

# Using a Participatory Research Process to Make a Difference in Policy on Aging

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## RÉSUMÉ

Alors qu'une stratégie politique émerge de l'interaction des forces économiques, politiques et sociales, il reste qu'il est très difficile à déterminer si la recherche a eu un impact favorable sur les choix politiques concernant des questions relatives au vieillissement. Afin de mesurer cet impact il faut porter son attention sur la «boîte noire» de la procédure politique, et sur le contexte dans lequel la politique opère en définitive. Cette communication présente un Programme de Recherche sur l'Indépendance des Personnes âgées, en guise d'illustration de la façon dont la recherche a eu un impact favorable sur les choix politiques, grâce à l'engagement des principaux intéressés au cours de la procédure des recherches. Des stratégies garantissent la collaboration des principaux intéressés dans les recherches sur la politique à suivre, et sur le rayonnement, la définition, les questions prioritaires; sur l'engagement dans la conception, la mise en vigueur et l'évaluation des modèles de services de santé; et garantissent la participation, à partir des faits établis, aux changements à long terme apportés à la politique à suivre et à sa mise en pratique.

## ABSTRACT

As policy emerges from the interplay of economic, political, and social forces, determining whether research has made a difference to policy choices on aging issues is extremely difficult. Such a determination demands attention to the "black

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box” of the policy process, and the setting within which policy ultimately operates. This paper presents a Seniors’ Independence Research Program as a case illustration of how research *has* made a difference to policy choices by stakeholder involvement throughout the research process. Strategies ensure stakeholder collaboration in policy issue search, filtration, definition, and prioritization; involvement in the design, implementation, and evaluation of health services models; and participation in achieving long-term evidence-based changes in policy and practice.

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Bridging policy and research on aging holds the promise of more evidence-based policy outcomes; hence, improved health and social policy for Canada’s seniors. To date, however, the impact of research at the legislative policy level has been notoriously minor (Lomas, 1990; Orosz, 1994; Torres-Gil & Wray, 1993). Indeed, the promise may continue to elude us if we focus only on outcomes.

Policy emerges from the interplay of economic, political, and social forces, all influenced by the human elements of power, conflict, and ideology (Simeon, 1976) enacted at all stages of policy development and implementation. Policies materialize in complex ways, their ultimate forms reflecting many unintentional, un contemplated, indeed, human elements. Thus, the question: “Has research made a difference to policy choices on aging issues?” is extremely challenging. Finding an answer demands attention to the “black box” of the policy process, and the setting within which the policy ultimately operates (Foster, Susman, Mueller, Bowman, & Lunt, 1994; Simeon, 1976).

This paper presents a Seniors’ Independence Research Program (SIRP) as a case illustration of how research *has* made a difference to policy choices on aging issues. This achievement has materialized not through tangible policy outcomes, but through attention to the “black box” – in this instance the *process* of conducting research intended to shape policy promoting the independence of seniors with chronic conditions in their use of community-based primary health care.

## **The Theoretical Premises**

Policy has been defined as “a consciously chosen course of action (or of inaction) directed towards some end” (King, 1975, p. 298). Policy is theoretically differentiated from “quasi-policy,” described as situations in which governments may have a wide variety of actions, past and present, within a given policy area, without necessarily having adopted consciously an overall set of goals (King, 1975). In reality, both must be considered, for to concentrate only on explicitly stated actions and plans would be to rule out a vast proportion of government activity (King, 1975).

Policy can have two different levels of impact: “output” or what is done; and “outcome,” or the consequences for society of what is done (Sharkansky, 1970). The output of policy includes its scope of influence and the means by which the policy direction is enacted. The outcome of policy (i.e. distribu-

tion) refers primarily to the effects of policy (Simeon, 1976). Thus, to say that research has made a difference to policy choices on aging is not to limit judgement to the ultimate effects of written policy. One must consider what was done, who was influenced, and by what means.

In attending to the "output" of policy over the past few years, governments (e.g., Ontario Ministry of Health, 1993) and researchers (e.g., Charles, Schalm, & Semradek, 1994; Gray & Phillips, 1995; Haines & Jones, 1994) alike have begun to recognize that engaging key stakeholders in the process of developing, implementing, and disseminating policy-related research has the potential to make a positive difference in achieving policy outcomes. Collaborative and participatory approaches permit those affected by new public policy directions the opportunity to be involved in the process that produces inputs, such as research information, used to inform policy. Such approaches are consistent with theory on how people change behaviour (Prochaska & DiClemente, 1992) and recognize that in order for research information to be usable for policy-making or any other purpose, it must reflect the values and interests of those affected and accommodate to the realities of their environment (Durning, 1993; Foster et al., 1994; Lomas, 1990; Lomas, 1993).

