Health

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# <u>Health Platform for People with Disabilities</u>

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# Introduction

This package is intended to provide disability advocates with an outline of how the BC Coalition of People with Disabilities (BCCPD) plans to continue its advocacy around health care reform in BC. The New Directions restructuring, which has now been underway for about three years, has been a series of frustrations and few successes. The BCCPD, and other community groups, have been participating, observing and constantly re-evaluating how best to use our energy and resources.

For community health advocates, the process has often been difficult, as we try to remain true to our vision in the face of unclear and sometimes contradictory messages from the Ministry of Health. Real recognition of consumer input has yet to emerge and we have sometimes felt unsure of our role in the reform process.

A recent example of this is the provincial government's proclamation of Bill 54—An Act to Preserve Medicare. The most critical section of the legislation, which would have given the government more than rhetorical power to protect medicare, was omitted. This section would have enabled government to regulate the billing activities of private clinics delivering health services. The removal of this section completely undermines the intent and effectiveness of the legislation, and was made without prior consultation with community health advocates. Another example is the decision to "cluster" rehabilitation services in BC with acute care. This major decision was made without consultation and before the government's own province-wide tour on rehabilitation had issued its report. The disability community was also consulted after the fact concerning the Ministry of Health's "Health Policy Framework for People with Disabilities".

We have therefore decided to step back and define our own process, and to share that process with other concerned groups and communities. We hope that by doing so we can strengthen one another and, collectively, begin to infuse health care restructuring with community-based ideas and priorities.

Through the months to come, we hope to build a two-way relationship with groups and communities who are involved in health care reform. The following sections provide an outline of how we feel we should proceed, and how we can best pool our resources and strengths.

# **Guiding Principles**

We have come to see that our goals of health reform cannot be realized within the current framework and philosophy which continue to be built around a medical-model, top-down approach. In order for health care reform to move beyond mere reorganization, we will be recommending and raising the importance of guiding principles at each opportunity. We believe that principles, along the following lines, need to be introduced into the reform discussions:

- Consumer-driven reform
- Consumer choice
- Accessibility
- Partnerships
- Public process and accountability

### Consumer-driven Reform

Consumers of health care services must become full partners in defining health care needs. Consumer advisory groups need a legitimized role and real power in policy and program development, implementation and evaluation.

The problems within the present health care system stem primarily from the entrenchment of the medical model, including a reliance on the opinion of "experts"—and all indications are that this model is still driving (and limiting) the health reform process. Health care consumers—the people who live with the consequences of health care decisions—are the real experts and we need to be involved in all aspects of health reform.

There is a thread running through much of the New Directions materials which goes something like this: "We agree that we need to change the system, but you have to remember that there are only so many dollars, so we can't meet every need." This rationale is used to justify service reductions, such as the recent cutbacks on home support hours for some of the most vulnerable people in the system. While we can agree that health care dollars are not a bottomless well, we can disagree on what is draining the well and how best to use the dollars we do have.

Many health dollars are misspent because services and programs are not necessarily what consumers need. For example, "high-tech" health care solutions continue to be favoured

over grass roots illness prevention and education programs, and consumers are limited in the kinds of health care they can pursue, even if they clearly benefit by non-sanctioned forms of therapy.

Cost-effective services and programs can be developed that meet consumer needs, and empower people to take control over their health. We are looking to be full partners in the development of a new health care system, rather than "advisors" who are consulted after health needs and priorities are defined by service providers and medical professionals.

## Consumer Choice

Consumers need information to make informed choices around health care—and alternatives need to be available. We need a health care system that is structured to meet the needs of people, rather than the present situation in which the system defines "legitimate" needs.

# Accessibility

All health care consumers have the right to access quality health care services, including alternative therapies. Disability, age, income level, geographic location or ethnocultural factors do not alter this right.

