

DISCUSSION PAPER NO.23

Practical Strategies for Facilitating Meaningful Citizen Involvement in Health Planning

Jayne Renee Pivik
University of Ottawa



Catalogue No. CP32-79/23-2002E-IN ISBN 0-662-32795-0

Although the views expressed in the paper are those of the author(s), each of the papers was subjected to an independent peer-review process. The Commission would like to thank the Institute of Health Services and Policy Research (IHSPR) of the Canadian Institute of Health Research for their oversight and administration of the peer-review process for these papers. The work of the authors, the reviewers and IHSPR will serve to make these papers an important contribution to the Commission's work and its legacy.

Contents

Highlights Executive Summary	
Support for Citizen Participation	1
CP and Health Planning	2
Types of CP in Health Planning	2
Advantages of CP	2
Challenges of CP	2
Canadian Experiences Involving Citizens in Health Planning	5
Case Illustrations	5
Federal Government Recommendations	7
Federal Government Sponsored Research Initiative	7
Provincial Government Recommendations	{
Social Influences on Health	8
Ensuring Equitable Representation	8
Improving Accessibility for Involvement	10
Regional Level Recommendations	12
The Multi-Modal Continuum Model	12
Collaborative Health networks	13
Community Consultants	13
Providing Educational and Training Support	14
Community and Institutional Recommendations	16
Nurturing a Supportive Climate	16
Citizen Involvement Processes	17
Knowledge	19
Support	21
Conclusion	23
Appendix A	24
References	20

Highlights

- Citizen participation in health planning is widely supported by international, national and regional governments, non-governmental organizations, consumer organizations and health researchers.
- Reported advantages to citizen participation have included: a health care system that reflects
 the specific needs, values, culture and attitudes of the community; a more efficient use of
 resources; increased support for resulting programs and services; greater access to local skills
 and resources; increased community awareness of health issues; and an enhanced sense of
 control and empowerment.
- Challenges to citizen participation have been reported to include resource limitations, lack of representativeness, conflicting vested interests, time constraints and a lack of knowledge and training for both citizens and health planners. Recommendations for federal, provincial, regional and community-based organizations are designed to address these challenges.
- Federal recommendations include instituting a national research initiative that addresses access to equitable citizen involvement in health.
- Provincial recommendations focus on developing policies that address the social influences on health, accessibility and representation of involvement.
- Regional level recommendations center around the Multi-Modal Continuum Model that
 involves the development of formalized collaborative health networks and the establishment
 of informational, educational and support venues for promoting informed and considered
 citizen input.
- Community and organizational recommendations include specific suggestions for: ensuring a climate conducive to community participation; process issues; knowledge requirements; and support requirements. A Conceptual Framework for Community Involvement in Health Planning has been developed to assist in this effort.
- Process, outcome and evaluation research is recommended.

Executive Summary

For the past 25 years, citizen participation (CP) in health planning has been considered an important feature of responsive and equitable health systems. The reported advantages to CP in health planning include a system that addresses the specific needs, values, culture and attitudes of the community. Furthermore, it provides the opportunity for greater support of resulting decisions and services, a more efficient use of scarce resources, an enhancement of community awareness of health issues, a mechanism for public feedback and increased networking, access to local resources and skills of community members, and an enhanced sense of control and empowerment within the community (Bracht and Tsouros 1990; Feather, McGowan and Moore 1994; Lilley 1993; and White 1982).

However, challenges to CP have been reported. These include: time constraints, lack of representation, difficulty reaching marginalized populations and a lack of education and training specific to CP (Weaver and Pivik 1997a). As well, a lack of resources, perceived status differentials, processes that are not fully accessible, poor communication, differing definitions of participation, conflicting vested interests, incongruence between stated purpose and practice, tokenism and role strain (Lilley 1993; Lord 1989; and Valentine and Capponi 1989) have impeded CP efforts.

The purpose of this paper is to identify which strategies have worked in the past and which have not in order to develop clear guidelines for facilitating CP in health planning. Sources for this information have come from health planners, governments, consumer organizations and health researchers, both here in Canada and abroad. The final recommendations have been organized into federal, provincial, regional and community-based initiatives.

Meaningful citizen participation is the focus of this paper, and thus the main emphasis is on citizen involvement strategies, as opposed to citizen consultation. Principles of collaboration and equity are stressed throughout the recommendations. Collaboration refers to the sharing of information, opinion, problem solving, decision making and responsibility (Consumers' Health Forum of Australia 1990) and is illustrated by the recommendation for collaborative health networks and partnership alliances. Equity issues that are examined include recommendations that facilitate improved accessibility, informed and considered opinion and methods for gaining information from marginalized populations.

Federal level recommendations include assessing the interest and accessibility of involvement of citizens and vested interest groups in health planning across Canada through a national survey. It is recommended that this survey include the following questions: the level and type of participation they consider being involved in; climatic factors that would assist CP; process issues considered important and necessary; knowledge and skill requirements that would promote their participation; support requirements necessary for participation; and potential solutions for overcoming constraints of current CP mechanisms. Concurrently, a database could be developed that would include names, experiential knowledge, skills and expertise of individuals who express an interest in participating in health planning.

Provincial level recommendations focus on the development and implementation of policies that address the social influences on health, issues of representation of citizen involvement and processes that improve accessibility to involvement.

The regional level recommendations consolidate those policies into an organizational structure entitled The Multi-Modal Continuum Model. Intrinsic to this model are collaborative health networks, which are comprised of formalized partnerships with organizations dealing with health, social services, community organizations, businesses, etc. Along with health professionals, social service and outreach workers, health planners and community partners, it is recommended that collaborative health networks employ community consultants whose sole aim is to identify concerns, needs and priorities from members of the community. These consultants will particularly focus on marginalized populations and will be hired based on their experiential knowledge of the targeted initiative.

Salient to meaningful citizen participation is the need for training and education for all members of the collaborative health network. Resources will be required to develop training programs that focus on health issues, current health policies and programs, meeting procedures, health planning and evaluation, communication skills, group facilitation techniques, partnership building, conflict resolution, community building and research skills related to CP. The development of guides that focus on contacting the community, needs assessment mechanisms, priority setting and evaluation are also recommended.

Involving citizens in health planning at the community level also requires education, training and support. A Conceptual Framework for Citizen Involvement in Health Planning has been developed specifically for community-based participation. The recommendations comprising this framework are grouped into four broad categories and include: 1) nurturing a climate conducive for citizen participation (mobilizing the community, fostering respect and trust, developing an attitude shift for professionals and utilizing a partnership approach); 2) process issues (defining partners, developing a common vision, clarifying roles and responsibilities, defining a decision-making process and assessing participation); 3) knowledge requirements (information, education and training); and 4) support requirements (financial, organizational and political). Concrete strategies are provided for each of these categories and the recommendations are presented in a checklist format for ease of use (see Appendix A).

Finally, it is recommended that the Multi-Modal Continuum Model and the Conceptual Framework for Citizen Involvement be assessed and that all health initiatives are evaluated for process, outcome and satisfaction. Many countries in the world have made great strides in CP in health planning in the past 25 years since the World Health Organization's recommendation (1978). However Canada, once again, has the opportunity to excel in health care if we develop policies and procedures that promote equitable and inclusive participation in health planning and provide the resources to support them.

Description of Citizen Participation in Health Planning

Support for Citizen Participation

The concept of including citizens in the process of defining their health needs and developing solutions to meet those needs has been supported by the World Health Organization (WHO 1978), the federal government (Epp 1986; Ministry of Health 1993), provincial governments (Government of Quebec 1988; Ontario Ministry of Health 1989; Premier's Commission on Future Health Care for Albertans 1989; Nova Scotia Royal Commission on Health Care 1989; and Saskatchewan Commission on Directions in Health Care 1990), regional health organizations (e.g., Association of District Health Councils of Ontario 1991; Regional Municipality of Ottawa-Carleton 1995; and Regional Municipality of the Halton Health Department 1993), consumer organizations (Consumers' Association of Canada 1993, Consumers' Health Forum of Australia 1990, 1996) and health researchers (Gott and Warren 1991; Lilley 1993; Meleis 1992; Mhatre and Derber 1992; and Siler-Wells 1988), just to name a few. Support for increasing citizen participation (CP) in health planning was in large part influenced by the World Health Organization and the United Nations International Children's Emergency Fund's 1978 Alma Ata Declaration (World Health Organization 1978). Central to this declaration is the conviction that individuals have the right and responsibility to participate in the planning and implementation of their health care. The result of this declaration aimed at bringing international health for all by the year 2000 was an increase not only in CP but also decentralization of health services, an emphasis on health promotion and a focus on deinstitutionalization.

In response to this initiative, the Canadian government released a document entitled *Achieving Health for All: A Framework for Health Promotion* (Epp 1986) that encouraged CP in policy development for health care reform. Specifically,

Encouraging public participation means helping people to assert control over the factors which affect their health. We must equip and enable people to act in ways that preserve or improve their health. By creating a climate in favour of public participation, we can channel the energy, skills and creativity of community members into the national effort to achieve health. (p. 9).

