STRUCTURAL DIMENSIONS OF THE COMMUNITY PARTICIPATION PROCESS:

THE HEALTH PROMOTION CONTRIBUTION PROGRAM

by

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ABSTRACT

Community participation is an important concept in human service programs, although there is little consensus on its meaning, practice, and requirements, especially in relation to disadvantaged groups. A structural sociological perspective was used in this exploratory study to investigate the relationship between various dimensions of structure (social-cultural, organizational, political-legal-economic) and the community participation process (types of participants, participation strategies, roles and activities, influence and power). Cohen and Uphoff's descriptive framework for the participation process was adapted for use by including elements suggested by a variety of social change theories. The Health Promotion Contribution Program (HPCP) of the Canadian federal government was used as the study focus. Five community health promotion projects which involved disadvantaged persons in the Ontario Region were examined using a comparative case study methodology which utilized in-depth interviews, documents, and secondary sources. Document analysis, within-case analyses, and a comparative cross-case analysis were performed. Analysis revealed relatively low numbers and restricted range of participants; difficulties in recruiting and maintaining participants; declining rates of active participation over time; and, limited target group influence and power. Structural factors in the HPCP and community projects were identified and potential mechanisms for their relationship with the community participation process were posed. Organizational dimension factors (mandates, governance, resource mobilization) had direct influence on these processes, although social-cultural (marginalization) and political-legal-economic factors (bureaucratic practices) also had indirect, but important, influences. Control and operation of projects by target group members, rather than by service agencies, was an important overall factor which allowed community members to achieve active influence in projects. Key issues are discussed in the interpretation of findings: variable purposes for participation; effect of advocacy project objectives; volunteerism and financial incentives for disadvantaged groups; and preconditions for target group influence and power. The study concludes that key structural obstacles from federal and local levels restricted the participation process.

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CHAPTER 1

INTRODUCTION

Voluntary community involvement has long been a valued concept and social practice in Western democratic societies. Forms of community involvement have been claimed as one of the five essential 'locality-relevant functions' of any community system, along with an economic base, resources for socialization, social control mechanisms, and mutual aid arrangements (Warren 1963). The role of community involvement has been understood historically in terms of collective responsibilities for community self-improvement, volunteerism in charitable organizations, and citizen responsibilities for local governance.

Pateman (1970) notes that during the late 1960's, however, the word 'participation' became part of the popular political vocabulary. Dramatic changes had occurred in modern society due to factors such as technological change, increased educational levels and professionalization, increased urbanization and mobility, and bureaucratization. These factors reduced the functional cohesiveness of communities and increased the state's role in community affairs (Ross 1960, Chetkov-Yanoov 1986). At the same time, post-colonial liberation movements worldwide had stimulated the emergence of social movements in the west (for example, student, women, environment, urban renewal movements) which demanded more say in public matters. This resistance to the state's control, coupled with the state's inability to afford the level of public services which were in demand, provided the context in which early calls for community participation were advanced.

Community members were called upon by governments, more than ever, to participate in local activities. The purpose of participation was proclaimed variously to improve efficiency, through community member contributions to public services, or to achieve empowerment, through increased public involvement in decision-making. There were both hopes of cost-savings and legitimation of emerging political agendas evident in these calls for participation. Thus, governments appeared to cede to external demands for participation since it could be fashioned to meet the state's needs as well (Litwin 1986).

Today, community participation appears in three strata. First, and most commonly, general members of the public are involved in local community improvement activities, in periodic consultative mechanisms such as referenda, and in mass activities such as 'Participaction' and 'Earth Day'. Second, those members of the public with available time and personal resources are involved in traditional volunteer activities either for the benefit of the larger society, or for the benefit of less advantaged members of society. Third, disadvantaged members of society are being organized in specific, small scale projects for self-improvement and advocacy, often by local community agencies funded by the state itself. Community participation in these strata appears to differ on a host of dimensions such as purpose, motivation (or benefits), effects, opportunity, and control.

In the public health sector, both the concepts and practice of health promotion are claimed to rest on community participation. Conceptually, health promotion's acceptance of the World Health Organization's (WHO) definition of health as "... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1946) appears to coincide with a broad interpretation of participation. Practically, community participation is viewed as a mechanism for mobilizing society which can contribute to these health states through various health promotion programs. Indeed, health promotion, with its focus on improving health through strategies which vary from self-care, to social marketing, to healthy public policy, has become an arena for demonstration of all these various strata of participation (Kelly 1989).

In the case of disadvantaged groups, however, there are many reports of relatively poor performance of community participation strategies in the United States (Windle 1981), Europe (Watt 1988), and developing countries (DeKadt 1982). Given these disappointing experiences, serious questions arise as to whether programs entailing the community participation of disadvantaged groups in health promotion should be supported by the state without critical analysis. In this context, there is a need to re-examine the purpose and mechanisms of community participation.

Since participation is a popular term which has numerous dimensions and lacks clarity or consensus in its definitions, it is difficult to conceptualize. When studying community participation, it is vital to clarify the primary perspective of analysis. Participation can be studied at the personal level, with an emphasis on individual motivation, personal benefits, and prediction of involvement based on psychological characteristics. Participation can also be studied at the interpersonal level, with emphasis on group communication, interaction between participants, and resolution of disagreements. Finally, participation can be studied at the structural (social-cultural, organizational, political-legal-economic dimensions) level, examining the external and macro-level forces which shape the participation process. Sociological analysis can assist in this task through its tradition of studies of both micro and macro phenomena.

There are a number of reasons for adopting an approach that focuses broadly on the study of structural factors in local community projects which aim to involve disadvantaged persons. First, there has been a dramatic increase in self-defined interest groups and self-help groups of disadvantaged persons in Canadian society. Many of these groups rely for their existence on public financing, which may affect state-directed participation strategies. Secondly, low rates of participation of disadvantaged persons in community-wide initiatives have been attributed usually to low socioeconomic status and poor motivational levels. However, due to the recent emphasis on victim-blaming in the literature, health promotion planners are now aware of structural influences and constraints on participation of disadvantaged groups. Finally, certain structural factors (primarily organizational) may be amenable to change from a policy perspective. Other structural influences (social-cultural and political-legal-economic) may be extremely difficult to change, of course, and expectations of participation should be altered accordingly.

The thesis provides an in-depth identification and analysis of how structural factors influence the process of community participation in projects for disadvantaged persons funded by the Health Promotion Contribution Program (HPCP) of Health and Welfare Canada. Specifically, the research analyzes the mechanisms by which structural factors affect: who is involved in community health promotion projects; how participation is organized; what roles and activities are taken by participants; and the expression of power between interests in the projects. However, this research does not undertake a comprehensive evaluation of health promotion project outcomes and benefits to various interests.

Since the control and organization of these types of health promotion projects are intended to occur locally, the primary unit of analysis in this thesis is the community organization. However, since these projects are funded and directed as part of the Canadian state's agenda for health development, structural factors related to the bureaucratic context of health promotion are also investigated to help examine linkages between macro-level influences and micro-level participation.

A descriptive framework of community participation developed by Cohen and Uphoff (1980) identifies a number of structural factors which are investigated in this research. In addition, structural sociological theories in the areas of Community

Organization, Interest Groups, Social Movements, and Political Economy are used to identify other factors for inclusion in the study.

The research utilizes a qualitative case study methodology to focus on the experiences of community project participants and those of key informants. Participants' perceptions regarding structural influences are deemed to be important as they may have specific insights into how structural factors affect the ways in which individuals actually participate. The thesis proposes that this method not only allows the identification of structural influences which affect community participation, but also provides exploratory understandings of the mechanisms which link them.

In summary, there is a need for studies of community participation within the Canadian health promotion context which take an emphasis on structural influences. The thesis aims:

1. To identify structural factors which are associated with types of community participants, participatory strategies of sponsor organizations, roles and activities of community members, and influence and power in health promotion projects.
2. To explore mechanisms by which these factors affect the community participation process.

The thesis is also intended to clarify the conceptual elements of community participation, as well as to improve understanding of the process of community participation in Canadian health promotion. The findings of this study are relevant not only to planners and participants in health promotion activities for disadvantaged groups, but also to community participation programs which involve the general public in health and other sectors.

CHAPTER 2

LITERATURE REVIEW

The purposes of this literature review are threefold. First, an overview of community participation is presented which focuses on major conceptual issues in its study. A structural sociological perspective is introduced as a relevant approach for studying aspects of the phenomenon. Next, a definition of community participation is developed utilizing a structural perspective. Then, existing research on structural influences on the community participation process is reviewed briefly.

Second, the development of community participation rhetoric and practice in health promotion programs is examined. The Canadian federal Health Promotion Contribution Program is introduced as an example of an initiative which claimed to use this strategy in practice with disadvantaged groups.

Thirdly, existing research frameworks are examined for their suitability in studying structural factors in participation. Sociological theory is then utilized to identify other key question areas on structural dimensions of community participation for application in this research. The review concludes by proposing a set of study objectives.

2.1 Key Concepts in Community Participation

Community participation is a vast field of study which has been investigated in many sectors such as health, environment, governance, international rural development, and urban renewal. Community participation has become a central value and strategy in these sectors for a variety of reasons including efficiency, equity, and social cohesiveness (Midgeley 1986).

The phenomenon of participation has been the subject of lengthy debates on its historical origin, its theoretical basis, and its practical application (UNRISD 1979, DSU 1986-92, Tidemand 1989). There is general consensus among authors that primary needs in the development of community participation theory are: to clarify concepts used to discuss participation; to delineate the factors believed to have an impact on participation; and to develop comprehensive methodologies for gathering information about participation which can be applied practically in a variety of settings (Rifkin 1988, Oakley 1991, Mikkelsen 1995).

Prior to developing a definition of participation suitable for this research, there are two central and linked conceptual issues in its study which need to be addressed:

- Is community participation a means or an end?
- What are the purposes of participation? (See Figure 1).

Purpose	Means		Short term end		Long term end
contribution	instrumental participation	⇨	improved common conditions		
organization					
empowerment			transformational participation	⇨	social equity and self-management

Figure 1. Conceptual Elements of the Community Participation Process

Participation, like other social phenomena such as education, can be conceptualized as both a means and an end in itself. When understood as a means, the term 'instrumental participation' is used to indicate the process of involvement to achieve some predetermined common social goal or objective. Participation in this sense is a way of utilizing the existing physical, economic, and social resources of people to attain a valued outcome or benefit, and is also a means to achieving efficiency in project management. This form of community participation tends to be short term and does not necessarily lead to an increased capacity of individuals to participate.

In contrast, when understood as an end, the term 'transformational participation' is used to indicate a longer term process intended to develop and strengthen the self-capabilities of people to be involved in social development. Participation in this sense promotes ideological and normative goals such as social justice, equity, and democracy (Pitkin 1969).

In many sectors, participation is viewed as either a means or an end (Doyle 1990). For example, in the area of public health, it has been proposed that community participation is means, or process, leading to improved health status (Cohen & Syme 1985, House 1988). Others argue that participation is a valued end, or outcome, in itself (Oakley 1989). However, the logical assumptions, implicit strategies, and methodological approaches differ in these two understandings of participation and lead to considerable conceptual confusion (Pitkin 1969, Mikkelsen 1995).

The ends and means argument is linked to the issue of purpose. Currently, there are three broad interpretations of the purpose, or function, of community participation (Cohen 1980, Oakley 1991, WHO 1991, Mikkelsen 1995).

1. Community participation as 'contribution' is the voluntary donation of people's resources to a common good or goal (participation as an instrumental means). This purpose values the efficiency obtained in meeting project objectives through people's own efforts. It implies that community interests are cohesive and that internal, community conflicts can be resolved through democratic processes. Participation as 'contribution' is intended to be initiated by the state in a top-down fashion and does not necessarily imply

that control and direction of activities pass to the local people (Cohen 1980). Barriers to participation are addressed by educational and motivational strategies.

2. Community participation as 'organization' is the process of organizing or arranging people in common activities (participation as both means and end). In this interpretation, the origin and form of organization are crucial. Some community organizations are conceived and introduced by external agents such as the bureaucracy, while others emerge and take form from the process of community members' own involvement (WHO 1991). In either case, this purpose of participation values the process of organizational development to achieve social integration of individuals, group cohesiveness, and common objectives (Pateman 1970). Barriers to participation are derived from operational problems and are addressed by technical and resource mobilization strategies.

3. Community participation as 'empowerment' is a more recent interpretation and implies both the development of management skills in local people and the ability to make decisions which affect their lives (participation as a transformational end). There is an assumption that people have a right to self-organize and that internal conflicts between social groups are resolvable at the local level. Rifkin (1986) identifies the core concern: "To address the issue of participation, is to address the issue of power" (p.243). This empowerment purpose of participation acknowledges the need for community members to exercise power and values the social equity which is achieved when this happens. Barriers to participation are derived from social conflict and are addressed through compromise on conflicting policies or removal of social barriers through political reform (Mikkelsen 1995). Thus, analysis through an 'empowerment' lens entails study of the mechanisms by which participation addresses inequitable power relations among people (Stone 1992).

If the purpose of community participation is 'empowerment' and it is conceived as a transformational phenomenon influencing the process of decision-making, there are a number of implicit assumptions (Arnstein 1969, Katan 1986, Rifkin 1988). First, there is a basic right to participate and the objective is to introduce change in social conditions. Second, active participation improves relationships between community members and organizations, and thus reduces alienation. Third, through participation, disadvantaged groups will gain access to resources and positions of control. Finally, participation will result in attitudinal changes in community members, organizations, and society at large.

These different purposes are often not clarified in project planning, thus creating the potential for the rhetoric of instrumental participation to mask the maintenance of inequality in community activities (Stone 1992). In practice, community participation activities often emphasize more than one purpose, although not often all three. Oakley (1991) suggests that a broad distinction can be drawn between projects which emphasize the purpose of participation as 'contribution' and those which focus on the purpose of participation as 'empowerment'. The latter type of projects are claimed to be used increasingly with disadvantaged groups. Additionally, however, the purpose of participation as 'organization' appears to accompany many health promotion projects and may be useful as a conceptual tool for specification of factors believed to have an impact on participation. Prior to the investigation of such factors, however, it is necessary to clarify the sociological perspective to be used in this study.

2.2 A Structural Sociological Perspective

Cuff and Payne (1984) note that social phenomena can be viewed from different sociological perspectives. Studies from interactionist and ethno-methodology perspectives focus on the personal and interactional experiences of individuals and groups and utilize social psychological concepts such as 'labelling' and 'common sense knowledge'. These types of studies primarily address the issue of 'agency', or how individuals' perceptions and actions influence each other and the development of social relationships. In the field of community participation, a recent example of such studies is found in Kelly (1996), which investigates the dynamics of group members' roles in community projects. Parameters for personal dimensions of participation include measures of individual satisfaction and self-efficacy. Parameters for inter-personal dimensions of participation include measures of group formation, social support, and inter-personal conflict. These social psychological perspectives and dimensions of participation are important, but are not the focus of this study.

In contrast, another sociological perspective, termed structuralism, focuses on the forms of social organization which exist and how these may influence experience. Implicit in studies which address 'structure', is an assumption that human actions are to a large extent determined by the social environment. Values, attitudes, activities, and relationships are believed to be the result of, or greatly influenced by, factors in the organization of society. Generally, an approach based on structuralism is intended to allow clarification of fundamental relationships which are often masked by assumption or habit (Cuff 1984).

It is important to clarify further the meanings of 'structure' and 'structural' to be used in this thesis. Williams (1976) has documented historical changes in the usage of these terms in the biological and social sciences (particularly anthropology and linguistics) and notes their particularly complex development. Currently, 'structure' refers to "the mutual relation of constituent parts or elements of a whole" (Williams 1976, p.253), a definition which emphasizes the inter-relationship between the internal and the entirety. This understanding underlies Levi-Strauss' concept of structure as the systemic interdependence of elements and the whole. This interpretation identifies structure as a 'process' (Rocher 1972). Alternately, and more concretely, Parsons (1961) defines 'structure' in the field of sociology as 'object', or as institutionalized patterns of normative culture" (p.36).

Drawing on Durkheim, Rocher (1972) defines culture itself as "an interconnected set of ways of thinking, feeling and acting which is more or less formalized and which, having been learned and shared by a plurality of individuals, serves both objectively and symbolically to unite these individuals in a particular and distinct collectivity" (p.89). Thus, culture includes a broad range of human activities which are learned and accepted by a majority of people. In Parson's view, structure is the objective result of the process of institutionalizing cultural elements into patterns of social action. Structure, as an objective organization of culture, does not include a focus on individual adaptation but does address collective functional social systems. (The term 'structural' is used here as an adjective describing these objective concepts of structure and this form of analysis.)

Within the 'structure as object' view which is taken in this thesis, there is tension between notions of structure as a fixed, static entity versus a flexible, dynamic form. In the social sciences, the 'orthodox' approach considers structure to be a permanent, constitutive human formation defined by human consciousness. Examples of structure in this tradition include kinship, myth, and various psychoanalytic generalizations of human nature. The orthodox approach tends to emphasize general 'relations' in human behaviour, for example domination, which abstracts human actors out of the analysis.

In contrast, the 'genetic' approach considers structures to be semi-permanent, evolutionary formations which change over time in a historical sense, for example, capitalism and bureaucracy. The genetic approach with its emphasis on the change which occurs in structures, appears better able to include human actors and observe their 'relationships', or interactions, with elements of structure and with each other. Both traditions assert that structures influence human life, either absolutely or historically. A tendency in each also suggests the reverse, that social structures exist only through the efforts of individual human beings.

Acknowledging this dynamic, C. Wright Mills (1959) notes that sociological research needs to "grasp the interplay of man and society, of biography and history, of self and world" (p.3). Social science researchers attempt to link social structural, or macro aspects of society, and social psychological, or micro level phenomena. Several sociological theories have attempted to explain how these links between structure and agency are made.

Functionalist and structuralist theories in sociology have been largely deterministic in approach, relegating the influence and decisions of the individual (agency) as being secondary to that of the context and forces (structure) of society (Cuff 1984). Recent behavioural theories, which are individualistic in focus, also conceive of structure as being a deterministic constraint to the individual's freedom of choice (Poland 1992).

Alternately, symbolic interactionist theory (Blumer 1969, Meltzer 1975) shows how structure and agency are interdependent. This theory suggests that actions develop from meaning and agency, but that structure is the framework within which social life takes place. Overall, symbolic interactionist theorists give the primary role to agency in the explanation of human actions, and do not adequately explain non-reflexive behaviours such as habit and emotion (Poland 1992).

Giddens' (1984) structuration theory attempts to transcend the dualism, or distinctions, between structure and agency by explaining the ways in which "systems grounded in the knowledgeable activities of situated actors, who draw upon rules and resources in the diversity of action contexts, are produced and reproduced in interaction" (p.25). To Giddens, agency involves habit, as well as intentionality and reflexivity, or the purposive monitoring of social life. Structure is understood as recursively organized systems of rules (that is, the constitution of meaning and sanctioning of modes of conduct) and resources which are central to routine life. Social systems link the individual to structure and are recursive, that is, they are both the medium and the outcome of social interaction. This view of structure and agency appears to accommodate the phenomena of community participation, as conceptualized here, particularly its means/ends distinction.

The discussion thus far illustrates that a broad view of structure may be informative, especially when investigating meso-level phenomena such as community participation. To further clarify the range of structure which is relevant in this thesis, concrete elements such as activities, division of labour, networks, social relationships, organizational groups, hierarchies, physical or material conditions, financial requirements, age, and environment can all be considered as structure (Rocher 1972). These elements are reflected in concrete social institutions which may affect community participation.

Oakley (1991) categorizes these elements of structure into three dimensions. The **social-cultural** dimension includes structures of social relationships which have developed historically, such as dependency and marginalization of minority groups and women. Dominant norms and values regarding deviant groups, such as disabled or poor persons, are also considered to be social-cultural structures. This dimension also includes the socioeconomic nature and capacities of various groups. The **organizational** dimension includes administrative networks, procedures, and attitudes of planners which shape decision-making roles. This dimension includes resources for participation as well as organizational history, mandates, and program objectives. Finally, the **political-legal-economic** dimension includes ideology, political entities, legislation, and economic systems which facilitate or limit community participation. The political-legal-economic dimension also includes policy decisions to include or exclude certain groups from community programs. Any, or all, of these broad dimensions of structure may be operative in a participatory setting.

It is important to emphasize, however, that factors in these structural dimensions do not act alone, but are mediated through the 'agency' of individuals (Freeman 1983). This view is compatible with the previous discussion of human beings' influence on social structures. Thus, macro and micro influences can combine in the phenomenon of community participation and require study methodologies which can capture this interaction (Kelly 1989). Utilizing the perceptions of community members about structural influences on participation may be one way of studying this synthesis.

Each of these dimensions also emphasizes the exercise of power as a central feature of the structural perspective. However, the concept of power is itself problematic. Some authors equate power with force and coercion (Dahrendorf 1959); some use the notion of authority (Weber 1947); and others suggest that power is a bi-polar concept entailing both dominance and dependency on the part of the oppressed (Emerson 1962). More recent conceptualizations have incorporated Gramsci's concept of 'hegemony', in which the dominance of a group rests upon its ability to translate its own world view into a pervasive ethos (Femia 1985). In these recent views, power is not an object (which can be possessed), but is a medium or process through which social relations involving conflict are expressed (Giddens 1979).

A number of power typologies have been proposed utilizing these concepts. Alford (1985) proposes different types of power which include: pluralist, or situational, power which is measured by the outcomes of conflict between interest groups; managerial, or structural, power which is measured by the capacity of elite state, corporate or professional interests to dominate each other; and class-based, or systemic, power which is demonstrated by relations between major social classes. Alford suggests that these types are exclusive of each other, yet they all appear to be useful conceptualizations with respect to participatory processes which focus on disadvantaged groups.