## Partnerships

The health care system needs to move from a "doing for" to a "doing with" philosophy. Consumers from many sectors of our communities are becoming educated and involved in social change, and health care is no exception. To take advantage of this wealth of experience and expertise, governments and health care professionals need to be encouraged to challenge their assumption that "they know best" and that solutions can be reached in isolation from consumers. Working in true partnership with all members of our community will help us to create a health care system that meets everyone's needs.

# Public Process and Accountability

In order to ensure ongoing evaluation of health care reforms, all levels of the process need to be out in the open and accessible to public scrutiny. An independent provincial body, with representation from consumers and advocacy organizations, is

needed to establish standards and monitor health care services. It is also crucial that an appeal body be established.

# Action Plan

The BCCPD has outlined an action plan in order to build and sustain a health care reform strategy that will meet the needs of the disability communities. We need to define our own needs, goals and strategies, rather than compromising them to fit into the New Directions frameworks.

In some areas, we know where we need to go and how. In others, we are proposing ways to gather more information and to stimulate an ad hoc network of community health advocates to provide an ongoing voice in the reform process. A summary of our proposed action plan follows.

# Community Development Workshops

The BCCPD is seeking funding to hold community workshops. We want to meet with community health activists to coordinate our ideas, roles and plans, and to develop strategies. We also want to learn what consumers see as the health priorities in their regions. In this way, we can broaden our understanding of both the regional and global health needs of people with disabilities. We are concerned that the discussions thus far about "core services" have not addressed the essential health needs of our communities.

We will use this package, and other materials that may be developed, to focus discussion at the workshops. Through these workshops, we will let consumers in the regions know what we've learned about how New Directions is unfolding, share our advocacy skills and strategies, and support consumers as they gain the skills necessary to negotiate with the system for themselves.

Consumers in the Cowichan Valley have developed a grass roots model which we plan to follow. Specifically, the regional workshops will assist people with disabilities as they:

- determine health issues and priorities,
- develop a strategic plan to make recommendations and implement priorities,

- assist the Community Health Councils and Regional Health Boards with their job of identifying and prioritizing the regional needs of people with disabilities.
- create linkages across communities on common goals, and
- form ad hoc committees to provide ongoing evaluation of progress on the identified goals.

## Our Role as a Resource

With packages like this one, the BCCPD will continue to keep in touch with those interested in health care reform. We will also use Transition magazine as a vehicle to keep you up-to-date on our concerns and strategies. In addition, we will facilitate meetings with interested groups to maintain a unified vision and approach.

# Reclaiming Our Language

We have found that many of the public servants working on New Directions use terms developed by the community in ways that misrepresent their meaning. We believe that health advocates need to reclaim the true meaning of these terms and to "raise a red flag" when proposals don't reflect that meaning. For our own purposes, we have therefore adopted the glossary provided at the back of this paper.

# Conclusion

This package is intended to provide information and assistance to other groups lobbying around health care issues. Please feel free to reprint these materials and to use them in any way that will support your lobbying in your own regions. More copies can also be obtained by contacting the BCCPD office.

Also, if you support our position and the strategies we suggest, a letter of endorsement would be helpful to us in our future lobbying at the provincial level. Please direct any correspondence or inquiries to May Ng at the BCCPD.

# Glossary of terms

**Access**: The freedom and ability to enter, approach, communicate with or pass into and out of physical surroundings, programs and services.

**Community**: The space in which citizens associate in their own individual and collectives interests.

**Community development**: The deliberate attempt by community people to work together to guide the future of their communities and the development of techniques that help people in such a process.

**Consumer**: A person with any kind of disability who is the one most affected by a particular service.

**Consumer-controlled**: Consumers manage and direct their own services.

**Consumer-determined:** Consumers decide what they want, when they want it and how they want it.

**Consumer-focused**: The needs of consumers are the primary concern, in contrast to the needs of service providers, for example.

**Consultation**: A process for change that understands and respects the need for stakeholders' input on issues that concern them.

