive directors assigned 4-5 regions each (list of names and numbers below)

#### Role:

- let people know about the changes taking place and help communities develop Interim Planning Groups, Community Health Councils and Regional Health Boards
- money available for: community development and skill training; community forums; planning; development of alternative ways of delivering health services; and, start-up costs

### Regional Executive Directors • Contact Numbers

Vancouver	Sharon Martin	775-1866
Burnaby/Richmond/North Shore	Karen Abramson	775-1866
North	Ron Crawford	565-4338
Vancouver Island/Coast	Paul Becklake	755-2377
Thompson/Okanagan/Kootenay	Gary Olsen	492-1432
Fraser Valley	Pat Wolszuk	660-0155

# What's Happening in the Regions (as of September 1/93; compiled by the BC Nurses Union )