In an inter-related typology, which assumes that power types can co-exist, (Lukes 1974) describes three embedded dimensions for the expression of power (force/authority, non-decision, hegemony). Furthermore, Foucault (1979) argues for a typology of power relations which includes exploitation, an additional overt systemic type of power. In combining these latter views, a power typology which may be suitable in the study of community participation may include:

1. Exploitation - the power to control people's economic lives through the imposition of an economic system
2. Dominance - the direct power to control people's choices
3. Non-decision - the power to control decision-making processes
4. Hegemony - the power to control people's perceptions of themselves, and their own capacities.

Overall, a structural perspective which recognizes a variety of structural dimensions, the role of human actors, and the importance of power, appears to be relevant for illuminating the process of community participation and is used in this thesis.

2.3 Definition of Terms

Having presented some of the important conceptual issues in the study of community participation and the sociological perspective to be taken, issues of definition are now addressed. The review begins by describing current definitions of community, before proceeding to more contentious issues of participation.

Definitions of Community

The origins of the modern notion of community are traced to European social philosophers in the late eighteenth century. These scholars noted that the growth of capitalism, industrialization, and urbanization altered the relationship between humans and society in a fundamental way, resulting in the loss of inter-dependence (Plant 1974). Since then, sociological inquiry has attempted to categorize communities empirically, but with only limited success (Jewkes 1996). Currently, the term 'community' has two general meanings. The first refers to social ideals of solidarity, sharing, and consensus. This is a relatively recent usage. The second meaning of community refers to actual groupings of people. This is the older and more common usage, but it is also idealist in many ways (Williams 1976).

Community groupings are defined usually in two ways -- through affinity or through geography. Affinity groups share human characteristics of ethnicity, gender, age, disablement, sexual orientation, etc. Occasionally, affinity includes socially defined characteristics such as education, social class, and political affiliation, but this usage is less common. It is generally the case that, the greater affinity or shared characteristics present in a group, the more cohesive is its members' sense of community (Schwartz 1981).

In contrast, geographically based groups use physical location to define communities and assume that physical proximity provides a set of material and social conditions which result in shared interests. Affinity and geography sometimes co-exist to strengthen a community's sense of shared interests. This is not always so, however, since many geographic communities differ markedly on many affinity characteristics such as wealth and education. Nonetheless, geography can provide a powerful incentive for individuals to assume a shared set of interests since proximity increases the likelihood of social interaction (Cohen 1985).

Of interest to this study, community has also been defined in terms of voluntary organizations, that is, entities which have recognized their affinity or geographic relationships and which value these enough to join together formally (Drake 1992). In this sense, community implies a 'community of organizations', or formal associations, and the emphasis on individual community members decreases. Both of these understandings of community, as individuals and as organizations, will be used in this thesis.

In reference to the first meaning of community, Williams (1976) asserts that: "Unlike all other terms of social organization (state, nation, society, etc.) community seems never to be used unfavourably" (p. 66). Community is associated usually with positive descriptors and conjures up ideal images of supportiveness, natural ties, and cooperation. It rarely seems to generate a negative impression unless it is attached to a specific affinity (e.g., welfare community) or geographic descriptor (e.g., north end community).

These examples illustrate Cohen's (1985) position that two central ideas are found in the notion of 'community'. One of these is aggregational and the other is relational. The former idea involves the aggregation, or grouping together, of people who have something in common. The latter idea, however, expresses the opposition of one community in relation to others which are different. This viewpoint contradicts idealist notions of community as being non-conflictual and is supported by numerous empirical studies which demonstrate heterogeneity and conflict in communities (Jewkes 1996, Midgely 1986, Rifkin 1986, Stone 1992).

Definitions of Community Participation

Considering the various analytic perspectives which may be taken in this field, it is not surprising that there are numerous definitions for community participation. The challenge for the researcher is to select or develop definitions which are consistent with the assumptions of the study. Specifically, a suitable definition of community participation should address human agency as well as structure. The definition should incorporate the means/end issue, as well as focus on an 'organizational-empowerment' interpretation of community. Finally, the definition should address concepts of power explicitly.

Participation has a variety of meanings, focussed on sharing in activities by entitlement or right, which derive from basic constructs of democratic theory (Neufeldt 1988). Pateman, in her classic political science work Participation and Democratic Theory (1970) notes that the notion of participation is used widely, often with an imprecise or no definition, to include almost any situation in which some minimal amount of interaction takes place. This can imply little more than that a particular individual was present at a group activity. Pateman suggests that suitable definitions of participation must include four elements - participation by someone, participation with someone, participation in something, and participation for some purpose. She accepts the following definition of participation by French (1960):

> 'a process in which two or more parties influence each other in making plans, policies or decisions. It is restricted to decisions that have future effects on all those making the decisions and on those represented by them' (p.3).

Pateman suggests that this definition excludes the following situations: where an individual merely takes part in a group activity; where an individual is merely given information on a decision affecting him/her before it is executed; or, where an individual is present at a meeting but has no influence.

However, Pateman's suggestion illustrates a key problem in definition, that is, specification of a qualitative form of an activity versus specification of the activity alone, regardless of its effectiveness in the decision-making process. In other words, one can define participation to be an ideal form of interaction, or one can allow its definition to suggest the discrepancy between rhetoric and reality. For example, terms such as 'involvement' and 'consultation', which are often used inter-changeably with participation, reflect qualitative forms of the phenomenon rather than fundamentally different activities. It seems that use of a broader, non-evaluative definition is more pragmatic, but also requires the researcher to develop methods for determining whether the participation has been useful to those concerned. The range of definitions of community participation is now illustrated through analysis of their goodness of fit with criteria suggested by Pateman and by this review.

One definition from the health sector states that community participation is:

> "... the effective **adaptation** by people to their **individual needs** for **health protection** and **health enhancement**" (Green 1986, p.229).

Concepts of personal adaptation, health protection, and health enhancement in this definition emphasize the focus on individualism and physical agents of disease in a behaviourist approach. This definition does not appear to meet Pateman's basic criteria as it fails to distinguish between types of participants nor identify the participatory activity. In addition, there is no indication of the importance of organization or power relations.

Another definition of participation from the environment sector states that community participation is:

> "... an **interaction** between people and officials, rather than a one-way flow of information. It implies some citizen **influence** on subsequent developments, and it suggests they **learn** as a result of the experience" (Sadler 1979, p.2).

Concepts of interactive communication and partial influence by the public are combined with an element of public education in this interactionist definition. This style of participation is portrayed as a technical and somewhat egalitarian process, but which may in reality be limited by the extent of expert knowledge required by community members to assess and influence environmental factors. The definition does not identify the participatory activities which occur, nor the influence of structure on the participation process.

From a more structural perspective, community participation in health development has been defined as:

> "... a process by which **partnership** is established between the government and local communities in the planning, implementation and utilization of health services in order to benefit from increased local **self-reliance** and **social control** over the infrastructure and technology of health care" (Fonaroff 1983, p.13).

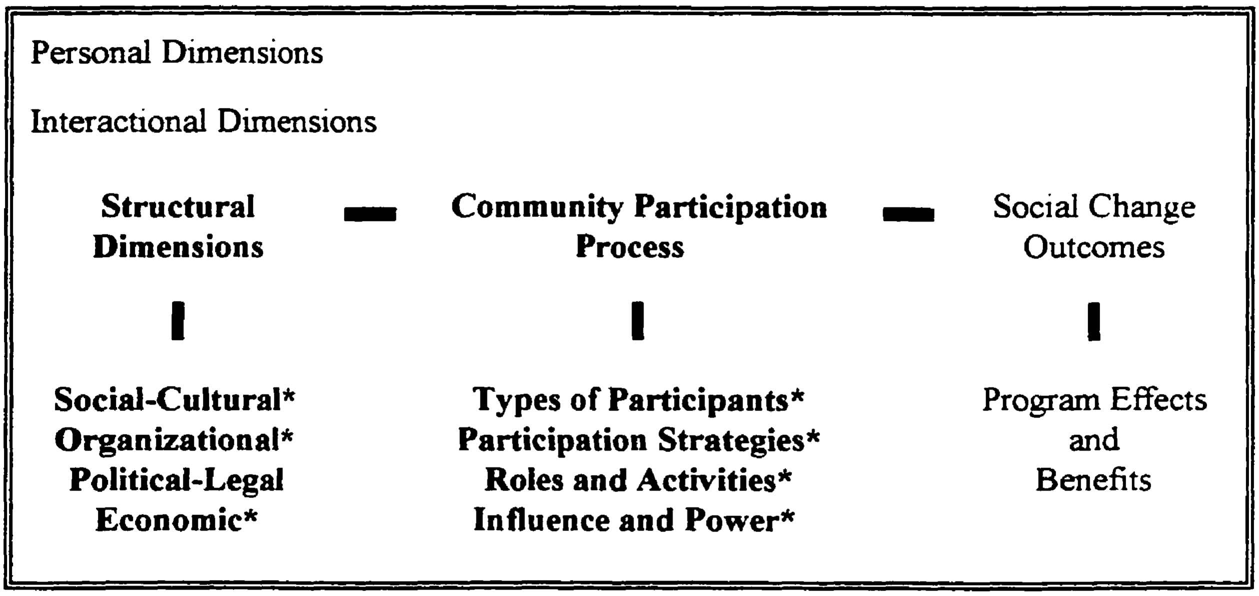
Concepts of partnership, self-reliance, and social control are evident in this type of participation which appears to have an 'organizational' purpose. Principally, participation is intended to support the existing health system and must contend with established authority based on scientific knowledge, professional privilege, and bureaucratic practice. This style of definition meets Pateman's basic criteria, but does not address the inherent inequity of disadvantaged groups.

From a more egalitarian perspective, Pearse (1979) defines community participation, which has an 'empowerment' purpose, as:

> "the organized efforts to increase **control** over resources and regulative institutions in given social situations, on the part of groups and movements of those hitherto **excluded** from such control" (p.8).

This definition reinforces the centrality of the issue of power in community participation. Pearse identifies the outcome of participation as 'control' over resources and institutions by the 'excluded'. Changes in political and economic relationships are also implied. The community is not seen as a cohesive whole with mutual interests, but rather as a constellation of distinct advantaged and disadvantaged groups. Pearse's definition of community participation satisfies Pateman's general criteria, addresses both 'organizational' and 'empowerment' purposes of participation, utilizes a structural perspective, and is applicable to disadvantaged groups within communities. Thus, it will be used later as a basis for defining community participation in health promotion in this research.

From the preceding conceptual and definitional review, a model for the community participation process can be posed (see Figure 2).



*** = principal issues addressed in the thesis**

Figure 2. Model of Community Participation Process

This thesis investigates the specific effect of factors in social structural dimensions on the process of disadvantaged persons' participation. Social change outcomes, or consequences of participation, are not a major focus of the thesis for a number of practical reasons. An adequate assessment of social change outcomes would require a broad analysis of individual, organizational, and community conditions. Attribution of the causes of social change would also require suitable investigative methodologies such as control groups, or at least longitudinal studies. These types of outcome studies appear to be premature without an adequate theoretical understanding of basic structural influences on community participation.

Four major research issues from a structural perspective arise from this conceptual and definitional review of community participation:

1. How do structural factors affect <u>who is involved</u> in the community program?
2. How do structural factors affect <u>strategies</u> which organizers use to facilitate participation?
3. How do structural factors affect the <u>roles and activities</u> of community members?
4. How do structural factors affect <u>participant influence and the expression of power</u>?

Existing literature on these four research issues illustrates considerable gaps and is now summarized.

2.4 Structural Factors in Community Participation

Virtually every field which has attempted to involve community members in organized development activities has contributed to the knowledge base of community participation. There is an extensive literature in this area encompassing the disciplines of sociology, political science, management, psychology, health, social work, environmental studies, etc.

Research themes in participation have included analysis of **what** community participation is, **how** it occurs, **who** participates, **what** effects and benefits are realized, and finally, **why** participation is promoted (Cohen 1980, Rifkin 1988, Oakley 1991). However, much of what has been written on community participation, and especially its structural dimensions, is descriptive and non-theoretical (Sadler 1979, Howell 1987, Canadian Council on Social Development 1988). In particular, the mechanisms by which structural factors affect the expression of participation are unclear. Participation theories (which will be examined later in this literature review) seek to explain why people participate, but are often silent on what structures should exist to enhance participation.

Consequently, this review of structural influences on participation of disadvantaged persons in community organizations focuses on four key elements in the participation process: the types of participants; organizers' strategies to encourage participation; participatory roles and activities; and participant influence and power.

Information on community participation in voluntary associations is utilized as the basis for the review, however, there are limitations to this literature. First, by definition (Sills 1968), voluntary associations are not related to the business of making a living or to the economic activities of their members. However, this may not be the case in projects for disadvantaged persons in which economic activity may be a primary goal. Thus, information on participation in voluntary associations may not be completely relevant to the study.

Second, since the mid-1970's, certain disadvantaged groups have received considerable state funding for participatory programs. These programs rely much less on community-generated resources than did earlier voluntary agency programs (Pal L 1993, Phillips 1992, Phillips 1994). Thus, information on the role of state actors and structures should also be considered.

Third, traditional charitable voluntary agencies have been supplemented recently in the social service field by community agencies which purport to represent and include disadvantaged persons in their organizational structures and decision-making. Hadley and Hatch (1981) highlight the diversity of form as well as function in these agencies which vary from: "...organizations no less formal than those found in the statutory sector to some that are so informal that they hardly merit the term organization" (p.93). There is scant literature available on these very informal community agencies. Notwithstanding these limitations, Brenton's (1985, p.7-13) criteria for voluntary or community agencies (self-governing, non-profit, and serving individuals or sections of the community) are used for the purposes of this review of structural influences on participation in community organizations.

Types of Community Participants

The types of participants in community organizations are numerous and may include:

- those who have a specific condition or problem
- clients or consumers of specific agency services
- experts or consultants
- persons of authority, prestige, or power
- representatives of other organizations
- professional staff persons or practitioners
- residents of specific geographic areas
- advocates for change

This review focuses on structural influences on the types of community members who are involved in local organizations. Factors such as geography, socioeconomic status, gender, and group heterogeneity have been noted to affect both the numbers and range of community participants.

Geography

Community members' geographic location affects their likelihood of participation. Geography is associated with the existence of voluntary associations, since an increased number occur in urban areas, probably due to higher population density (Cohen 1985).

However, there is also evidence that rural communities have high numbers of voluntary associations if rapid urbanization is occurring (Sills 1968).

Socioeconomic Status

Higher socioeconomic status (income, occupation, education) has often been cited as the greatest predictor of participation (Pateman 1970). Sills (1968) suggests that since membership in a voluntary association is a form of social interaction, people who are deprived of a broad range of social interaction opportunities (e.g., rural, poor, non-Anglo-Saxon, elderly) due to social, geographic, physical, and economic barriers are less likely to participate. However, variations in participation do exist cross-culturally and may be better explained by the functions which voluntary associations play in different societies. For example, Woelk (1992) and Stone (1992) note that in the West, voluntary associations promote self-reliance and equality, while in Asia they often promote ‘contribution’.

Widmer (1987) notes several explanations for the low rate of participation in individuals of lower socioeconomic status. The 'needs' approach suggests that the poor have unmet subsistence level needs which preoccupy their attention, while higher status persons have more resources and are free to seek self-esteem and self-fulfilment through voluntary participation. The 'civic culture' approach suggests that lower status persons do not believe in the importance of community participation and do not see it as their responsibility. The 'incentive' approach suggests that lower status individuals do not participate because they do not expect valued outcomes from their efforts. Both 'needs' and 'incentive' approaches coincide in their emphasis on the material basis of participants’ logic. Widmer notes that it is easy to demonstrate that individuals participate in response to incentives, but considerably more difficult to demonstrate why people do not participate.

Gender

A gender disproportion (females more than males) has been reported frequently for participation in volunteer activities. Lower workforce participation of women, and thus their availability, is often cited as a structural reason. However, this claim predates the increase in women's employment rates and is thus unconvincing (Wells 1990).

Heterogeneity

Heterogeneity in group social characteristics has been thought traditionally to reduce active involvement, since dissimilar members become discouraged in trying to reach consensus. However, more recent evidence indicates that ideological homogeneity may be an important unifying factor. For example, class consciousness among the poor can overcome ethnic barriers, and feminist consciousness can overcome ethnic and socioeconomic barriers (Litwin 1986). Finally, the number of participants in community-wide, heterogeneous voluntary associations has been found to be related more closely to non-demographic factors, such as length of residence and home ownership, skills and training, and expectations about benefits and costs (Wandersman 1987, Prestby 1990).

Overall, the mechanisms by which structural factors affect the types of community participants are not yet clear. From existing literature, it is apparent that local ideological and opportunity contexts may be crucial in modifying relatively static demographic influences to improve participation.

Participation Strategies

Community organizations utilize specific strategies to recruit and retain community participants. Structural factors which have been noted to affect community agencies' strategies to encourage participation include organizational structures, leadership, resources, coalition formation, and legislation.

Organizational Structures

There are two elements of organizational structure (membership size, formalization) which have been noted to affect participation strategies. First, according to Olson's (1968) theory of collective action, development of a large membership base inhibits the rationale for participation of individuals in voluntary activities since they can access public goods through a 'free-rider effect'. More recent trends in communication technology (electronic email networks, voting by cable television), however, have created situations in which wide-based community participation in decision-making can occur, although individuals may not yet have control of the process itself (Litwin 1986).

Secondly, Sills (1968) states that strategies of functional specialization (which precludes those with interests at the fringe) and institutionalization/formalization (which decreases spontaneous access to activities) decrease the numbers of participants. In contrast, Oakley (1991) indicates that functional specialization, with clear roles for members, is necessary for maintaining participant interest. He also suggests that formalization of group structure is necessary to manage organizational growth which is achieved through increased member involvement. These findings illustrate the reciprocal nature of structure and participation. As participation increases, structures are developed to manage it and subsequently may prevent further growth. Alternately, structures may be introduced too early in the participation process, which then inhibits initial activity. In either case, the precise form of the organization and its fit to the participants' needs and context may be crucial.

Leadership

Traditionally, strong leadership has been thought to promote community participation in voluntary associations. For example, social exchange theory suggests that a leader's chief task in promoting participation is to manage the organization's incentive system (Knoke 1985). However, Wilson (1973) argues that while leaders are important to achievement of functional goals of the program, they are not important necessarily to participation of members, since leaders often have distinctly different, and more extreme, ideological positions than members. Finally, Oakley (1991) identifies leadership structure, or access to positions of power, as important to the recruitment and retention of participants.

Resources

At the organizational level, it is self-evident that community agencies utilize financial resources to facilitate community participation through expenditures on staffing, rent, meeting costs, etc. (Butterfoss 1993). Limitations on agency funding have been shown to affect participation levels adversely (Van Til 1984). In addition, funding conditions and short term grants create organizational uncertainty, diversion of purpose, staff turnover, and increasing bureaucratization, all of which affect recruitment negatively (Ng 1990, Shragge 1990). The state may also take advantage of organizational dependency on financial resources to control local agency strategies for participation of disadvantaged groups by funding only compliant groups, or by co-opting non-compliant individuals with employment or state appointments (Loney 1977, Pal L 1993).

At the individual level, studies of participatory programs directed to the general community have shown that 'solidary' incentives (group identification and status) and 'purposive' incentives (achievement of goals) are more important than 'material' (monetary) incentives for participants (Prestby 1990, Butterfoss 1993). However, Wilson (1973) notes that low income persons will not participate readily without some immediate material gains, and are not satisfied with an emphasis on policy changes. This finding is supported by studies in work site health promotion programs which show improved participation rates of women, minorities, and those with low level jobs in those organizations which actively inform workers, make incentives available, and reduce barriers to participation (Crump 1996). Although these findings are consistent with Olson's (1968) view of the rational actor, it is not clear what balance of incentives and resources is necessary for disadvantaged groups.

Coalitions

The formation of coalitions may be used as a strategy for involving wider groups of persons in common objectives or activities of mutual interest. Thus, coalitions can be considered examples of 'community agency participation.' Some of the structural factors which stimulate coalition formation are resource scarcity, legislative mandates, an effective catalyst organization, previous history of collaboration or competition, and a capacity to maintain linkages (Butterfoss 1993). Factors which contribute to coalition maintenance include formalized rules and procedures, and strong core leaders who support member concerns and are competent in negotiation, gathering resources, and problem solving (Roberts-DeGennaro 1986). However, the purpose and strategies for developing coalitions of general community agencies may not be identical to strategies for increasing participation of groups of disadvantaged community members.

Legislative Mandates

During the 1960's in the United States, 'War on Poverty' legislation mandated "maximum feasible participation" in community organizations which were funded by federal initiatives. Criteria were set for the number and proportion of community members to be involved in local programs. Although the legislation was intended to provide financial resources and influence for disadvantaged groups, these initiatives were weakened by a lack of resources, fewer staff than planned, and consequently more program implementation responsibilities for volunteers. This dual expectation for participants as policy makers and as implementors eventually compromised their independence, credibility, and influence in communities. In addition, the range and numbers of community members did not achieve expected levels.

Gittell's (1983) comparison of community agencies with and without participation mandates revealed that the former agencies were completely dependent on state funding, had weak leaders and links to other agencies, utilized formal bureaucratic structures, and had a narrow range of activities. It is not clear whether less formal 'participation guidelines' may have a similar effect on community member involvement and local agency operations.

Participatory Roles and Activities

It is necessary to clarify distinctions between organizational positions, roles, and activities of participants as used in this thesis. An organizational 'position' is a formal office or title which designates rights, responsibilities, status relationships, and rank in the organization. Organizational 'roles' are more dynamic and functional. Roles may include possibilities such as 'leader', 'initiator', or 'follower'. Organizational 'activities' are operational events related to the objectives of the programs. These may include attending a meeting or creating health education materials. The literature identifies a number of structural factors (organizational structure, leadership, program objectives) which influence the positions, roles, and activities of community members.