Consequently, many provinces developed a decentralized health care system that included regional boards of health that are responsible for budgeting, service management, monitoring and evaluation of health and social services. A review of six Canadian provincial health commissions and reports conducted by Mhatre and Derber (1992) identified increased CP as an important principle for improved health care, along with de-centralization and, in some cases, devolution of authority from the provincial to the regional level (also see Godbout 1981; Zakus and Lysack 1998, for reviews).

Recently, a national consultation process was conducted to identify priority areas related to health services and policy issues by five large Canadian organizations (Federal/Provincial/Territorial Deputy Ministers of Health, the Canadian Coordinating Office of Health Technology Assessment, the Canadian Health Services Research Foundation, the Canadian Institute for

Health Information and the Institute of Health Services and Policy Research). Human health resources were identified as the dominant issue for health research for the next two to five years with particular emphasis placed on meeting the health needs of marginalized or underserved groups in a sustainable and cost-effective manner (Canadian Health Services Research Foundation 2001).

Consumer and advocacy organizations have also rallied together to insist on an equitable and influential role in health planning. One example is the recommendations from the Research to Action Forum, that people with disabilities play a central role in the development and implementation of policy related to disability and have better opportunities for involvement in service planning (Research to Action Forum: Recommendations and Summary of Findings 1999).

CP and Health Planning

Health Planning. Health planning essentially involves identifying problems or gaps within a specific area and developing an action plan for implementing solutions. A framework described by Rice (1993) for assessing health services typifies the problem identification stage. Initially, the area is defined in terms of social systems, environmental factors and demographics. Community members are then recruited from community organizations such as school boards, public health organizations, elected officials, etc. Following recruitment, a community health profile with key indicators and measures that assist with setting priorities is developed (e.g., census data, hospital records, police records). Finally, a list of problems to be solved as well as available resources by obtaining citizen input is developed.

Once the goals and objectives have been identified, the community under investigation examined, an inventory of existing services taken and demographic and epidemiological data gathered, the second stage of the health planning process is to develop a plan for implementing the solutions. Based on the results of the needs assessment, planners then determine priorities, develop recommendations and implementation strategies, define evaluation criteria, prepare a final report and establish mechanisms for updating the plan (Association of District Health Councils of Ontario 1991).

Citizen Participation in Health Planning. CP in health planning refers to involvement in the identification, development and evaluation of services, programs, policies and laws aimed at keeping citizens healthy, i.e., their emotional, physical, social and spiritual well-being (Lilley 1993). Strategies for including citizen input in health planning can be broadly categorized as passive or active, depending on participation level and amount of decision-making power involved.

Types of CP in Health Planning

Consultation Strategies. Traditionally, CP in health planning has involved a more passive or consultative role, where community members are asked to provide input related to their needs and concerns, program planning and resource allocation (Regional Municipality of the Halton Health Department 1993). Citizen consultation is aptly described by Saltman (1994) as a "voice" and conducted using such methods as surveys, community forums, focus groups, public meetings and key informant interviews.

Involvement Strategies. Active participation or citizen involvement reflects a "voice and choice" for community members (Saltman 1994). In citizen involvement mechanisms, community members are involved in the development, implementation and evaluation of health planning (Meleis 1992). Examples of citizen involvement strategies include membership on boards or committees in provincial health councils, regional health agencies, local boards of health, hospital advisory committees, hospital boards of directors, or specific task forces (Lilley 1993). Another form of citizen involvement is the rapid participatory appraisal process developed by the World Health Organization (WHO 1988), where key community informants work collaboratively with health professions to collect and analyse community information and determine priorities based on that effort (Rifkin 1996). It is clear that the main criteria differentiating citizen involvement from citizen consultation is the citizens' level of participation in decision making.

Advantages of CP

Many advantages to CP in health planning have been reported (Bracht and Tsouros 1990; Feather, McGowan and Moore 1994; Lilley 1993; Rifkin 1996; and White 1982). A compilation of these include:

- health care that reflects the specific needs, values, culture and attitudes of the community
- decision making that is more accountable by incorporating the specific concerns identified in the community
- a more efficient use of scarce resources
- an enhancement of community awareness of health issues
- increased support for the resulting programs and services
- the opportunity for increased networking between health care service providers and community members
- access to local resources and skills of community members
- a mechanism for public feedback
- the opportunity for training and educating community members for future community development activities
- an enhanced sense of control and empowerment within the community.

Including community members in needs assessment and problem solving provides the opportunity for different perspectives, pooling resources and creative problem solving. For example, one of the projects of the "Healthy Localities" strategy utilized a brainstorming session with community members on the topic of nutrition. Creative community-based solutions involved convincing local grocery stores to set up a fruit and vegetable stand for people in a high rise development, the introduction of healthier food in school canteens and a change in the menus based on feedback from individuals receiving Meals on Wheels (Turner 1990).

Challenges of CP

With such reported advantages, one would expect that CP in health planning would be the norm and practised consistently, which unfortunately is not the case. Reported barriers to CP include: resource limitations (Checkoway, O'Rourke and Bull 1984; and Weaver and Pivik 1997a), perceived status differentials, processes which are not fully accessible, poor communication, differing definitions of participation, conflicting vested interests, an incongruence between stated purpose and practice, lack of representativeness, tokenism and role strain (Lilley 1993; Lord 1989; and Valentine and Capponi 1989). As well, Weaver and Pivik (1997a) found that health planners identified time constraints, difficulty reaching marginalized populations and a lack of knowledge and training as significant challenges to CP.

Canadian Experiences Involving Citizens in Health Planning

Case Illustrations

In order to identify what methods have been successful in the past and where changes can be made for the future, a few illustrations of CP in health planning in Canada are presented. Aronson (1993) describes a public consultation process conducted by the Ontario Ministry of Community and Social Services where elderly people were asked for their feedback on a reform document for long-term care policies. This exercise was a clear case of citizen consultation, not involvement. Further, citizens' contributions were solicited in the later stages of the policymaking process, calling into question its purpose. Finally, the consultation process was flawed. When citizens gave their input, ministry facilitators attentively listened to the concerns, anecdotes and questions and then asked them to turn their comments into suggestions for reform (which was difficult for many of the participants). Lessons that can be gleaned from this experience include ensuring that CP occurs at the formative stages of planning, that processes are accessible, and realizing that citizen input reflects experiential knowledge and may be delivered as stories or personal experiences. For this last point, it is the job of the planner to take those stories and interpret them, not the role of the citizen to make their experiences fit the health plan or objectives. Fortunately Labonte and Feather (1996) have developed a unique and user-friendly way in which citizens' story telling can be analyzed and used to identify health concerns and priorities.

Factors that facilitated and hindered CP in health planning were examined for regional health planning organizations in Eastern Ontario (Weaver and Pivik 1997a). Six District Health Councils and six Public Health Units were surveyed to study the following: the organizational culture of the agency in relation to CP, when CP is used, which mechanisms are used, important skills of citizens and staff for facilitating CP, resources, barriers to CP and suggestions for eliminating those barriers. Facilitators identified for public involvement and consultation included clear organizational policies and guidelines, adequate staff and time to pursue community involvement, resources for training, information, education and materials and financial resources for involving community members.

Regarding community-based health planning, an effort in British Columbia can serve as an example. Community-based health planning groups were organized with a mandate to develop a health plan that reflected the needs of its constituents based on the policy "New Directions for a Healthy B.C." (Higgins 1999). The effort was proactive in that it involved citizen input in the early phases of planning and comprehensive in terms of including a plan that involved public education. However, this experience speaks to the challenge of ensuring representation of citizen input or involvement, and particularly, in developing processes accessible to marginalized populations. Of the four health planning groups that were developed, youth, single parents, persons with physical disabilities or mental illness and members of First Nations were not adequately represented.

In another community-based experience, Nelson, Lord and Ochocka (2001) closely examined the factors and processes of citizen involvement in mental health planning and policy development. Three different organizations were studied over 2.5 years; a Canadian Mental

Health Association, an organization geared toward housing for survivors/consumers with mental illnesses and a local self-help organization. This study clearly indicates that citizens are capable of successful involvement in health planning and service delivery given the opportunity and proper support. Factors such as value-based mandates, participatory processes and structures, willingness for power sharing, and flexible and individualized support services were a few of the key factors influencing successful involvement. Constraints inhibiting citizen involvement included a lack of governmental funding, inconsistent support from some stakeholder groups, and the need for skills training and education.

Understanding successful strategies and existing challenges provides useful information for facilitating CP. Based on previous experiences, recommendations for facilitating meaningful CP have been developed for federal, provincial, regional and community-based initiatives.

