Consumers and Health Policy Development: Confessions of a Guarded Optimist

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Using the example of a large coalition of senior citizens in Ontario, Canada, the potential of consumer input to contribute to policy development and some key barriers to fulfilling that potential are explored. The political appeal of consumer involvement in policy development is highlighted, as is the potential for opposition from providers. The critical issue of finding sustainable funding to support consumer activities is also identified, along with the worrying trend of diminishing government support for such involvement in Canada. Copyright © 1996 Elsevier Science Ltd.

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The group known as the Senior Citizens' Consumer Alliance for Long-Term Care Reform originally formed to respond to a government discussion paper which explicitly sought consumers' reactions to new directions being considered for long-term care in Ontario, Canada's largest province [1]. As a private consultant, I began providing policy advice to the Alliance during the summer of 1991 in anticipation of this document's release. In November 1992, I withdrew from working with the Alliance (to write a book) but have continued to follow their activities with keen interest to the present day.

This article reflects my personal observations about the potential of consumer input to influence the direction of health policy. Specifically I am interested in:

- whether consumer perspectives can actually change government policy;
- what consumer input adds to the policy process; and
- what are the best ways to ensure consumer participation in policy development.

CAN CONSUMER INPUT INFLUENCE GOVERNMENT POLICY?

I feel relatively confident in saying, "Yes, it can", but this needs qualification. Certainly the Alliance experience showed that engaging credible consumers in high profile activities can influence some policy makers: notably politicians. Indeed, the Alliance's campaign urging government to rethink long-term care reform may even have convinced a few providers and some professional public servants.

Although public funding for long-term care is not required under Canada's health insurance program, each province has developed its own program for both institutional and community long-term care. In Ontario's case, the system that evolved was both extremely complex, and inequitable:

"It is the overall assessment of our Seniors' Consumer Panel that the existing long-term care system is uncoordinated with acute and primary care services; fragmented at both the provincial and local levels; insensitive to the needs of"
consumers; poorly managed; regionally unequal; lacking an appropriate balance between health and social services and lacking in meaningful orientation to consumers' real needs." [2] Indeed this critique was widely shared and is presumably what motivated the government to propose making changes to the system in the first place. However, from the consumers’ perspective, the government’s initial proposals did not go far enough in making the delivery system more responsive to consumers’ needs.

For example, the province’s home care program was operated on a regional basis. Home care staff assessed clients for eligibility and arranged for care by purchasing services from agencies with whom they had service contracts. In 1991, there were over 1200 separate agencies delivering home nursing and in-home support services in Ontario, most of them offering a single type of service or provider. Specific criticisms by the Alliance of this aspect of the system include [3]:

- lack of coordination and fragmentation between services, with the result that consumers are often shuffled from agency to agency, assessed numerous times and still left without the care they really need;
- dissatisfaction with the “brokerage model” that artificially separates assessment from case management, making it difficult to organize care or respond quickly to changing client need.
- the artificial distinction between “health” and “social services” at both the provincial and local levels; and,
- high administration and overhead costs associated with having so many single service agencies.

A key recommendation from the Alliance [4] called for major restructuring of the delivery system by creating neighbourhood-level “multiservice agencies”. These multiservice agencies were supposed to consolidate a broad range of services (including assessment, case management and service delivery) under a single organization headed by a community board.

The success of the Alliance in pursuing this and other policy proposals owed much to the large population of seniors it represented. By bringing together the leaders of two major seniors’ organizations and adding representatives from the Consumers Association of Canada (Ontario), the Alliance was in a position to claim that it represented most seniors in the province [5]. Every politician in Canada knows that a high proportion of seniors vote in every election, making it almost certain that the Alliance would capture the attention of elected officials. This could translate into a direct impact on policy, provided they came forward with workable proposals.

Toronto consultant Ted Ball invited the Alliance’s founding groups to an initial meeting in the spring of 1991 to explore the potential of forming a grand coalition. He noted that they got off to a good start by agreeing to bury the hatchet on some old grievances and committed themselves to working together towards a common objective [6]. Settling on a process to resolve differences of opinion allowed the Alliance to present a united front and make it possible to convey clear messages. In addition, deciding that their work together would be time-limited and subject-specific helped soothe any fears that the Alliance would turn into yet another competitor organization.