Stakeholders bring constituency values and interests to refining policy research questions, thereby ensuring that emerging policies reflect public priorities and beliefs. Because they are an integral part of the systems under investigation, stakeholders can play an invaluable role in identifying and gathering research data. In fact, they can frequently open the doors to the real world of policy implementation for their often more cloistered academic collaborators. Once policy-related research projects have been completed, stakeholders can lend their knowledge to determining the policy choices suggested by research findings, generating and reacting to policy directions, including their potential feasibility. As well, stakeholders can serve as opinion leaders in policy implementation, communicating research findings to a broader stakeholder audience, and promoting acceptance of the policies that emerge (Charles et al., 1994). The following case illustrates how stakeholders engaged in the research process have already made a difference to achieving government policy direction in promoting seniors' independence.

### **Using the Research Process to Achieve Policy Choices**

"Evaluation of Models of Community-Based Primary Care Which Foster Seniors' Independence" is a collaborative, multi-disciplinary research program to evaluate and compare models of community-based primary care designed to promote and support the independence of seniors with chronic medical problems. "Independence" is defined as encompassing a relationship between an individual and a care provider rather than as a personal attribute rooted in illness and impairment associated with old age (George, 1991). Thus, the research focusses on models of care that promote inde-

pendence by empowerment or capacity enhancement through more equitable distribution of resources (for example, knowledge and information), status (that is, the right to manage care) and authority (that is, autonomous decision-making).

The program is multidimensional, containing 14 projects testing models of one of three components of community-based primary care: home care; medical care; and public health programs. Projects address models of health promotion, case management, medication management, preventive medical care, self-care, public health programming, and the effectiveness of Freirian educational approaches<sup>1</sup> (Freire, 1970, 1973, 1978) for improving the knowledge, attitudes, and skills of health and social service practitioners in promoting seniors' independence. Research findings are intended to inform public policy and service delivery protocols and procedures related to community-based primary care.

In particular, home care studies inform the evolution of in-home services for chronically ill older people across Canada, but especially, the implementation of the new Community Care Access Centres in Ontario. Several policy and program delivery issues in this arena have been identified: Would an alternative health-oriented approach to case assessment and care delivery be more cost effective? Who needs case management? How much and what kind of case management do they need? What is the effect of case management on seniors' independence, health service utilization, and health?

In the medical component of community-based care, the impact of service delivery protocols and guidelines on seniors' independence was at question. In particular, the practice policy issues arose from questions about the effectiveness of Canada's Periodic Health Review preventive care guidelines, medication management, and hypertension management approaches for seniors.

In the public health arena, the research aimed to address policy and programming issues regarding influenza immunization and public health programming for seniors. Policy questions included: What is the most cost effective approach to providing influenza immunization to seniors? What public health programming do seniors need? What is the most effective approach to developing and delivering public health programs for seniors?

The great potential of this three and one-half year research program to contribute to policy choices on aging arises from its process-oriented design. The initial projects in the program were developed by researchers in collaboration with a few key professional providers. Thus, seniors and the community at large had no opportunity to participate in collective decision-making processes which determined the overall agenda of policy and practice issues to be addressed. Nevertheless, researchers did extract ideas from the participatory research literature (Green et al., 1995), applying principles to the implementation of an entire research program. Consequently, the program's design reflects a "middle of the continuum" (Maclure, 1990) participatory process in which researchers share the power and control of decision-making to evolve, implement, and evaluate the research program

with representatives of a broad range of constituencies who have a vested interest in community-based primary care.

This approach has ensured an on-going engagement of key stakeholders (seniors, family caregivers, professional providers, and the public at large) in the policy-making process. Specific elements of the approach include: (1) an active advisory committee representing key stakeholders; (2) stakeholder collaboration in baseline policy issue search, filtration, definition, and prioritization (Hogwood & Gunn, 1984) through deciding and refining specific research projects; (3) stakeholder involvement in analysing, implementing, and evaluating optional models of fostering seniors' independence in community-based primary care through the research projects pursued; (4) dissemination activities using stakeholders as opinion leaders to promote change in keeping with agreed policy and practice directions; and (5) fora for stakeholder participation in analysing, discussing, and integrating findings of the research studies into practice guidelines and consensus statements to set public policy, programming, and service delivery.

#### *The Advisory Structure and Process*

The program advisory committee is comprised of nine seniors and family caregivers (four representatives of seniors' organizations and five representatives of the community at large), seven professionals representing a variety of disciplines and agencies involved in community-based care delivery, three health services policy and planning personnel representing both the provincial government and district health councils responsible for health policy and delivery, and the three principal investigators, *ex officio*. To ensure representation of the values and interests of a wide range of constituencies interested in each of the three components of primary care, stakeholders were identified through a multi-staged selection process.

At the outset of the program, home care programs, public health units, and primary care physicians were asked to make both consumers and professional providers aware of the research program and the opportunity to provide personal views on the impact of existing care delivery approaches on seniors' independence. From a long list of individuals who expressed an interest in participating, 65 ultimately agreed to discuss their views at focus group meetings.