Federal Government Recommendations

Federal Government Sponsored Research Initiative

Typically, deciding when, where and which type of citizen input is needed for a particular project is under the auspices of health planners and bureaucrats. In fact, only a few studies have attempted to determine from the public which type of participation would interest them. Notably, Abelson et al. (1995) questioned 46 randomly selected citizens and 46 attendees at a town-hall meeting about their willingness and interest in participating in health and social services needs identification and decision making. From this sample, more interest was expressed in assuming a consulting role (73.9 and 50.0%, respectively) than being held responsible for decisions (8.7 and 15.9%). However, as most of these respondents reported middle-class incomes and high education levels, with a third of the randomly selected citizens and over half of the town-hall attendees employed in either health or social services, this sample was clearly not representative. Further, these authors did not ask respondents to indicate what informational needs, resources or training they might need to participate.

It is recommended that the federal government initiate a research program focused on access to equitable health. This can be achieved by either funding a research chair position or a special competition through the federal granting agencies associated with health. It is recommended that this mandate include conducting a national survey to assess interest, accessibility and challenges to citizen participation in health planning to be targeted at citizens at large, consumer groups, and advocacy organizations. Questions should be asked about: the level and type of participation that they might be interested in, the resources needed for participation. accessibility issues, current barriers and possible solutions to participation and their current skills, knowledge and expertise. This information will not only provide a guide for better methods for reaching citizens but may also provide a database of citizens interested in participation. As well, information about the perspectives and needs between citizens-at-large compared to vested interest groups can be determined. Instead of resting on the opinion that citizens are typically anothetic toward participating in health planning (Abelson et al. 1995: Church and Barker 1998), this effort will pro-actively determine where and how to facilitate their involvement. Concurrently, surveys sent to health planners would provide valuable information about current practices, resources and support needed for enhancing CP and the challenges that make CP difficult to conduct. Policies based on the results of this research can then be developed in order to address accessibility, representation and processes issues associated with facilitating citizen participation in health planning.

Provincial Government Recommendations

Tangible political support is considered essential for facilitating CP in health care planning and decision making (Church and Reville 1989; Kushner 1996; Mattessich and Monsey 1992; Meleis 1992; Siler-Wells 1988; and Sullivan and Scattolon 1995). The following recommendations for provincial governments center on the development and implementation of policies associated with social influences on health, ensuring representation and improving accessibility to participation in health planning by its citizens.

Social Influences on Health

It is recommended that provincial governments develop and implement policies that directly link health with social services. One of the greatest determinants of health inequalities identified by Raphael (2000) is poverty. He argues that communication among health, social development, policy organizations and municipal sectors needs to occur more frequently in order to address the problem collaboratively. Babwin (1998) also stresses the need to be cognizant of the health impacts associated with housing, crime reduction and safety issues.

Labonte (1992) has shown that public health workers are aware of the health influences of unemployment and homelessness, but regard poverty more in relation to lifestyle factors than health. Interestingly, Labonte also found that health professionals view health inequalities more narrowly than either individuals or community groups. This finding was confirmed by Rowan (1998), where both consumers and health providers identified depression, isolation and stress as negative influences on health. However, the consumers focused on the broad-based social impact of these factors on family and community whereas the providers focused on how these issues affected the aged or persons with disabilities. These results indicate the influence one's role has on the type of information elicited, further stressing the need for representative feedback. When the relationship between social issues such as unemployment and homelessness (Church 1996) is linked with health consequences, it is likely that more individuals (particularly marginalized populations) will understand the importance of participating in health planning.

Ensuring Equitable Representation

It is recommended that provincial governments develop and implement policies that promote equitable representation in health planning. What is a truly representative group? According to Checkoway (1979) representativeness in CP reflects consumers who are broadly representative of social, economic, linguistic and racial populations as well as geographic proximity of the health service area. He further suggests that citizens who are representative of constituency organizations have more support and are more likely to represent a stronger and more diverse voice for consumers, an opinion supported by consumer organizations, planners and researchers alike (Bastian 1996; Brotchie and Wann 1993; Consumer's Health Forum of Australia 1990, 1996; Gott and Warren 1991; Lilley 1993; Siler-Wells 1988; and Sullivan and Scattolon 1995).

However, whether citizens or consumers/users are sought for participation is dependent on the goal of the initiative. Citizens can provide a community-based perspective reflecting the specific needs and priorities identified by their communities as important. Leaders in the community have often shown to be very effective in this role. Users or consumers on the other hand, can provide very specific experiential knowledge of a health issue such as barriers to equitable health care services or the social impact of a disease. Both types of participation are important and should be sought as needed. In relation to health policy development, Kuschner (1996) recommends participation by "consumerists" or individuals with a focus on consumer rights (e.g., access, choice, information, advocacy and equity) and an understanding of the policy process. She suggests approaching national umbrella organizations that deal with consumer issues such as the Consumer Association of Canada.

One of the major concerns associated with representativeness is the lack of marginalized individuals providing their perspective. We need to identify the underrepresented groups and develop mechanisms for gaining their input. Marginalized populations have been defined by Laverack and Labonte (2000) as "those most in need, not already able to meet their own needs, with limited access to resources or who exist outside power structures" (p. 258). For example, marginalized populations in relation to health planning have included individuals who are stereotyped due to unemployment, disabilities, ethnicity, age or gender. Disadvantaged groups tend to have higher health needs but are also the least likely to have a say or participate in identifying needs and priorities for health services (Robertson and Minkler 1994; Kieffer 1984; and Whitehead 1992), and without active support and involvement are unlikely to participate (Laverack and Labonte 2000).

Higgins (1999) examined the strategies for increasing participation in marginalized populations (First Nations bands, street youth, youth, single parents, persons with physical disabilities and persons with mental illness) using focus group discussions. She found that traditional strategies such as committee meetings, public forums and surveys were not useful mechanisms for these groups. They were interested in participating but wanted that participation to happen in their own settings; such as day care settings, community organizations, an Aboriginal friendship centre, via the Internet or at school for the youth. These citizens suggested that health planners spend time "walking in their shoes" in order to better understand their realities—the first step toward experiential participation. Higgins recommends that to reach underrepresented groups, go to where the people are, be it coffee houses, churches, community centres, etc., and actively listen and observe. Then proactively engage individuals in discussing their needs and concerns. Finally, acknowledge and respect the diverse contributions and strengths of citizens to participate. She suggests that

Meaningful participation may constitute sharing experiences as recipients of services, providing input and feedback about the quality of health care, as well as identifying needs in the planning of programs. This may be in the form of citizen panels, discussion groups or innovative methods such as at religious gatherings and as display structures in malls (p. 33).

The importance of gaining this particular input is especially important since "average citizens" rate the needs of disadvantaged populations very low (Lomas 1997).

Improving Accessibility for Involvement

It is recommended that provincial governments develop and implement policies that promote improved accessibility to citizen involvement in health planning. Improving accessibility in health planning involves determining how and where participation is requested. Church (1996) describes the barriers that survivors of mental illnesses faced in trying to have their voices heard during legislative subcommittee hearings on mental health. The meetings were held in large cities and the survivors were expected to pay for their travel and accommodations (with reimbursement given later), respond to a committee agenda that focused on legislated issues such as centralization/decentralization and deal with the difficulties associated with public speaking. A more accessible process would have included up-front travel and accommodation expenses, an agenda that allowed these survivors to address issues of which they have clear expertise (e.g., what it is like to have a specific illness and society's response to that illness) and optional formats for expressing opinions, such as having letters read to the committee from survivors.

Regarding where to gain citizen input, the need to go to the people was also indicated in a study by Rowan (1998), where less than half of the consumers from a variety of organizations (service clubs, social service groups, religious groups, schools, community groups, self-help groups, others) attended focus group meetings at a local hospital to discuss health services needs, whereas over 90% of the participants from the hospitals attended. Babwin (1998) also found that going into the community and meeting with community leaders on their turf is important for participation. A finding that has been proven successful over and over again (Deville-Almond 1998; Pivik and Weaver 1997; Rodney et al. 1998; and Weaver and Pivik 1997b).

Other policies that would facilitate meaningful participation reflect the processes for gaining input. It is recommended that the following four principles be adopted based on the legal requirements of consultation identified by Edwards (1998). These include: 1) consultation should take place in the formative stages of the initiative; 2) the consultee must have sufficient and adequate information to make informed decisions; 3) adequate time must be given to make decisions; and 4) community decisions must be given conscientious consideration. Citizens need to know that their participation is valued. Policies that require that participation be sought in the formative stages of the initiative will strengthen the belief that their opinion was given conscientious consideration, as noted earlier by Aronson (1993).

It is also important to give citizens an opportunity to reflect on their opinions, as shown by Shiell, Hawe, and Seymore (1997) in their test-retest study of health outcomes, where a substantial number of individuals changed their opinion following consideration of the issues. Jordan et al. (1998) recommend that, if health authorities are interested in substantive recommendations from the public, opportunities for informed and deliberative participation such as citizens' juries or user consultation panels be used.