**Empowerment:** A process of change in which power and information are shared so that individuals gain more and more control over their own lives.

**Expert**: A person who is recognized for having experience and knowledge in a certain area. Health care consumers are the experts about their own experiences, needs and abilities.

**Medical model**: A hierarchical way of looking at health which emphasizes elite professional expertise, disease and medical intervention, such as drugs and surgery.

Partnership: A relationship which requires the sharing of power, work, support and information with others.

**Power:** The capacity of a person or group to produce intended, foreseen and unforeseen effects on others.

**Self-help model**: In relation to health, the self-help model emphasizes individuals' right and ability to determine their level of health. This model recognizes how control and choice improve a person's well-being and health.

**Service-provider**: A person or organization that provides a service.

**Stakeholders**: Individuals or groups who are affected by a certain issue or process.

# Acknowledgements

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# HEALT FACT



For more information on this fact sheet, please contact Geoff McMurchy at BC Coalition of People with Disabilities: (604) 875-0188 fax 875-9227

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# HIV/AIDS

Since 1994, a meaningful process of community consultation, conducted by a representative of the Premier's Office for Public Issues and Consultation, has been dealing with AIDS issues in BC. In Phase one the focus was funding priorities, responsibilities and commitments. In Phase two the focus is a strategic plan to guide provincial efforts in the years 1996 through 1999. The BCCPD fully supports this important process, because it's only with the insight of those infected and affected that we as a society can respond to the challenge of AIDS.

Important issues remain to be dealt with through the strategic planning process. Some of these are:

### **Funding**

Short-term project funding has several drawbacks for organizations, a few of which are: creating expectations in the community which may not be fulfilled later; being at the mercy of restraint and changing government priorities for funding; stress and insecurity at fiscal year-end; high staff turnover and the retraining and supervision of new staff that this entails; and the concentration of thought and effort on developing short - term proposals rather than broader long-term planning.

Established groups with ongoing programs should have access to core funding on a multi-year basis. This will necessitate reaching some agreements on a percentage split between project and core funding within the overall government budget, as well as what evaluation checkpoints would be appropriate for longer-term contracts.

### Communication

We support the re-institution of a provincial AIDS network, with government representatives from various ministries. Through pacific region members of the Canadian AIDS Society, there is currently movement toward re-establishing a network. It would provide a crucial forum for communication, mutual support and collective action for HIV issues in BC. The BCCPD supports an open structure and membership in such a network, although funding support will need to be established and channeled through an accountable organization.

### **New Directions**

At this time, AIDS services **must** be considered "core services", and not subject to provincial guidelines with regional implementation. It is only recently that the provincial Health Ministry has taken an open strategy to legitimize the role of AIDS programs and community partnerships. It would be unfair to expect community groups to take on the task of educating regional health boards.

### **Poverty**

The BCCPD has been arguing for almost two decades that **poverty is the main determinant of health**. The correctness of our argument has been acknowledged, however practical solutions are usually at a "band-aid" level. The current provincial administration has failed to develop fiscal policy that would allow the development of strategies to address poverty. In fact, what we have seen in the past year is a mass of MSS policies which actually reduce supports to those already living well below the poverty line.

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### **Rural** Issues

There is a need for informed medical assistance and support where people live. Travel can be detrimental to the health of PWAs, yet they are forced, by lack of access to treatments and trials, either to move or commute.

### The BCCPD continues to advocate strongly for:

- the development and implementation of a provincial AIDS strategy containing commitments in the areas of funding and time-lines,
- funding support for community-based AIDS groups and other stakeholders throughout BC to communicate on a regular basis,
- ensuring that the provincial strategy includes ongoing mechanisms for development and distribution of HIV/AIDS prevention education programs and materials for people with disabilities,
- promoting partnerships between HIV/AIDS and disability organizations,
- having the provincial Ministries of Health, Education, Social Services, Housing and the Attorney General commit to sharing responsibility for responding to the AIDS crisis,
- recognition, across the board, of the care and support needs of individuals living with HIV and AIDS,
- recognition of emerging issues around multi-diagnosis (HIV infection/AIDS with other disabilities and/or substance abuse), and
- support to needle exchange programs from alcohol and drug programs, and not solely from AIDS funding.