Organizational Structure and Linkages

Contrary to organizational theory which predicts control through hierarchy, Sills (1968) states that incorporation and board activities have few consequences on participant activities in voluntary associations. Furthermore, Miller (1988) notes that it has not been established that board composition in non-profit organizations influences agency objectives and activities. An alternate interpretation, in fact, is that board involvement in various activities leads to the recruitment of directors with particular kinds of expertise. Other factors, such as the specific types of services provided by agencies and their primary sources of funding, may also create the need for particular board member characteristics and involvement (Miller 1988). Thus, the influence of an incorporated board structure on member participation is unresolved.

Nonetheless, Butterfoss (1996) reports that a climate of order and organization within projects is associated with participants taking on formal positions. He also reports that participants in those projects which have more inter-organizational linkages volunteer to do extra work outside their regular activities.

Leadership

Leadership has been conceptualized as including elements of competence, performance, support, and control (Knoke 1990). The balance between these elements may be critical for the encouragement of participatory roles of community members. For example, Butterfoss (1996) notes that strong leadership is associated with community members taking on extra roles outside of project meetings. This may connote the motivational function of leaders in a 'contribution' style of participation. However, weak leadership is also associated with community participants actively taking responsibilities during project meetings. This may indicate that community members assume influential roles in the absence of opposition from leaders. Overall, however, it is unclear how leadership actually affects participation in an 'empowerment' style of community organization.

Program Objectives

Some voluntary associations have goals and objectives which maintain the status quo. Their membership tends to be placid and their organizational structure tends to be formal, with little involvement of participants in initiator and leader roles. Other associations, which have more radical, change-oriented goals and programs, tend to have more ideologically oriented members and their organizational structures tend to be more informal and fluid. Members in these associations have access to multiple positions, roles, and activities (Sills 1968, Knoke 1990).

An absence of concrete tasks, for example in systemic advocacy projects, will decrease member activity in organizations (Sills 1968). Work site health promotion projects, in which activities demand extensive personal time commitments, also require a positive social environment (normative support), and organizational resources (policies and instrumental support) for workers to participate. Organizational resources are required especially for the participation of minorities and persons with low level jobs (Crump 1996). Thus, persons with less occupational flexibility and less ability to 'volunteer' their time require programs with more supports for participation. However, little information is reported on the types, frequency, and intensity of project activities which are optimal for participation of community members who are not employed.

Goal displacement, or changes in program objectives, is said to discourage participation (Klandermans 1984). Goal displacement is claimed to occur due to factors such as leaders' desire to preserve their status, an overemphasis on procedural tasks and relationships, and the creation of informal cliques for sub-group solidarity within the organization. However, others view these changes in objectives as 'goal succession' and a natural and desirable part of group development (Sills 1968). Whether changes in objectives are functional for the participation of disadvantaged groups working with powerful leaders and professionals is unknown.

Influence and Power

It is important in this review, to distinguish between the terms 'influence' and 'power'. Influence does not necessarily imply power, or the ability to determine the outcome of a decision-making process. Influence only implies a contribution to the processes of information gathering, deliberation, and argument (Pateman 1970). In the context of community participation, this thesis attempts to determine structural factors which determine both participants' influence and participants' expression of power. Studies illustrating these relationships are relatively few, however, factors such as leadership, organizational structure, and community group cohesion may be relevant.

Leadership

Even though most organizations have constitutions or bylaws that call for full participation by the members, they tend to be ruled by a minority through the 'iron law of oligarchy' (Michels 1959). The social structure of role obligations and the structural needs of the organization itself usually prevent full and equal participation (Sills 1968).

Leaders with specialized skills, available time, and temperament or charisma will tend to dominate in any interaction (Sills 1968, Knoke 1985). However, those participants with greater perceived influence are also persons who are involved more frequently, indicating that 'opportunity structures', or the ability to access situations which foster influence, may be important in the empowerment process (Tarrow 1989).

Organizational Structure

There is some evidence that the requirement for a formal board of directors and executive director can undermine the democratic process, especially in large and expanding community organizations. Smaller organizations are able to maintain a democratic decision-making process more readily (Shragge 1990). When selection of members for governing bodies is done by invitation, rather than by open election, target group members may be precluded from occupying authoritative positions. Similarly, exclusion of community members from staff positions may reduce their overall influence in the organization (Drake 1992).

The concept of 'access' is useful in a discussion of structural influences on power. Lack of access can reflect exclusion from power in physical (e.g., distance, location of meetings), informational (e.g., lack of information for decision-making, technical jargon, language, means of communication), and temporal domains (e.g., timing of meetings) (Drake 1992).

Community Group Cohesion

Finally, the selection of disadvantaged target groups, which may have a low degree of internal cohesion, can reduce community members' influence in community agencies (Drake 1992). This point may be especially pertinent for involvement of disadvantaged groups in participation programs whose selection priorities are set by the state.

In summary, a structural perspective on participation has led this investigator to focus on structural influences on types of participants, organizational strategies, roles and activities, and participant power. A number of factors, primarily from the social-cultural and organizational dimensions of structure, have been noted to have an effect on the community participation process. Fewer factors from the political-legal-economic structural dimension have been reported to have a direct influence on community participation. It is possible, however, that these factors act primarily through the organizational dimension, especially in state-initiated programs such as health promotion. There is little clarity, however, on the exact effects of structural factors and their mechanisms. In addition, there is little information on the applicability of these relationships to disadvantaged groups' participation in health promotion projects which is discussed next.

2.5 Community Participation in the Context of Health Promotion

A social structural perspective has been gaining credence in both academic discourse and community practice in health. This perspective proposes that health status is determined primarily by social, economic, and political structures and relationships in society, for example, gender and socio-economic status, rather than by more individually oriented biomedical and behavioural factors. In this perspective, community participation is viewed as an intermediate mechanism which can modify these social determinants and facilitate social change, including improved health status, for individuals and communities (Figure 2).

There are a number of potential areas for the study of community participation in health. For example, community members' influence on hospital boards (Eakin 1984) and in local planning (Sullivan 1995) has been examined. The area of health promotion also presents an important arena for community participation studies for a number of reasons.

First, health promotion, which has incorporated a social-structural perspective of health recently, has been defined as "...the process of enabling people to increase control over, and to improve, their health" (WHO 1986, p.1). Health promotion aims to attempt to improve health through achieving fundamental conditions of social justice and equity, using a consensual process and intersectoral planning for institutional and environmental change (WHO 1986, Rootman 1988, Pederson 1989). These objectives are essentially compatible with Pearse's definition of community participation, however, they are largely silent on structural barriers to participation and the structural supports which are necessary for its success.

Second, health promotion as a principle and as an activity is claimed to stand at the interface of structural forces and human agency and thus is an ideal setting for sociological study (Kelly 1989). However, there are few studies in the health promotion field which demonstrate this linkage (Labonte 1993, MacDonald 1993).

Third, health promotion utilizes disadvantaged groups, both, as a focus and as a testing ground for its strategies, but without a clear conceptualization of the interdependence of structure and agency, nor of the effect of bureaucratic factors on community level phenomena. Overall, community participation in health promotion has not been analyzed critically from a structural perspective.

Thus, health promotion appears to be a suitable venue for investigation of structural influences on community participation. The review now summarizes the context for the development of health promotion in Canada before examining the development of participatory concepts in this field.

The Context of Health Promotion in Canada

To understand the evolution of community participation in health promotion programs, it is useful to describe briefly the social, economic, and political context in which Canadian health promotion has developed. Beginning in the 1960's, changes in Canadian social institutions such as the family, work, church, schools, and the health care system were accompanied by decreasing influence of experts, alienation from institutions, and increasing interest in a consumerist philosophy (Blishen 1973). Simultaneously, deficit financing of state functions and global trade initiated a worldwide economic fiscal crisis (O'Connor 1973). The percentage of state expenditures devoted to the health care system in Canada increased through the 1970's and 1980's, principally due to the demographics of an aging population and the rising costs of technology (Bennett 1987, Charles 1987). These events were interpreted to have resulted in 'contradictions of the welfare state', in which the state was unable to afford services which softened the impact of a capitalist economy, resulting in a legitimacy crisis in the political system (Gough 1979, Offe 1984). Calls for community participation in health, social welfare, environmental, and other arenas increased throughout these various social, economic, and political crises.

There is long-standing support in Canada for the involvement of voluntary community organizations in various aspects of social life, including health programs. Since the early 1900's, individuals in Canadian communities were involved actively in health care planning on hospital and public health boards, District Health Councils, and in community health centres (Crichton 1972). Most of this activity was conducted by relatively healthy members of the community. Ill, disabled, or disadvantaged persons were considered to be members of 'target groups' for the development of services and programs and did not have a major role in these decision-making processes (Labonte 1981). However, the recent emphasis on community participation in the health promotion field is intended to be substantively different from these earlier approaches.

Participatory Concepts in Canadian Health Promotion

To outline one context in which community participation currently manifests itself, the review now addresses the development of participatory strategies in health promotion in Canada and their recent shift to 'empowerment' and 'organizational' purposes. Major Canadian government reports and international documents are utilized to chart the development of concepts of participation in health promotion and to justify the application of a structural perspective in the analysis of participation in this field. The focus on official documents as primary sources is necessary to highlight the influence of government rhetoric and bureaucratic thinking on the forms of participation which have occurred in federal health promotion programs (Laframboise 1990, Pinder 1994). In particular, the parallel development of thought on structural influences on health and on community participation are noted.

Canadian government conceptualizations for community participation in health promotion activities were first articulated in 1974 by Marc Lalonde, a Liberal Minister of Health and Welfare (and former Minister of Finance), in the discussion paper, A New Perspective on the Health of Canadians (Lalonde 1974). Lalonde's description of community participation in the Health Field Concept primarily addresses individuals' responsibilities to prevent disease. Proper utilization of health services, changes in lifestyle behaviours, and support for environmental protection measures are claimed to be ways in which the individual can participate. The Health Belief Model appears to underpin this approach to understanding the individual's response to health issues (Becker 1974). However, the Health Belief Model has not demonstrated its validity in research of group, community, or system level responses to health (Kelly 1989, Badgley 1994).

The New Perspectives report does identify some structural health influences which are beyond the individual's control. Lalonde recognizes the "... arguments that personal choices were dictated by environmental factors" (p.35). In addition, Lalonde outlines areas of political and economic responsibility in health noting that:

> "... at the most basic health level of all, the Federal Government has important activities in maintaining economic progress and in ensuring through a redistribution of income, that most Canadians can provide for the essentials of life,..." (p.53).

Finally, Lalonde notes that "one of the main problems in improving the health of Canadians is that the essential power to do so is widely dispersed among individual citizens, governments, health professions and institutions" (p.33). Coordination of this decentralized power is proposed as the solution in the health field. However, Lalonde specifies that the principal decision-makers with the federal government include the provinces, professions, and voluntary health associations. Although Lalonde acknowledges that the general public should be consulted about their priorities, there is no indication of how individuals could be involved in these activities.

Thus, although there is some recognition of structural influences on health in the discussion paper, the roles of individual community members are limited to either being passive recipients of services or being responsible for personal health choices. The purpose of participation in health promotion at this time appears to be as a 'contribution' to personal and societal health. This purpose also appeared to be reflected in the establishment in 1977 of the Lifestyle and Health Promotion Directorate in Health and Welfare Canada, with social marketing programs in such areas as alcohol, tobacco, drugs, nutrition, family planning, and child health (Pinder 1994). There were almost immediate denunciations of these new 'lifestyle' health education approaches by critics who viewed them as 'blaming the victim' (Crawford 1977, Brown 1978, Labonte 1981).

In the next decade there was a shift in rhetorical emphasis with respect to structural influences in health. Jake Epp, the new Conservative Minister of Health and Welfare, reported in another discussion paper, Achieving Health For All (Epp 1986), that "the first challenge we face is to find ways of reducing inequities in the health of low versus high income groups" (p.4). Social factors such as age, single parenthood, and ethnicity are also cited as being associated with poor health. Target groups in the population (youth, women, elderly, persons with disabilities, native persons, and persons with low incomes) are identified as being at risk for developing health problems.

Now, community participation is suggested as a strategy for "...helping people to assert control over factors which affect their health ... and enhancing people's capacity to cope" (p.9), presumably with their current situation. Self-care groups and mutual aid voluntary associations are cited as prime mechanisms for participation which are intended to enhance coping skills in disadvantaged groups. Participation with an 'organizational' purpose appears to be emerging in health promotion discourse. There is some suggestion that participation could be used to reduce health inequities, however there is no mention made of community decision-making or community control of health programs. This appears to continue the earlier interpretation of individual and community participation as meaning taking responsibility for one's own health circumstances.

At the policy level, however, Epp explicitly acknowledges the need to revise the political decision-making process through a healthy public policy strategy, although particular political mechanisms are not identified. While this strategy is cited as having the potential to address some of the social and economic structural influences on health, control of the policy process is portrayed as remaining firmly in the hands of the politicians and bureaucracy. There is recognition that public policies "... must respond to the health needs of people and their communities"(p.11), but there is no indication as to how these needs will be identified in the community.

The Ottawa Charter for Health Promotion of the World Health Organization (1986), of which Canada was a signatory and prime contributor, represents a further shift in emphasis towards a social structural perspective of health, although biomedical and lifestyle considerations are not discarded. The fundamental conditions and resources for health are identified as "... peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity" (p.1). The majority of these conditions depend, at least initially, on the social, economic, and political structures and relationships in a society.

The Charter also marks a shift in emphasis in the discussion of community participation in health promotion (Raeburn 1989). The Charter notes that people are the main health resource, not the government or health services. This orientation requires that the latter two groups "...share power...with people themselves" (p.4). The community is expected to assume an expanded role of "... setting priorities, making decisions, planning strategies and implementing them" (p.3). Community participation as 'empowerment' has emerged conceptually.

Community participation is integrated into each of the Charter's areas of action - healthy public policy, supportive environments, personal skills, health services, and community action. The community action strategy specifies that communities should control local health determinants through a 'community development' process. This process appears intended to incorporate decision-making into the community itself as a local level political mechanism. The Charter also briefly recognizes that skills and structural supports such as information, education, and funding are required for community development.

Drawbacks in the Charter's approach to participation include its lack of emphasis on the role of disadvantaged groups in community development. Whereas inequity is implied throughout the document, it is noted specifically only with respect to gender, and the community is conceptualized as a homogenous entity with similar interests and needs. This view ignores differences due to class, age, disability, ethnicity, and geographic factors which have been noted to make a community development approach difficult to achieve (Freire 1970, Labonte 1994).

By 1988, Canadian government views on participation appear to have changed in a similar direction. In another discussion paper, Mental Health For Canadians: Striking A Balance, Epp (1988) extends the earlier understanding of environmental influences on health to include structural factors related to social, cultural, economic, and regulatory conditions. Health inequities are to be addressed by public participation which gives "... a greater voice to those who, for such reasons as age, sex, socio-economic status, disability or ethnicity, have historically had little or no say in shaping the policies and systems that affect their lives" (p.14). Disadvantaged members of communities are now addressed, but how participatory principles are to be implemented without compartmentalizing the community is not clear (Labonte 1994).

Epp's new characterization of the community member is one of a marketplace consumer influencing the design and choice of health services. Although acknowledging the expertise and influence of professionals in the planning process, Epp asserts that there should be nothing token about consumer participation and that it should not be relegated to an indirect, unspecified advisory role. Participation is intended to be achieved through involvement in mutual aid and community development processes that "enable people to work collectively to identify and deal with common concerns" (p.14). This intention reflects both 'organizational' and 'empowerment' purposes for participation. These progressive principles are retracted somewhat in the specification that it is primarily consumers of services and caregivers, rather than the general public, who have a legitimate role in the planning of particular health programs. This focus, along with the emphasis on professional participation, raises questions as to the degree of control actually intended for the wider community (Grace 1991).

Finally, in the international sector, the Alma Ata Declaration specifically notes peoples' rights to "...participate individually and collectively in the planning and implementation of their health care" (article 4) (WHO 1975). The World Health Organization, in its publication Targets for Health For All (1985), is specific in identifying the need for formal community representation on local health councils which could analyze plans for the improvement of health in communities. However, the established health care sector continues to be given primary responsibility to formulate such plans and to "... determine what matters require special attention and change" (p.24). More recent WHO documents continue this emphasis on a professionally led health research and planning process, with community involvement mechanisms adapted to local conditions (WHO 1991). How such an emphasis on participatory approaches meshes with bureaucratically defined priorities and targets is not clear (Kelly 1989).

It should be noted that many Canadian health promotion documents of the 1980's are not as progressive as the Ottawa Charter and Epp's mental health document in their discussion of community participation (Spasoff 1987, Podborski 1987, Premier's Council on Health Strategy 1988). On the other hand, more recent documents in Ontario clearly identify social structural determinants of health and potential mechanisms for community involvement (Kendall 1991, Premier's Council on Health Strategy 1991). However, Hancock (1994) notes that while these progressive interpretations of community participation have been enshrined in policy (Ontario Ministry of Health 1992), there is little evidence that they have been implemented in practice.

In summary, there has been considerable rhetoric through government discussion papers about community participation in health promotion in Canada. As social structural influences on health have become increasingly recognized there has been a parallel, yet somewhat reluctant, conceptualization of participation from a structural perspective. Community participation has been primarily portrayed in its 'instrumental' sense, as a strategy to achieve health objectives, rather than as a 'transformational' process of community development. This hesitancy to commit to a transformational participation may have its roots in the bureaucratic initiation of health promotion itself.

2.6 Definitions of Community Participation in Health Promotion

Having reviewed the conceptual, contextual, and rhetorical development of community participation, it is necessary to address its practical application in health promotion. Definitions of 'community' and 'participation' in health promotion research are similar to those in other sociological research. Some authors define community in health promotion from a geographic perspective (Nutbeam 1986), while others utilize an affinity perspective (Thompson 1990). However, neither of these perspectives adequately reflects the tensions and conflicts within geographic, or for that matter, affinity groups. Similarly, neither of these traditional sociological approaches to community capture the influence of the external environment on community dynamics and identity, especially in an era of multinationals and a global economy (Nilsen 1996).

As noted earlier, there are numerous definitions of participation which reflect a variety of underlying philosophies. Thus, analyses of participation may vary significantly in concepts, descriptions, and explanations depending on the definition and perspective which is used. With these conceptual and methodological issues in mind, Pearse's (1979) work has been adapted in order to propose a definition of community participation in health promotion for this thesis:

> **Community participation is the organization of activities by groups of persons who are at a structural disadvantage, in conjunction with others who are not, to increase control over the means to influence health conditions, and in doing so to improve their health.**

This working definition incorporates many of the key concepts discussed thus far. The definition satisfies Pateman's criteria by identifying the actors, the activities, and the reasons for participation. It also satisfies requirements of a structural perspective to focus on organization/empowerment and structure/agency linkages. Finally, the definition incorporates health promotion's focus on disadvantaged groups and health conditions. The definition appears suitable for delineating phenomena which can be termed community participation in health promotion and is now used to critique the practice of community participation in the health promotion field.

2.7 Critique of Community Participation in Health Promotion

There is considerable literature on community participation in health which is dominated by broad conceptual and normative arguments (Powell 1988). In addition, there are numerous descriptive case studies and a few detailed evaluations of the practice of community participation (WHO/UNICEF 1977, PAHO 1984, WHO 1987). However, the links between normative and empirical sets of literature are not strong and there have been few specific theoretical positions proposed about structures required for participation in these programs (Thompson 1990). This review does not examine in detail many reports of health promotion programs and projects as these accounts are largely descriptive in nature, non-contextual, and do not assume a theoretical perspective.

Contemporary types of community participation in health promotion activities can be organized into three strata and analyzed across a number of features (purpose, benefits or motivation, opportunity, control, and perceived effects) (Hancock 1985, Haro 1987, Labonte 1988, Pederson 1988, Lefebvre 1993, Thorogood 1993, Kelly 1996)(See Table 1).

Table 1. Types of Health Promotion Participation

FEATURE	MASS PARTICIPATION	TRADITIONAL VOLUNTEERISM	SELF-HELP/ ADVOCACY
Purpose(s) of Participation	Contribution	Contribution Organization	Empowerment Organization
Primary benefits or motivation	To benefit oneself and one's wider community	To benefit another group	To benefit oneself and one's group
Opportunity	All can participate in theory. In practice, many do not and some are excluded	Elite members with extra resources	Disadvantaged members, need support
Control	By organizers	By volunteers and organizers	By disadvantaged and organizers
Perceived effects	Efficiency in achieving goals -instrumental -means to an end	Efficiency, Equity of situations and groups	Equity, Involvement -transformation -end in itself
Examples	Social marketing Participaction Earth Day Referenda Large community development projects	Healthy Public Policy District Health Councils United Way	Self-help groups Advocacy groups Support groups for women, disabled, or ethnic persons

Proponents of 'Mass Participation' health promotion advocate the participation of everyone in improving the health of the community. In national health promotion programs, the involvement of virtually all sectors of society is advocated in lifestyle and environmental awareness campaigns such as 'PARTICIPACTION' and 'EARTH DAY'. This proposal, however, is at odds with the widely observed phenomenon of non-participation by the majority of community members. 'Traditional Volunteerism' is another type of health promotion participation which has extensive roots in Canadian society. Altruistic in philosophy and often focussed on target groups, volunteerism alone does not allow a transformational process nor an empowerment experience for disadvantaged persons in these sectors.

Finally, there are 'Self-Help and Advocacy' types of participation in health promotion. Primarily small scale in design, these approaches attempt to balance their limited numbers of participants with a wider impact due to transformational processes and to public advocacy. This type of participation is the principle focus of this thesis. A structural perspective on participation in health promotion is not very evident in the literature. Most reports of health promotion programs assign minor importance to participation, or simply count the number of community members who are involved in program activities (Nilsen 1996). In explaining problems in community participation in health promotion projects, as in other fields of study, analysts have tended to criticize the motivations of individual community members, or the negotiation process between different interests, as being deficient rather than examining the basic organization and structures which inhibit or support the process.