Policies that promote information provision to citizens are another important antecedent for meaningful participation. It is recommended that provincial governments provide resources to support the development of coalitions, opportunities for public debate on health issues

(Sabatier 1987) and the development of citizen research centres to assist community involvement in rule making and policy decision (MacDermid et al. 1993). Partnerships with academics could assist in this initiative for educating the public, as evidenced by the public workshops on health put on by St. Francis Xavier's University Extension Department (1999). Entitled "People's School on Health," these workshops covered such topics as Globalization, Inequalities in health, Health public policy: what is it and how can we influence it? Health impact assessment and Solutions.

In summary, provincial government recommendations that would support meaningful participation include the development and implementation of policies that: promote social and economic alliances with health, ensure representation of citizen input, facilitate accessibility of CP and provide informational and education opportunities that promote informed decisions.

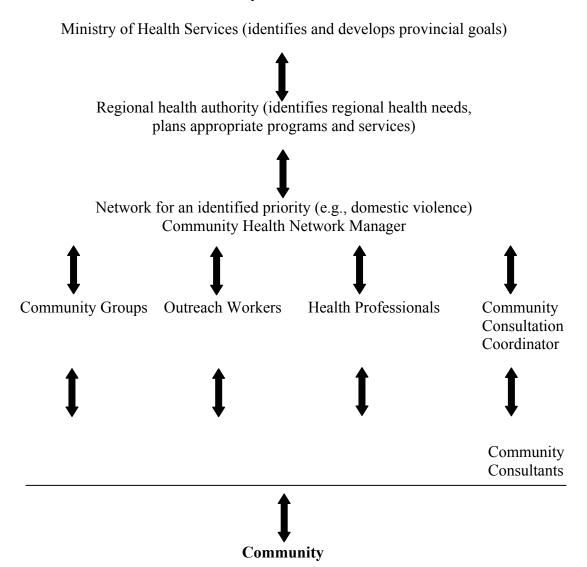
Regional Level Recommendations

The Multi-Modal Continuum Model

The regional level recommendations focus on the development of a comprehensive working model that incorporates the provincial policy recommendations. Entitled the Multi-Modal Continuum Model, it addresses the challenges associated with ensuring accurate feedback from the community, the difficulty in reaching marginalized populations, the social influences on health and the need for representativeness of community feedback. The model is based on the concept of data triangulation (Jick 1979), where multiple methods of data acquisition are used simultaneously to promote accuracy.

The Multi-Modal Continuum Model

Jayne R. Pivik



Collaborative Health Networks

It is recommended that regional health authorities formally develop collaborative health networks. Creating formalized collaborative health networks addresses the social impacts on health and provides a mechanism for pooling skills, talents, resources and a vehicle for information collection and dissemination (Proenca 1998). Collaborative health networks would involve organizations whose mandates intersect with health issues (e.g., poverty, housing, crime, social support, education, etc.) such as public health units, social services, law enforcement, schools, community organizations such as the Independent Living Resource Centres, shelters, religious organizations, businesses, etc. Each network would have a specific focus, such as the priorities identified by the regional health authority. According to Proenca (1998), effective collaborative health networks are characterized by high levels of connectivity and integration, have organizational cultures that emphasize teamwork, mutual respect, reciprocity, and community accountability and are coordinated by a community health manager or leader. Gamm (1998), in his study of effective health networks, stresses the importance of carefully designing a program and the need for information sharing across the organizations involved. These networks then become a means of identifying community needs and priorities, and a vehicle for addressing the problems identified. The development of the network must be a collaborative effort with all those involved, where all participants mutually identify prevailing values, goals and principles. A collaborative partnership approach will prospectively identify roles, responsibilities, expectations, participants' strengths and constraints, and define decision making and conflict resolution strategies (Pivik 1997).

Community Consultants

It is recommended that regional health authorities dedicate resources for hiring **community consultants**. The most salient feature of the model related to meaningful CP is the introduction of community consultants whose sole aim is to assist in identifying the health needs and priorities of the community. Once provincial priorities have been identified, consultants with experiential knowledge of the targeted priority can be identified. For example, the identified priorities of the Ontario Community Health Centres health promotion programs related to child and family health (Ontario Ministry of Health and Long-Term Care 2002) include: 1) domestic violence prevention/treatment; 2) parenting education, both individual and group, to improve healthy child development; 3) anti-racist initiatives and other programs to promote tolerance, cultural diversity and acceptance of minority groups; and 4) education and counselling related to weight/body image issues, peer relationships, healthy sexuality programs for street youth including drop-ins, programs for teen mothers. Community consultants for this program may include survivors of domestic violence situated at a halfway house, individuals of different races or religions within their communities, people who have dealt with eating disorders or teen mothers who are situated at youth drop-in centres. With their experiential knowledge, these consultants understand first-hand the realities of social and health services associated with these issues. Further, people in similar situations are more likely to open up to them and they probably already have contacts in the community. Finally, they represent marginalized populations and are likely to provide unique perspectives and experiences. In order to facilitate access to community members, community consultants need to be situated within the community. According to

Rodney et al. (1998), the benefits of using community members for outreach work includes "improved accessibility and sustainability of health services, increased sense of power in the community to effect change and increased communication and collaboration between community members and health care providers in problem identification and resolution" (p. 372).

Hiring the consultants is paramount to the success of this model. We do not expect our outreach or health workers, health planners, politicians or researchers to volunteer their time for identifying community needs and priorities. The community consultants should be treated equally and compensated for their time and effort (Meleis 1992; Pivik 1997; and Pivik and Weaver 1997). This suggestion was reinforced in Abelson et al.'s (1995) study of community participation in health planning, where citizens indicated that payment for their time would motivate their involvement. Hiring is expected to increase continuity of citizen involvement. One of the greatest challenges related to citizen involvement in health planning is associated with the idea that in order to provide meaningful input you must volunteer your time. This restricts involvement of those individuals who must work to support themselves or their families. Understandably, concerns for basic needs will supercede volunteering efforts. As such, only those individuals who are not concerned with ensuring continual sustenance tend to participate in citizen involvement positions long term, such as retired individuals (Weaver and Pivik 1997a). As such, the representativeness of the individuals participating in citizen involvement mechanisms is skewed toward a particular group and hence a particular perspective. Research has shown that one's role can influence what information is attended to and given priority (Canter 1977). Further, Howell et al. (1998) found that job creation appears to be the most effective way to involve citizens. In fact, many of the individuals hired through their community empowerment initiative had previously been welfare recipients or in community health and social service programs. The success of this initiative provides another motivation for the use of community consultants and, by hiring the community consultants, we address the challenge of representativeness and access to underserved populations.

The Community Consultants would work collaboratively with Community Consultation Coordinators who will be responsible for coordinating their activities. This may involve identifying current concerns and methods for acquiring information, providing information from the community health services to the consultants and the public, training consultants, organizing involvement opportunities such as community forums, networking with outreach workers and health planners, and collecting and forwarding the data from the Community Consultants to the Community Health Services Department. Experience from the Healthy Start Program (Howell et al. 1998), a large American health initiative, has indicated that effort in mobilizing the community and coordinating citizen input is labour intensive and requires adequate staffing resources to succeed.

Providing Educational and Training Support

It is recommended that regional health authorities provide tangible support for educating and training all individuals involved in health planning. Increased education and training is another necessary component for all individuals involved in health planning. For example, further education and training has been suggested for: communication skills (written,

verbal and listening), process issues associated with health planning and evaluation, interview techniques, procedures for meetings, partnership building (Brotchie and Wann 1993; Lilley 1993), group facilitation techniques, conflict resolution, community building, process issues and the value of CP (Lilley 1993), community networking, research skills related to CP, stress management and assertiveness training (Brotchie and Wann 1993). How-to guides that focus on contacting the community, needs assessment mechanisms, priority setting and evaluation can supplement the training and be a very useful resource (Dwyer 1997).

The continued effort by outreach workers and health planners in assessing needs and priorities will provide a multi-layered assessment opportunity (data triangulation). After an evaluation of the proposed model, outreach workers, health planners and community consultants may find that duplication of activities is unnecessary or, conversely, that it provides a broader base of citizen input.

In summary, recommendations for regional health authorities focus on the development of collaborative health networks that involve formal partnerships with social services. These networks would include community consultants who are dedicated to the role of obtaining citizen input in health planning, which is expected to provide increased citizen input into health planning. Choosing community consultants based on experiential knowledge will provide more meaningful information since it is expected that they will have better access to marginalized populations, thereby improving representation of citizen involvement in health planning. Hiring and training those individuals is expected to improve continuity of citizen involvement. Combining the information of community consultants working on the same topic from different communities (e.g., youth suicide) may provide a greater breadth of knowledge, thereby promoting more representative data.

