Involving Consumers with Disabilities in Nova Scotia’s Reformed Health System

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This paper describes our recent efforts to maximize the involvement of consumers with disabilities in Nova Scotia’s reformed health system. A series of Town Hall meetings were held across Nova Scotia with the aim of a) educating consumers with disabilities about changes to the health system, b) soliciting their thoughts and concerns about the proposed changes to the health system, c) determining individuals’ interest in participating on health boards, and d) providing feedback to the Department of Health on the concerns raised by consumers with disabilities. The majority of issues raised by consumers concerned threats to the availability of services and programs, and accessibility. In addressing solutions to these concerns, participants emphasized the need for individuals with disabilities to be represented on health boards, the importance of organization and networking among individuals with disabilities, the need for accessible transportation, as well as accessible information about changes to the health system. Respondents indicated that transportation and accessibility were the two primary barriers to their participation on health boards. Strategies for overcoming barriers to the involvement of consumers with disabilities in Nova Scotia’s reformed health system are discussed.

Key Words: Consumer involvement, health reform, disability, CBR

As in many other Canadian provinces, Nova Scotia has been taking steps to maximize consumer involvement in its health care system. The main feature of Nova Scotia’s reformed health system is a move away from a centralized health care system to a devolved regionalized system, where Regional Health Boards (RHBs) and Community Health Boards (CHBs) have administrative and budgetary control over primary and secondary health services. Consumer involvement is achieved through equal representation on CHBs and majority representation on RHBs. This paper describes some of our recent efforts to maximize the involvement of consumers with disabilities in Nova Scotia’s reformed health system.

Regionalization and consumer involvement are expected to foster and strengthen the development of a community-based model of health service delivery. In Nova Scotia’s reformed health system, primary health care services such as health education and promotion, illness prevention and rehabilitation will be coordinated at the community level. Regionalization will offer individuals within communities the opportunity to play a more significant role in meeting the health and rehabilitation needs of their constituent members. Community involvement in health policy is not seen simply as a strategy for community empowerment, but also proceeds from the view that individuals within communities will be better able than centralized organizations to assess the health and rehabilitation needs of their constituent members, and will likely hold greater investment in ensuring that health and rehabilitation programs are implemented and maintained.

At least in principle, the goals of a community-based model of health care are consistent with the philosophy of community-based rehabilitation (CBR) (Helander, Mendis, Nelson & Goerdt, 1989). According to Helander and colleagues (1989), CBR consists of a host of strategies that aim to enhance the quality of life of individuals with disabilities. These programs or strategies should involve maximal community participation, they should integrate all relevant domains of society (e.g., education health, policy making), and they should develop health and rehabilitation resources at the community level.

As will be discussed below, Nova Scotia’s reformed health system clearly aims to integrate relevant domains of society in maintaining healthy communities and intends to develop health and rehabilitation resources at the
community level. Our main goal in initiating the current project was to ensure that consumers with disabilities were included in this process; in other words, that individuals with disabilities were an integral component of the reformed health system.

Why Involve Consumers with Disabilities?

In the Manual on the Equalization of Opportunities for Disabled Persons, the United Nations Secretariat put forth a set of guidelines to assist governments in developing programs to equalize opportunities and promote full participation of persons with disabilities at all levels of social life (WHO, 1984). Canada was responsive to the call for equalization of opportunities for individuals with disabilities. During the Decade of Disabled Persons (1983-1992), the Federal Government undertook a number of initiatives to facilitate the full participation of individuals with disabilities in mainstream society (Government of Canada, 1991; Social Sciences and Research Council of Canada, 1993). Through these initiatives, it has become increasingly clear that the needs of individuals with disabilities will most likely be addressed if individuals with disabilities play a significant role in policy planning and program development (Francis, Lascelles, Cappon, & Ware, 1993; Secretary of State, 1994).