At the end of these meetings, individuals were asked to indicate their interest in availing themselves of the opportunity for continued involvement in the advisory process of the three and one-half year program. From this self-selected short list, researchers next selected representatives of major stakeholder constituencies for each of the three components of community-based primary care. The selection reflected an attempt to achieve gender equity, in-depth familiarity with the primary care component in question, and maximum variation in age, socio-economic status, educational level, occupation, and any relevant special interest group affiliations. As well, representation of the more easily marginalized elderly service users (for example, those who were wheelchair-bound, on portable

oxygen, and/or without transportation) was promoted through use of para-transit services, easily accessed facilities, and inclusion of informal caregivers. This effort enabled participation of seniors otherwise incapacitated.

Provider stakeholders were selected to represent a wide variety of disciplines and health service agencies, including non-professional providers (e.g., visiting homemakers). Policy and planning personnel were selected by their respective jurisdictions, including the provincial Ministry of Health and the area District Health Council. The aim was to obtain representation from the policy and planning constituencies to whom the policy issues to be addressed through research would be of concern.

The names of all who had indicated an interest in involvement but were not selected immediately as advisors were kept on file, so that these individuals could be involved in specific activities and projects during the course of the research program. This resource list has served its purpose. Many individuals on the list have participated in research workshops, contributed time and effort to specific project activities, and/or have assumed advisory committee roles for retiring advisors.

The major limitation of the overall process of engaging participant constituencies has been the inevitable limitation that physical frailty has placed on a few of the senior participants. Informal caregivers and involved professional providers have facilitated participation of this typically under-represented group in select activities, including focus groups and workshops. However, none of this group has been able to participate regularly in the more demanding advisory roles. Therefore their voice has had to be incorporated more indirectly.

Brought together at the outset of the program, advisors have continued to meet a minimum of four times per year to advise on all aspects of program evolution and to monitor and evaluate overall progress. The process of facilitating participation by stakeholders with different degrees of formal power and different levels of knowledge has been a mutually shared challenge. The elected senior chairperson of the Advisory Committee has consistently worked to encourage expression of the voice of all constituencies. All participants have made a concerted effort to exchange knowledge, skill, and resources in openly confronting tensions and potential conflicts.

Confronting tensions and potential conflicts has not been an easy task, of course. For example, at the first Advisory Committee meeting, several senior advisors objected openly to being labelled "seniors". Observing that age-related terminology was not being applied to other constituencies represented amongst advisors, these seniors ultimately had to transform the perspective of other advisors. After much open discussion and debate about alternatives (including "consumers"), those chosen to represent people aged 65 and over decided that the "Seniors' Independence Research Program" title and overall purpose made the label of "seniors" appropriate and, indeed, necessary. While initially both challenging and uncomfortable, this discussion has had a long-term positive effect on the discussion of



research issues and directions.

Another challenge arose from concern about the power imbalances created by professional knowledge and expertise. The concern was short-lived, however, as seniors very wisely and openly confronted researchers and professionals whenever “jargon” unfamiliar to them entered into discussions. Both researchers and providers have become much more conscious and conscientious about their use of language. Consequently, improved communication skills have been one positive outcome of the participatory research process. This improvement has been reflected not only in interpersonal exchanges, but also in research project questionnaires, presentations, and media releases.

Participant openness has actually heightened the potential for open conflict. For example, some of the advisors representing professional provider constituencies openly supported the addition of new projects that linked the research endeavours of their constituencies with those of SIRP. Researchers openly shared their enthusiasm for expanding the research network. Senior advisors, largely unfamiliar with the historical evolution and ultimate purposes of the work proposed, felt pressured to endorse the additional projects proposed on the basis of the brief presentations made at an advisory meeting. The value-laden nature of decision-making and power imbalances between constituencies became uncomfortably apparent in post-adjourment discussions. Researchers and the senior chairperson of the committee together tackled the problem of how best to confront the conflict and prevent further occurrences of power imbalances in decision-making. As a consequence, this situation was openly addressed at the next advisory meeting, and apologies exchanged. The Advisory Committee ultimately decided to develop a procedure for review of any new projects to prevent similar occurrences in the future. Several senior advisors worked with researchers to refine a procedure enabling them to be fully informed participants in the decision-making process. Both this conflict and its resolution have provided experiential learning for all participants. Time and effort have helped to achieve a more informed, flexible, and negotiated distribution of power among all participants (Goepfinger, 1993; Labonté, 1993).

As a consequence of ongoing attention to power imbalances, tensions, and conflicts, senior consumers on this committee have contributed their experience and practical knowledge to policy choices in a wide variety of ways. They have helped to identify key issues and to refine research questions related to seniors’ independence in the use of community-based primary care services. Their contribution to developing project models of care has already shaped the practices of seniors and physicians. For example, seniors have: worked with professionals to design materials intended to help seniors initiate discussions with their physicians about preventive medical care; refined research instruments to capture key elements of the policy issues as they experience them; developed and implemented recruitment strategies to ensure senior participation in the research; and liaised

with organized lobby groups such as Councils of Seniors. All of this activity has brought greater public opinion to policy issue filtration and definition, thereby refining the research direction toward achieving evidence-based policy. As well, by vetting ongoing dissemination of research project activities to the public through newsletters and press releases, senior advisors have helped to develop a mutual understanding of the policy-related issues.