This model may be considered radical by those who believe that only "well-educated professionals" should be involved in obtaining public input, or that people who have had difficulties in the past may not be up to the task of such an important role. One of the main challenges associated with CP in health planning is the issue of sharing power. Power differentials occur when one group (historically, health professionals) believe that their expertise is the only element necessary to make informed decisions. Fortunately, a paradigm shift is occurring where health professionals are realizing that the experiential knowledge of the consumer, user or citizen is invaluable and a necessary component for effective and valid decision making. When more and more organizations and agencies incorporate collaborative and participatory approaches in their policies and procedures (where all participants are valued for their specific knowledge and expertise) power struggles will start to dissipate. Along with power struggles, our greatest challenges to gaining meaningful input in health planning are ensuring representation, reaching marginalized populations and keeping sustainable input. Evaluation of the Multi-Modal Continuum Model by Regional Health Authorities will determine whether it addresses these challenges.

Community and Institutional Recommendations

Community and institutional recommendations focus on the mechanisms involved in conducting CP in health planning. Although citizen involvement in health planning typically takes place within communities and institutions (whereas consultation strategies are mainly used federally and provincially), the principles and strategies involved in the following recommendations can apply at all levels. These recommendations are based on a Conceptual Framework for Community Involvement in Health Planning, that was derived from an extensive literature review that synthesized the wisdom and opinion of health professionals, governments and consumers who have had experience and expertise related to CP/involvement in health planning (Pivik and Weaver 1997). Information describing the techniques, strategies and recommendations for facilitating CP came from journal articles, occasional papers and reports from consumer organizations, health care institutions and governments. It is recommended that community organizations and institutions consider the following four categories when conducting CP in health planning: 1) ensuring a climate conducive to CP; 2) process issues; 3) knowledge issues; and 4) support. For ease of use, the recommendations have been consolidated into a checklist format (see Appendix A).

Nurturing a Supportive Climate

The first stage in facilitating CP is nurturing a supportive climate. For promoting a climate conducive for CP, four categories have emerged: mobilizing the community, fostering respect and trust, an attitude shift for health professionals and utilizing a partnership approach. Concrete strategies identified for mobilizing the community include utilizing communication tools and techniques such as press releases and conferences, public meetings and written materials (Rice 1993), utilizing existing networks (Gott and Warren 1991; Weaver and Pivik 1997b; and Siler-Wells 1988), providing public education about community needs, community dynamics, status and the availability of health care participation (Meleis 1992; Siler-Wells 1988), ensuring information is clearly understood (Lord and Farlow 1990; O'Neill 1992), and providing motivation and rewards for participation (Meleis 1992).

Fostering Respect and Trust. The second category for nurturing a climate conducive for CP is fostering respect and trust between health care professionals and community members. Tangible ways identified for this purpose include really listening to each other, building on an individual's capacities instead of deficiencies (Lord and Farlow 1990), ensuring participation is not tokenism, ensuring meetings are inclusive for all partners, providing equal information to all participants, acknowledging the different perspectives, values, skills and experiences of all partners (Brotchie and Wann 1993; Consumers' Health Forum of Australia 1990; and Lord 1989) and recognizing that building trust takes time (Lord 1989; Singer 1995).

Minimizing Power Differentials. Also recommended for nurturing a climate for CP is the minimization of power differentials between community members and health professionals (Lord 1989; Lord and Farlow 1990; Meleis 1992; Sen 1994; Siler-Wells 1988; and Weaver and Pivik 1997b). These authors have suggested that health professionals take off the hat of expert and view themselves as partners and learners, and accept that community members have a right to

identify their own needs and solutions by promoting methods that are more inclusive, empowering and participative.

Partnership Approach. Related to an attitude and role shift is the use of a partnership approach when participating in health planning. Factors identified by Audet and Rostami (1993) for promoting effective partnerships include: a positive attitude by all participants, shared values, good communication skills, the capacity to evolve, a shared commitment, trust and a balanced and qualified team. Concrete strategies for encouraging partnerships include effective communication of different realities, values and assumptions (Lord 1989; Meleis 1992), agreement between partners of the purpose and vision of the task (Gott and Warren 1991; Meleis 1992) and holding meetings in community locations (Siler-Wells 1988).

Citizen Involvement Processes

Once a climate conducive to CP is established, the mechanisms for conducting citizen involvement can be initiated. Citizen involvement may include working with Community Consultants, or being members of boards or committees in provincial health councils, regional health agencies, local boards of health, hospital advisory committees, hospital boards of directors, or specific task forces (Lilley 1993). Proponents of CP in health care planning stress the importance of focusing on process issues in a partnership context (Bastian 1996; Bichmann et al. 1989; Brotchie and Wann 1993; Consumers' Health Forum of Australia 1990; Lilley 1993; Lord 1989; Meleis 1992; and Siler-Wells 1988). Examples of process issues important to partnerships include determining: who to involve, the reason for their involvement, their role and responsibilities and how decisions will be made

Criteria for Defining Partners. Identifying the composition of the group to work on a health issue is one of the first process issues to be addressed. Accessing input from members of the community who have the life experience to fully understand all of the issues associated with the problem is an important consideration. Meleis (1992) identifies such life experiences as language, culture, location and experience with health concerns as important considerations for citizen involvement. Further, she suggests increasing the awareness of the diversity of the community in question and ensuring equitable representation of underserved or vulnerable groups.

One strategy identified for ensuring community representation is to recruit community members from organizations that are primarily consumer-based (i.e., individuals who come together voluntarily because of common experiences or conditions) (Bastian 1996; Brotchie and Wann 1993; Consumers' Health Forum of Australia 1990, 1996; Gott and Warren 1991; Lilley, 1993; Pivik 1997; Siler-Wells 1988; and Sullivan and Scattolon, 1995). The various advantages identified from these authors for utilizing existing community networks or organizations include:

- the opportunity for support in terms of knowledge and skills from other members
- information sharing
- accountability
- ensuring a strong mandate from the community

- greater representation
- nurturing a sense of community for consumers.

Shared Vision. Once a group of individuals is organized to work on the problem at hand, the next stage in health care planning is to ensure all partners share in the vision and goals of the project. Specifically, Meleis (1992) suggests that participants develop common or agreed upon definitions of purpose and how to achieve that purpose. Similarly, the consensus of participants in a series of health care forums, whose purpose was to solicit public attitudes and values underlying health care and resource allocation, noted that the criteria for successful participation was a common purpose, common agreement, shared commitment and active participation (Gott and Warren 1991).

Clear Roles and Expectations. The Consumers' Health Forum of Australia (1996) recommends that clear expectations of the roles and reasons for consumer participation are evident to all participants. One method for formalizing expectations and roles is the development of a partnership agreement, which incorporates the parameters and levels of involvement of partners in relation to the implementation and continuation of the action plan (McComas and Carswell 1994; Meleis 1992; and Pivik 1997). Along with a partnership agreement, several authors have noted the importance of strong leadership for facilitating community participation (Brotchie and Wann 1993; Lord 1989; and O'Neill 1992). As either a facilitator or chairperson, this individual can assist with identifying different values and assumptions and clarify points of disagreement.

Decision-making Process. Having an open and transparent decision-making process will facilitate effective citizen involvement and promote a partnership approach to health care planning (Consumers' Health Forum of Australia 1996). Singer (1995) has identified a series of questions that can assist in determining the decision-making process. These include:

- Who in the community should be the representative decision-making body?
- What information is necessary for effective decision making?
- Is a consultation role sufficient or does community participation require decision-making power in relation to resource allocation?
- What types of decisions should community groups be responsible for?
- How much of a decision is impacted by group membership?

Assessing Community Participation. The final process consideration is measuring the impact of this partnership approach. The Consumers' Health Forum of Australia (1996) developed a series of questions in order to access the impact of consumer involvement. Answers to the following questions can assist in measuring the process as well as the outcome and satisfaction of consumer participation:

- Where is community participation taking place?
- What strategies have been used to encourage consumer involvement?
- Have individuals with specific disadvantages been involved?
- Have there been identified changes in the behavior/attitudes of health professionals?
- What are the benefits of community participation identified by the health professionals?

- Have the attitudes of the consumers changed from the beginning of involvement and at one year?
- What are the benefits the consumers have identified?
- What barriers are impacting on community participation and how can they be resolved?
- What levels of resources were given for encouraging and supporting community participation? (p. 33).

At a systemic level, perhaps the most widely known approach to measuring citizen participation was developed by Bichmann, Rifkin, and Shrestha (1989). Based on a review of 200 case studies, these authors identified the following five factors important to community participation: management, needs assessment, leadership, organization and resource mobilization. Using a series of questions (e.g., How were needs identified? Was the community involved in needs identification and assessment?), a score is given for each of the components of community participation. This approach allows a quantifiable measurement of the process of community participation at different time points, or between different programs, planners or participants.

Knowledge

Knowledge is a powerful and necessary component for both community members and health professionals for understanding the value and process of community participation (Bastian 1995). Methods for increasing knowledge include information provision and exchange, education and training. Information is integral to understanding the needs, potential solutions and the process for affecting change in health care planning. Along with the necessary information to do the job, information exchange is important for all participants of this process, i.e., between health care professionals and the community, between participants in the health care planning process, between community members and their community organizations and within health care agencies.