# HEALT FACE SAGE



For more information on this fact sheet, please contact Ronnie Phipps at BC Coalition of People with Disabilities: (604) 875-0188 fax 875-9227 TTY 875-8835.

# Respite

For informal caregivers (usually family and friends) who work in the home, respite from their caregiving duties is essential to ensure ongoing quality care for the person with a disability and well-being of the caregiver.

The Seaton Report and New Directions have both recognized the huge role played by informal caregivers—in financial terms and in the quality of life for people with disabilities who depend on this care. We plan to use this recognition to advocate for a flexible range of respite services that:

- ensure the development of a consistent, coordinated approach to primary, unpaid caregiver support,
- increase awareness of primary, unpaid caregivers' needs among caregivers themselves and within the medical community, and
- ensure consumer-driven, quality respite services.

Here are some specific areas which are of concern to our members and which must be part of the problem-solving around respite care:

- There are 152,000 unpaid caregivers in BC, three-quarters of whom are women. It is very important that moving health care "closer to home" does not mean further increasing women's share of home and family care.
- The number of acute care beds is being gradually decreased. The dollars "saved"
  through this reduction must be redirected into community supports, including
  respite. Along with financial support, caregiving families need comprehensive and
  flexible respite support options, from in-home respite, to day care, to intermediate
  and extended care facilities.
- We feel that respite services must be part of the core services formula for home care to be an effective and caring health care option for people with disabilities.
- Continuity of respite service personnel is needed. At present, union rules and regulations (regarding seniority) are taking precedence over consumers' needs. Frequent staff turnover means that consumers must train a succession of new personnel which takes valuable energy, puts recipients at greater risk and makes the development of ongoing, caring relationships difficult.
- Emergency respite services are not available in many communities. Acute care beds are therefore being used for this purpose. This is a costly and inappropriate option for caregivers and recipients.
- Caregivers must have more control over the decisions made around respite care. At
  this time, these decisions are made almost exclusively by the Extended/Continuing
  Care Assessor. In-home care must also be the choice of those concerned. People
  should not be forced to care for family or friends at home if they don't choose to.
  This can create fertile ground for family breakdown and/or abuse.

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### (Respite, cont'd)

- There are serious financial problems around home care and respite. Informal caregivers are not paid. Family poverty becomes a reality for many people due to lost income (often of the caregiver and the person with a disability) and the increasing costs of maintaining recipients at home. In addition, caregivers are not compensated for lost employment earnings or for the services they provide, e.g., there are no early pension benefits or accumulation of pension credits, and the spouse is not given attendant status for federal income tax credit.
- A centralized, accessible information source on respite options is needed throughout the province.

# HORITA FACE SINGE



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### Women

For women, with and without disabilities, the largest obstacle to receiving proper health care is the lack of attention to women's health issues. Recognition within the health establishment of the unique and pressing health needs of women has been slow to unfold-and, even more so, the health concerns of women with disabilities. Two Royal Commissions which women hoped would provide that recognition were disappointing. The Commissions on Health Care and Costs, and New Reproductive Technologies reflected the shallow understanding of women's health issues and the continuing reluctance to allow women to define their own health needs.