Professionals and policy and planning advisors have made an equally important contribution to the output of policy. Professionals have brought expertise and knowledge of programs and services to ensure that policy-relevant research is developed in the context of the current system, with the ultimate goal of effecting practice changes. Policy and planning representatives likewise have contributed their knowledge of, and expertise with, the broader system to assist in the prioritization of policy issues and model options. These advisors will fulfil a key role in identifying and acting upon the policy implications that ultimately emerge.

The interactive involvement of these stakeholder groups exemplifies a grass-roots approach to the dynamic process of policy development. The advisory process does much more than afford a bridge between researchers and policy-makers. Through the advisory committee, knowledge generation about policy choices on aging issues is an ongoing, interactive process (Durning, 1993). The process itself sets the stage for much more extensive "policy-oriented learning" among groups who hold different values, beliefs, or interests on a particular policy issue (Sabatier, 1987, 1988).

#### *Collaborative Policy Issue Refinement*

Expanding the impact of the research process beyond those engaged in the advisory process, several projects in the research program also have served as vehicles for making a difference to policy choices on aging issues. At the outset of the research program, a focus group study identified the policy issues, specifically, the barriers and facilitators to seniors' independence in using community-based primary care health services. Seven focus groups, each comprised of 10 to 15 seniors, informal caregivers, and health care providers from both the urban and surrounding rural communities, were purposefully selected to represent medical, home-based, and public health primary care areas. A pair of trained facilitators used a high level involvement approach (Morgan, 1988, 1993), guiding the discussion with a semi-structured schedule of open-ended questions previously piloted with seniors and with both informal and formal caregivers. All participants were actively encouraged to share their experiences. Analysed results from approximately 15 hours of audiotaped data (presented in-depth elsewhere: Brown, McWilliam, & Mai, 1996) have identified practice and policy issues related to: consumer and professional provider attitudes and attributes expressed in health care delivery; service accessibility; and system policy, design and implementation approaches related to communication, co-ordination, and continuity of care. Findings of this study have confirmed the importance of investigating models of care designed to improve both the self-confidence



and participation of seniors in the management of their care and the attitudes and approaches used by professionals in providing health care to seniors.

Participants also identified several barriers and facilitators related to seniors' independence not previously contemplated as part of the research program. Barriers identified by seniors and informal caregivers, confirmed by professional providers, included lack of support for informal caregivers, limited access to information on how to address health problems and what services are available; inadequate supportive services to enable seniors to remain in their own homes, and inappropriate and/or inaccessible public health programs. As a consequence, several other practice and policy issues are now incorporated into model options to be studied in additional or refined projects in this program of research.<sup>2</sup>

The focus group study findings also have been used to develop a follow-up randomized telephone survey of 1,141 seniors to determine the prevalence of the barriers and facilitators in the community. Data measuring the prevalence of barriers and facilitators have helped to prioritize both practice and policy issues. For instance, preliminary analysis of study findings has indicated that 38 per cent of seniors have inadequate information about influenza immunization, and only 8.7 per cent avail themselves of public health promotion programs. These findings suggest the need to review public health policy and programming directions.

A program refinement workshop constituted the third component of the expanded policy issue refinement effort. Sixty-four seniors and caregivers, and 48 health care providers and researchers participated in a day-long session to consider program directions in light of baseline data and their own experience of community-based primary care. Themes emerging reinforced our project foci, but also identified public and practice policy issues related to: communication between professionals and clients, especially physician-patient relationships; accessibility of health care services; public education about service availability; and the role of volunteerism in providing public health care programs. These policy issues are being addressed in the development of models to be tested in specific research projects, and in the selection of instruments and items to measure model effectiveness in achieving these policy directions.

Clearly, as previously cited examples have indicated, all phases of policy issue refinement are highly political processes, influenced by the distribution of power within or between organizations and society at large. Issue definition and selection are at least as much influenced by value-judgements as by the careful sifting of facts. Who defines and decides policy issues deeply influences the later stages of the policy-making process, and the ultimate outcomes (Hogwood & Gunn, 1984). By involving senior consumers, care providers, and policy and planning personnel together in issue refinement, the research process in our program has already made a positive difference to policy choices related to seniors' independence. The initial research agenda has been refined substantially. The case management project has

been revised to encompass the policy concerns of program planners and policy personnel wanting to address policy issues associated with planned changes in program delivery approaches. Original professional provider perspectives on preventive medical care practice issues have been refined to encompass the value judgements and priorities for practice changes identified by senior consumers of health care. Research related to public health programming priorities and policy issues has been modified as a consequence of the input of both seniors and professional providers. Not only have the outcomes to be achieved changed, but also policy issue refinement through the participatory research process has heightened the sensitivity and commitment of all constituencies to ensuring seniors' independence. Conscious awareness of the value-motivational framework of all constituencies, and the negotiations this necessitates, has enabled all participants to more effectively participate in policy issue refinement.