Information Provision. Lack of access to adequate information has been identified as a barrier to effective citizen participation (Brotchie and Wann 1993; Consumers' Health Forum of Australia 1990, 1996; Lilley 1993; and Sullivan and Scattolon 1995). Health planners need to ensure that their community partners have full access to information to do their part and access to individuals for advice. Various techniques for information provision recommended by Human Resources Development Canada (1994), Siler-Wells (1988), and Brotchie and Wann (1993), include developing or providing:

- guides describing agency or governmental policy
- background information on the consumers' roles
- background information on the decision-making process
- consultation material related to the subject being addressed
- information on effective programs, policies and models that describe effective leadership.

Information Exchange. Information was the key element used in the people-centred approach for improving health services in Wales. Wilson (1992) describes how information was used to:

1) identify people's views of their own health needs and that of their families and their community; 2) show the health care agencies' response to the identified needs; 3) provide a description of how the data were analysed; 4) describe current health care services; and 5) inform on the short- and long-term options of current health care plans. This information, given in a series of seminars, resulted in the development of local planning groups, allowed future networking among participants, demonstrated that the community's opinion was valued and encouraged a collaborative approach between health care providers and their communities. However, how the information is presented is important. Lubalin and Harris-Kojetin (1999) recommend that information be clear, easily understood and include examples.

It is also important that community representatives have effective mechanisms in place for communicating with their organizations about their progress and for receiving consultation and support (Brotchie and Wann 1993; Consumers' Health Forum of Australia 1996; Lilley 1993; O'Neill 1992; and Sullivan and Scattolon 1995). Sullivan and Scattolon (1995) recommend the use of newsletters or electronic mail systems for promoting information sharing between consumers. Another suggestion for information sharing between consumers is a "skills exchange" program, where consumers could access names of community members with specific skills such as planning, development, research and evaluation, for advice or assistance (Siler-Wells 1988).

Education and Training. Increasing education and skills training for both consumers and health care professionals has been suggested as a means of facilitating community participation in health planning (Brotchie and Wann 1993; Church and Reville 1989; Lilley 1993; and Sen 1994). Checkoway, O'Rourke and Bull (1984) identified training as one of the most important factors differentiating agencies who have effective CP from those who do not.

For Community Members – For community members, Lilley (1993) suggests educating the public about health issues, current health policies and programs, meeting procedures, health planning and evaluation. Similarly, training needs for consumers identified by Brotchie and Wann (1993) focus on communication skills and updated information sessions on policy and process issues. In relation to communication skills, it was determined that an education module related to the ability to listen, understand and communicate other people's views would be most useful. Checkoway, O'Rourke and Bull (1984) recommend that consumers on boards have training in skills and initiatives conducted in the community that promote leadership, organization and public awareness of health planning. Research has shown that consumer involvement is enhanced with training, resulting in individuals who attend more meetings, take on greater leadership and communication duties, and perceive themselves as more influential (Checkoway 1979). Also recommended for successful CP is ongoing support and educational opportunities (Zakus and Lysack 1998). Methods suggested for disseminating knowledge to consumers include the use of workshops and the development of easy-to-read manuals (Sullivan and Scattolon 1995).

For Health Care Professionals – Lilley (1993) recommends that health professionals be provided the opportunity for education and skills development in group facilitation techniques, partnership building, conflict resolution and community building, as well as training on the value and process of community participation. Brotchie and Wann (1993), in

their study of training needs, also recommended: training in community networking and participating in meetings, as well as enhancing communication skills (verbal, written and listening), research skills related to community participation and personal development training (stress management and assertiveness). In order to balance power differentials between consumers and health professionals, it has been recommended that both groups be provided information on ways that power hierarchies can undermine community involvement (Sullivan and Scattolon 1995; Valentine and Capponi 1989).

Support

The final and perhaps most necessary criteria for ensuring citizen participation in health planning is the availability and provision of concrete support. Areas where support could influence citizen involvement include the provision of funds for community involvement and organizational support from health organizations.

Financial Support. As indicated earlier, it takes time, resources and effort for community members to participate in health planning. If not part of their employment, participation has often meant voluntary work on off hours and costs associated with travelling, parking and child care. In consideration of these issues and with the belief that the community member's participation is an important component of health planning to be respected and valued, there is a call for ensuring resources for their participation. This includes payment for participation (e.g., consultation) as well as reimbursement for out-of-pocket expenses such as child care, travel, parking and time off work (Brotchie and Wann 1993; The Consumers' Health Forum of Australia 1996; and Lilley 1993). It has also been recommended that community members be provided with resources to obtain, analyse and present information to support their views (Lilley 1993). This may involve funds necessary to access pertinent information or the payment of educational or training courses relevant to community participation.

Organizational Support. Support from the organizations that are responsible for health care planning and delivery is integral to facilitating effective CP. Organizational support covers many areas such as having a mandate for CP, a climate where CP is acknowledged, supported and expected in health planning, adequate human resources and the provision of support and resources needed to include community partners in the decision-making process. Specifically, Weaver and Pivik (1997a) found that organizational support for involving community members, recommended by health care staff, includes the following factors:

Policy and procedure

- clear organizational policies
- clear procedural guidelines
- a framework for involvement (e.g., recruitment methods)
- a framework for evaluation

Human resources

- adequate staff
- sufficient time frames

Financial resources and support

- in-service training
- funds for training community members
- public education funds (to describe the mandate of the agency, the issues and policies, constraints and options, research methods and the impact of decisions)
- resources for involving community members (e.g., transportation/travel expenses, child care expenses, available meeting rooms, meals and refreshments, and monetary reimbursement for participation)
- materials and information
- valid and reliable measurement tools

Conclusion

The most important consideration when conducting CP in health planning is to follow guiding principles and values that are inclusive, participatory and equitable. As such, citizens should be respected for their experiential knowledge and expertise. Valuable information can be obtained about the best way to obtain citizen input into health planning by simply asking them. Recommendations for federal involvement in facilitating CP in health planning involves support for the development of research initiatives focused on access to equitable health for Canadians. National surveys targeting citizens and health planners are recommended to identify how to best facilitate CP. Provincial level recommendations focus on developing policies that address the social impacts of health, and the issue of representation and accessibility. Regional level recommendations include developing and implementing structures that address these policies and establishing informational and educational venues for promoting informed and considered citizen input. The Multi-Modal Continuum Model has been developed to facilitate this process and involves formalized community health networks and community-based individuals dedicated to collecting citizen input. Lastly, a Conceptual Framework for Community Involvement has been developed to provide strategies for facilitating CP within communities.

Appendix A

Conceptual Framework for Community Involvement in Health Planning

Jayne R. Pivik and Lynda Weaver Health Information Partnership, Eastern Ontario Region, 1997

Create a Climate for Citizen Participation

Mo	obilize the Community
	Develop a sense of "community" among affected citizens
	Clarify community needs, community dynamics and community status
	Inform citizens of opportunities to participate in health care planning
	Provide information about the community using existing local networks, advertising in public places, word of mouth, door-to-door information sheets, newsletters, and a community-based information office representing your agency
	Ensure information is accessible to all citizens (plain language, interpretation, etc.). Use creative visuals such as photographs describing a story, videos, posters, and dramas.
	Involve other community agencies to reach families, neighbourhoods and social groups to stimulate interest in community action around health issues
	Ensure all participants are aware of the time commitment, energy and effort required prior to their involvement
	Motivate citizens to participate; reward efforts required to participate
Fo	ster Respect and Trust
	Really listen to people
	Focus and build on individuals' capacities rather than their deficiencies
	Ensure participation is not tokenism
	Conduct meetings that facilitate inclusion of all participants
	Recognize the unique perspective, skills, and experience of community members
	Treat community members as equals by providing equal information and heeding advice equally
П	Acknowledge different perspectives and values
	Ensure language is understood by all
	Recognize that building trust requires time
_	Recognize that building trust requires time
Sh	ift Attitudes
	Health professionals should consider themselves partners, helpers, learners, enablers, coaches and supporters rather than experts or advisors
	Minimize power differences between professionals and community members
	Allow community members to determine their own needs and solutions
	Allow consumers to play a strong role in health care planning through self-determination and
	empowerment