Consumer involvement has become a central theme in the health reform efforts of several provinces, most notably Alberta, Ontario, Quebec, and Saskatchewan (Charles & DeMaio, 1992; Eyles, 1993; Government of Quebec, 1990; Premier's Commission on the Future of Health Care for Albertans; Rachlis & Kushner, 1989, 1994; Report of the Ontario Health Review Panel, 1987; Saskatchewan Commission on Directions in Health Care, 1990). Over the past five years, consumer involvement has also become a central theme of health reform in Nova Scotia (Provincial Health Council, 1992; Sullivan & Scattolon, 1995).

In 1990, the Government of Nova Scotia established the Task Force on Primary Health Care with a mandate to: 1) examine the health needs of Nova Scotians; 2) to review existing health services; 3) to examine different models of providing primary health care; and 4) to select initiatives that would encourage the growth of primary health care in Nova Scotia.

The Task Force on Primary Health Care identified several shortcomings of Nova Scotia's health care system (Nova Scotia Department of Health, 1992). It was noted that within the existing system, there was no mechanism in place to allow resources to be directed to areas of greatest need, and there was a lack of responsiveness to the changing needs of consumers. There was little opportunity for consumer involvement in the planning and delivery of health services, and the system was not seen as accountable to the people (Nova Scotia Department of Health, 1994; Provincial Health Council, 1992).

In 1994, the Blueprint Committee was established with the goal of reforming the health care system in Nova Scotia (MacLean, 1994). The Blueprint Committee consisted of 25 members including consumers, providers, administrators, health advocates, government representatives and members of the academic community. Following their preliminary work, the Blueprint Committee recommended the establishment of a decentralized and regional system that supported decision making at the community level. The Committee identified objectives and criteria for establishing regional boundaries, and outlined distinct roles and responsibilities to be carried out at the provincial (Department of Health), regional (RHBs), and community (CHBs) levels.

The Blueprint Committee recommended that there should be four RHBs administering regional populations of not less than 150,000. The RHBs would consist of 12 or 16 members with consumers occupying no less than two thirds of Board positions. The recommended role of RHBs included responsibility for community funding allocations, development and review of regional health plans, and administration of secondary health services (i.e., consultation or management by health care specialists).

CHBs would consist of 12 to 16 members with an equal number of consumers and service providers. The recommended role of the CHBs included responsibility for appointing members of the RHBs, thus establishing a way for communities to have decision-making authority at the local level, and direct input into decision-making at the regional level. CHBs would develop and coordinate community health service plans, and would be responsible for all
locally provided primary health care (i.e., health promotion, prevention, rehabilitation).

Although the Government of Nova Scotia was taking steps to establish a health system that allowed for significant consumer participation, there had been no discussions specifically addressing the participation of consumers with disabilities. The Government reports that were available (detailing the outcome of task force, committee and public meetings) made no mention of the health or rehabilitation needs of consumers with disabilities, nor of efforts that would be made to facilitate their involvement in the reformed health system. When news came that some public meetings on health reform were held in buildings that were not accessible to individuals with mobility impairments, and that during these meetings, no consideration was given to the needs of individuals with sensory impairments, it became clear that the health and rehabilitation concerns of consumers with disabilities were not high on the agenda of those responsible for reforming the health system.

To address how individuals with disabilities could be included in the process of health reform, we adopted a two-phase qualitative methodology aimed at: 1) determining the key issues relevant to increasing the involvement of individuals with disabilities in health reform, and 2) planning and implementing the strategies that would achieve this goal most effectively (Basch, 1987; Helman, 1991). In the first phase, we assembled a group of experts in various aspects of disability issues and held a focus group to identify potential directions for project planning (Krueger, 1988; McQuarrie, 1990). In the second phase, we launched a series of “Town Hall” meetings (described in more detail below), coordinated and implemented by consumers with disabilities, in order to achieve the goals identified through the focus group (Feingold, 1977; Oakley, 1989).