Some issues that are of ongoing and deep concern to women with disabilities are:

- Women with disabilities seeking health care too often experience "emotionalization" of their concerns. Health care professionals can presume that the disability itself is psychosomatic or pursue a psychological treatment rather than investigating physical complaints. Women with disabilities feel that the expectations for their health, by many medical professionals, are low and that they are treated accordingly.
- Women with disabilities are often still perceived to be asexual, so information on sexuality and sexual health is scarce. These women are at risk for abuse, sexually transmitted diseases and unwanted pregnancies. Women have also reported that they receive sporadic basic medical care, such as pelvic exams and STD screening, because of limitations like inaccessible examination tables.
- The extent of sexual, emotional and physical abuse of women with disabilities is
  gradually being uncovered. A recent DAWN Canada survey showed that women with
  disabilities are among the most poor and isolated people in our communities. The
  physical and mental health of these women is at risk-including a disturbingly high
  rate of attempted suicides. Along with expanding existing services to support women
  with disabilities in recovery from abuse, education for women and for service providers is sorely needed on abuse prevention.
- New Reproductive Technologies (NRTs) are an area of great concern for women's
  health advocates. These expensive technologies are proliferating very quickly with
  little regulation, evaluation of their effectiveness or, most importantly, scrutiny of
  their ethical premises. The bio-medical industries present NRTs as a vehicle to offer
  women reproductive choices. These choices include detection of fetuses with disabilities, sex selection, in vitro fertilization of post-menopausal women, and exploitation of coloured women around surrogacy.

These technologies divert attention (and funds) from the need to understand disabiling environmental factors, the lack of support that parents of children with disabilities will face, and the host of other issues that these "choices" imply. Also, women with disabilities who are pregnant or contemplating having children continue to be subject to subtle and overt pressures around their choices. Women are in dire need of community-based information on their reproductive rights, and the personal and social implications of the "choices" offered by NRTs.

 Women with disabilities who are marginalized, in inner cities or rural areas, have expressed the need for mobile health units to provide health services and information, such as breast examinations and sexual health materials.



For more information on this fact sheet, please contact Sam Rizvi at BC Coalition of People with Disabilities: (604) 875-0188 fax 875-9227

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### Rehabilitation

People who use the rehabilitation system are among the most vulnerable because they have acquired a disability or condition that changes their lives. Ideally, the rehabilitation system is the bridge that takes people with a disability into a new life, but in fact it is too often an obstacle in itself and does not offer the education, understanding or support that people need.

The following aspects of the rehabilitation system are in need of development and change:

- Redirection of dollars from medical-model priorities. It is a reality that the health care system still leans heavily toward the medical model approach to health and rehabilitation. Much of the rehabilitation budget therefore is prioritized to acute care, at the expense of comprehensive rehabilitation programs and maintenance therapies. The recent clustering of rehabilitation services with acute care will worsen the situation. Also, people with disabilities who find alternative therapies, such as acupuncture, helpful in rehabilitation have limited or no financial support in pursuing these health options.
- Education of clients and service providers. People who use rehabilitation services need
  more and better information on the realities of their condition or disability. The present
  system does not make this a priority, so clients do not know enough about what
  changes they can expect or what the optimal possibilities for rehabilitation are. Service
  providers also need more comprehensive training in the broader sense of "rehabilitation", rather than only the medical treatment of a condition or disability.
- Integration and coordination of services. Services within the rehabilitation system are splintered among different departments, within government and the community. The person using the system therefore encounters different policies, approaches and goals in rehabilitation.
- Limited resources. Because of funding limitations, clients of rehabilitation services do
  not have access to the best possible range or duration of services. This is, in part,
  because of a narrow definition of rehabilitation which recognizes only a certain level of
  remedial therapy or treatment. Ongoing rehabilitation, which in many cases is needed to
  maintain the best possible level of health after initial rehabilitation, is often difficult for
  people with disabilities to access. There is also a two-tiered system where people who
  come to the rehabilitation system through ICBC or WCB have access to more funds and
  services for a better quality of care.
- Limited vocational training. Again, because of the health system's medical-model focus, people in the rehabilitation system have limited vocational training options. More funding and flexibility is needed to allow broader choices for people with disabilities who need vocational training.
- Lack of transition planning. The transition that people encounter when moving from an acute care or rehabilitation setting to the community is a very sensitive one that is not adequately provided for. It should be the responsibility of the discharging facility to provide clients with the information they will need to find ongoing rehabilitation services in their community. In many cases, clients are discharged only to find that the services they need are not available, or are overloaded, in their community. Because of cutbacks in health care, hospital stays are becoming shorter and people can be discharged without the necessary community supports being in place.