Pa	rtnership Approach
	Match the type of partnership arrangement with the level of participation required with the decision at hand
	For decision making and collaborative partnerships, ensure equal power among partners for all stages of health care planning (planning through to implementation) For advisory partnerships, ensure all partners have the capacity to influence decisions For consultative partnerships, select key individuals who are knowledgeable on the issue and
	give them opportunities to provide information All partnerships require these fundamental elements
	- a positive attitude by all participants
	shared valuesgood communication skills
	- capacity to evolve
	- commitment
	trustbalanced and qualified partnership team
	Discuss and clarify differences between values (personal opinions) and assumptions
	(underlying facts or circumstances to be considered).
	Agree to a common purpose, agreement or commitment Enhance empowerment by holding meetings in community environments or locations where
_	the majority of participants are most comfortable
Pr	ocess Issues
De	fine Partners Recruit community members who have life experiences to share, such as language, culture,
De □	fine Partners Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns
De	fine Partners Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups
De	Fine Partners Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community
De □	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights
De	Fine Partners Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community
De	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights groups (e.g., local branch of the Consumers' Association of Canada) welop a Common Vision
De	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights groups (e.g., local branch of the Consumers' Association of Canada) velop a Common Vision Work with all partners to develop a common or agreed upon definition of the purpose of the
De	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights groups (e.g., local branch of the Consumers' Association of Canada) velop a Common Vision Work with all partners to develop a common or agreed upon definition of the purpose of the team and a plan to achieve that purpose
De De	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights groups (e.g., local branch of the Consumers' Association of Canada) velop a Common Vision Work with all partners to develop a common or agreed upon definition of the purpose of the team and a plan to achieve that purpose Foster a sense of shared commitment and active participation from all partners
De De Cla	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights groups (e.g., local branch of the Consumers' Association of Canada) velop a Common Vision Work with all partners to develop a common or agreed upon definition of the purpose of the team and a plan to achieve that purpose Foster a sense of shared commitment and active participation from all partners
De De Cla	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights groups (e.g., local branch of the Consumers' Association of Canada) velop a Common Vision Work with all partners to develop a common or agreed upon definition of the purpose of the team and a plan to achieve that purpose Foster a sense of shared commitment and active participation from all partners urify Roles and Expectations Collaboratively decide on each partner's role, involvement, expectations and tasks
De De Cla	Recruit community members who have life experiences to share, such as language, culture, location and experience with health concerns Aim to maintain equitable representation of underserved or vulnerable groups Recruit from existing consumer-based groups (e.g., self-help, interest groups, advocacy groups), networks (e.g., volunteer agencies, seniors helping seniors groups), community organizations (e.g., community associations, business associations), and consumers' rights groups (e.g., local branch of the Consumers' Association of Canada) velop a Common Vision Work with all partners to develop a common or agreed upon definition of the purpose of the team and a plan to achieve that purpose Foster a sense of shared commitment and active participation from all partners

Define a	Decision-	-Making	Process
----------	------------------	---------	----------------

- ☐ Have an open and transparent decision-making process
- ☐ Consider these decision-making issues:
 - Who in the community should be the representative decision-making body?
 - What information is necessary for effective decision making?
 - Is a consultation role sufficient or does community participation require decision-making power in relation to resource allocation?
 - What types of decisions should community groups be responsible for?
 - How much of a decision is impacted by group membership? (Singer 1995)

Assess Community Participation

- ☐ Remove or reduce barriers and constraints to community participation by considering these questions:
 - Where is community participation taking place?
 - What strategies have been used to encourage consumer involvement?
 - Have individuals with specific disadvantages been involved?
 - Have there been identified changes in the behaviour/attitudes of health professionals?
 - What are the benefits of community participation identified by the health professionals?
 - Have the attitudes of the consumers changed from the beginning of involvement, 1 yr?
 - What benefits have been identified by the consumers?
 - What barriers are impacting on community participation and how can they be resolved?
 - What level of resources were given to encouraging and supporting community participation? (Consumers' Health Forum of Australia 1996)
- ☐ Consider the following areas for measuring community participation (management, needs assessment, leadership, organization, and resource mobilization)

Knowledge

Information

- ☐ Ensure that all partners have full access to information necessary for them to fulfill their roles ☐ Ensure that all partners have full access to advisors, representative bodies, etc.
- Develop or provide the following items for all partners:
 - guides describing agency or governmental policy
 - background information on roles and responsibilities
 - background information on the decision-making process
 - consultation material related to the subject being addressed
 - information on effective programs, policies and leadership models
- ☐ Share information between all partners in a format that is accessible to all
- Develop a registry of community members who have skills to share, such as those interested in planning, development, research or evaluation.

	Educate the public on health issues, and health policies and programs Educate the public on procedures for meetings, on planning and evaluation processes Provide education sessions on communication skills, such as the ability to listen, understand and relate to other people's views Discuss ways that power hierarchies can undermine community involvement Use workshops or easy-to-read manuals for education purposes
	Educate professionals in the following areas: - group facilitation - partnership building - conflict resolution - community development and networking - community participation - procedures for conducting meetings - communication skills (verbal, written and listening) - research skills related to community participation activities - personal development (stress management, assertiveness training) Discuss ways that power hierarchies can undermine community involvement
Su	pport
	Budget for payment for community members' involvement Reimburse community members for out-of-pocket expenses such as child care, travel, parking, time off work. Ensure pertinent information or resources are purchased Cover costs of pertinent training or educational sessions necessary for meaningful involvement
	Create an organizational climate that favours community involvement in health care planning Have clear and widely-known mandates, policies, procedures and guidelines for community participation Have a framework for evaluating community participation Ensure adequate staffing and timeframes

- □ Lobby government to support community participation through policies and guiding principles, and support the development of regional coalitions
- □ Request that government establish mechanisms to involve community members in health care decision making at the regional level.

References

- Abelson J. et al. 1995. Does the community want devolved authority? Results of deliberative polling in Ontario. *Canadian Medical Association Journal* 153(4), 403-412.
- Aronson, J. 1993. Giving consumers a say in policy development: Influencing policy or just being heard? *Canadian Public Policy* 19(4), 367-378.
- Association of District Health Councils of Ontario. 1991. *Planning Ontario's health care services in the 1900s: Guide to DHC planning.* Toronto: Ontario District Health Council.
- Audet, B. A. and J. Rostami. 1993. *Partnership strategies for community investment: Findings of national consultants*. Ottawa, Canada: Conference Board of Canada.
- Babwin, D. 1998. The patient as partner. *Hospitals & Health Networks*, Nov. 5, 24.
- Bastian, H. 1996. Raising the standard: Practice guidelines and consumer participation. *International Quality in Health Care* 8 (5), 485-490.
- _____. 1995. *The power of sharing knowledge: Consumer participation in the Cochrane Collaboration*. Oxford: UK Cochrane Centre.
- Bichmann, W., S. Rifkin and M. Shrestha. 1989. Toward the measurement of community participation. *World Health Forum* 10, 467-472.
- Bracht, N. and A. Tsouros. 1990. Principles and strategies of effective community participation. *Health Promotion International* 5(3), 199-203.
- Brotchie, J. and M. Wann. 1993. *Training for lay participation in health: Token voices or champions of the people?* London: The Patients Association.
- Canadian Health Services Research Foundation. 2001. *Listening for direction: A national consultation on health services and policy issues*. Ottawa, Ontario.
- Canter, D. 1977. The psychology of place. London: The Architectural Press Ltd.
- Charles, C. and S. DeMaio. 1993. Lay participation in health care decision-making: A conceptual framework. *Journal of Health Politics, Policy and Law* 18(4), 881-904.
- Checkoway, B. 1979. Citizens on local health planning boards: What are the obstacles? *Journal of Community Development Society* 10(2), 100-116.
- Checkoway, B. T., W. O'Rourke and D. Bull. 1984. Correlates of consumer participation in health planning agencies: Findings and implications from a national survey. *Policy Studies Review* 3(2), 296-310.
- Church, J. and P. Barker.1998. Regionalization of health services in Canada: A critical perspective. *International Journal of Health Services* 28(3), 467-486.

- Church, K. 1996. Beyond "bad manners": The power relations of "consumer participation" in Ontario's community mental health system. *Canadian Journal of Community Mental Health* 15(12), 27-44.
- Church, K. and D. Reville. 1989. User involvement in the mental health field in Canada. *Canada's Mental Health* 37(2) 22-25.
- Consumers' Association of Canada. 1993. *The role of the consumer in health: A discussion paper*. Ottawa, Canada: Consumers' Association of Canada.
- Consumers' Health Forum of Australia. 1996. *Working with consumers: A guide for divisions of general practice*. Lyons, Australia: Consumers' Health Forum of Australia.
- _____. 1990. Guidelines for consumer representatives: Suggestions for consumer or community representatives working on public committees. Canberra: Consumers' Health Forum of Australia.
- Deville-Almond, J. 1998. Power points. Nursing Times 94(36), 32-34.
- Dwyer, S. 1997. Improving delivery of a health-promoting-environments program: Experiences from Queensland health. *Australian and New Zealand Journal of Public Health* 21(4), 398-402.
- Edwards, P. 1998. Question time. Health Services Journal, July 23, 10.
- Epp, J. 1986. *Achieving health for all: A framework for health promotion*. Ottawa: Minister of Supply and Services Canada.
- Feather, J., V. McGowan and M. Moore. 1994. *Planning health needs assessment: The basic choices*. Occasional paper #1. Saskatoon: Prairie Region Health Promotion Research Centre, University of Saskatchewan.
- Gamm, L. D. 1998. Advancing community health through community health partnerships. *Journal of Healthcare Management* 43(1), 51-67.
- Godbout, J. 1981. Is consumer control possible in health care services? The Quebec case. *International Journal of Health Services* 11(1), 151-167.
- Gott, M. and G. Warren. 1991. Neighbourhood health forums: Local democracy at work. *World Health Forum* 12, 413-418.
- Government of Quebec. 1988. *Rapport de la Commission d'enquête sur les services de santé et les services sociaux*. Québec: Les Publications du Québec.
- Higgins, J. W. 1999. Closer to home: The case for experiential participation in health reform. *Canadian Journal of Public Health* 90(1), 30-34.
- Howell, E. et al. 1998. Back to the future: Community involvement in the healthy start program. *Journal of Health Politics, Policy and Law* 23(2), 291-317.
- Human Resources Development Canada. 1994. *Facilitating consumer involvement in policy planning and program development*. Proceedings from the Focus Group Discussion. Nova Scotia: Dalhousie University.