As a counterpoint, it has been noted that structuralist critiques alone often lead to untenable models for social change. In health promotion, the appropriate role of the individual must also be considered (Allison 1982) and recent efforts to incorporate methods of critical consciousness espoused by Freire (1970) have reflected this attempt to link structure and the self in health promotion (Labonte 1994).

Numerous contradictions have been noted about community participation in health promotion projects (Tesh 1988). For example, many projects utilize forms of community 'health education' which emphasize personal behaviour change alone and do not address social structural determinants of health, such as poverty. Farrant (1991) points out that participation is supposed to be a key strategy in health promotion but there is little resource support for it in practice. Health promotion projects are often understaffed and limited in their funding terms which preclude public involvement in needs identification, skill development, and ongoing participatory activities.

Community members are supposed to be central in participatory strategies, but competition between more powerful health professional and bureaucratic sectors often marginalizes the community in health promotion (Smithies 1987). Similarly, community experience is claimed to be the primary basis for planning projects, but scientifically based knowledge is often given more credibility by funders (Stacey 1988).

Pederson (1988) notes that participation often implies mass community activities, but in reality interest groups tend to dominate. Participation may be intended to promote equity, but there is always a risk of inequitable distribution of benefits in a project depending on who is involved and how the process is controlled.

On a macro level, Navarro (1984) notes that there is a contradiction in the state's advocacy of local autonomy through health promotion while maintaining centralized, bureaucratic planning of health programs. At the local level, there is a parallel contradiction in the use of the rhetoric of empowerment without an understanding of power relations in the community (Farrant 1991).

There are similar concerns about health promotion participation in Canadian jurisdictions. In Ontario, Pederson and Signal (1994) note ambiguity between calls for participation which, on the one hand expect individual responsibility, and on the other hand promise empowerment. They question whether this ambiguity results in a false consensus in advisory groups, such as the Premier's Council on Health Strategies, which may mask internal conflict and make concrete policy progress unlikely. In Quebec, Local Community Service Centres (CLSCs), which originally had a mandate to involve community members in numerous initiatives which resembled health promotion (O'Neill 1992), have been urged recently to re-orient towards curative medical services (O'Neill 1994). In the North West Territories, participation on community health committees was reported to be limited due to a lack of honoraria for members, in contrast to honoraria provided for members of other community committees (Yazdanmehr 1994).

From the preceding review of participation in the health promotion field, there appears to be a need for analyses, based on a structural perspective, which move beyond examining the motivations of participants to consideration of how programs are organized. In particular, the literature suggests a focus on structural factors such as the availability and use of resources, the roles of professionals and bureaucrats, and power dynamics in health promotion.

2.8 The Health Promotion Contribution Program

It is useful to distinguish in this thesis between health promotion 'programs' and 'projects'. Health promotion programs are defined as large scale activities linking national and provincial organizations and bureaucrats which are focussed on the health of entire populations, for example, social marketing and healthy public policy campaigns. On the other hand, health promotion projects are defined as small scale activities of local sponsor agencies and target group members which are focussed on the health of disadvantaged, or high-risk persons. Health promotion projects are usually not linked intentionally with other projects.

Part of the Canadian federal government's commitment to the principle of community participation in health promotion is claimed to be demonstrated in the Health Promotion Directorate (HDP) of Health and Welfare Canada. (Further information on the development of the Health Promotion Directorate and its influence on community participation will be presented in the Results section of the thesis.) Health promotion programs in HPD such as the 'Healthy Communities' program and the 'Strengthening Community Health' program (Hancock 1994) focused on improving health and developing the capacity of broader communities, rather than focussing on target issues or groups.

In the Health Promotion Directorate, the Health Promotion Contribution Program (HPCP) was designed specifically to address this concern (Pinder 1994). This funding program was initiated in 1981 to provide financial resources to certain community groups for local projects to help them to identify and solve their health problems (Health Promotion Directorate 1981). Early HPCP participatory activities, which were organized around individual behavioural changes in areas such as smoking, alcohol, and nutrition, reflected a lifestyle view of health promotion (Pinder 1988, Pinder 1994). Subsequent to the 1986 Ottawa Charter, however, public participation in HPCP projects received an increased focus of attention in line with the new 'social' model of health (Raeburn 1987). The HPCP was now intended to support disadvantaged groups in controlling their own health conditions and projects (Law 1989, Pinder 1994).

However, an internal program evaluation of HPCP in 1989 indicated that, in a sample of 100 projects, sponsors reported the involvement of community members in project activities to be quite modest: only 41% of projects had public involvement in planning; 29% had involvement in implementation; 19% noted public attendance at meetings; and, only 11% had participation in evaluation activities (Health & Welfare 1989). These estimates by Health and Welfare staff are quite low for a program whose primary strategy was intended to be community participation.

There is no further information published about the extent, mechanisms, or effectiveness of community participation in the HPCP. Thus, in this national health promotion program, it is unknown how participation of disadvantaged persons in community priority setting, planning, and resource allocation actually occurs and to what degree. From the perspective of this thesis, the structural factors which influence this participation are also unknown.

In summary, calls for community participation in health promotion have arisen during a time of general social change in Canada. Many local and provincial jurisdictions have developed extensive health promotion programs. The Canadian federal government has also played a role in the development of health promotion principles, strategies, and programs.

The emerging perspective espoused in health promotion rhetoric since the Ottawa Charter of 1986, is that of a social structural model of health. Community participation is now advocated as a necessary component in many areas of health, although its meaning and structural requirements have yet to be clarified. This thesis uses a structural perspective as the basis for analysis of community participation in Health Promotion Contribution Program projects. Analytic frameworks for this task are now reviewed.

2.9 Frameworks of Structural Factors in Community Participation

To study structural factors and their mechanisms, researchers often utilize tools which vary from conceptual models to evaluative frameworks. It is useful to clarify the components of such tools prior to reporting on their current status in the field of community participation.

Meehan (1968) identifies three principal components of research models - **concepts, descriptions, and explanations.**

Concepts are the rules used to organize perceptions of objects and events. Concepts are used to identify entities, to classify them into sets, to relate them in time and space, and to define their attributes or characteristics. For example, in the study of community participation, a structural perspective would require a focus on concepts such as 'context', or the social environment, of participatory activities.

A **description** is an organization of perceptions of objects and events which utilizes conceptual rules. Description requires a theoretical basis that can assign significance to different perspectives - for example structural, rather than interactionist, concepts in community participation. This theoretical base must suit the descriptive situation. Description also requires an unambiguous classification of phenomena to record differences between two or more things.

An **explanation** is the application of a logical system of relationships and general laws to a description. Explanations are not just a recording of differences between two events or situations. Explanations also imply cause-effect relationships and thus indicate the potential for change in a situation. Explanations allow understanding of the past, generate expectations of the future, and suggest interventions to alter or control events. Preliminary explanations are derived from exploratory studies and provide potential cause-effect relationships which have yet to be demonstrated. In the social sciences, preliminary explanations provide the basis for generating hypotheses for future studies.

A further step in analysis of events can be termed **evaluation** and requires that sufficient conceptual, descriptive, and explanatory work has been done in a field to allow comparison of the events to some accepted standard. Premature application of evaluative methods to social phenomena without adequate standards risks serious questions on the validity of judgements obtained in the evaluation.

There are relatively few analytic frameworks for studying structural factors in community participation. Nonetheless, there has been a gradual development of conceptual and descriptive frameworks which are now reviewed.

Davie (1975) developed the Shared Process Evaluation System (SHAPES) methodology to evaluate the process of participation in community development projects. SHAPES is used to describe:

1. who was involved in a project
2. critical events which occurred
3. the perspective of the community development worker.

This information is collected and collated by community members to describe the involvement of individual participants (community members, workers, and government planners) in various critical activities (e.g., meetings, data gathering) at particular stages in the project (e.g., needs identification, planning). SHAPES provides a systematic methodology to describe the types of participants and their roles for comparison with the community worker's perceptions of participation. This comparative information can then be used by the worker to make adjustments to the program.

The SHAPES methodology provides a thorough description of certain components of the community participation process. However, since SHAPES was not intended to address the social, organizational, or political context explicitly, it is limited in the explanation of participation from a structural perspective. For example, analysis of the impact of organizational strategies for participation in community development projects could not be well explained using the SHAPES method.

In an important work which has provided a base for other researchers, Cohen and Uphoff (1980) define participation as "the involvement of a significant number of persons in situations or actions which enhance their well-being, for example, their income, security or self-esteem" (p.214). These authors suggest that participation is not a 'thing' which can be clearly defined, but rather may be treated as a theoretical concept, or rubric, under which a number of specific concrete components can be identified. Their approach to this theoretical concept involves documenting descriptive indicators of the presence of participation (e.g., collective actions taken by a community) rather than direct measures. Through the Rural Participation Project at Cornell University, the authors developed a framework for analysis of structural factors in community participation in international development projects which has had practical field application in the area of water management in Sri Lanka (Uphoff 1990).

The framework distinguishes between 'Contexts' and 'Dimensions' of participation. The Context of participation includes the overall historical, environmental, and societal milieu in which the project operates. As well, Context includes the project's operating characteristics (e.g., resource requirements, immediacy of benefits, and program flexibility). Participatory Dimensions include the kinds of participation, the sets of individuals involved, and the features of the participatory process.

Cohen and Uphoff's methodology for analysis of participatory projects is comprehensive and focuses on benefits to various parties. However, its conceptualization of project operating characteristics as Context, and separate from the influence of the agency and government, is problematic. In their view, bureaucratic or donor agency directives to local project managers regarding the style and extent of participation of community members has only an indirect influence on the involvement of the public. In addition, the framework does not explicitly address the exercise of influence and power by participant groups in the program. For example, direct and indirect expressions of participant control in the project are neglected in the framework, which focuses principally on tangible and observable factors and does not explore the more subjective dynamics of influence and power in community settings.

Significantly, Cohen and Uphoff note that the purpose of participation is critical for the interpretation of a program. They recognize that there will likely be disagreement on any assessment of the purposes of participation since this depends on the particular interests of groups involved in the program, for example, community members, program staff, professionals, and bureaucrats. They do not clarify how an analysis of purposes could be achieved other than through identification of who is participating in different aspects of the program.

Overall, Cohen and Uphoff's framework encompasses many aspects of a structural perspective on participation. However, the framework does not explicitly investigate the structural bases for power differences nor does it adequately address the empowerment process. In addition, the framework was developed for use in international community development programs and is not appropriate for analysis of participation in Canadian health promotion projects without modifications.

Wandersman (1981) originally developed a methodology for evaluation of participation in community organizations in urban American settings. This methodology identifies the antecedents of participation, the parameters of participation, and the effects of participation. Antecedents of participation are identified as environmental, ecological, and social characteristics of the community plus individual 'readiness to participate' variables. Parameters of participation are assessed in a manner similar to the 'Dimensions' of Cohen and Uphoff's model. Effects of participation are assessed over a period of time at individual, organizational, and community levels.

Wandersman's methodology is very comprehensive and includes many psychological variables at the individual and community levels. However, it clearly implies a uni-directional system of antecedent causes, participatory processes, and differential effects. Drawbacks of the framework for this research include: a lack of sociological variables at the group level which may influence participation, such as interest group identification and resource availability; a minor emphasis on governmental influences; and limited consideration of mediating variables or possibilities of recursiveness in relationships.

Overall, Wandersman's methodology is not a set of practical descriptive instruments, but rather a conceptual plan for detailed research of the psychological processes inherent in community participation. The framework has supported numerous studies of organizational behaviour (Prestby 1990), and more recently community coalitions (Butterfoss 1996).

Finally, Rifkin (1988) has developed a methodology, derived from the work of Cohen and Uphoff, for evaluation of community participation. Rifkin focuses on the process of participation ('direct participation'), rather than the immediate effect or impact of a project which she terms 'social participation'. She identifies five key project areas in which direct participation can be rated. These factors include needs assessment, leadership, organization, resource mobilization, and management. In focusing on the evaluation of participation, Rifkin's model assumes that satisfactory explanations and standards for participation currently exist. However, she also asserts that communities are not readily comparable and that establishing standards for participation is unrealistic. Instead, a community project is assessed repeatedly on these 'direct' factors with a 5-point scale to give a series of visual-numerical profiles for a demonstration of change in community participation. Rifkin's methodology has been applied in a number of international studies of the community development approach to health (Bichmann 1987, Laleman 1989).

While Rifkin's work is one of the few attempts to quantify the degree of participation in community projects beyond the mere counting of participants, there is likely to be a significant loss of qualitative information in Rifkin's methodology as well as reliability and validity problems with the scoring procedure. The methodology also does not consider how community members interpret the project and how the project's benefits are distributed. It is unlikely that the depth of understanding necessary to analyze project participation from a structural perspective could result from this methodology which does not consider the context, purpose, or power relations of the project. In particular, the influence of community members vis-a-vis the influence of other project participants such as professionals, project staff, and local elites is not addressed. Rifkin does emphasize that development of an evaluation methodology for 'social participation', or empowerment and equity, has yet to be accomplished. She suggests some indicators for equity and stresses the critical importance of analyzing the links between 'direct' and 'social' participation.

These four frameworks (Davie 1975, Cohen 1980, Wandersman 1981, Rifkin 1988) address many of the structural factors of participation through various conceptual, descriptive, and evaluation methodologies. All of the frameworks have shortcomings, however, and do not seem capable of being used to analyze the complexity of the phenomenon. Most significantly, these frameworks do not explicitly address the concept of power or the achievement of equity and control by community members in projects.

Recent attempts by Uphoff (1990) and Green (1986) to use these frameworks to develop theory in community participation also suffer from lack of analysis of basic concepts such as project structure, project context, and power issues. These efforts illustrate that the existing frameworks cannot be used alone for the analysis of participation from a structural perspective.

Nonetheless, Cohen and Uphoff's work provides the best methodological starting point for this thesis as it contains many of the structural components which have been assessed traditionally in participation. In this thesis, however, structural 'Dimensions' will be used to refer to social-cultural, organizational, and political-legal-economic characteristics rather than to the participatory process itself.

Plant (1974) reinforces the use of a structural perspective by suggesting that conceptualizations of community participation cannot be separated from the wider context of political and organizational life: "To be plausible, a theory of community and in particular the place of participation within it, needs to be counter balanced by a theory of the political organization of society in which issues such as bureaucracy, democratic theory, and organizational theory receive their due consideration" (p.63). A number of social structural theories related to community participation will now be examined for their usefulness in suggesting additional elements to include in this research.

2.10 Social Change Theory and Participation

The study of community participation has its primary roots in the disciplines of political science and sociology. This review focuses principally on sociological theory but benefits from a brief overview of participation in a political sense.

A key distinction in political science theories of democracy is that between representative democracy and participatory democracy (Pateman 1970). Underlying this distinction is the struggle between the liberalist values of free choice espoused by Locke, Hobbes, Bentham, and Mill and the democratic values of equality promoted by Rousseau and JS Mill (Weingert 1976, Wolfe 1977). Liberalist views are reflected in 'first generation human rights' of free speech and private property and assert that all citizens have the right to influence political decisions which affect them (Howell 1987). Representative democracy and political parties are claimed to be participatory mechanisms to implement this view (Mill 1859, Mills 1959, Dahl 1961). Others claim that the concept of participation itself implies the breakdown of representative democracy: "at base, the demand for participation connotes criticism of the existing system of representation" (Sadler 1979, p.3).

'Second generation human rights' have emerged in this century from a broader view of democracy which recognizes that liberalism results in great differences between individuals in most nations in terms of political and economic power. The state has assumed the responsibility to ensure equal access to 'safety nets' of public services such as health care, education, housing, and social welfare. These services both prepare individuals for, and protect them from, the economic competition of first generation rights (Howell 1987). Notions of participatory democracy which are used to support this view primarily involve an educative process in which individuals learn to cooperate together, beyond their individual interests, to achieve both public and private security (Pateman 1970).

Thus, participation in the political science domain reflects fundamental tensions between the right to compete in a market economy and the right to an equitable standard of living. Participation also reflects basic tensions between individual and collective rights.

In the sociological domain, a variety of theories have been used to explain community participation. At the individual level, social exchange theories, such as Olson's

(1968) rational actor model and Knoke's (1990) motivational model of collective action can be used to explain personal reasons for participating in community activities. At the group level, theories such as negotiated order (Day 1977) and collaboration theory (Gray 1989) can be used to explain group dynamics in participation. However, it is a contention of this thesis that social change theories are more useful for exposing the structural factors which facilitate or limit participation.

Early sociological studies of community power (Lynd 1937) and community organization (Young 1963) examined the role of the community from a structural perspective. These studies focussed attention on the community as a legitimate setting for the development of knowledge about social change processes. However, these studies also conceptualized the community as an organism which evolves naturally according to a particular developmental sequence. This organic view was suitable for Western communities in the early to middle twentieth century which were oriented towards small town and rural life. However, the recent tendencies towards state-initiated change in communities and the influence of global factors, such as multinational corporations, on local conditions appears to require new concepts (Harper 1989).

More recent studies from a structural perspective emphasize social change aspects of communities, which may refer either to the introduction of planned change or to fundamental social changes (Dixon 1989). The major bodies of contemporary social change theory related to participation are those concerned with Community Organization, Social Movements, Interest Groups, and Political Economy. Each of these are examined here to explore their potential application to the analysis of the influence of structural factors on community participation in Canadian health promotion projects.

Community Organization Theory

Community organization theories usually assume the involvement of community members either in affinity or geographic groupings. The literature on participation in community organizations can be divided into that which addresses functions of participatory organizations, and that which addresses the process of participation.

In a classic analysis, Rothman (1968) identifies three functional models of community organization - **locality development, social planning**, and **social action**. **Locality development** organizations pursue community-wide economic and social change through broad participation of a spectrum of citizens in the community. Locality development utilizes a view of the public interest which assumes that a common good exists and can be determined instrumentally through a broad, cooperative decision-making process. Values of harmony and communication are implicit in this model which appears to underlie the calls for community participation in the healthy public policy strategy of health promotion (Milio 1988).

Social planning organizations emphasize a technical process of problem solving to achieve rational, deliberate, and controlled change. Participation of consumers in the community varies depending on the problem, the organization, and the knowledge which expert planners judge to be needed. Social planning utilizes a view of the public interest which assumes that, with the proper combination of expertise, judgement and conscience, the community's needs can be met. Professional elites play the key role in a social planning model which values rationality, objectivity, and professional purpose. Social planning principles appear to underlie health services planning and social marketing approaches which are espoused in some forms of health promotion (Lalonde 1974, Epp 1986, WHO 1986).

Social action organizations aim at making fundamental changes in local social conditions and institutions. Participation of disadvantaged groups of victims is emphasized. Social action utilizes a view of the public interest which assumes that a disadvantaged group's vested interest is legitimate. Central concepts in community development include inequalities in health-producing conditions, imbalances in power, and values of community control and autonomy (Schler 1970, Morley 1983). Values of social justice and equality are implicit in this model which appears to underlie the community development approach in health promotion (Labonte 1981, Dixon 1989). These social action concepts closely reflect the structural perspective on community participation as defined in this thesis.

Rothman (1968) notes that these functional organizational models often overlap in practice to meet different needs of the community, but in doing so often result in contradictory activities and confusion amongst staff and participants.

A variety of theorists in the field of community health have developed compatible typologies of community organizations. Rifkin (1981) classifies community organizations to include public health, health planning, and community development models. Similarly, Labonte (1988) proposes that community organizations tend to adopt advocate, neutralist, or activist planning models. Stirling (1989) suggests that community organization functions have developed beyond early social action conceptualizations of 'enabling', 'mediating', and 'activism' towards more recent trends of 'institutional access', 'local cooperation', and 'intersectoral coordination'. These trends demonstrate an increasing bureaucratization of the functions of community organizations in their relationships with the state.

A second stream in community organization theory focuses on participatory processes which concern the depth of community involvement, or influence and power in local projects. In a key paper, Arnstein (1969) proposes that the community participation process is fundamentally concerned with the institutionalization of power relationships. The process of participation in any project varies from non-participation, through tokenism, to full citizen control. Arnstein's typology implies a zero-sum power situation in which there is a fixed amount of power or benefits in society. The power which one group wins is achieved only through loss of power by another group. Arnstein's 'Ladder of Participation' typology underlies many of the efforts to develop scales for evaluating the degree of community participation (Rifkin 1988).

Alternately, Susskind (1983) proposes a non-zero-sum gradient of participatory influence: from paternalism (centralized decision-making), to conflict (citizen confrontation over control of policies), to co-production (negotiated decision-making wherein power is shared and both parties gain information about community problems). Crenson (1983), however, notes that while the co-production process tends to occur more often in low-income neighbourhoods, it usually benefits high-income residents of these neighbourhoods. This raises the issue of who benefits from a negotiated decision-making process.

Most theorists view community participation practice as a blend of these organizational functions and participatory processes. Particular methods of community work are appropriate at different times for different issues. This conceptualization makes analysis and evaluation of community projects problematic. However, there is a consistency of view that, over time, community organizations must address their relationships with outside groups, institutions, and social structures which influence the health of the community (Jackson 1989). This consensus on the need for a structural analysis is consistent with currently espoused health promotion principles.

Overall, community organization theory is concerned with explaining the structure, function, and process of participatory activities in local project models and is important in the analysis of factors which contribute to successful involvement of the community and also in the development of evaluation strategies for community participation (Rifkin 1981, Rifkin 1988). Some additional characteristics of community organizations which are suggested by these theories, and which can be incorporated into a study of structural dimensions of the community participation process, include:

Composition of the sponsor group - Health promotion projects may be organized by health professionals, by community development personnel, or by target group members (consumers). The sponsor group composition, or degree of participation by the former groups in the structure of the organization, could be an important factor in the involvement of community members.