# Health Fact Short



For more information on this fact sheet, please contact Robin Loxton at BC Coalition of People with Disabilities: (604) 875-0188 fax 875-9227

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## Mental Health Act

A few years ago, a full re-evaluation of the Mental Health Act was undertaken with input from all sectors of the community and government. The changes recommended by the community have not been implemented and fundamental changes to the Mental Health Act are still needed.

Now, with new guardianship legislation on its way to becoming law, an improved Mental Health Act is even more important. One of the basic premises of the new guardianship legislation is that every individual, including people with disabilities who often have decisions made for them, has the right to exercise as much choice over their life decisions as possible. The legislation assumes decision-making capability for everyone and describes clear guidelines that must be followed before that capability can be guestioned or superceded.

However, this new legislation can be overridden by the Mental Health Act. For a person with a mental illness who is involuntarily admitted to an institution, the guardianship legislation will not apply. This is an unacceptable situation and we will be advocating for immediate changes to the Mental Health Act to bring it into harmony with the progressive guardianship legislation.

We need a Mental Health Act that will:

- establish a philosophy that promotes voluntary admission and treatment, instead of involuntary admission,
- state society's responsibility to persons with mental illness,
- ensure that there are objective and observable criteria for involuntary admission and detention,
- clearly state the equal rights under the Charter of all people, including people with a mental illness,
- enforce the least restrictive and least intrusive treatment methods,
- ensure patients' rights as per the Riverview Hospital Charter of Patients' Rights, and
- ensure that patients have access to independent review of treatment.



For more information on this fact sheet, please contact Mary Williams at BC Coalition of People with Disabilities: (604) 875-0188 fax 875-9227

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# Patients' Charter of Rights

One of the ways we can try to ensure the best possible health care in BC is to give users of the system as much information as possible. Along with information about health services or procedures, people need to know their health care rights.

We will therefore be proposing that a Patients' Charter of Rights be adopted and circulated broadly to the public through hospitals, doctors' offices, pharmacies and other public health facilities. Other groups in BC have seen the need for developing a patients' rights model. Most recently, in early 1994, the Patient Empowerment Society was successful in having Riverview Hospital adopt a Charter of Patients' Rights.

A provincial Patients' Charter of Rights will let the public know that they are not passive recipients of health care-that they can and should exercise their own choices to be as healthy as possible.

The proposed Patients' Charter of Rights would state that each health care client in BC has the right to:

- Know their rights as a patient prior to any medical treatment.
- Be treated with dignity and respect.
- Appeal health care decisions through a patients' advocate and/or bio-ethics committee.
- Good care without harassment, abuse or threats of abuse.
- Choose their own doctor or to get a second opinion.
- The best possible standard of care.
- Full information on their illness/condition in language they can understand.
- Know the risks, benefits and side effects of any treatment.
- Know the names and qualifications of anyone treating them.
- Refuse treatment, assuming there is no public health risk.
- Have their medical files confidential and the right to see any medical records pertaining to them.
- An interpreter when needed.
- All protections under the Canadian Charter of Rights and Freedoms regardless of place of residence or disability.

# HEDIT FACT STORY



For more information on this fact sheet, please contact Mary Williams at BC Coalition of People with Disabilities: (604) 875-0188 fax 875-9227 TTY 875-8835.