Focus Group on Facilitating Consumer Involvement in Policy Planning and Program Development

In 1994, with funding assistance from Human Resources Development Canada, we organized a focus group discussion to address means by which consumers with disabilities could play a more significant role in Nova Scotia’s reformed health system (Secretary of State, 1994). Twelve participants were chosen to represent a wide range of interests and expertise in areas relevant to the role of disabled consumers in policy planning and program development. These included consumer advocates, representatives of disability organizations, academics with expertise in health policy issues relevant to disability, and federal and provincial representatives from the Department of Health.

One of the first proposals that was tabled at the focus group discussion was that consumers with disabilities should be given proportionate representation on CHBs and RHBs. While such a strategy may ensure that individuals with disabilities would be represented on health boards, several participants cautioned that legislating proportionate representation would only serve to yield token involvement of consumers with disabilities.

A second proposal addressed the possibility of establishing a national strategy or framework to influence health policy in a manner that ensured that the health and rehabilitation needs of individuals with disabilities would be considered. Government representatives at the focus group meeting indicated that the establishment of a national or provincial strategy addressing the health and rehabilitation needs of individuals with disabilities ran against the general philosophy of decentralization.

It was within the context of the latter discussion that a number of participants noted that while the philosophy of regionalization had merit, regionalization may have a particularly negative impact on health and rehabilitation services for individuals with disabilities. In Canada, significant changes to federal and provincial health policy have taken place as a function of the lobby efforts of various disability organizations. The lobby power of disability organizations is markedly reduced when decision-making authority is spread across numerous regional boards.

When the focus group ended, there was general consensus that, regardless of the limitations of the proposed health reform in Nova Scotia, consumers with disabilities needed to be represented on RHBs and CHBs. If the health and rehabilitation concerns of individuals with disabilities were to be addressed, consumers
with disabilities needed to be represented at the policy making level. There was also consensus that if consumers with disabilities expected to have equal voice on CHBs and RHBs, they would need to compete for these positions on the same basis as non-disabled consumers.

The Ad Hoc Committee for Persons with Disabilities in Health Care

If consumers with disabilities were to compete for health board positions on the same basis as their nondisabled peers, it was necessary to ensure that consumers with disabilities were aware of the changes taking place in the health care system, were aware of the need to participate on these boards, and understood the mechanisms by which members were appointed. Toward this end, we created the Ad Hoc Committee for Persons with Disabilities in Health Care.

The primary goal of the Ad Hoc Committee was to mobilize strategies to a) educate consumers with disabilities about how changes to the health system would impact on their needs, b) solicit their thoughts and concerns about proposed changes to the health system, c) determine individuals’ interest in participating on health boards, and d) provide feedback to the Department of Health on the concerns raised by consumers with disabilities.

The Town Hall Meetings. In collaboration with several disability organizations in Nova Scotia, we organized a series of 9 Town Hall meetings that were held in different regions of Nova Scotia. Town Hall meetings were held in Halifax, Sydney, Antigonish, Amherst, Truro, Bridgewater, Yarmouth, Digby, and Kentville in October of 1995.

Prior to the Town Hall meetings, educational materials were prepared summarizing the essential components of the proposed changes to the health system. Educational materials were developed from existing Government documents regarding reform; specifically, Blueprint to Health Reform (1994), Leading the Way; Report of the Task Force on Primary Health Care (1994), and From Blueprint to Building (1995). Information from these documents was synthesized into 4 single-page fact sheets. The topics included, 1) What is Health Care Reform?, 2) What is Primary Health Care?, and 3) Who are Health Care Consumers?. A fourth fact sheet contained a list of contact numbers outlining how consumers could contact the newly formed RHBs.

Alternate formats (i.e., braille, large print, disc, plain English) were used to increase the accessibility of the information presented at the Town Hall meetings. All meetings were held in wheelchair accessible buildings. In recognition of the financial barriers that may impede the participation of individuals with disabilities, travel and child care subsidies were made available to participants. A total of 155 individuals with disabilities attended the Town Hall meetings.

Each Town Hall meeting began with an information session followed by open discussion of participants’ concerns about health reform efforts, and their proposed solutions to these concerns. A flip chart was used to record the issues raised by participants. Flip chart records were later transcribed and analyzed for recurring themes.