Bureaucratic directives - Health promotion projects funded through federal or provincial sources may be influenced by bureaucratic suggestions, or even directives, regarding appropriate forms of participation. These influences may be shaped by the personal experiences of bureaucratic staff, by the degree of direction which project officers give to projects, by available funding for participatory processes, and by current mechanisms for evaluation of projects.

Project objectives and activities - Health promotion projects which focus principally on self-help and mutual aid strategies may involve different forms of participation than projects which focus mostly on advocacy, public awareness, and education.

Local leadership - Community leaders may facilitate or inhibit participation in project activities. Hierarchies of community members may evolve in local projects, with benefits accruing to more influential members and leaders.

Social Movement Theory

A second stream in social change theory which is applicable to community participation in health promotion is contained in the literature on social movements. Social movement theory is concerned with the development, maintenance, and impact of collective organizations of social change (Hannigan 1985). Early theories of social movements focused on the emergence of social problems, and the motivations of aggrieved populations and leaders in responding to these problems (Turner 1987). However, these analyses of collective behaviour gave little explanation for the participation of non-aggrieved persons (Olson 1968) or community organizations in the social movement (McCarthy 1987). There are two social movement theories which have particular applicability to community participation in health promotion - Resource Mobilization theory and New Social Movement theory.

Resource Mobilization theory proposes an economic analogy to explore the ability of specific social movements to acquire and use monetary and labour resources to facilitate organizational objectives (McCarthy 1987). The resource mobilization approach examines the variety of resources required, linkages of organizations with external supporters, and the creation of change in the organization by this resource dependency. In the context of health promotion, Resource Mobilization theory can be used to explain the ability of community organizations to secure funds for community participation in projects and thus become intermediary change agents between the state and the community. While this theory provides explanations of how an organization is set up and maintains levels of participation, it does not explain why the organization initially arises or its potential for long term survival. This issue is important in a transformational type of participation and in participation of community agencies in coalition activities.

New Social Movement theory addresses these issues. Castells (1983) argues that recent social movements have developed due to particular historical and cultural events which are anti-institutional and self-identifying in nature. He asserts that survival of a social movement organization depends on more than a rational mobilization of resources alone, since this inevitably leads to institutionalization and loss of purpose. Castells proposes that the future of such organizations depends on improved collective conditions, an autonomous community culture, and political self-management. Similarly, Touraine (1981) identifies autonomy and self-identity as crucial for new social movements which are more concerned with reform, or creating alternatives within the dominant society, than with increasing their own power. More broadly, Castells (1989) conceptualizes community participation itself as a component of a general social movement for local autonomy.

The issue of whether health promotion is a social movement is not resolved. New Social Movement theory has been used to analyse the development of health promotion and its potential for creating lasting social change. Pederson (1989), in a study of the development of health promotion in Ontario, notes that it was initiated mainly by professional and bureaucratic social reformers, and concludes that health promotion can be interpreted as a professional social movement. In contrast, Stevenson (1991), Labonte (1994), and O'Neill (1994) argue that health promotion is not a social movement per se, but a professional and bureaucratic response to challenges put forward by other social movements such as feminist, environmentalist, and disability groups.

In sum, social movement theories may be important in an analysis of the ability of health promotion projects to develop, promote change, and survive within communities. Some structural characteristics of participatory organizations which are suggested by these theories include:

Securing and utilizing resources - Community organizations which do not have a secure funding base may spend inordinate amounts of time ensuring their own organizational survival, rather than involving community members. Similarly, organizations with limited personnel resources may have unrealistic expectations of the abilities of community members to conduct project activities.

History of the organization in the community - Previous experience of the organization with community participation, and previous experiences that the community has had with the organization, may be predictors of success in effectively involving community members in projects.

Organizational culture - The successful development of an organizational culture, or a set of values and identity in a project, may attract and maintain community members as participants.

Autonomy - The organization's degree of autonomy in setting its own directions may allow community members to balance the influence of the bureaucracy and other powerful professional groups.

Alliances with community groups - A conceptualization of disadvantaged target group members as isolated individuals may not be adequate to explain the evolving self-identification of local organizations as 'communities' in Canada today (Pal L 1993). Project alliances constitute 'community group participation' in health promotion, especially in organizations where project objectives are oriented towards advocacy and policy change.

In summary, social movement theories may assist in the explanation of how community participation is supported, why it arises, and its potential for sustainability. Another body of social change theory can be used to explain, from a structural perspective, who participates and what benefits occur from participation.

Interest Group Theory

Interest group theories assume that societies are comprised of different constituencies with different goals. Conflicts between these interests are thought to be resolved in various decision-making forums. Pluralism is an interest group theory which assumes that the government acts in response to the pressures of competing interest groups (Dahl 1961). Pluralist research in health attempts to identify who the competing interests are, to what extent these interests are mobilized, what resources they command, and what strategies are used to gain funding (Milio 1988).

Pluralism has been criticized for its assumption that competing interests have equal power bases and for neglecting structured power imbalances in society. Specifically, the system of democratic pluralism is criticized as one of limited pluralism and the poor are the major collectivity excluded from full participation in the system (Herman 1983). Elite theorists argue that political power is concentrated in established elite groupings (Mills 1959). Neo-marxists also argue that elite groups control the political process through the state, which acts as an instrument of economic class domination (Miliband 1969).

In Canada, the medical profession has been identified as the elite group in the health arena, although this privileged position appears to be in decline (Coburn 1983). Specific involvement of health professional, voluntary, and bureaucratic groups is now expected in health services planning and the development of healthy public policy. Disadvantaged persons are identified as target groups for empowerment in local community development projects in the belief that those with more power will become healthier (Smithies 1990, Labonte 1993). The involvement of these different constituencies in the common field of health promotion implies that an interest group analysis may be useful in determining who benefits from specific initiatives.

An alternative interest group theory is concerned with identifying the dominant, challenging, and repressed interests in decision-making groups and how these positions are maintained in relationship with the predominant institutional and class structures (Alford 1975). Alford argues that the traditional power of the dominant medical 'professional monopolizers' has been challenged by 'corporate rationalizers', or groups of health administrators, bureaucrats, and business persons intent on rationalizing the health care system to make it more efficient. Community 'equal health advocates' are identified as a third interest group which has largely been repressed in its attempts to gain influence. This repression can be partially explained by lay-professional conflicts (Young 1975) but Alford also identifies a more fundamental factor.

Alford emphasizes a structural component underlying the overwhelming influence of professionals and corporate reformers. The alignment of their interests with the dominant institutional and class structure ensures that "... change is not likely without the presence of a social and political movement which rejects the legitimacy of the economic and social base of pluralist politics" (Alford 1972, p.164). In the absence of such movements, Alford's structural interest group theory predicts incremental change rather than large scale fundamental reform (Weller 1977). Application of this theory to programs such as the Health Promotion Contribution Program may explain a contradiction in health promotion which identifies the necessity of fundamental change for health improvement, but does not seem to be able to deliver on it due to health promotion's structural confinement within the socioeconomic system and its inattention to the politics of competition (Stevenson 1991, Hancock 1994).

Pluralist interest group theory, as the predominant political theory of western democracy, is important in the analysis of who participates and benefits in health promotion projects. Some additional characteristics of community organizations which this set of theories suggest may influence participation include:

Target group selection - Many health promotion projects are directed towards target groups (women, seniors, youth, persons with disabilities, ethnic minorities) which may have characteristics which impede efforts at gaining their participation. Health promotion projects directed towards caregivers or towards persons at risk of developing health problems may not be successful in obtaining participation when these groups have competing demands on their time.

Definition of issues - Since community organizations are usually funded to undertake projects with specific goals, comprehensive efforts to involve community members may only occur once the project direction has been set and issues have been defined. Determining who defines the health issues may clarify which group has major influence in the project (Kelly 1989).

Group consensus - Interest group theories assume a consistency of interests within specific groups. While this may be more likely with professional, staff, and bureaucratic groups due to common socialization and financial interests, it may not be applicable in a heterogeneous group of community participants with different needs.

Similarly, structural interests theory may be important in the analysis of the constraints on participation as a strategy of social change. This theory suggests further structural characteristics of community organizations which may influence participation:

Inclusion/exclusion biases - Health promotion programs which identify specific target groups as eligible project participants, also exclude other groups (e.g., low income persons, psychiatric survivors, institutionalized persons) from consideration by virtue of their condition or situation.

Purposes of participation - Different interests may desire community participation for varied, and sometimes competing reasons. Particularly important is the gap between corporate, or publicly identified, purposes and the privately expressed purposes of powerful interests.

Overall, one of the limitations of interest group theories has been their inadequate conceptualization of the role of the state. Traditionally, the state has been viewed as a neutral mediator (Latham 1952), as an equal player (Dahl 1961), or as primarily interested in maintaining the status quo (Alford 1975). These views do not explain the current tendency of the state to actively promote a health agenda, based rhetorically on fundamental change, through such mechanisms as the HPCP. Theories of political economy of the state may help to clarify this tendency.

Political Economy Theory

Political economy theories provide an alternate structural perspective for analysis of participation in health promotion programs. These approaches connect health programs to the larger society, acknowledge powerful interests which rule Canada, consign an important role to ideology in health, and utilize assumptions of critical theory such as emancipation, structural influences, and the power of knowledge (Salmon 1989). These assumptions are consistent with those of a structural perspective on community participation.

A political economy interpretation of health has emerged in western Europe and North America since the 1960's due to dissatisfaction with functionalist analyses and the failure of many studies to position health within a societal context (Navarro 1976, Baer 1982). There are two general streams in the political economy literature which have application to health promotion. The socioeconomic determinants of health, or the effect of structural factors on health status, incorporates a structural perspective but is not the topic of this thesis. Another theoretical stream, which discusses the impact of political and economic factors on health improvement strategies, for example community participation in health promotion projects, is pertinent to this study.

The Canadian state's subscription to the importance of structural influences on health, which assumes that the ability to implement improvements in health lies beyond individuals, professionals and communities, raises the question as to why the state emphasizes community level solutions. More specifically, why does the state espouse community participation as a primary strategy for health promotion? State support for participation may be related to structural power relations within society. In addition, legitimation of different groups as participants in decision- making is a core consideration in a political economic view.

Theories of political economy are generally concerned with influences on the role of the state and its actions by broad economic and political factors (Dahrendorf 1959, O'Connor 1973). Specific theories are based on differing views of the role of the state in a class society. Dahrendorf's (1959) view of class structure describes post-capitalist society as having a new middle class, increased social mobility, and more equality between classes. Power does not derive from the economic base directly, but through political authority relationships which the state controls. The state camouflages the real source of control by espousing 'participatory democratic' institutions, of which community participation may be viewed as a recent example.

Dahrendorf notes that with increased state control of the economy in a welfare state there is a need for legitimation of this control, in the form of public participation, to augment that legitimacy usually received through formal electoral support. In a purely representative democracy, electoral support for the ruling party does not supply sufficient legitimation for the increasing bureaucratization of society, and it is this deficit in support which is actively solicited by those in power. The public is likely to accept their new role in community participation since it seems to represent an opportunity to exert influence, even for those who are not supporters of the ruling party. Thus, Dahrendorf emphasizes the 'political' function of community participation as a form of participatory democracy.

In contrast, a neo-marxist perspective is based on a view of the capitalist state as the instrument of the economic ruling class (Miliband 1969, O'Connor 1973, Poulantzas 1974, Gough 1979). The state is dominated by the ruling class principally for economic purposes, that is to maintain capital accumulation (Poulantzas 1974), but also for reasons of class solidarity (Miliband 1969). In current neo-marxist thought, the degree of ruling class control is conceptualized as being only partial, with the state being 'relatively autonomous' in order to manage internal conflicts between factions of the bourgeoisie. Consequently, the state can make decisions with some independence from the ruling class as long as the capitalist economic system is not fundamentally disturbed (Poulantzas 1974).

O'Connor (1973) argues that the state must also have a legitimation function, in addition to its accumulation and coercion functions, in order to maintain social harmony. This legitimation function is facilitated by a perception of the state's relative autonomy from capital interests. Welfare state programs, which can include a ‘contributory’ participation component (e.g., workfare), are seen as legitimizing the participation of the public in non-economic activities (Gough 1979, Offe 1984).

Neo-marxist theory supports these interpretations with respect to health promotion strategies, such as participation of the public. On a societal level, Navarro (1976) explains that highly capitalist states prefer democracy to be exercised through a limited electoral system which functions to legitimize the political process rather than to change it. At the community level, Navarro (1975) documents the domination of decision-making bodies within health institutions by corporate and upper middle class citizens. Similar dominance has been noted in Canada (Clement 1975). Community participation in health programs is viewed by neo-marxists as a legitimation strategy of the state, through which the community can be given apparent control over non-economic aspects of the health sector in so far as this does not result in capital accumulation problems (Waitzkin 1978, Midgeley 1986).

Other views of community participation have been expressed utilizing a political economy perspective. The state may encourage community participation in order to gain support in its challenge to conservative health interests which may, for example, desire to restrict access to health care (Alford 1975, Crichton 1980). Castells (1989) also notes that there are major world forces (techno-economics, international influences, and global network structures) which are weakening the effectiveness of intermediate social movements such as community participation. However, the potential for community participation to seriously affect these macro structural determinants of health is doubtful in Castells' analysis.

Neo-corporatism is an alternate political economy theory derived from liberalism which may have application to participation since it is concerned with management of decision-making processes by the state (Mulgan 1984, Van Til 1984). Neo-corporatism asserts that important decisions should be made by three primary institutions: the state bureaucracy, large corporations, and labour organizations (Panitsch 1980, Cameron 1984). In the health promotion context, the process of 'co-determination' by government, business, labour, and other key social sectors has been proposed as a mechanism to integrate economic, social/health, and environmental policy making (Hancock 1994). Although undemocratic in principle, neo-corporatist models may represent an advancement over traditional 'representative' majority rule political bodies in their explicit acknowledgement that no single sector can make structural changes unilaterally. In addition, neo-corporatism may ensure a public accountability in corporations and labour which is absent in the present system.

Voluntary associations and disadvantaged groups have tended to be excluded from these recent decision-making processes since they are not believed to control the resources necessary to affect basic socioeconomic conditions (Van Til 1984). However, according to neo-corporatist theory, there is no inherent reason that community groups could not participate in a corporatist model. The key condition for participation, however, is the perceived legitimacy of the community sector (Mulgan 1984). If health promotion actually represents an attempt by the state to legitimize formal community involvement in a neo-corporatist model of decision-making, then the state would also be expected to provide ongoing funding and other mechanisms for supporting community organizations in their decision-making roles.

Political economy theories are important for the analysis of motivations underlying the state's promotion of community participation and for understanding limitations in the state's ability to facilitate it. These theories are also important in analysis of the legitimation of community groups in decision-making. Some characteristics of the state, as suggested by these theories, which may influence community participation include:

Government interest in health promotion and community participation - Both public and private expressions of ideology related to community participation may be important in the promotion of participatory programs and strategies. Support of senior government personnel may be instrumental in securing resources and legitimation necessary for projects to proceed.

Division of government powers - In Canada, health services are primarily the responsibility of provincial governments, while overall funding policy has been influenced largely by federal cost-sharing initiatives. These may account for continuing sensitivities between the federal and provincial levels regarding the development of, and fiscal responsibility for, participatory health promotion programs.

Institutionalization of participation - Government interest in formalizing participatory structures and processes can be viewed both as a tendency to organize and bureaucratize public activities as well as a mechanism to legitimate interest group involvement in decision-making. Either interpretation could influence the form of public participation which appears in health promotion projects.

Health policy - The federal government's willingness to modify the focus of the Health Promotion Directorate and the Health Promotion Contribution Program may illustrate its changing views on health promotion and community participation. Specifically, the funding allocated to the program and its coordination with other federal departments gauge the government's priority for facilitating community participation.

In sum, political economy theories provide an important perspective on the motivations of the state and may explain the resources provided to participation in health promotion, and the states's expectations of it. They also provide a balance to theories of community organization, social movements, and interest groups by focusing on the societal conditions emphasized in recent health promotion literature.

2.11 Study Objectives

This review of literature on community participation, situating this phenomenon within the Canadian health promotion context, suggests that there is a need for analysis from a structural perspective. The literature also suggests four relevant issues in the participation process: who is involved in community health promotion projects; how participation is organized; the roles and activities of participants; and the expression of power between interests in the projects. Although structural influences on these aspects of participation have been reported, there is considerable conflicting and missing evidence, especially in relation to participation of disadvantaged persons. The extent to which the various dimensions of structural influences (social-cultural, organizational, political-legal-economic) are operative in health promotion participation is currently unknown. Furthermore, the mechanisms for these relationships are not well understood.

Conceptual and theoretical developments in this field have been hampered by the lack of appropriate models and frameworks for analysis of this complex topic. Cohen and Uphoff's (1980) framework appears to have the most potential in this regard, apart from its lack of focus on power issues. The value of a deeper theoretical contribution to studies in this area has also been illustrated through references to Community Organization, Social Movements, Interest Group, and Political Economy theories. These theories suggest additional structural factors which may be of importance in the study of participation in the health promotion context.

The objectives of this thesis are:

1. To identify structural factors which are associated with types of community participants, participatory strategies of sponsor organizations, roles and activities of community members, and influence and power in health promotion projects.
2. To explore mechanisms by which these factors affect the community participation process.

As noted earlier, the currently identified structural factors and parameters of participation may not be complete, nor easily interpretable, especially in isolation from each other. To ensure that all important structural factors and participation parameters are identified and to examine their possible mechanisms, it seems advisable to utilize a qualitative research process.

CHAPTER 3

METHODOLOGY

The literature review has underscored the importance of structural factors in the process of community participation in health promotion projects. In this chapter, methodological issues in health promotion research are reviewed to clarify why a qualitative case study approach is appropriate for research on structural factors in community participation. Secondly, a detailed description of the methods used in this thesis is provided.

3.1 Methodological Issues in the Study of Community Participation

The choice of an appropriate research methodology for this topic depends on the purpose and timing of the study, epistemological considerations, and the suitability of various methodologies in the study of causal mechanisms.

Purpose and Timing of Study

The practical needs for research information vary over time. At some points, information for explanation and theory building is required. At other points, information and indicators for policy development are necessary. Generally, there is a need for development of theory and models before indicators can be developed adequately. Even so, in health promotion, there is a need for indicators of processes, such as community participation, as a means for health improvement, as well as indicators of health status as an end (Hayes 1990).

Previous research has developed indicators of participation, including preliminary efforts in the field of health promotion (WHO 1991), and appropriate use should be made of this work. However, a number of authors have argued persuasively that it is premature to develop evaluative indicators in health promotion, especially for dynamic processes such as participation, without establishing an adequate theoretical base which can supply validity to the selection of these indicators (Noack 1988, Kelly 1989, Hayes 1990, Stevenson 1991, McQueen 1994). Indicators need to be developed with a coherent rationale when used for policy making or decision-makers will not use them (Haro 1987). Haro also points out that, for policy purposes, there is a need for timely studies:

> "The use of an exaggeratedly careful 'scientific' approach may take too long to provide the necessary timely insights, and as a consequence, questionable ideas may be introduced uncritically as a basis for action" (p.64).

The paradox to this call for timeliness is that dynamic phenomena, such as community participation, require innovative and complex data collection procedures and analysis. Thus, policy utility may be in conflict with analytic prerequisites. On balance, for the topic of health promotion participation, a research method which focuses on explanation and theory building appears preferable at this time.

Epistemological Basis of Study

There has been a continuing debate over health promotion research epistemologies (objectivist-subjectivist) and the methodologies (quantitative-qualitative) which are consistent with them (Poland 1992). An emerging paradigm of research in health promotion, which is not accepted by all, recommends a subjectivist epistemology, which is to say, the world, or reality, is what we say it is (O'Neill 1989). This approach is derived from hermeneutics, or the interpretation inherent in social inquiry and reflexivity, or 'action involving thought' (Guba 1989). The subjectivist-qualitative approach fits well with the ethos of both health promotion and community participation which asserts that communities know what they want.

One extreme view of epistemological-methodological consistency suggests that investigations of participation that incorporate an interpretive, subjectivist approach must themselves be done in a participatory manner (Bopp 1994). One way of accomplishing this is through a participatory evaluation of participation, wherein the community members co-direct the collection and analysis of data. This approach may be suitable for evaluative situations in which indicators are applied to projects and in which there are policy and funding implications. However, participatory evaluation may be less suitable for explanation and theory building research, in which gaining insight and understanding the underlying process of participation are primary goals. In addition to the practical limitations of a participatory methodology when studying diverse constituent groups and geographically separate sites, there is a danger of confounding the measurement process. Are participants to analyze their participation in the research study, as well as in the health promotion project?

An alternate method, which satisfies most epistemological and practical considerations, involves utilizing the participants' own understanding the issue as the data. This goes beyond merely recording the participants' descriptions of their experiences as pieces of data, but requires them to interpret these experiences and provide some insights about the relationships between community participation and structural influences (Denzin 1989). This approach assumes that interested, involved people can have a reportable experience and subjective understanding of structure, in the same way that they can develop an understanding of other phenomena such as the dynamics of group interaction and the process of self change. It also partially meets the need for a participatory approach by giving attention to the subjects' views and interpretations of how structure and agency are interrelated, rather than only the researcher's constructions of these links. Finally, the approach accepts that community members' perceptions that structural factors affect participation will in fact influence their actual involvement. This assumption is consistent with Giddens' (1984) view that reflexivity, or the purposive monitoring of social life and social systems, is a component of agency. The researcher's role under these assumptions is to ask relevant questions about structure based on previous knowledge, to probe for inconsistencies in factual elements, and to take responsibility for summarizing evidence, comparing across situations, and developing suitable theoretical explanations for the findings.