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# Continuing Care

As more and more people with disabilities have moved into the community, inadequacies within the Continuing Care Act have become more apparent. The Act does not reflect the disability communities' growing expectations for autonomy and independence in how they live their lives. The regulations governing continuing care are inflexible and often seem designed to offer only a bare minimum of service rather than a level of service that would support an independent, healthy lifestyle. Recent policy changes that have cut back housekeeping services for people with disabilities support this assessment.

Since the Continuing Care Act governs home support, it can effectively limit people with disabilities' choices and health. We therefore will be working toward changes in the following areas:

- The Act needs a guiding principle stating that the main objective of continuing care is to facilitate the highest degree of autonomy and independence for recipients in accordance with their wishes. This principle will guide the development of a consumer control continuum where a client can have the degree of control that they want over their services: individuals will be able to choose to manage none, some or all of their services. Different levels of direct funding will be a part of this self-management structure.
- The Act should also state that community living is a right for people with disabilities. At present, a person who has a disability and requires a high level of care usually has a struggle on their hands if they want to live in the community. It is assumed that a certain level of support would best be handled in an institutional setting. We want to see a shift in this philosophy and an elimination of the maximum support hours allocated for in-home care.
- The Act must also spell out a minimum standard and level of service, and eliminate the duty and scheduling restrictions for homemakers.
- An appeal mechanism must be built into the Continuing Care Act.
- Fair wages are needed for homemakers to ensure quality care for people with disabilities.
- The separation of intermediate care and extended care facilities creates difficulties for people living in these facilities. People whose condition improves or deteriorates from one care level to another must usually move to another facility, away from the relationships and support they have developed. Incentives and simplified funding formulas are needed to encourage the development of multi-level care facilities.
- Extended care units that are presently administered by the Hospital Programs Division should be moved under the Continuing Care Division so all long term care services will be managed by one entity.
- The Continuing Care Division needs to ensure uniform formulas for staffing, bed planning and quality assurance programs for all long term care facilities.



For more information on this fact sheet, please contact Mary Williams at BC Coalition of People with Disabilities: (604) 875-0188 fax 875-9227 TTY 875-8835.

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# Direct Funding

A sense of ownership and control over one's own life has been shown to be a key component in health status. Disability advocates know very well how consumers of home support services are subject to a range of arbitrary regulations that limit the control they have over their own services. Many advocates are lobbying for a flexible system that puts the control of health care dollars in the hands of consumers. A direct funding option for home support will empower individuals and build accountability into the system, without any additional costs.

At this time, there are isolated services or pilot projects that operate on a direct funding basis. Direct funding simply means that service dollars from support programs go directly to the consumer, based on an evaluation of need, and the consumer then chooses how and where they want to spend those health care dollars. We don't recommend direct funding as a mandatory service, but one option on a continuum of service options available to all people with disabilities.

Some consumers in BC have designed and implemented a training program for people with disabilities interested in participating in a direct funding project—with excellent results. The **Choice in Supports for Independent Living (CSIL)** demonstration project, implemented by the Community Support Branch of the Continuing Care Division, completed its pilot year in April 1995.

As employers, the participants were responsible for selecting, training and paying home support staff, as well as all bookkeeping and recordkeeping. Of the 106 consumers who participated, 104 remained on the program for the full year (one person died and another was terminated). The six-month interim report showed that the participants were enthusiastic about the program. They enjoyed having control over their own supports, the majority felt they were receiving better care than they were under the traditional system, and all hoped that the program would be continued beyond the one-year pilot period.

Continuing Care has agreed to renew contracts for one year with the participants who wish to continue. After that time, home care services will be under the direction of the Regional Health Boards.

The Advisory Committee set up in 1993 to guide development of the project needs to have an ongoing role as the transition of services to the regions unfolds. CSIL has provided an excellent model, right here at home, for how well direct funding can work. Consumers and advocates need to build on this momentum and work toward a system-wide direct funding option for home support. The Advisory Committee will also be needed to explore other options and levels of service delivery, like client support groups and brokerage models.