The following is a qualitative summary of the concerns that were raised by participants about the direction of health reform, and solutions they offered to the concerns that were raised. Our purpose in collecting this information was to provide feedback to the Department of Health and representatives of the RHBs.

Participants’ Concerns. The majority of issues raised by consumers concerned threats to the availability of services. Many areas of Nova Scotia had been affected by significant cutbacks to health and rehabilitation programs, and other areas, particularly rural areas, were struggling with ongoing shortages of health professionals. Participants feared that health reform would simply represent a mechanism by which services could be cut back even further. Several individuals also questioned the degree to which consumers would really have a voice in determining the direction of reform in their communities.

“Health reform is about cutbacks, longer waits, and user fees.” (Antigonish Town Hall meeting, October 10, 1995).

“My fear is that people will be denied things that are necessary for them to function.” (Sydney Town Hall meeting, October 10, 1995)
"I worry that it will end up being not health reform but an excuse to put expenditures to the community level in order to shift the blame." (Kentville Town Hall meeting, October 13, 1995)

"I have concern over whether consumer control is really going to take precedence. Is it going to be a community-based model in name only?" (Antigonish Town Hall meeting, October 10, 1995)

Most of the remaining concerns dealt with issues about accessibility. Several participants also noted that accessibility was not just a matter of physical barriers, but also concerned accessibility to information, public awareness and attitudes toward the disabled. Many consumers expressed their frustration with the persevering public attitude that disability was equivalent to sickness.

"I am tired of being seen as sick. I am not sick." (Kentville Town Hall meeting, October 13, 1995).

Participants’ Solutions. Approximately one third of solutions proposed by participants focused on the health reform process. Several participants emphasized the need for individuals with disabilities to be represented on health boards, or for mechanisms to be put in place that would allow disability issues to be brought to health board meetings.

"It will be important to have representation at the meetings of both the Regional and Community Health Boards." (Sydney Town Hall meeting, October 10, 1995)

"Resources need to be put in place in order to enable persons with disabilities to become involved in the new community-based model of health." (Amherst Town Hall meeting, October 11, 1995)

"I would prefer to have disabled people speaking up rather than depending on others to do it for them." (Sydney Town Hall meeting, October 10, 1995)

There was also recognition that organization and networking would be necessary components of a system in which consumers with disabilities could be influential participants in health reform.

"We need to utilize more community-based groups representing disabilities. We need to spread the word about existing groups.” (Digby Town Hall meeting, October 13, 1995)

"Increasingly, we are going to have to have more networking between and among groups. This will allow for sharing of resources and information.” (Sydney Town Hall meeting, October 10, 1995)

Improving accessibility was also a primary focus of the solutions proposed by participants. Issues concerning inadequate accessible transportation, as well as access to interpreteive services were raised on numerous occasions.

"We need accessible and affordable transportation in order to get to the health board meetings.” (Sydney Town Hall meeting, October 10, 1995).

"We need to have information in accessible formats so that it is available to all people.” (Antigonish Town Hall meeting, October 10, 1995).

Finally, there was recognition that individuals with disabilities will need to stay informed about several areas of health reform in order to be effective participants in community-based services.

"More education is needed about what is going on with this health reform.” (Truro Town Hall meeting, October 11, 1995)

"Being informed is a two-way street. It is up to consumers to take initiative and become more involved, but it is also up to those in positions of power to create access to education and information, and inform consumers about what is happening.” (Truro Town Hall meeting, October 11, 1995)

At the end of each Town Hall meeting, participants were asked to complete a short questionnaire addressing their interest in participating in activities related to health reform. One question asked respondents to rate the probability that they would serve as a health board member. Responses were uniformly distributed with 22% of respondents indicating that it was very likely that they would serve as a health board member. Respondents indicated that transportation and accessibility were the two primary barriers to their participation on
health boards. For respondents who were not interested in participating on health boards, 72% indicated that they would be interested in some other form of participation if it were available. Only 28% of respondents indicated that they were not interested in any form of participation in health reform.