#### *Collaborative Model Development, Implementation, and Evaluation*

Two projects exemplify the impact of stakeholder involvement in the actual development and implementation of evaluative research projects on policy choices. The first project illustrates how the involvement of service providers can change professional practice. In the home care sector, professional providers who had participated in the baseline studies and workshop, providers and policy personnel on the advisory committee, and a random sample of senior home care clients indicated a need for in-depth study of approaches to case management. Previous research of seniors' experiences of case management during the transition from hospital to care at home also had indicated the potential for case management to negatively affect independence (McWilliam, 1992; McWilliam, Brown, Carmichael, & Lehman, 1994; McWilliam, Stewart, Sangster, Brown, & Wong, 1993).

With this recognition of need, collaborative work to identify the policy issues, develop the research questions, and refine potential models of case management for implementation and evaluation began. Administrators, case managers, and representatives of professional providers from five home care programs in rural, semi-rural, moderately sized urban, and large urban areas across Ontario came together with researchers at monthly meetings that transpired over an entire year. Together, these professionals and researchers explored the three major models of case management in Canada.<sup>3</sup> Literature review identified the similarities and differences in approaches, yet uncovered little evidence about the comparative effectiveness of each alternative. The group therefore decided to develop descriptions of the three models, to reflect the most consistent practice and theoretical characteristics of each option. As well, group members worked with other colleagues in their respective agencies to evolve research implementation strategies. The planning phase encompassed meticulous attention to processes and procedures to ensure project success. Subsequently, Ontario policy and planning personnel have participated in identifying the key policy and planning issues which currently need consideration in implementing

the new Community Care Access Centres in the province. Collaborators are now in a position to determine the policy and planning implications of the three models of case management within their respective jurisdictions, using rigorous evaluative research that controls for differing demographics, organizational size, and provincial health care systems.

This feat could not have been achieved by researchers and policy personnel, individually or collectively, working to promote the independence of seniors who might require case management. Uninvolved home care professionals would likely have expressed some resistance to changing their case management approaches. Fear of potential policy implications, perceived threat to personal security, or simply the burden of trying new approaches to health service delivery all constitute normal human reactions to externally imposed organizational change. These reactions are currently very much a part of the experience of the organizational change from Home Care programs to Community Care Access Centres across Ontario. Because of the involvement of key stakeholders, however, implementation will now be possible and results of the study will inform related policy, health care system refinement, and selection of community-based models of case management, as well as the role of providers in the case management function. Agreement on the definition, purposes, auspices, authority, and approaches of case management has the potential to shape health care system administrative policy, thereby contributing to quality of care, cost-effectiveness, and both consumer and provider satisfaction.

Throughout this process of model identification and planning for implementation, participating stakeholders have benefited from policy-oriented learning. Furthermore, having been involved from the outset, these individuals will be much more ready to pursue the achievement of long-term changes in case management to promote seniors' independence. Perhaps more importantly, a wide variety of other providers has benefited as well. Collaborations with community-based professionals in the development of this project has led to opinion-leader dissemination of the policy-oriented learning. As a consequence, researchers have fulfilled several invitations to speak on models of case management and their potential impact on seniors' independence. Invited workshops have reached over 200 professionals from various components of the health care system across Canada. Thus, the development phase has created a positive impact on quasi-policy and practices related to community-based care, even though the project has not yet begun.

The second project illustrates the impact of consumer involvement in research of health care approaches. The process of practical action research was used to evolve a model of health promotion. Of 203 chronically ill seniors who were randomized to either the usual home care services or to those services augmented by a series of 12 to 16 health promotion visits, those who participated in the intervention process of critical reflection learned much about their own health and ability to manage their health at home (McWilliam, Stewart, Brown, Desai, & Coderre, 1996; McWilliam, Stewart,

Brown, McNair et al., 1996). Preliminary quantitative findings suggest that seniors engaged in critically reflecting on their own health and health promotion make greater, although non-significant, gains in perceived health and independence, and statistically significant gains in perceived ability to manage their own health and perceived quality of life, than do seniors who have not participated in this process.

Regardless of the ultimate quantitative research findings, the many seniors with chronic illnesses involved in developing this model of health promotion through the research project have acquired greater confidence and independence in their approach to managing their own care at home. Their stories, contained in the qualitative research findings, will undoubtedly inspire other seniors to greater independence in their approach to health care. Once again, stakeholder involvement in the research process has achieved policy-oriented learning that will shape consumer behaviour, thereby indirectly affecting policy choices. Equally important, stakeholder involvement in evolving the model of health promotion has helped practitioners to better understand the subtle aspects of how their approaches affect the independence of senior clients, and how they might refine their practice. "Quasi-policy" has been achieved.