- Jick, T. D. 1979. Mixing qualitative and quantitative methods: Triangulation in action. *Administrative Science Quarterly* 24, 602-611.
- Jordan, J. et al. 1998. Health needs assessment: Whose priorities? Listening to users and the public. *BMJ* 316, 1668-1670.
- Kieffer, C. 1984. Citizen impowerment: A developmental perspective. *Prevention in Human Services* 3, 9-35.
- Kushner, C. 1996. Consumers and health policy: Confessions of a guarded optimist. *International Journal of Quality in Health Care* 8(5), 479-484.
- Labonte, R. 1992. *Community health responses to health inequalities*. North York: North York Community Health Promotion Research Unit.
- Labonte, R. and J. Feather. 1996. *Handbook on using stories in health promotion practice*. Ottawa: Health Canada.
- Laverack, G. and R. Labonte. 2000. A planning framework for community empowerment goals within health promotion. *Health Policy and Planning* 15(3), 255-262.
- Lilley, S. 1993. *Making it work! Community participation in health planning in Nova Scotia*. Discussion paper for the Strengthening Health Partnership of Nova Scotia. Nova Scotia: Dalhousie University.
- Lomas, J. 1997. Reluctant rationers: public input to health care priorities. *Journal of Health Services Research and Policy* 2(1), 103-111.
- Lord, J. 1989. The potential of consumer participation: Sources of understanding. *Canada's Mental Health*, June, 15-17.
- Lord, J. and D. M. Farlow. 1990. The study of personal empowerment. *Health Promotion*, Fall, 2-8.
- Lubalin, J. S. and L. D. Harris-Kojetin. 1999. What do consumers want and need to know in making health care choices? *Medical Care Research and Review* 56(1), 67-102.
- MacCormack, C. P. 1983. Community participation in primary health care. *Tropical Doctor* 13(2), 51-54.
- MacDermid, R. et al. 1993. *The limits and possibilities of democratic participation: A review of selected literatures*. North York, Ontario: York University.
- Mattessich, P. W. and B. R. Monsey. 1992. *Collaboration: What makes it work, A review of research literature on factors influencing successful collaboration*. St. Paul, Minnesota: Amherst H. Wilder Foundation.
- McComas, J. and A. Carswell. 1994. A model for action in health promotion: A community experience. *Canadian Journal of Rehabilitation* 7(4), 257-265.
- Meleis, A. I. 1992. Community participation and involvement: Theoretical and empirical issues. *Health Services Management Services* 5(1), 5-16.

- Mhatre, S. L. and R. B. Derber. 1992. From equal access to health care to equitable access to health: A review of Canadian provincial health commission reports. *International Journal of Health Services* 22(4), 645-668.
- Nelson, G., J. Lord and J. Ochocka. 2001. *Shifting the paradigm in community mental health.* Toronto: University of Toronto Press Incorporated.
- Nova Scotia Royal Commission on Health Care. 1989. *Towards a new strategy*. Halifax, Nova Scotia: Royal Commission on Health Care.
- O'Neill, M. 1992. Community participation in Quebec's health system: A strategy to curtail community empowerment? *International Journal of Health Services* 22(2), 287-303.
- Ontario Ministry of Health. 1993. A Healthier Ontario: Progress in the '90s. Toronto: Ontario Ministry of Health.
- _____. 1989. Deciding the future of our health care: An overview of areas for public discussion. Toronto: Queen's Printer for Ontario.
- Ontario Ministry of Health and Long-Term Care. 2002. Community Health Centres (12 April 2002).
- Pivik, J. R. 1997. Facilitating collaborative research: Strategies from the perspective of health researchers. Ottawa, Canada: University of Ottawa.
- Pivik, J. R. and L. Weaver. 1997. Facilitating community participation in health care planning: Recommendations from consumers and health professionals. Kingston, Ontario: Health Information Partnership.
- Premier's Commission on Future Health Care for Albertans. 1989. *The rainbow report: Our visions for health*, vol. 1. Edmonton's Queen Printer for Alberta.
- Proenca, E. J. 1998. Community orientation in health services organizations: The concept and its implementation. *Health Care Manage Rev* 23(2), 28-38.
- Raphael, D. 2000. Health inequities in Canada: current discourses and implications for public health action. *Critical Public Health* 10(2), 193-216.
- Regional Municipality of Halton Health Department. 1993. *Community consultation resource guide*. Halton, Ontario: Halton Health Department.
- Regional Municipality of Ottawa-Carleton. 1995. *Public consultation policy: Health department implementation guide*. Ottawa, Canada: Ottawa-Carleton Health Department.
- Research to Action Forum. 1999. *Recommendations and summary of findings*. Halifax, Nova Scotia: Dalhousie University.
- Rice, J. A. 1993. *Community health assessment: The first step in community health planning*. Chicago: American Hospital Association.

- Rifkin, S. B. 1996. Paradigms lost: Toward a new understanding of community participation in health programmes. *Acta Tropica* 61, 79-92.
- Robertson, A. and M. Minkler. 1994. New health promotion movement: A critical examination. *Health Education Quarterly* 21(3), 295-312.
- Rodney, M. et al. 1998. Three evaluation methods of a community health advocate program. *Journal of Community Health* 23(5), 371-381.
- Rowan, S. 1998. Provider and consumer perceptions of allied health service needs. *Australian Health Review* 21(1), 88-97.
- St. Francis Xavier University, Extension Department. 1999. *People's school on health*. Antigonish, Nova Scotia.
- Sabatier, P. 1987. Knowledge, policy-oriented learning, and policy change: An advocacy coalition framework. *Knowledge: Creation, Diffusion, Utilization* 8, 649-692.
- Saltman, R. B. 1994. Patient choice and patient empowerment in Northern European health systems: A conceptual framework. *International Journal of Health Sciences* 24(2), 201-229.
- Saskatchewan Commission on Directions in Health Care. 1990. *Future directions for health care in Saskatchewan*. Regina: Saskatchewan Health, Public Affairs Branch.
- Sen, R. 1994. Building community involvement in health care. *Social Policy*, Spring, 32-43.
- Shiell, A., P. Hawe and J. Seymore. 1997. Preferences and values are not necessarily the same. *Health Economics* 6, 515-518.
- Siler-Wells, G. 1988. Public participation in community health. *Health Promotion*, Summer, 7-12.
- Singer, M. 1995. Community participation in health care decision making: Is it feasible? *Canadian Medical Association Journal* 153(4), 421-424.
- Sullivan, M. J. and Y. Scattolon. 1995. Health policy planning: A look at consumer involvement in Nova Scotia. *Canadian Journal of Public Health* 86, 317-320.
- Turner, T. 1990. Healthy Localities. Nursing Times 86(17), 59-61.
- Valentine, M. B. and P. Capponi. 1989. Mental health consumer participation on boards and committees: Barriers and strategies. *Canada's Mental Health* 37(2), 8-12.
- Weaver, L. and J. R. Pivik. 1997a. Community participation among members of the Health Information Partnership. Waterloo, Ontario: Health Information Partnership, Eastern Ontario.
- _____. 1997b. Out of the mouths of experts: A community participation reader. Waterloo, Ontario: Health Information Partnership, Eastern Ontario.
- White, A. T. 1982. Why community participation? A discussion of the arguments. *Assignment Children* 59, 17-34.

- Whitehead, M. 1992. The concepts and principles of equity and health. *International Journal of Health Services* 22(3), 429-445.
- Wilson, B. 1992. Establishing a people-centred health service in Gwent, Wales. *Journal of Health Quarterly* 14(3), 32-35.
- World Health Organization. 1988. *Guidelines for rapid appraisal to assess community needs*. Geneva: WHO/SHS/NHP/88.4.
- _____. 1978. Primary Health Care, Report of the International Conference on Primary Health Care, Alma Ata, USSR, September, 6-12. *Health for All Series*, No. 1. Geneva: World Health Organization.
- Zakus, J. D. and C. Lysack. 1998. Revisting community participation. *Health Policy and Planning* 13(1), 1-12.