Evaluation of Impact and Future Challenges

Our primary goal over the last two years has been to develop and implement strategies that would increase the involvement of consumers with disabilities in health policy planning and program development. Consistent with the philosophy of CBR, our efforts have proceeded from the assumption that the health and rehabilitation needs of consumers with disabilities will most likely be addressed if they are participating directly in the decision-making process. The focus group meeting of 1994 identified strategies by which our goal could be achieved, and the Town Hall meetings were chosen as the most accessible and feasible means of accomplishing this goal.

Our project completed, an essential question concerns the degree to which our efforts have had their intended impact. The success of our efforts will be determined to a large degree by the number of consumers with disabilities who become members of RHBs and CHBs. Our questionnaire results indicate that 20% of participants at our Town Hall meetings believe they will become members of health boards. If these individuals are indeed able to secure positions on RHBs and CHBs, then clearly our efforts could be considered successful.

As noted earlier, an additional goal was also to ensure that consumers' concerns about the process and direction of health reform, and their proposed solutions to these concerns would be communicated back to the Department of Health. On May 1, 1995, members of the Ad Hoc Committee met with the Minister of Health, Dr. Ronald Stewart, to summarize the outcome of the project. In addition, a document summarizing the outcome of the project was circulated to representatives of all the RHBs. The document contains several recommendations outlining methods of facilitating access to information about health reform, and maximizing the involvement of consumers with disabilities in all aspects of health reform.

As we have proceeded in our efforts to maximize the involvement of consumers with disabilities in health reform in Nova Scotia, we have been mindful that our activities are only a small part of the solution. Raising awareness of disability issues in health policy does not automatically break down the barriers that have traditionally led to the relative neglect of these issues. Previous research on consumer involvement in health policy, shows that consumer representation does not guarantee effective consumer involvement (Godbout, 1981; O'Neill, 1992; Sullivan & Scattolon, 1995). The power hierarchies that favour professional authority and consumer complacency, consumers' lack of experience and knowledge in matters related to health policy, and consumers' lack of ties to constituency support networks have been, and continue to be, significant barriers to effective consumer involvement in health care (Checkoway & Van Till, 1978; Checkoway, Thomas, O'Rourke, & Bull, 1984; Percarchik, Ricci, & Nelson, 1976; Sullivan & Scattolon, 1995). If these barriers cannot be effectively overcome, then meaningful consumer involvement will not be achieved and Nova Scotia's reformed health system will fall short of establishing a system that espouses the philosophy and goals of CBR.

From the work we have completed to date, it is appears that there are even more basic barriers to the involvement of consumers with disabilities. Health reform information has not been made readily available in alternate formats, and most areas of Nova Scotia do not have accessible transportation. Due to the lack of accessible information and transportation, many consumers with disabilities may not be sufficiently aware of health system issues that will impact on their health and rehabilitation needs, and those who are aware may not be able to reach the board meetings where these issues are discussed. It is ironic that the basic needs of consumers with disabilities may not be addressed at health board meetings simply because these unmet needs interfere with their ability to attend health board meetings.

Attention also has to be given to developing more effective feedback mechanisms so that information about the community's health and rehabilitation needs can be made available to members of health boards. Although regionalization has been proposed as a solution...
to the relative lack of responsiveness of centralized health systems, regionalized systems even with consumer involvement, can be as unresponsive as centralized systems. Disabled consumers on health boards cannot be expected to be spokespersons for all individuals with disabilities, in the same way that non-disabled consumers cannot speak for all individuals who are not disabled. The success of Nova Scotia’s regionalized health system will be determined in part by the degree to which a process can be established that will allow health boards to receive ongoing feedback about the community’s health and rehabilitation needs, about the utility of current services, the utility of current changes, and the nature and extent of unmet needs.

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REFERENCES


Secretary of State (1994). Facilitating Consumer Involvement in Health Policy Planning and Program Development. Ottawa, ON: Disabled Persons Unit.


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