Implementation of models of health services delivery must be seen as an important part of policy-making, since actions shape policy as much as policy shapes actions (Hogwood & Gunn, 1984). The final results of this and planned follow-up research, as described in the following section, may have ramifications for policy choices related to what kind of health services should be funded for chronically ill older persons and how, where, when, and by which professionals they should be delivered.

### *Participatory Dissemination*

The Seniors' Independence Research Program to Evaluate Models of Community-based Primary Care to Foster Seniors' Independence also contains several participatory dissemination approaches which help to translate research into policy choices through enhancing the political will of the public for specific actions. This strategy for using the research process to make a difference to policy choices differs from the usual unidirectional dissemination approach in that it is highly interactive and participatory.

The dissemination approach most frequently begins with program advisors who identify the vehicles for dissemination, often through personal contacts or liaison efforts. Advisors also participate in vetting materials for dissemination, to ensure their appropriateness for the selected audiences. Once each vehicle for public dissemination is established, the process becomes highly interactive, with personnel of these communication media often taking the initiative to engage program researchers in meeting specific public information needs.

To illustrate, as the program has progressed, each project has been disseminated through presentations to seniors' groups, professional association meetings, and appropriate newsletters. Additionally, the program's

quarterly newsletter, and releases about specific projects in the newsletters of The Ontario Ministry of Health's Public Health, Home Care, and Long-Term Care Divisions, the District Health Councils of Ontario, in various professional association newsletters, and in community newspapers help to keep the public informed as the program proceeds.

Several other community links have facilitated more effective program promotion and project dissemination, fostering further collaborations with community senior groups, and other professionals and researchers. Collaborative endeavours have included: community consultation services (for example, to municipal agencies attempting to better meet the needs of seniors for community information services); committee involvement (for example, representation to provincial government committees on Long Term Care Reform), and research collaborations with others conducting projects that are appropriately linked to the mandate of this SIRP.

By combining researchers' dissemination skills with the experiential wisdom of professionals, policy and planning personnel, seniors, and key public informants, a cohesive, meaningful presentation of findings aligned with the value-motivational base of major public sectors is being created. This approach effectively extends the potential to influence policy choices both by mobilizing political will and by promoting acceptance of policy change.

#### *Participatory Fora for Setting Practice and Policy Direction*

Two fora to engage stakeholders in setting practice and policy direction also comprise part of this research program. As a follow-up to the Study of Home-Based Health Promotion for Chronically Ill Older Adults, health care providers (nurses, social workers, physiotherapists, occupational therapists, speech therapists, and homemakers) and seniors from a selected home care program will engage in four one-day "dissemination for practice" workshops. The overall workshop design is premised upon the Freirian educational method<sup>4</sup> (Freire, 1973, 1978, 1985; Minkler & Cox, 1980) and action research methodology (Argyris & Schön, 1991; Holter & Schwatz-Barcott, 1993; Karlsen, 1991; Schön, 1987; Sheehan, 1990; Whyte, 1991). Participants will engage in experiential learning to refine a practice approach that uses research findings about the model of health promotion developed. In transferring this refined practice model to the "real world," professionals will adapt it to an interdisciplinary health promotion team model integrated into the usual delivery of home care to chronically ill seniors. Day 1 of the "dissemination for practice" will consist of formal presentation of the findings of the home-based health promotion study, reports of seniors who have experienced the intervention, and provision of a self-directed learning package of related theoretical materials. Day 2, to be staged one to two weeks later, will consist of an open forum to discuss the findings and theoretical materials in light of current practices, opportunities for improvements, and perceived barriers and facilitators of positive change in care approaches to facilitate seniors' independence. On Day 3,

one week later, participants will be assigned to one of several focus groups comprised of four to five providers and one or two seniors who are home care consumers. Each focus group will proceed through the action research process to: (1) assess the findings of the health promotion intervention study for their relevance and adaptability to the usual approach to providing home care; (2) plan ways in which each individual provider and the team collectively involved in any one individual's care can implement findings and related theory in practice; and (3) participate in consensus group decision-making about revised approaches of care to be adopted for integration into home care delivery for all seniors on the home care roster. Participants will then be asked to implement the agreed strategies over a period of six months, holding weekly team meetings facilitated by research project staff, to discuss and refine approaches based on the implementation experience. On Workshop Day 4, to be held at the end of the six-month implementation period, the focus groups created on Day 3 will meet again to discuss the refined model of care to promote seniors' independence and to recommend appropriate practice and policy follow-up.