Another factor in their success was the fact that the three Ministers responsible for long-term care reform in Ontario [7] agreed early on to provide funding support. (Other sources of funds and in-kind support came from the groups themselves, some private foundations, some corporate sponsors and some individual hospitals.) These resources permitted the seniors to publish and disseminate a number of position papers, to host two policy conferences, and to mount their own public hearings process at which over 100 provincial organizations and individuals (including government officials themselves) presented briefs and written submissions to a panel of Alliance members. In July 1992, the Alliance submitted its report on long-term care, which included a set of recommendations calling for a comprehensive restructuring of planning and service delivery [8]. Shortly afterwards, the Ministers privately indicated their desire to implement many of the Alliance’s ideas, including the creation of multi-service agencies.

This is not to suggest that the Alliance was the only source of consumer input on long-term care reform. In fact, the government ran its own extensive consultation process right across the
province and had received a mountain of input. However, the 70,000 consumers and providers who participated in the government’s process mainly focused on problems with the existing system. Few offered structural or policy solutions. By contrast, the Alliance used its critique to develop a concrete alternative. During the spring, summer and fall of 1993, a series of policy documents from the Ontario Ministry of Health signalled a major change in direction [9-12]. Ultimately, legislation was introduced and passed to create the mechanisms for long-term care reform, largely along the lines recommended by the Alliance [13].

And there were other smaller victories along the way. Twice during this period, there were rumours that the Ontario Cabinet was considering user fees for the Ontario Drug Benefit Program, an insurance plan that offers first-dollar coverage for medications prescribed to those over 65 years of age and those on social assistance. On both occasions the Alliance lobbied hard to make sure the Premier and other Cabinet members were aware of the evidence that user fees can adversely affect access, especially among the poor and the elderly. They also pointed out that user fees were unlikely to improve the appropriateness of prescribing behaviour of physicians, a problem they wished government would tackle instead [14]. Both times the Cabinet decided against introducing the fees.

Now for some reservations and qualifications. The first and perhaps most important is that these successes were very short-lived. In the fall of 1995, Ontario elected a Conservative government which quickly repealed the legislation for multiservice agencies, as they had promised to do during their campaign. As for Ontario’s Drug Program, it now has user fees. As does every other drug program for seniors in the country.

The newly elected government’s directions for long-term care are strikingly similar to the proposals which were always favoured by service providers and bureaucrats alike. This illustrates a vital limitation on consumer impact. The case that fundamental restructuring is rare in public policy, with most change occurring incrementally was made convincingly long ago [15]. Since then, it has become even more apparent that the concentrated interests of providers are almost certain to hold more sway than the diffuse interests of consumers or taxpayers even if the latter are far more numerous [16]. The experience of health care reform in general and long-term care reform in particular, suggests that government officials found it more expedient to keep providers happy than to worry too much about consumers. After all, when it comes to health care, consumers and consumer groups are virtual transients through the system. It is the providers who have the staying power [17].

Providers also have the resources. For consumer organizations to assert a countervailing force, they need similar economic backing and their funding needs to be relatively free from “strings” [18]. This was a perennial problem for the Alliance and I suspect this is true of consumer organizations around the world. Without secure and stable funding, groups lurch from project to project, threatened with possible extinction as each winds down.

WHAT DOES CONSUMER INPUT ADD TO THE POLICY PROCESS?

The really important question here is whether consumers have meaningful information to impart about the system and its functioning to those who are in a position to take action. Again, my preliminary answer is “Yes”, although with some qualifications. Certainly the consumer perspective is a distinct viewpoint that only sometimes aligns with that of providers or funders of services. The current focus on quality of care increasingly emphasizes the importance of incorporating patients’ preferences into clinical decision making in order to ensure appropriateness [19]. The information consumers have about themselves and their values can be highly relevant to making good clinical decisions. What about policy?