Methodologies for Examination of Causal Mechanisms

In order to advance knowledge and theory of the role of structural factors in community participation, two approaches can be taken. First, one could collect detailed quantitative information about these factors and the participation process from surveys, document reviews, standardized rating scales, etc. Analysis would entail a variety of descriptive, correlational, and inferential procedures which allow the testing of appropriate hypotheses about participation. Ideally, this approach would utilize a representative sample of health promotion projects for collection of data to allow statistically generalizable conclusions to be posed. Essential prerequisites for this approach include valid, reliable instruments and indicators which have a sound theoretical base. These prerequisites are not yet present in this field of study.

One stream of contemporary sociology criticizes this generalizing methodology as being deficient, as it cannot identify what has caused particular phenomena in community settings (Nilsen 1996). Community projects are seen as examples of 'black box' problems in which complex causal and mediating processes relate stimuli to behaviour. The mechanisms for these processes are thought to be revealed more appropriately through an emphasis on local contexts, rather than on identifying causal correlations between variables. Such contextual analysis can vary from historical reconstructions to examination of current social conditions, both of which may yield lower generalizability but more detailed insights into causal mechanisms. Bamberger (1990) notes problems, however, in studying the process of participation in this contextual way, since it is difficult to observe or record all the interaction which might be occurring. Additionally, there is a tendency to under-estimate participation if using researcher observation, and over-estimate it if using organizers' responses.

Many authors recommend comparative case studies to compare similar social processes in as many different contexts as possible (Pawson 1989, Ragin 1991, Nilson 1996). Case studies are also appropriate for use when there is lack of consensus and clarity in definition, when the boundaries between phenomenon and context are not clear, and when many sources of evidence are available (Miles 1984). Multiple case studies are especially useful for examination of complex contextual phenomena such as community participation, which are likely to vary across locations and time (Bamberger 1990).

Yin (1989) distinguishes between descriptive, exploratory, and explanatory case studies. Descriptive case studies describe the real-life context of phenomena. Exploratory case studies examine situations in which phenomena have no clear, single set of characteristics in order to develop ideas and hypotheses for further study. Explanatory case studies explain causal links in situations that are too complex for survey or experimental methodologies. In the context of health promotion participation, exploratory case studies appear to be appropriate methodologies for assessing the relevance of broad theoretical propositions, such as the influence of structure on participation, and for generating hypotheses prior to testing them in more generalizable settings (Yin 1989).

It is important to note that the purpose of case studies is not to make generalizable conclusions about other settings, as this would require findings with a set of acceptable statistical probabilities. Yin (1989) and Miles (1984) suggest that the logic of a case study resembles that of a single experiment, rather than a sample survey in a population. In an experimental paradigm, conclusions are rarely based on a single experiment, but are based on a multiple set of experiments in which the same phenomenon is replicated under different conditions. Experimental scientists and case study researchers generalize from study results to theory, that is, they pose a general proposition (e.g., structural factors influence community participation) and attempt to determine the conditions under which it is true. The proposition should be tested under different conditions, or settings, to determine the robustness of the general theory, rather than to determine the applicability of the findings to different groups. One important implication of this view is that the selection of case studies does not follow a sampling logic wherein the respondents are assumed to represent a larger pool. Instead, cases are selected so that they are likely to provide similar results, or to provide contrary results, but for predictable reasons.

Using a case study approach, one could collect intensive qualitative interview data about the experience of community participation from the perspectives of project participants and knowledgeable key informants. If the general theoretical proposition that structure influences participation is valid, then clues to the existence, importance, and mechanisms of these structural factors would be embedded in respondents' experiences and perceptions of community participation. Individual case analysis would involve the examination of the data for illustrative examples of relationships between structural factors and participation. The data would be used as illustrations of how structural factors are manifested at the level of action and experience, thus linking structure and agency. Comparative analysis would involve extracting those structural factors which are common to different projects and situations and providing preliminary explanations of their mechanisms of action.

This is the methodological approach taken in the thesis. There are three reasons for this choice. First, a qualitative case study approach appears to be more feasible at this time considering the state of quantitative frameworks, instruments, and indicators for community participation. Second, a qualitative approach may reveal the mechanisms by which structural factors are linked to community members' experiences of participation. This may have important theoretical implications in the fields of the sociology of health and health promotion.

Finally, the approach directly links evidence from participants' experiences to the analytic process in a way which is consistent with new methodologies of health promotion research. Participants' experiences and perceptions are important if one assumes that people behave in ways which reflect their understanding of a variety of external influences. If one understands the nature of these external factors and how they work, it may be possible to promote changes which would facilitate improved participation.

In summary, there is a need for a methodology in this study which:

a) utilizes the existing state of knowledge of community participation regarding structural dimensions;

b) allows the researcher to examine the links between structure and agency rather than identify generalizable findings of participation;

c) allows exploration, or preliminary explanation of these mechanisms; and.

d) allows the incorporation of participant perspectives.

This thesis uses an existing framework of structural factors in community participation, and other relevant theoretical sources, as the bases for deriving study questions which are appropriate for a health promotion setting. This research does not pre-specify what participation resembles, but examines evidence to determine the existence of, and general relationship between, structural factors and the participation process. Self-reported experiences of participation which focus on the effect of potential structural factors are the primary sources of evidence. Examples of situations in which the actions of individuals shape these structural factors are also sought. Data are obtained from persons directly involved in projects as well as from key respondents who have developed insights into the issue from their experience in the community health field. The experience of participation is interpreted in terms of the structural factors perceived to be important by most respondents and for which convincing explanations can be developed. This approach allows the development of preliminary theoretical explanations of participation which may contribute to the generation of hypotheses and the development of evaluation indicators in future studies.

3.2 Methods

This research involved the comparative study of community participation in five projects funded within a single health promotion program in Canada. A multiple case study methodology was used to compare and contrast structural features which influence community participation in different settings.

Study Setting

It was decided to study projects under a single health promotion program, rather than studying examples of participation from a range of government-supported programs, to provide some degree of consistency in contextual factors. For example, the particular style of community participation in health promotion projects could be influenced by such contextual factors as health policies, funding and review procedures, and government personnel activities. By studying projects under a single program, the variability in these factors would be minimized.

When the study was designed in 1992, the HPCP was a national program which focussed on disadvantaged groups that had been in operation for eleven years. The HPCP was intended to be a primary channel for federal efforts to involve these local communities in health promotion activities. The HPCP had a continuing fiscal allocation, a secure institutional base in Health and Welfare Canada, and the approval of political leaders (Pinder 1988, Raeburn 1989, Pinder 1994). As such, the HPCP provided a suitable source of community participation projects that fit the needs of this study.

It was not the intention of this study to evaluate the suitability of the HPCP model itself, nor to generalize conclusions about community participation in health promotion to other settings, but rather to demonstrate general relationships between structure and participation and suggest plausible mechanisms in programs of this type.

Pilot Study

A pilot study was conducted to:

a) determine possible target groups for review in HPCP;

b) formulate project selection criteria;

c) develop interview questions;

d) pretest the interview plan with respondents and determine an appropriate number of respondents; and

e) assess information content in project documents.

The results of this pilot study were used to formulate the study methods.

a) Target Groups for Review

The original (1981) target groups for the HPCP were identified as women, children and families, seniors, persons with disabilities, and adolescents. Subsequent to 1987, a number of changes were made to the program. Project funding for seniors was transferred from HPCP to the Seniors' Independence Program. In addition, child and family project funding was absorbed into other Health & Welfare Canada programs. Native persons' projects began to receive funding under the HPCP. Thus, the HPCP target groups at the time of this study included women, persons with disabilities, adolescents, and native persons.

b) Project Selection Criteria

Criteria for selection of a group of projects for comprehensive case study were developed by the researcher through interviews with community and bureaucrat respondents and analysis of available project documents. These data indicated that a group of five projects could be selected for in-depth study based on one of five **primary modes of participation** of community members: as **board directors, advisory committee members, volunteers, employees, or clients/service recipients**.

Kelly (1996) recently used 'modes of participation' to categorize respondents in a qualitative study of interactions between sponsor staff and participants in a community health project. However, 'modes' in that study referred to observed interests of individuals in the group. For example, Mode 1 referred to persons participating from the perspective of having organizational resources and special project skills. In the current study, mode of participation was defined as the most frequently cited participant position in the project documents (board director, committee member, employee, volunteer, client).

This criterion for selection of the case sample was consistent with potential indicators of community members' roles and degrees of control in the project and thus was linked to issues of major theoretical importance in the thesis. Other project characteristics which Cohen and Uphoff (1980) identify, such as 'type of participatory activity', 'stage of participation', and 'target group membership', were considered for use in case study selection but were rejected as they were difficult to identify from the project documents or were not evenly distributed across the projects.

c) Development of Interview Questions

The general interview framework was based on traditional questions about participation: What is community participation? How does it occur? Who participates?

What effects and benefits are realized? Why is participation promoted? (Cohen 1980, Rifkin 1988, Oakley 1991). Specific questions were derived from Cohen and Uphoff's framework and incorporated issues such as purpose of participation, types of participants, participatory strategies, participant roles and activities, and community member influence. The framework was supplemented by questions derived from social change theories relevant to community participation. The latter included issues such as sponsor history, relationship with community members, resources, alliances, project management and evaluation, roles of other interests, and government views on participation.

(d) Pretest of Instrument

Five pilot interviews (one sponsor staff, one Health and Welfare Canada staff, and three community members of a health promotion project) were conducted to assess the feasibility and suitability of the recruitment and interview plan. These pilot interviews indicated that comprehensive information about structural factors and participation in projects could be obtained from interviews with one HPD project officer, one to two sponsor organization staff, and three to five community respondents. Thus, the number of interviews which would be required with project respondents from five projects was estimated to be approximately 25-40.

Respondents were cooperative and appeared interested in the questions which required approximately 40 minutes to answer. Most of the research questions could be answered by all respondents, however the Health & Welfare Canada program officer was the only person able to answer questions related to the bureaucratic context of the HPCP. This indicated that comprehensive answers to questions related to influence of the political-bureaucratic context required a separate set of interviews with expert respondents. The interview guide was revised to focus the questions more precisely and to specify which questions would be asked of particular respondent groups (see Appendix A for final interview guide).

e) Content of Project Documents

Project documents were in the form of proposals for funding, quarterly progress reports, evaluations, and correspondence. Content analysis (Holsti 1969) of the document data from five health promotion projects indicated that the HPCP project documents contained only a moderate amount of information concerning community participation, especially the relationship between structural factors and the process of participation. There was very little information in the documents relevant to the bureaucratic context of HPCP. The amount of information about participation in documents varied from project to project and over the duration of each project. This problem has been reported in other studies of participation where secondary sources were utilized (Bamberger 1990). It was also evident from the pilot study that the objectivity of project document materials could be questioned, since they were created as reports for Health and Welfare Canada management purposes. To ensure that undue weight was not given to these reports, documents were analyzed as secondary sources.

Case Study Selection

Selection of a group of health promotion projects in the HPCP for study was based on a number of practical and program-related considerations. The Health Promotion Directorate had five regional offices across Canada. To obtain a national range of cases, it would have been necessary to travel to each region to review project files and conduct individual interviews since documents were not archived in a central location. Consequently, projects from one of the five Health and Welfare Canada regions (Ontario) were studied.

As noted in the literature review, the Ottawa Charter of 1986 marked an important development in health promotion programs on a conceptual basis regarding community participation. Thus, the time frame of this study included only those projects initiated during the period January 1987 through December 1991. To ensure that the participatory process in projects had an opportunity to develop, only projects in operation for more than six months were selected. There were twenty-four Ontario HPCP projects which met these criteria in the target group areas of women, persons with disabilities, adolescents, and native persons.

Since community participation as defined in this thesis is considered to involve the community directly in a process of change, five projects which were short term, such as those which limited their activities to producing an educational package or conference, were excluded. Three Francophone projects were also excluded as the researcher was not fluent in the French language. Their exclusion may have introduced bias in the study with respect to the social-cultural dimension of structure, but not necessarily the organizational or political-legal-economic dimensions. In sum, the criteria for selection of projects were:

INCLUSIONS

- Ontario region projects of HPCP
- initiated between January 1, 1987 and December 31, 1991
- six months duration or longer
- target groups
  - women
  - persons with disabilities
  - adolescents
  - native persons

EXCLUSION

- short term conference and media development projects
- French language projects

A group of sixteen eligible projects from a base of twenty-four was compiled utilizing these criteria by reviewing project files at the Ontario regional office in Toronto. Brief summaries of the projects' objectives and activities were derived from project documents (Appendix B).

From the population of sixteen HPCP projects, five projects were selected as in-depth case studies. The purpose of this selection was to gather projects that would represent a broad range on a single structural characteristic of interest (Miles 1984). The **primary mode of participation** of the community members - i.e., the most frequently cited participant position in the project (as board directors, advisory committee members, volunteers, employees, clients/service recipients) was used as an observable characteristic by which to select projects.

A content analysis of documents for the 16 projects was performed to identify the most frequently cited mode of participation in each case. Projects were then categorized into one of five primary modes. The primary mode of participation varied sufficiently across the sixteen HPCP projects so that selection by this characteristic provided a range of cases per category. Appendix C illustrates the eligible projects and their location, target group, and primary mode of participation.

One case study per category, or five projects in total, were selected from this list for in-depth study. An attempt was made to include cases representing all HPCP target groups to allow detection of similarities and differences in participation across various groups. Final selection of case studies depended on the completeness of project files and obtaining consent for interviews from individual project sponsors. A project involving native persons was not included due to a lack of documentation.

The five cases selected and their primary modes of participation were:

Inner City Youth Program	(ICYP)	- Employees
Persons United For Self-Help	(PUSH)	- Board of directors
InterCommunity Health Centre	(ICHC)	- Clients
Handicapped Action Group Inc.	(HAGI)	- Volunteers
DisAbled Womens Network	(DAWN)	- Advisor Committee Members

Only one case (ICYP) was located completely in Toronto. Other single site cases were located in London (ICHC) and Thunder Bay (HAGI). Two cases (PUSH, DAWN) had multiple sites across Ontario. The group of cases included two projects related to youth issues, two projects related to disability issues, and one project related to women and disability issues. The inclusion of three projects related to disability was not considered to be problematic since there were eight projects for persons with disabilities in the Ontario region and these were diverse in scope. One disability project which was selected (PUSH) had a single focus, yet utilized multiple demonstration sites across the province. Another disability project had multiple foci and a single location (HAGI). The third disability project had multiple foci and multiple locations across the province (DAWN).

Interview Respondents

Case study respondents were associated with the projects either as community members, local project staff, professionals, or Health and Welfare Canada staff. The researcher did not initiate contact directly with project sponsors or community members for ethical reasons. Health and Welfare Canada program staff were approached first for interviews through the Ontario regional director of the Health Promotion Directorate. Requests for interviews with local project sponsors were arranged through these Health and Welfare Canada respondents. Subsequent interviews with community members were then arranged through project sponsors as intermediaries. Thirty-one interviews with respondents from five projects were conducted. Further details on respondents in each case are reported in the Results section of the thesis.

Additional interviews with nine expert respondents were conducted to provide perspectives on political-bureaucratic characteristics and their general relationships to participation in HPCP projects Since health promotion in Canada involves a variety of interests (bureaucrats, health promotion professionals, academics) beyond community members, an attempt was made to select expert respondents from across this range (Pederson 1989, Pederson 1994). Expert respondents were selected on the basis of their reputation (that is, being active in the HPD, having publications on the topic, being active in other community based health promotion programs) and were approached directly by the researcher through an introductory letter.

Four senior officials from Health and Welfare Canada who had 8 - 12 years of experience in the Health Promotion Directorate were also interviewed. These included officials who had directly managed the HPCP. Three academic scholars from Ontario and British Columbia universities who had publications in the areas of health promotion, community health systems, and public health policy were also interviewed. Finally, two health promotion practitioners were selected for interview, one of whom had national and international experience in health promotion programs and projects.

All expert respondents were asked to provide information specifically about HPCP and the Health Promotion Directorate, about promotion participation in general, and about participation in other community development sectors. Many of the academic and practitioner respondents had experience with HPD either directly as employees, or indirectly through consulting and committee work. Thus, these latter respondents were familiar with the federal health promotion program but had no direct connection with it at the time of interview.

Data Collection

Primary data collection occurred between September 1992 and December 1993. All interview data were collected prior to beginning analysis. The methods of data collection were semi-standardized interviews and a review of available project documents (Guba 1989, Rubin 1983, Rossi 1985). See Figure 3.

Interviews were the primary source of data. A semi-structured interview format was used to ask questions appropriate to the background of respondents (Appendix A). Since it was anticipated that respondents would offer considerable qualitative information in answer to the research questions, the interview was informal and the researcher had the flexibility to change the order of questions, to use appropriate terminology, and to probe for further information. Interviews were taped and transcribed into Ethnograph 3.0 (Seidel 1988), a qualitative data management software program, prior to analysis.

Document data provided a supplemental source of information for the study. Permission was received from HPD national office and the Ontario regional Health & Welfare Canada office to access sixteen project files and background program data.

Project document data included:

Initial project proposals
Quarterly project reports
Final project reports and evaluations

Background program data included:

Project listings - national and regional

HPD program evaluation report, technical documents, surveys

Review of evaluation procedures (Health & Welfare 1985)

Program resource data

Program descriptive data

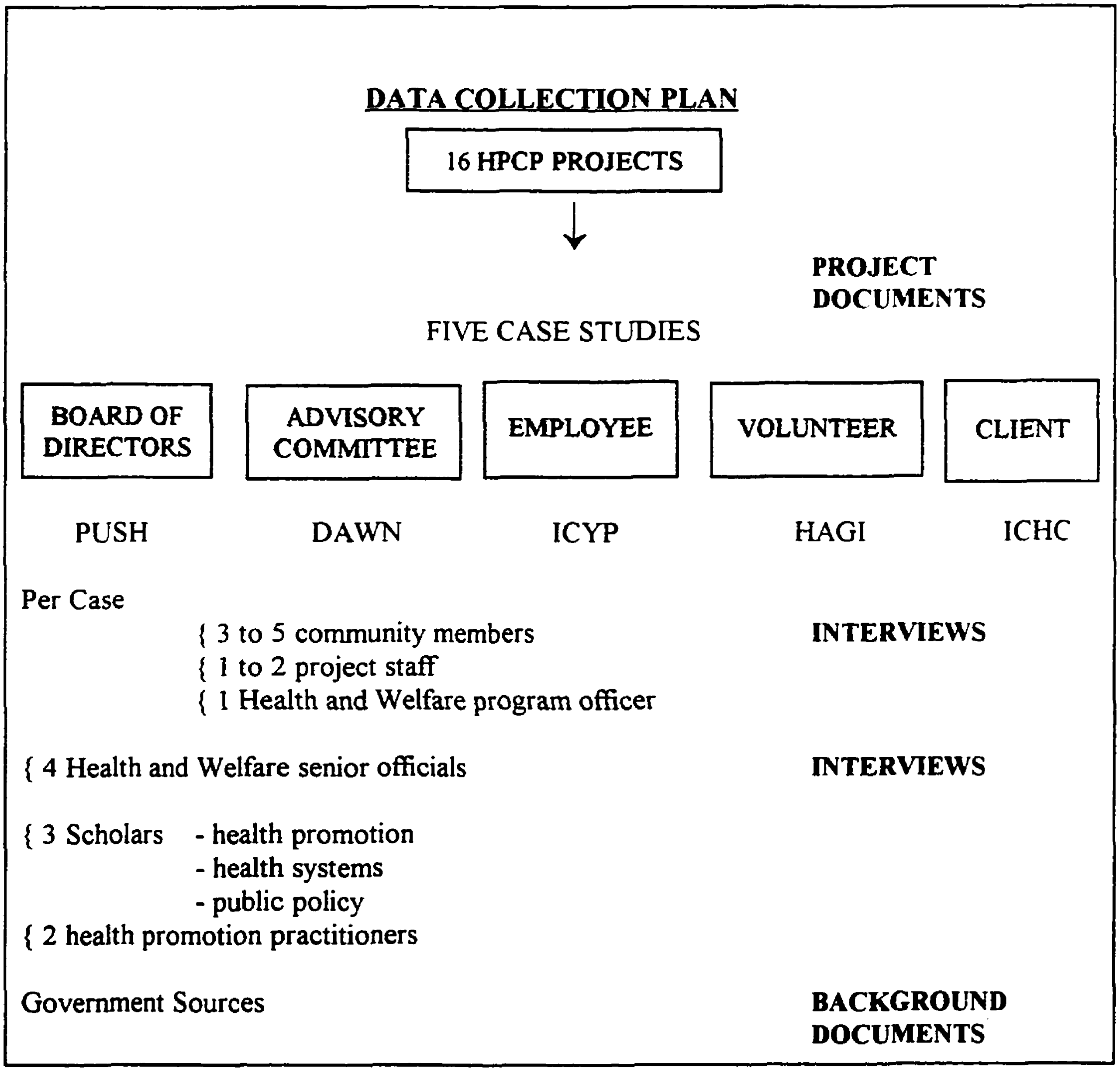


Figure 3. Data Collection Plan

Health and Welfare Canada policy papers and limited government statistical data regarding human and financial resources involved in the program were also collected.

Ethics

There were few ethical concerns associated with this study which received ethical approval from the University of Toronto. Project files were considered to be public documents by Health and Welfare Canada. An interview consent form (Appendix D) was presented to all respondents prior to interviewing to inform them of the use of their information and to obtain their permission. Written consent was obtained from respondents with the exception of those who stated that self-identification could be damaging. A copy of the consent form was left with the respondent and the researcher retained the original form. Tape recordings of the interviews were transcribed and an identification number matched to the respondent was marked on the transcript. Code numbers and respondent identities were stored separately Tapes and transcripts were reviewed only by the researcher and were kept in locked storage. Tapes and transcripts are to be destroyed after the study unless the respondent agreed that these could be archived. Data from respondents are not attributed directly to persons, however, where it is an aid to understanding their comments, their general personal characteristics are included.