The second forum for setting practice and policy direction will be a consensus process culminating in a three-day consensus conference using a modified version of the National Institutes of Health consensus development model<sup>5</sup> (Lomas, 1991; Veatch, 1991; Wortman, Vinokur, & Sechrest, 1988). Participants will include professional providers, representatives of professional bodies responsible for policy and practice guidelines, agency administrators, government program, policy and planning personnel, senior consumers and researchers. For several months prior to the conference, opinion leaders from these stakeholder groups will be engaged in a preparatory process of reviewing research project findings and related literature to identify and prioritize the policy, programming and practice implications. Links with other research on seniors' independence will be identified and weighed as part of this process. Ultimately, synthesized reports of issues, implications, and recommendations for changes in policy, programming, and practice approaches will be prepared for each of the three components of primary care. Appointed consensus panelists with policy, programming, and professional practice expertise and influence in these arenas will be contracted to conduct an independent review of these reports and relevant research materials prior to the conference. At the conference, consensus panelists, along with all other participants, will conduct further review of the research, hold open forum discussions to refine recommendations, and, ultimately, finalize consensus statements for ratification by all conference participants. Statements will specify appropriate evidence-based policy, program and practice changes for models of community-based care. The consensus process and conference will thus extend the research program's bridge to the practice and policy world into the future by gaining the commitment of key change agents to specific policy, program and practice changes through their involvement in the process. Evaluation of changes in knowledge, attitudes, and behaviours of both seniors and providers, identi-



fied as outcome measures of specific projects, will be done six months following the consensus conference.

## Conclusion

Policy development is not just a “top-down” linear process of effecting change in the public and in specific public service sectors. Those engaged in the policy process from the outset inevitably also contribute to creating the policy. Their experiential knowledge and reflection of the values and beliefs of their constituencies contribute to the making of sound policy.

In the real world, policy outcomes are determined by the “street-level discretion” (Elmore, 1979–1980; Weatherly & Lipsky, 1977) of those engaged in their implementation. The experiential learning that is required to adapt a broad policy to a specific set of circumstances (Elmore, 1979–1980, p. 610) can come through participation in identifying the questions, investigating the options, and through developing, implementing, and evaluating those options. Simultaneously, the readiness to change in accordance with policy directions is reinforced, as the process mobilizes the commitment of those involved from the outset in planning for the change (Prochaska & DiClemente, 1992).

So has research made a difference to policy choices on aging issues? The Seniors’ Independence Research Program used as a case illustration in this paper, and others like it across Canada, through both their structure and processes, are engaging and preparing seniors, professionals, policy and planning personnel, and the public alike in both making and implementing sound policy choices to promote seniors’ independence. Each Seniors’ Independence Research Program may be seen as a specific set of circumstances in which a broad policy related to promoting the independence of Canadian seniors is being developed and enacted. The research process itself *has* made a difference in policy choices.

## Notes

- 1 Freirian educational approaches are premised on learning through conscientization and praxis. Conscientization, the central concept of Paulo Freire’s theory of learning and education, is a process whereby learners “achieve a deepening awareness of both the sociocultural reality which shapes their lives and their capacity to transform that reality through action upon it” (Freire, 1970, p. 27). Through conscientization, learners develop a conscious awareness that allows them to participate in a dialogic educational process that focusses their attention on testing assumptions concerning norms, codes, and ideologies that foster dependency and oppression. Through praxis, defined by Freire as the union of reflection and action, learners then engage in actions to bring about change. While Freire’s theory of education and learning arose from his work to achieve social transformations in Third World Countries, the process of moving individuals from a pre-reflective posture to a post-reflective posture has broad applicability to different cultural settings. We have chosen to apply it to the culture of professional practice, in keeping with the work of Schön (1987). In our application, through engagement in a process of critical reflection on research findings and factors in the socio-cultural professional practice context which are related to those findings, learners focus on the impact of professional practice approaches, procedures,

and beliefs.