Obtaining meaningful information from consumers requires taking into account the fact that there are different levels of consumer. A recent article making this point suggested three basic categories: 1) the patient and family caregiver, 2) consumer groups, and 3) consumerists, whilst noting that membership in more than one of these groups at the same time is not unusual [20]. Although the first two categories are self-explanatory, the third, the “consumerist” may be a less familiar term. It refers to those with a very broad understanding of consumer issues, one
that reaches beyond the scope of any single consumer group or personal experience and one that incorporates a commitment to consumers' rights and often a detailed understanding of the policy process and the bureaucratic language used within it. Consumers of all types can contribute to the policy process in different ways, but it is unfair to expect a consumerist's response from every patient or family caregiver. Jane Aronson spoke about this problem during the Ontario government's consultation on long term care reform which had facilitators throughout the province reviewing the government's proposals in front of large public meetings and:

inviting comments from participants ... the facilitators received comments attentively and then typically asked the speakers if they could "turn them into suggestions." For example, an elderly woman described at some length how, after a spell in hospital, a visiting homemaker was withdrawn after ten days. She then had no support and felt very insecure and fearful. After telling her story, she was asked if she could "turn that into a suggestion." She responded rather haltingly that: "It just shouldn't have been like that" [21].

Patients can talk about individual provider and system failures and their impact. The consumer group can help differentiate between individual and systemic failures by consulting their members and tracking their experiences. The consumerist, as Williamson points out, can often translate these kinds of experiences into policy proposals for better access, information, choice, advocacy, equity, safety or redress. The Senior Citizens' Consumer's Alliance was in a position to provide detailed policy input. Its leaders were a highly articulate and active group of seniors. They saw their role as fighting for a better system, not only for themselves but for their children and their children's children. While Alliance members also belonged to an official "consumer group", their determination to address broad concepts, especially equity, access, comprehensiveness and continuity of care, suggests that they merited the "consumerist" designation, too.

Along with new information and policy advice, consumer input can also sometimes moderate policy processes that have bogged down over disputes between those who are paid (the providers) and those who pay (the government funders). New voices entering the debate can sometimes break such stalemates. The Alliance attempted this by hosting two well-attended policy conferences (and one in-camera stakeholder session with providers), at which individuals and organizational representatives concerned about long-term care had the opportunity to air their respective positions.

WHAT ARE THE BEST WAYS TO ENSURE CONSUMER INPUT?

There are numerous ways to obtain input about policy directions from consumers. Traditional means include board representation, focus group sessions, satisfaction surveys and other feedback instruments, and direct involvement on service planning committees. None of these, however, (with the possible exception of board and committee representation) actually require those soliciting the information to pay attention and incorporate it. On the other hand, if it is true that consumers have information that is useful to the policy process in a given sector, how can we enlighten decision makers to make use of it? According to political scientist Paul Sabatier, governments can help foster policy-oriented learning in two ways: 1) by providing resources to support the development of coalitions and 2) by organizing numerous opportunities for public debate [18].

Governments actually have a lot to gain by funding consumer movements, but their increasing reluctance to do so may reflect their own discomfort with being the potential object of consumer criticism. This is a real risk. Funding for consumers can't be considered hush money. When the Alliance took on the Ontario Cabinet over user fees for medication, its members knew they risked offending their principle funding consumer movements, but their increasing reluctance to do so may reflect their own discomfort with being the potential object of consumer criticism. This is a real risk. Funding for consumers can't be considered hush money. When the Alliance took on the Ontario Cabinet over user fees for medication, its members knew they risked offending their principle funding support, but decided it was a risk worth taking.

However, governments in Canada are currently silencing consumer movements through policies that eliminate or greatly reduce public funding for "interest groups". Even the term "interest group", which used to be a reasonably neutral phrase, has somehow been transformed into something disreputable. This, along with the limited sources of alternative funding, has greatly destabilized the environment for the "repressed interests" in our health and social services
system, voices already weak and terribly difficult to organize into any coherent political force [17].

Evidence of this weakness is everywhere. The Consumers Association of Canada no longer publishes its magazine, since losing government support for its core operations. The National Action Committee on the Status of Women has similarly been cut off. One Voice, Canada's national seniors' network, is scrambling from project to project hoping to find enough funding to replace the planned withdrawal of its private sector donor.

Is it merely a coincidence that this widespread retreat from supporting consumer groups has coincided with a significant political shift to the right? At least theoretically, openness to consumer input should be able to cut across ideological lines. For the left, it may demonstrate a commitment to community participation symbolizing perhaps some sort of heightened democratic ideal. For those on the right, the same openness to input from users could be seen as a spur to innovation to satisfy “customer” demands, symbolizing some sort of marketplace ideal. Whatever the motivation or underlying ideology, consumer input would appear to have a legitimate role in the design and operation of many public and private services, not only health care.

In practice, however, governments are far from homogeneous when it comes to soliciting and responding to consumer participation. Some may appreciate the political value of keeping consumers involved and on-side, but most seem far more comfortable dealing with the better organized and more powerful interest groups representing service providers and industry.