Analysis

The overall goal of analysis in this research was to detect relationships between structural dimensions and the community participation process in Canadian health promotion projects. Analysis was organized around four major issues in the participation process which were discussed in the literature review - types of participants, participation strategies, roles and activities, and influence and power. The analysis proceeded in three stages:

a) Descriptive content analysis of project documents

b) Within-case analyses of five HPCP projects

c) Comparative analysis

a) Descriptive document analysis

Project documents from the population of sixteen Ontario HPCP projects were initially coded in discrete categories. To facilitate coding, operational definitions for each category were based on the Cohen/Uphoff (1980) framework. After initial coding, the categories and definitions were revised to reflect the context of health promotion projects and to include further structural factors identified in the literature review. The researcher attempted to use terminology which reflected an organizational perspective at this stage. See Appendix E for final operational definitions of categories. Brief descriptions of the projects (see Appendix B) were written to illustrate the general settings from which case studies were drawn. Analytic memos, which were primarily related to influence of the organizational dimension on the participation process, were later incorporated into the comparative analysis and discussion.

b) Within-case analyses

The case respondents' interview data were then analyzed to identify links between structural characteristics and processes of participation. Thirty-one taped interviews comprising 383 pages were sorted by project and reviewed to identify additional categories, such as program mandate, which were grounded in the data. The interviews were then coded by the researcher using the revised categories and definitions developed earlier in a), as well as the grounded categories. A total of 2,459 passages were coded. The researcher conducted a second reading and coding on 10 page sections of a random sample of 5 interviews after a one week (minimum) interval to determine the reliability of the coding process. Intra-reader agreement was 88%, a level which has been deemed satisfactory for qualitative analysis (Miles 1984, Strauss 1990).

Within each case, subsets of data were then sorted by the four elements of the participation process (types of participants, participatory strategies, roles and activities, influence and power). Through analysis of these discrete data sets, principal structural factors emerged which were linked to each element. These principal structural factors were selected for the following reasons:

a) the factors were coded most often in respondent interviews. In qualitative terms, the analytic codes were 'saturated' with these factors (Strauss 1990); and,

b) the factors were clearly related to elements of the participation process and had convincing links to a structural perspective on community participation.

It must be emphasized that these principal structural factors were identified from respondent interview data and were not independently verified from other measures, surveys, or observations. This is a known limitation of the qualitative methodology but is acceptable considering that data from a variety of respondents and project documents were used to substantiate findings (Strauss 1990).

A number of principal structural factors were developed from combinations of individual organizational factors which appeared to be conceptually related. For example, factors related to project funding, securing financial resources, and use of resources were combined into a single factor which was termed 'Mobilization of Resources'. At this stage, memos were written regarding theoretical constructs in participation which emerged from the coding, for example, 'Legitimacy of target groups', and 'Barriers to participation' of project participants. These memos were later utilized in the case study reports.

The four data sets in each case were then re-coded using these principal structural factors. Key parameters of the participation process (numbers of participants, range of participants, positions of participants, activities, influence) were identified from the data in this final coding. Structural factors were categorized as having an increased, decreased, or neutral effect on these parameters.

Finally, five case studies were written which first described the structural 'characteristics' of the organization and project. These characteristics were not all necessarily related to participation but were described to present an overall picture of the structural context. These case studies then described how principal structural 'factors' directly and indirectly affected elements of the community participation process. A separate report on the development of the HPCP and a description of its structural characteristics was also written (See Results, Chapters 4.1 to 4.6).

c) Comparative analysis

The comparative analysis combined data from separate within-case analyses, from Health and Welfare Canada documents, and from expert respondents' interviews. The expert respondent interview material was coded to identify structural factors in the HPCP program which were associated with the process of participation of community members, for example HPD personnel activities. A similar methodology to the within-case analysis was used in coding and organizing these expert respondent interviews.

Analytic tables for each case were compared to detect common structural factors associated with elements of the participation process. For example, all of the structural factors across cases which were associated with the 'types of community participants' were identified. To focus on the most prevalent influences, only those structural factors which affected participation in at least two of the five cases were reported (Yin 1989). This selection does not lead to claims of generalizability to other health promotion projects, yet it does ensure that the factor's claimed relationship to participation is not idiosyncratic. New summary tables were constructed for each element in the process of participation (see Appendices F, G).

Comparison of cases was then undertaken to establish the strength of factors across cases, to identify the conditions under which specific findings occurred, and to allow general relationships between factors to be proposed. Thus, the comparative analysis was used to raise the level of analysis from descriptive to exploratory and enhance the within-case analyses. A comparative report (Chapter 4.7) was written from this analysis.

CHAPTER 4

RESULTS

The results of this study are presented in three sections. First, as background to the HPCP projects, the development of the Health Promotion Directorate and its mandate to promote community participation are described. Also described are a number of structural characteristics of the HPD and HPCP (Chapter 4.1). Second, in separate case studies, the structural characteristics of five community organizations and their health promotion projects are introduced. How these structural characteristics were associated with components of the community participation process is also reviewed (Chapter 4.2 - 4.6). Third, a comparative analysis of structural factors, in both the HPD and community organizations, which affected participation is presented (Chapter 4.7).

4.1 HEALTH PROMOTION CONTRIBUTION PROGRAM

The Health Promotion Directorate of Health and Welfare Canada organized the HPCP as a mechanism for funding health promotion projects which were organized by non-government organizations. The following is a brief description of the general context of the Canadian health system in which this occurred, however, an extensive analysis of the development of social programs in Canada is beyond the scope of this thesis. Additionally, a brief history of federal and provincial promotion programs has been presented elsewhere (Pederson 1994). The principal focus of this program description will be the structural characteristics of the HPD that may have affected community participation in the HPCP, specifically in Ontario projects. Information regarding the overall effectiveness and impact of the HPCP are reported elsewhere in an internal departmental report, however, the information on community participation is very limited (Health & Welfare Canada 1989).

4.1.1 History and Mandate of the HPD

The federal health promotion program in Canada had diverse political, social, and health policy origins. During the 1970's and 1980's there were numerous pressing political issues in Canada: the election of a separatist government in Quebec; regional economic disparity especially in Atlantic provinces and the territories; discontent and a sense of disenfranchisement in the western provinces due to the National Energy Program; and a series of changes in the federal government and its leaders.

At this time, the Liberal party under Pierre Trudeau was the predominant federal political force. However, the strength of Trudeau's government was challenged at times, such as during a period of minority rule (1972-1974) in which the New Democratic Party maintained the Liberals in power in exchange for an extension of social programs. The brief tenure of a minority Progressive Conservative government under Joe Clark (1979-1980) did not seriously challenge the Liberal social welfare agenda, although the Liberals appeared to have depleted their energy before their rout by Brian Mulroney in 1984. During their nine year term in office (1984-1993), the Conservatives were preoccupied with restructuring the economy and Constitutional reform. Conservative financial cutbacks to health and social programs were a major departure from the previous Liberal agenda. National unity was a continuing concern through both of these major political eras.

Other major social trends in the 1970's which may have influenced the early development of health promotion included the emergence of new social movements, feminist critiques which challenged traditional authority, and doubts about the efficacy of the medical model (Labonte 1994). Some authors suggest that concepts, or ideals, such as a 'new welfare mix' (Kickbusch 1994) or a 'welfare society' (Crichton 1994) were also crucial. These concepts denoted that responsibility for the health and welfare of populations was not solely through private initiatives or the welfare state, but was shared between public and private sectors.

It should be noted that during the 1970's and early 1980's the Liberal federal government was increasingly involved in funding social development programs for disadvantaged groups such as women, ethnic organizations, and disabled persons through ministries such as the Secretary of State (Phillips 1994, Ng 1990). It has also been noted that the traditional role of the Canadian state was to foster democracy by supporting disadvantaged groups in the public policy process. In this time of political and social unrest, new programs (Multiculturalism, Official Languages, Women's programs) were established, in part, to aid the national unity effort (Pal L 1993).

There were three predominant issues in the health policy arena which accompanied these political and social trends and which may have influenced the development of the federal health promotion program. First, to contain spiralling health costs, the Established Programs Financing agreement (1977-1995) provided public financing of health services through transfer payments between the federal and provincial governments. This cost-sharing arrangement, which set limits on federal contributions, also allowed the federal government to claim a role in health policy (Charles 1987). Second, the user charges debate (Hall 1980) illustrated the divide between physicians and governments on the issue of personal responsibility for health and the payment of health costs. Third, there were overall attempts to curb the size of health budgets, both federally and provincially. At this time, overall health system reform was conceptualized generally in economic terms and health promotion was not a major player (Badgley 1994).

Nonetheless, many health reports early in this era suggested that there was a potential role for less expensive community programs in preventing disease (Canada 1973, Ontario 1974). Indeed, the Lalonde Report (1974) identified clear links between individual responsibilities for health and economic savings (Evans 1982). It is significant that Marc Lalonde, as Minister of Health and then as Minister of Finance during the 1970's, was supportive of health promotion as a cost-saving measure. This new concept also fit the emerging social reaction against the over-medicalization of health. Together, these political, economic, and social developments laid the groundwork for a new approach to health in the federal arena.

However, since jurisdiction for spending on health care lies with the provinces (except for the armed forces and aboriginal health), the rationale for a specific federal government role in health beyond financing was not clear. Nonetheless, Health and Welfare Canada claimed that it had mandates in other areas of health: to provide information regarding health (health education); to prevent health problems (health protection); and, to provide conditions for good health (social welfare), especially for disadvantaged groups (Health & Welfare Canada 1989). Under the latter mandate, Health and Welfare Canada also claimed responsibility for ensuring that resources for health promotion were distributed equitably across the country. That Health and Welfare Canada also assumed responsibility for health promotion for disadvantaged persons is not surprising as these groups were already included in Secretary of State programs. Health promotion appeared to be a way of conceptually, if not programmatically, unifying these federal mandates and creating a larger policy role for the federal ministry. However, a number of provinces saw these health education, protection, and promotion issues within their mandates and had already initiated health promotion programs (Pederson 1994).

In summary, Health and Welfare Canada may have developed a health promotion program for numerous reasons: to advance a model for economic cost-savings; to create a role for the federal health bureaucracy beyond the transfer of funds; jurisdictional overlap on health provision for disadvantaged populations; and, to use federal health and social programs as symbols of national unity in the face of Quebec separatism, western discontent, and regional economic disparity. Overall, health promotion was conceptualized as addressing both economic and social objectives and its administration may have also been intended to address the political jurisdiction dimension. The development of the federal health promotion program's focus on community participation will now be presented.

Early efforts by Health and Welfare Canada to promote health, in addition to financing health care, included hiring consultants and health educators to develop information sources (for example, the Health Education newsletter) and to provide consultation to the provinces (Palko 1982, Badgley 1994). As the prevention of chronic disorders and the threat of environmental and behavioural influences on health became recognized as fundamental challenges to the health care system, Health and Welfare Canada took the initiative by drafting a paper on the 'Health Field Concept' (Laframboise 1990). Marc Lalonde, as the federal Minister of Health and Welfare, utilized the paper to support a new vision of health which he outlined in the departmental publication A New Perspective on the Health of Canadians (Lalonde 1974). As noted earlier, this report linked health promotion both to the costs of providing health services and to their effectiveness, by suggesting that a lifestyle approach to health could be more efficient and effective in improving quality of life. These proposed linkages appeared to be influential in achieving rapid bureaucratic and public health organization acceptance of the report and it was followed by similar reports in other countries (McEwen 1979, Hancock 1985).

It is unclear whether or not the minority status of the Liberal government at that time provided the stimulus for this report. However, the Lalonde Report was not followed up with concrete federal action and new resources until 1977-78 when the Health Promotion Directorate (HPD), Health Services and Promotions Branch (HSPB), was established by Health and Welfare Canada with Ron Draper as its first Director-General. A 1981 memorandum to Cabinet, entitled "Health Promotion Strategy", noted that the primary objective of the Health Promotion Program was "the adoption and maintenance of healthy lifestyles by individuals in the Canadian population" (HPD 1981 as cited in Health & Welfare 1989). Also, the sub-objectives of the program encouraged the avoidance of health risks and the use of self-management and coping skills, making its individualistic focus quite explicit.

The HPD had responsibility for implementing health promotion 'lifestyle' programs using four principal strategies:

1. disseminating public information about lifestyles;
2. advertising to counteract tobacco and alcohol marketing;
3. co-operative health promotion planning with other sectors; and,
4. **supporting self-help and citizen participation** (Health & Welfare Canada 1978).

The first two strategies were intended to reach the Canadian population directly through informational and promotional materials. The third strategy sought to motivate and facilitate health promotion planning with provincial and local governments, and professional and voluntary associations (Health & Welfare Canada 1989).

The fourth strategy, self-help and citizen participation, was not specified in the 1981 Cabinet strategy paper, yet was clearly noted in other Health and Welfare documents and in presentations by Ron Draper (1982). The omission of citizen participation as a strategy in some documents should not be interpreted as a diminishment of its importance as it was considered to be one of the over-arching principles of the Health Promotion Directorate (Health & Welfare Canada 1985, Health Promotion Directorate 1982). Thus, even when it was not specified as an objective (participation as an 'end') or as a strategy (participation as a 'means') in particular programs, citizen participation was a core strategy of the HPD.

The HPD implemented two types of projects - operational and contribution. Operational projects, which utilized the first three strategies, were administered directly by the HPD and included: consultations with the provinces, voluntary and commercial organizations regarding health promotion; and the development and marketing of training, educational and promotional materials related to health. Coordination with provincial health promotion efforts was achieved through a federal/provincial Committee on Health Promotion from 1979-1984. This structure recognized the mutual federal-provincial interest in health promotion.

In 1980, the Health Promotion Contribution Program (HPCP) was launched as a means of implementing the Directorate's third and fourth strategies. The HPCP was essentially the funding and supervision of a series of health promotion demonstration projects at the local, regional, and national levels. The HPCP was intended to contribute, in a cost-sharing sense, to the funding of health promotion projects organized by external groups for terms of up to three years, with the possibility of extension up to a maximum of five years. The HPCP funding mechanism was not a completely new program but a carryover from an earlier Health and Welfare Canada program (Non-Medical Use of Drugs Program) which supported community projects, although some new monies were also added to the fund. Much of the HPD leadership also derived from this earlier program and may explain some of its philosophical leanings toward community involvement (Pinder 1994).

Overall, HPD respondents reported that the contribution program represented significant political benefits, such as increased visibility of federal activities at the local levels, with few potential liabilities. A senior Health and Welfare Canada manager noted:

> ... they were able to show through the first few experiences of the HPCP that this wasn't going to embarrass the system...we are talking about such a small sum of funds. (E-4)

The impact of the HPD's programs on health promotion in other jurisdictions in Canada is not the topic of this thesis, however, a recent text by Pederson (1994) clearly illustrated its influence. Case studies from each province noted the essential role which the Directorate played, especially after 1986, in funding innovative community projects (for example, Healthy Communities, Knowledge Development activities, school health programs, Heart Health) which stimulated health promotion initiatives, especially in the poorer provinces. More importantly, the federal support for local projects was consistent, even in the face of provincial funding cutbacks, for example in Saskatchewan (Feather 1994), or in the case of narrowly defined provincial health promotion activities in Atlantic Canada (Poel 1994). O'Neill (1994) concluded that:

> Important institutions and individuals have put Canada in this leadership position. Among the institutions, the federal government, and especially the Health Promotion Directorate of Health and Welfare Canada, has been clearly central. (p.375).

The influence of the HPD has also been noted in the development of health promotion in international settings (McQueen 1994, Raeburn 1994).

Whether or not the HPD was required for the development of health promotion in Canada ultimately depends on one's view of the balance between federalism and decentralization. During this historical period, the leadership of certain federal politicians and bureaucrats re-invigorated public health concepts in Canada. However in the establishment of a federal health promotion presence, there were also other economic, political, social, and bureaucratic imperatives at stake. This view of a temporary, although important, role for the HPD is supported by the lack of Canadian federal leadership in health promotion since 1986. Fiscal and political crises, loss of key HPD staff, lack of an effective political spokesperson for health promotion in the federal government, and the strengthening of local and provincial health promotion programs and leadership have all contributed to this demise (Pinder 1994, Hancock 1994, O'Neill 1994). The recent re-organization of the health functions of Health and Welfare Canada (including HPD) into Health Canada, and the separation of social welfare programs into a new federal Ministry of Human Resources Development may also indicate that the vision of an integrated health and social policy approach in health promotion has diminished.

4.1.2 HPCP Organizational Structure

The HPCP was administered to local and regional groups through Health and Welfare's five regional offices and to national organizations through the central Ottawa office. The HPCP was administered through a traditional hierarchical line of authority (Figure 4) which had little semblance to a bottom-up partnership with provinces, much less with local community organizations.

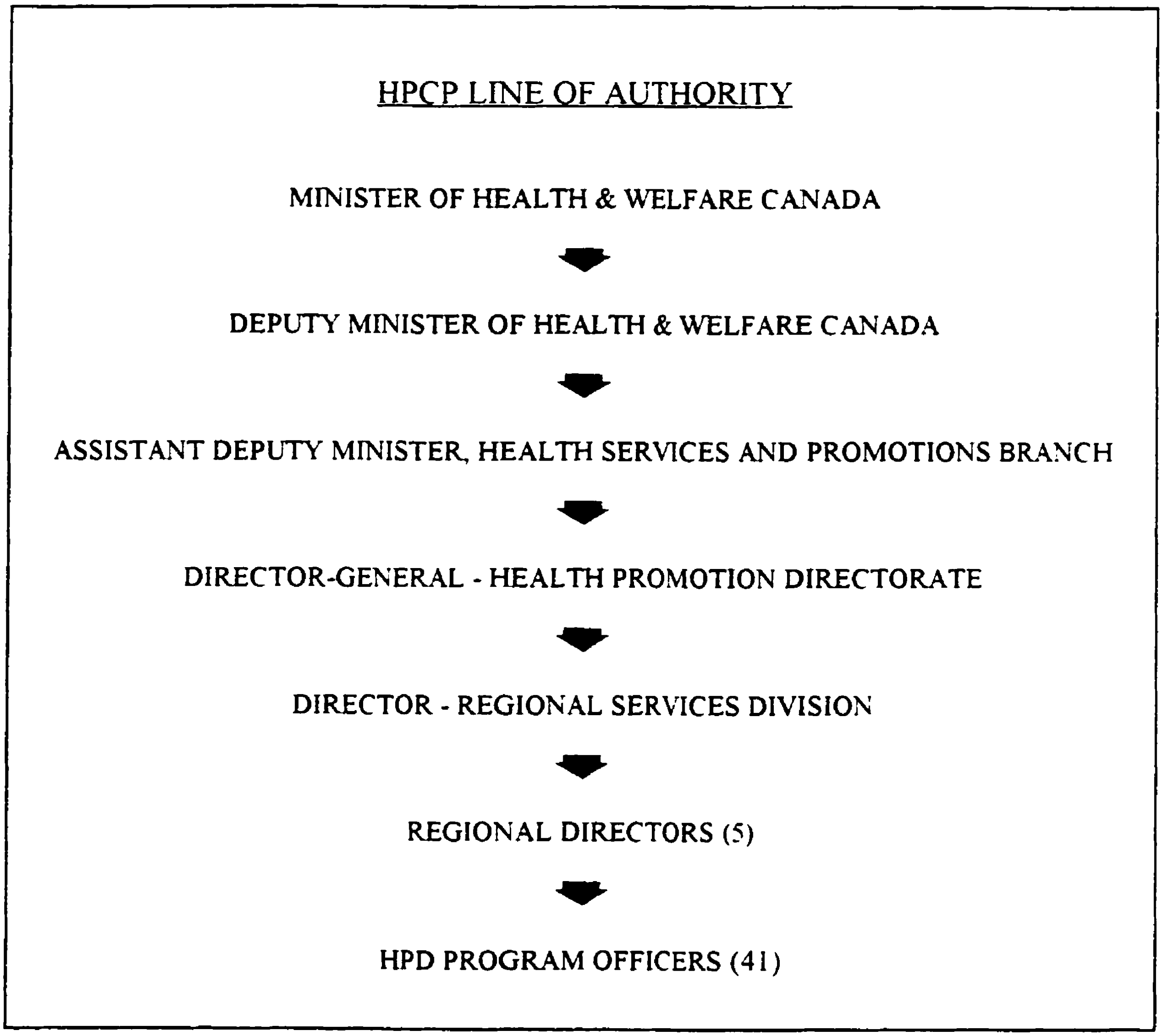


Figure 4. **HPCP Line of Authority**

Regional directors met four times per year to exchange information about the HPCP, as well as about other HPD programs. A total of forty-one program officers were assigned to specific HPCP projects in regional offices, as well as to other operational projects of the HPD. Program officers also met together once per year.

O'Neill (1994) and Raeburn (1994) noted that the regional offices of HPD played key roles in stimulating and supporting health promotion activities in the provinces and territories. In Ontario, however, the HPD was not a major player due to the large number of other organizations active in health promotion- for example, the Ontario Ministry of Health, city and regional governments, and health units (Pederson 1994). However, HPD respondents reported that Ottawa still had high expectations of the Ontario Health & Welfare region and allocated more funding to it than to other regions. While this allocation made sense on the basis of population, the Ontario regional office also had to manage more projects than other regions, with proportionately fewer program officers.

Ontario HPD respondents observed that there were tensions between the regional and national HPD staff in a number of areas. In addition to concerns about staffing levels and workload, there was also friction regarding the attribution of credit for project successes. Since local projects had to acknowledge HPD Ottawa on all public information material, public recognition accrued to national Health & Welfare Canada offices, rather than to regional offices. However, it is also interesting to note that recognition was occasionally avoided by federal bureaucrats and politicians due to the sensitivity of particular project topics, for example, in the area of sexually transmitted diseases.