- 2 New projects addressing the issues of concern include studies on the impact of respite care, health information hotlines, community support networks, and joint senior/professional provider strategies for planning and implementing public health programs on the independence of seniors.
  - 3 At present, variations of three generic models of case management prevail in Canada, each reflecting one of three case management orientations (Rose, 1992a). The brokerage model, in use in Ontario as well as in many other provinces, provides an impartial, interorganizational approach to a service care plan, thereby facilitating the co-ordination of services and containing system costs by preventing inappropriate client access and use of services (Joshi & Pedlar, 1992; Kane, 1988). The primary organizing value of this model is cost-effectiveness/cost reduction (Rose, 1992a). In this model, professionals (most frequently nurses, and occasionally social workers) are designated full-time to the case management role (Zawadski & Eng, 1988). Case managers determine client eligibility and needs, develop a care plan, requisition services, provide follow-up, reassess the need for services, and monitor client progress. The resultant client dependence upon case managers may be appropriate for acutely ill, cognitively impaired, or socially isolated clients, but those able and wanting to manage their own home health care may experience organizational control as an undesirable client outcome (Joshi & Pedlar, 1992). The integrated team model, as implemented in the Extra-Mural Hospital in New Brunswick, engages a multidisciplinary team to manage cases and provide services. While "nurse co-ordinator" variations of this model exist in Quebec and Alberta, in the truly integrated team model one of the team's professional providers (physician, nurse, social worker, physiotherapist, or occupational therapist) serves as the designated primary caregiver, with leadership responsibilities for case management (Zawadski & Eng, 1988). This approach fosters continuity of care, thereby enhancing perceived quality of care (McWilliam, Coderre, & Desai, 1995), comprehensive case assessment (Joshi & Pedlar, 1992), client-professional relationships, and professional autonomy and equality of status (New Brunswick Ministry of Health, 1991). The health professionals' shared goal of achieving client compliance with a care protocol reflecting their best professional judgement has been identified as the primary organizing value of this model (Rose, 1992a). However, negative system outcomes, including conflicts of interest (Kane, 1988), duplication of services, increased costs, and undesirable client outcomes, such as client dependence (Feldman, Olberding, Shortridge, Toole, & Zappin, 1993) and provider control over client's care, may also result (Feldman et al., 1993; Zawadski & Eng, 1988). The third model, recently implemented in Vancouver's Home Care Program and piloted in Alberta (Alberta Ministry of Health, 1993) and in Manitoba (Manitoba Ministry of Health, 1994) and still in an evolutionary state, is that of self-managed care. This model puts case management of personal and support services at a client-centred interpersonal level. Clients are assessed as appropriate for self-managed care at time of intake (using basic inclusion/exclusion criteria) receive information on services, and they themselves autonomously select and co-ordinate the resources they need within pre-established parameters. As of early 1995, results of the implementation of the Vancouver program indicated that approximately 50% of clients required comprehensive case management while the other 50% could manage their own care (Canadian Home Care Association, 1995). The Vancouver model was implemented to accommodate increased caseloads in a period of fiscal restraint. Client-centred sorting tools and cost-effectiveness/care outcomes have not been researched. Evaluations of the Alberta and Manitoba pilot projects of self-managed care indicate that the quality of care provided and the clients' well-being are not compromised. Indeed, clients report more satisfaction with, and greater personal control over, quality of care than in their previous traditional service delivery (Alberta Ministry of Health, 1993; Manitoba Ministry of Health, 1994). Client-driven models often identify the very positive client outcome of empowerment (Rose, 1992b). Other potential outcomes include: increased community tenure; increased incidence of living alone; increased involvement in meaningful and productive daily activities; and an enhanced natural social network (Rapp, 1986).
- 4 See note 1.

- 5 In the late 1970s, the National Institutes of Health was prompted by the U.S. Government to develop a means by which the results of medical research could be systematically evaluated for transfer to widespread use. This process, now known as the Consensus Development (CD) Program, has a conference format that brings together researchers, practitioners, consumers, and other relevant representatives to seek general agreement on the practical applications of research under review (Wortman, Vinokur, & Sechrest, 1988). At the conference, a group of experts, who serve as a consensus panel, listens to the researchers presenting their findings. The panelists discuss the findings and develop written recommendations, or consensus statements, that address specific issues concerning the technology in question. The main feature distinguishing a CD conference from a traditional research conference is the intended audience of the consensus statements. Whereas traditional research conferences aim to disseminate findings amongst and between academic colleagues, a CD conference is intended to provide recommendations for use by practitioners and the public, thereby allowing the products of research to be applied in service delivery (Veatch, 1991; Wortman, Vinokur, & Sechrest, 1988). One of the major challenges of the CD conference approach is the conference time frame, which is unrealistically limited when consensus has to capture broad stakeholder interests. Furthermore, Wortman et al. (1988) suggest several procedural and methodological refinements for improving the consensus development process: (1) screening topics to limit complexity and controversy; (2) using an established procedure for selecting the evidence to be presented to panelists; (3) using a very thorough search procedure for selecting questions, panelists, speakers and research evidence; (4) synthesizing the research evidence, for example, through meta-analysis, prior to providing it to panelists; (5) using a variety of formats for conducting the consensus conference, such as: an “adversarial” approach; convening larger panels over a longer time frame; and/or using key informant ratings; (6) giving panelists more time to draft the consensus statements; and (7) writing the final statement in a manner which captures the diversity of panelist opinions, rather than employing a “lowest common denominator” approach. Public engagement constitutes another tremendous challenge. One Canadian research study (Abelson, Lomas, Eyles, Birch, & Veenstra, 1995) found that only 72% of citizens from five potential decision-making groups (randomly selected citizens, attendees at town hall meetings, appointees to district health councils, elected officials, and experts in health care and social services) were personally willing to take on a role involving responsibility for overall decision-making related to governance of health care and social services, and far fewer thought that their group was suited to taking on responsibility (30%) or a consulting role (55%). Respondents tended to assign authority to traditional decision-makers (elected officials, experts, and the provincial government), but did favour a consulting role for citizens. With all of this information in mind, we have attempted to develop a strategy to identify respected opinion leaders of key stakeholder groups in order to heighten the potential for knowledge transfer. If action on research findings is to occur, the experts suggest that local agents, empowered by resources, are the best equipped for implementation activities (Lomas, Sisk, & Stocking, 1993).

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