Today, the consumer movement in Canada is in a very weakened state indeed. One final example from the Alliance will perhaps serve to demonstrate its vulnerability. More than two years after the release of their recommendations, the seniors were still waiting for multiservice agencies, their consolidated model of service delivery, to be implemented. In frustration, the Alliance hired a large well-established consulting firm (Price Waterhouse) to document that the model they endorsed would cost far less than the current system. In August 1994, Price Waterhouse released a report [22] confirming that when fully implemented, MSAs would permit about $90 million more each year to flow into direct service. Most of these “savings” reflected lower administrative and overhead expenses associated with service consolidation.

This study upset many provider groups who felt they were being accused of inefficiency [23]. One of these groups (St. Elizabeth Visiting Nurses' Association of Ontario) hired its own experts who then reportedly threatened a lawsuit. And then suddenly in November without warning, Price Waterhouse sent a letter to the Alliance announcing that the firm was withdrawing the report due to concerns raised about the approach it had followed. Curiously, the letter from Price Waterhouse was “cc'd” to the St. Elizabeth Visiting Nurses' Association of Ontario and was read aloud in the legislature on the same day the Alliance was lobbying there.

Stung by what it perceived as a betrayal by their own consultants, the Alliance nevertheless felt it had to commission a new report to address some legitimate concerns about the methodology used in the original analysis. The new report, which was also prepared by Price Waterhouse [24] still shows the senior's multiservice agency model would save lots of money, about $44 million per year. However, the damage was done. In a letter to the consulting company Alliance president Jane Leitch noted the harm done to a “committed group of senior citizen volunteers who have worked for the past three years to establish ourselves as a legitimate and forceful voice in the debate on the reform of Ontario's long-term care system”.

If I remain guardedly optimistic after such a tale, it is not because I doubt the existence of fierce opposition to consumer involvement. It is because I know consumers have something valuable to offer to the policy process and others know it too. And as health care systems around the world get “reformed”, it is more important than ever to ensure that these “other” voices get heard. Ultimately I feel certain that consumers in Canada, and indeed around the world, will win the right to participate more fully in policy development. I just wish it could happen quickly.

REFERENCES


5. The numbers in this case were impressive. One of the founding members, the United Senior Citizens of Ontario, has over 1,000 seniors clubs throughout the province. Another founder, the Ontario Coalition of Senior Citizen Organizations, is a non-profit umbrella group of organizations with extensive experience in lobbying and political activism, representing over 300,000 seniors. The third founding member of the Alliance was the Consumers’ Association of Canada (Ontario) with longstanding involvement in health issues. Together the Alliance boasted that it represented about 1 million people, which at the time made it the largest consumer organization in provincial history.


7. The three Ministers in question were: Frances Larkin, Minister of Health, Elaine Ziemb, The Minister for Seniors Issues, and Zanana Akande, the Minister for Community and Social Services.


9. Ontario Ministry of Health, Ministry of Community and Social Services, Ministry of Citizenship, Partnerships in Long-Term Care: A new way to plan, manage and deliver services and community support; a policy framework, Queen’s Park, Toronto, April 1993.

10. Ontario Ministry of Health, Ministry of Community and Social Services, Ministry of Citizenship, Building Partnerships in Long-Term Care: A new way to plan, manage and deliver services and community support; a local planning framework, Queen’s Park, Toronto, May 1993.

11. Ontario Ministry of Health, Ministry of Community and Social Services, Ministry of Citizenship, Partnerships in Long-Term Care: A new way to plan, manage and deliver services and community support; an implementation framework, Queen’s Park, Toronto, June 1993.

12. Ontario Ministry of Health, Ministry of Community and Social Services, Ministry of Citizenship, Partnerships in Long-Term Care: A new way to plan, manage and deliver services and community support; Guidelines for the establishment of multiservice agencies, Queen’s Park, Toronto, September 1993.

13. The legislation was introduced as Bill 173, An Act to Reform Long Term Care in Ontario, was passed into law in 1994.

14. For a discussion of user fees and their effects on medication use see: Strong Medicine, Chapters 5 and 6, op. cit.


23. What follows is largely paraphrased from an article in the Toronto Star by Thomas Walkom a regular columnist covering Queen’s Park, The article is dated November 29, 1994.