Finally, senior HPD bureaucrats reported that the federal government, through its five regional offices, did not have adequate organizational linkages nor supervisory capabilities to manage a large locally delivered program. A HPD regional manager who had helped initiate the program noted that management and accountability problems were more likely in projects without close administrative linkages to the funder:

> When you talk about community participation and community development and local level stuff, people wonder what the federal government is doing at that level ... The projects which see the federal government that way are silly too. There's much more to gain from lobbying the provincial and municipal governments.(E-5)

These views seemed to underlie changes in funding policies which will be described later.

4.1.3 Funding Policies - Target Groups and Issues

Community level health promotion priorities in the HPD, as distinct from operational priorities, were developed utilizing two distinct strategies -- the **target issue** and **target group** approaches -- which had different implications for community participation. It will be shown that early target issue approaches were eclipsed briefly by a focus on target groups of disadvantaged persons, but that this did not last.

In the years prior to the HPCP being established (1978-80), the HPD operational programs focused on six target issues (tobacco, alcohol, drug use, nutrition, safety, and mental health). Groups which were eligible for funding included universities, service institutions, provincial and local governments, and voluntary associations capable of developing and conducting health promotion projects (Health Promotion Directorate 1982). HPD respondents observed that community participation was minimal in these projects since professionals either initiated them or became involved due to their specific knowledge base and expertise in the target issues.

By 1980, when these target issue projects had not incorporated community members spontaneously, the HPD established the HPCP which included both target issues and target groups (children, youth, women, elderly, natives, persons with disabilities, and low income persons). A number of these groups were in the traditional Liberal 'welfare constituency' (Phillips 1994). Priorities for funding in both areas were set on an annual basis by HPD staff (Health & Welfare Canada 1985).

Target group priorization and individual project selection were intended to be separate activities. Once the groups were priorized for funding initiatives, project officers were to solicit applications from appropriate groups, arrange internal and external proposal reviews, and negotiate changes in project plans with sponsors. HPD accepted project proposals only from non-government, non-profit organizations and community groups which were "capable of developing and conducting health promotion projects" (Health Promotion Directorate 1982). Recommended projects were then forwarded to senior HPD staff and eventually to the Minister for final approval.

By 1987-88, systematic priorization of target issues had taken place in HPD and a special funding stream for priority topics (Seniors' Independence Program, National Drug Strategy, Driving While Impaired, Child Sexual Abuse, AIDS) was initiated in the HPCP. Figure 5 displays the operational and contribution project streams which were in place during the time frame (1987-1991) of this study. It is evident that there was considerable overlap of issues and groups in operational and contribution projects.

HEALTH PROMOTION DIRECTORATE PROGRAM (1987-91)

OPERATIONAL PROJECTS	CONTRIBUTION PROJECTS	
	TARGET GROUPS	TARGET ISSUES
Tobacco Driving Impaired Drug Use Nutrition Communication Family/Child Health Non-communicable Diseases Workplace Elderly School Health Education HP Survey/Evaluation HP Framework and Knowledge Development	Women Children/Youth Disabled Persons Native Low-Income People	National Drug Strategy Driving While Impaired Family Violence Child Sexual Abuse AIDS Seniors' Independence Strengthening Community Health Healthy Communities

Figure 5. Programs of the Health Promotion Directorate (1987-1991)

Interestingly, elderly persons and children were the only target groups moved to the new 'priority target issue' funding stream. Simultaneously, the national Healthy Communities Project and the Strengthening Community Health Project were funded to take a broader 'locality' approach to health problems utilizing community networks and partnerships (Hancock 1994). The target issue branch of the HPCP appeared to be well established with support from different ministries such as Transport and the Solicitor-General. Finally, the national operational projects expanded from six to thirteen areas, including coordination and information generation activities such as surveys and the development of the Achieving Health for All framework. Target issue and national level operational projects are not included in this study of target group community participation.

The new arrangement provided overlap between funding streams which appeared to allow complete flexibility for Ottawa based bureaucrats to initiate, or to delegate to community organizations, a wide variety of target issue program areas. There seemed to be little opportunity for bottom-up initiation of target issue projects. Additionally, the lack of separation between funding streams prevented internal evaluators from assessing whether the program was spending appropriate amounts on its priorities (Health & Welfare Canada 1989, p.12).

In contrast, priorities for the remaining target groups (children, youth, women, natives, persons with disabilities, low income persons) were not well established by 1987. Without such systematic priorization, Health and Welfare Canada respondents perceived there were increased opportunities for lobbying activities from within the Ottawa bureaucracy, from political staff, and from external groups to influence funding. Although Ontario regional staff felt they had been more autonomous in target group priorization earlier in the 1980's, they were now concerned that:

> Definition of the problem has been taken away from the regional offices and located in headquarters because it is easier to manage there. (E-5)

These HPD respondents noted that the interests of HPD regional bureaucrats and ministerial political staff diverged as the HPCP target group stream became more popular with community organizations. In particular, HPD respondents perceived that target group priorization became influenced by the Progressive Conservative Cabinet. While there is no evidence from this study that pressure extended to actual project selection, political influence has been claimed in project funding in other federal ministries such as the Secretary of State at the same time (Phillips 1992, Pal L 1993) and has been attributed to the political confidence achieved in a second Conservative majority government.

4.1.4 Resources for Target Group Health Promotion

Full details of HPD budgets were not available for review in this study. Summary data are derived primarily from HPD respondents, from records of Ontario projects, and from the 1989 evaluation report of the Health Promotion Program (Health & Welfare Canada 1989).

On the whole, the participation of target groups did not fare well in the priorities of the HPD as reflected in the division of HPD resources. In its early years, the HPD had an annual operating budget of approximately $12 million, which excluded HPD staff salaries. The HPCP itself operated with an initial project budget of $2.1 million in 1980-81, which increased to $4 million within the next few years. Thereafter, the combined HPCP budget for both target group and target issue projects remained relatively stable, varying from $3.6 million to $4.2 million per year. Overall, by 1987, the total funds dedicated to HPCP projects ($26 million) accounted for only 38% of the Health Promotion Directorate's non-salary expenditures, and did not represent a large sum of money when spread across five regions of the country (Health & Welfare Canada 1989). In comparison, 31% of the HPD budget was allocated to the costs of surveys, evaluations, and development of policy papers. Local project funding varied considerably since some groups were funded only to produce brief sets of educational materials, while others were funded for five years of activities. For example, in the 16 Ontario projects reviewed in this study, funding varied from $11,850 to $422,320.

By 1987-88, the Cabinet recognized the HPD as having sponsored an innovative HPCP program (Health & Welfare Canada 1989). As noted previously, a special centrally directed funding stream for priority target issues was established with a total budget of $146 million over five years. However, regional staff levels to administer all project streams were increased by only 15%. This new funding allowed additional local projects to be launched for special target issues, such as AIDS and impaired driving initiatives, but not target group projects which HPD staff claimed were oriented more toward community participation.

Seniors and children were the only target groups which appeared to benefit from the increased funding. It should be noted that AIDS projects in the special funding stream were intended to be highly participatory. Overall, important political and public health priorities (an ageing population, increased awareness of child abuse, a deadly disease) took precedence over funding the participation of traditionally disadvantaged groups in health promotion activities. During the period of this study, there was significant expansion of the HPCP into target issues, while the target group portion of the HPCP budget remained essentially the same. Thus, resource allocation to participatory health promotion projects for disadvantaged groups was modest and appeared to indicate an ambivalence on the part of senior HPD managers and Cabinet toward the grassroots target group approach.

The HPD staff appeared to be key players in the facilitation of health promotion projects, although they came from diverse backgrounds. In the late 1970's, a small group of health educators in the federal department was transferred to the new HPD and was instrumental in developing the initial lifestyle health promotion activities (Palko 1982). Other staff had worked for Health & Welfare Canada prior to 1978 in the Non-Medical Use of Drugs Program and had administered small grassroots projects with community groups (Pinder 1994). Significantly, many of the newer Ottawa and Toronto staff had been involved in community development and social movement activities, such as women's, disabled persons' and anti-poverty groups, prior to, and even while working for the federal government. Idealistic staff from community development backgrounds seemed to prefer to work directly with community target groups, in spite of these projects receiving fewer resources than the centralized target issue projects. A respondent with a community development background observed that HPD staff influence in health promotion was due to their being 'outsiders on the inside':

> In the grander scheme this is a response by the health sector, professionals, and institutions to the challenges of social movements that were raised in the 60's and 70's which were making demands for that kind of participation. The bureaucrats in Ottawa could have been deaf to that but weren't. One of the reasons why they weren't was that there were people who were part of those social movements who were moving through the institutions, chipping away from outside and creating those spaces. The primary motivation was from a critical mass of people in the Health Promotion Directorate who wanted to do good and had some grounding and awareness of social movement issues, awareness of political stuff coming out of the 60's and 70's and tried to see how they could put some of that into place in their own language, institution and sector. (E-3)

According to a senior HPD manager, these motivations influenced the program staff orientation towards community work: "We had almost an instinctive wish to view it (HPCP) as a popular approach to health" (E-2). These views emphasized the crucial role

(HPCP) as a popular approach to health" (E-2). These views emphasized the crucial role which HPD staff perceived they had taken with respect to participation and in promoting its formal use by the Canadian government in the area of health. It did not, however, acknowledge similar developments in participation in many sectors of Canadian society, including at the provincial health ministry level (Pederson and Signal 1994).

The formal roles of HPD program officers in HPCP projects were: to assist with information requests; to solicit project proposals; to suggest revisions to proposals; to monitor projects; and to negotiate extensions and funding supplements. However, an informal but crucial role of program officers was also to advocate for particular target groups to be placed on the HPCP funding agenda. This was achieved through annual internal HPD meetings and policy reports which were used to establish program eligibility for certain groups, such as street youths. In the Ontario office, for instance, specific staff were assigned to promote women, youth, and disabled persons' groups in the annual setting of funding priorities.

4.1.6 Administrative Links to Projects

HPD program officers' performance in project administration was highly rated by project sponsors (Health & Welfare Canada 1989), although this study reveals several indicators that this was a lenient assessment. Project proposals were solicited and reviewed through HPD regional offices, but only approved for funding by central managers in Ottawa, revealing another top-down tendency in HPD. Contribution funding agreements describing the legal obligations and rights of both HPD and participating community organizations were also developed centrally.

Local project sponsors were required to submit quarterly narrative and financial reports to HPD regional program officers who were supposed to monitor project activities.

Other HPD administrative officers performed systems audits on financial accounts, but not on program activities. Initially, all proposals for funding had to include a basic plan for evaluation and there was a specific requirement for external evaluators in long term projects. In addition, early Guidelines to Applicants (Health Promotion Directorate 1982) focused on measuring outcome indicators of health status and changes in health behaviours.

By 1986, however, these evaluation requirements had changed. Contribution agreements specified that evaluations of projects could be organized by the project sponsors themselves and included in the sponsors' final reports. The focus of suggested evaluations was expanded to include process indicators such as, "How did target group members participate in planning and running the project? What roles did they perform? What did they gain?" (Health Promotion Directorate 1986). Thus, evaluation requirements appeared to have been relaxed and designed to help sponsors to improve project activities, including community participation, rather than to document project outcomes.

Although superficial accountability mechanisms were in place, in practice , the requirements for project evaluation were largely ineffectual. From 1980-89, only 39% of 282 HPCP projects had done any evaluation and only 17% had conducted an impact study (Health & Welfare Canada 1989). Although this shortcoming was criticized in the 1989 HPCP evaluation, the pattern of non-compliance was repeated in the 16 Ontario cases in this study, of which only 6 projects had submitted evaluations to HPD during the study period. Final project reports sometimes referred to evaluation information derived from participant questionnaires, although documentation was rarely included.

A senior manager noted that HPD did not take responsibility for conducting evaluations of the projects primarily because of the additional costs which would be involved in evaluating small scale projects:

> It's such a little bit of money...I think you aren't as demanding as far as evaluation is concerned.(E-4)

However, this rationale for failing to document and evaluate projects is not entirely plausible in light of the significant HPD budget allocation for evaluation. Staff competence to utilize program evaluation methodologies must also be questioned. Other than two senior HPD respondents, none of the lower echelon program officer staff used evaluation terminology in their interviews. While it was not possible to assess staff competency in this area, lack of expertise must also be considered as an explanation for the lack of project evaluation. This inattention to documentation and evaluation has been noted generally in the field of health promotion (Eakin 1992, Badgley 1994, Hancock 1994).

In addition to problems of compliance, cost, and methodological competence, community participation and other project components may not have been evaluated for political reasons. Senior bureaucrats reported that politicians were intent on avoiding the embarrassment of discovering that popular local projects did not actually meet their goals. Although these claims could not be substantiated in this study, one bureaucrat who was experienced in developing evaluation guidelines for the HPD programs noted that:

> ... anything the government does, once it decides to do it, is sort of by definition a success...Most of the effort goes into pre-approval, making sure it doesn't screw up and embarrass the minister. Then once his name is on it, it's incumbent on everyone to say that this was the right decision. There's really not a high demand for evidence to the contrary and evaluations sometimes say that things didn't work...That political context makes it hard to devote much time or resources to real evaluation or reassessment of what was worthwhile. (E-6)

In this view, an objective evaluation was much less likely in government-administered programs than in more neutral peer reviewed funding programs. Thus, a variety of considerations appeared to influence HPD's disregard for monitoring local project activities. Overall, HPD staff appeared content to allow HPCP projects to develop without much scrutiny.

4.1.7 Government Guidelines for Projects

Administrative Guidelines

Regional HPD staff supervised local HPCP grants within the conventional framework of government-funded projects and were supposed to comply with administrative guidelines from federal ministries such as the Treasury Board. Contrary to the original concept of a contribution fund, HPCP funding was the principal source of support for most projects and had to cover the direct costs of community participation such as special transportation, access needs of persons with disabilities, and the costs of meals at meetings. However, budget guidelines for HPCP projects did not automatically allow expenditures for these costs nor for participant honoraria and child care (Health Promotion Directorate 1982, Health Promotion Directorate 1986). These items had to be negotiated with program officers and HPD administrative staff prior to project approval, or by substitution at annual reviews of the budget.

Participation Guidelines

HPD staff developed informal guidelines for community participation with other federal ministries, such as the Secretary of State, which co-sponsored some projects in the disability and women's target areas. By 1986, the HPD emphasized the involvement of target populations in developing and managing HPCP projects:

> Their participation is essential to the enabling process as it provides them with an opportunity to act on their own behalf and gives them more control over their own health. (Health Promotion Directorate 1986)

Project selection criteria emphasized that organizations with target group membership were preferred:

> Organizations that ensure target population involvement **such as consumer-based groups** will receive preference for funding. Other types of organizations will need to establish decision-making and management structures for the project that ensure significant target population participation. (Health Promotion Directorate 1986)

Specific organizational structures to ensure community participation were not formal requirements of the HPCP, but were strongly recommended to project applicants. For example, by the mid-1980's, program officers recommended to applicants that community members should form the majority of elected board members in an incorporated non-profit organization. HPD staff claimed that adhering to these recommendations would protect the interests of community members from personal financial responsibility, as well as ensure formal organizational bylaws. In addition, HPD program staff stated that incorporation would improve accountability for project commitments and help to build the capacity of the organization. However, this recommendation for legal incorporation also ensured a rigid hierarchy of members and officers, with set terms of office and unfamiliar roles for inexperienced target group members. Additionally, formal incorporation was not amenable to the participation of children or youths due to age restrictions on holding office. Finally, submitting to the lengthy process of incorporation may not have been a reasonable expectation for groups which received financial resources from HPD for only a few years.

HPD staff also recommended that projects have an advisory committee of community members, which would include target group members, in order to ensure representation of various community interests. However, this committee could be waived by consumer groups which were assumed to have target group members managing and directing their own projects.

Thus, through a series of formal financial accounting rules and informal organizational guidelines, HPD attempted to shape the ability of projects to plan and manage their activities, and to incorporate community membership into them. These practices appeared to emphasize the importance of building organizational capacity, skills, and accountability among community groups, rather than facilitating spontaneous forms of grassroots participation. The following section traces the development of these concepts of participation in the HPCP.

4.1.8 Values and Objectives of Participation in HPCP

As contemporary concepts and purposes of participation changed, so did the objectives of the HPCP fund. In an interactive fashion, it is also arguable that HPD's experiences in project funding influenced the understanding of participation in the health sector of Canadian society.

The early HPCP focused on participation of professional and voluntary organizations with governments as an instrumental means for improving the health of individuals through a lifestyle approach:

> The HPCP has been established to secure the **participation of voluntary, professional and government organizations** in achieving the HPD's overall objective of increasing the capacity of Canadians to enhance and maintain their health. (Health Promotion Directorate 1982)

Professionals and bureaucrats were to be fully involved in a top-down strategy to improve the health of general community members whose participation was to be a ‘contribution’ to this effort. Bureaucrats reported that the intent of community participation in HPD was gradually influenced by developments in social movements, especially in the women's movement and, to a lesser extent, senior citizens', disabled persons' and native peoples' groups. The foci of these groups on direct grassroots participation and 'empowerment' of disadvantaged persons in the broader social environment appeared to influence Health & Welfare's vision of health promotion (Epp 1986, Epp 1988).

Early in the program, the HPD had little experience in funding target groups, but began to take an interest due to the recommendations of HPD program staff. Based on this experience, by 1986 the HPD had gradually shaped HPCP as a mechanism to increase the capacity of local target group organizations to develop health promotion activities:

> The HPCP funds non-government organizations to conduct projects that increase public participation in health promotion. This is intended to **improve the capacity of non-government organizations** to develop and deliver health promotion programs, to improve information exchange among organizations and to develop a better knowledge base on health promotion programming. (Health Promotion Directorate 1986)

The purpose of participation as 'organization' had emerged.

At the same time, however, key documents such as the Alma Ata Declaration, Achieving Health For All, and the Ottawa Charter had been published and were repeatedly cited by HPD respondents as being critical in expressing an 'empowerment' vision of community participation. A senior HPD manager noted that the documents assisted in securing broader bureaucratic and political support for grassroots community participation in health promotion:

> In a concrete way, the publication of those documents ... they are ideas and ideas are powerful. Those ideas have not necessarily been acted on, they are complex ideas when you ask what they really mean, but they certainly have permeated this country, at least the public health aspect. (E-4)

HPD respondents noted that the public health bureaucracies of Health & Welfare Canada and the World Health Organization, especially the European Region, had a powerful interactive influence on the conceptual development and legitimization of community participation as a health promotion strategy. This point is supported by WHO officials (Kickbusch 1994). An initiator of the HPCP reinforced the view that participation in the Canadian context was developed from multiple, interacting sources:

> The European work was more conceptual and theoretically grounded in an intellectual tradition. Ours was more practical and grounded in our own experiences in working in community health, in having a funding program that tried to support a community action orientation in health. (E-2)

It is arguable that the European emphasis was on a 'transformational' empowerment which focused on community groups, while the Canadian emphasis was on an 'instrumental' organization of agencies.

Thus, by the late 1980's, target group agencies were the preferred HPCP project holders, development of small community organizations had become a goal, and the stated purpose of participation was both 'organization' and 'empowerment'. The role of individual community members as participants was to occur through their involvement in community agencies.

The Health Promotion Directorate's own evaluation (Health & Welfare Canada 1989) noted that the HPCP was highly rated by 100 local project grant recipients and concluded that it was one of the prime successes of the Directorate. In this report, largely substantiated by subjective ratings by project holders, the evaluators observed that "the HPCP has definitely increased community participation and produced key impacts... especially in increasing knowledge about health promotion among the sponsors" (p.21.). The report also indicated that the sponsor organizations considered themselves as being 'representative of the community'. The perceived participants and beneficiaries of the program were evidently sponsor organizations, and not community members.

This focus on the participation of organizations was further supported by the opinions of 50 key informants in the 1989 study. These provincial bureaucrats and representatives from non-government organizations stated that fostering grassroots public participation through local community projects should be a low priority for the federal government, for some of the jurisdictional and organizational reasons cited previously. Based on these views, the evaluators recommended that mechanisms for project funding should be transferred gradually to provincial and municipal governments, however, this was not done.

It is not surprising that, with a rhetorical consensus on participation based on vague generalities, there was confusion in the Directorate's program operations. Community participation had become 'all things to all people'. For example, in 1986, guidelines to applicants still advised that community participation in the HPCP was intended to:

- reduce inequities in health
- prevent illness, injuries, and chronic conditions
- strengthen the capacity to cope (Health Promotion Directorate 1986)

These objectives continued to emphasize an instrumental purpose for participation which focused on direct benefits to community members rather than on empowerment and capacity building.

Raeburn (1994) has noted the tension within HPD at this time between staff supporting the old guard lifestyle health education approach, which encouraged a passive participation of individuals, and those supporting the newer approach which supported an active participation of community organizations. Various purposes of participation (contribution-organization-empowerment) appeared to be key points of conflict.

Overall, by 1989, the actual practice of the HPCP vis-a-vis community participation again appeared to emphasize its 'organizational' purpose. Participation of community organizations was envisaged both in the development and management of projects and was consistent with its 1986 mandate. Grassroots mobilization of disadvantaged groups, or participation as 'empowerment' and transformation, did not appear to be a predominant theme, either in study interviews, official documents, or evaluations. This is in contrast to the continuing rhetorical emphasis on grassroots public participation in publications such as Mental Health for Canadians: Striking a Balance (Epp 1988).

Finally, by 1991, the HPD had completely de-emphasized both the ‘contribution’ and ‘empowerment’ purposes of participation. Instead of a focus on small scale organizational development, community participation was now conceptualized to have a broader purpose as a component of a wider community network and partnership for health development. According to a regional HPD manager at this time:

> The purpose of the fund was to increase capacity, acknowledge legitimacy of the issues, and build bridges between this community of interest and other communities of interest. (E-5)

This new approach had been recommended in the 1989 evaluation and was reflected in an emphasis on funding new organizational forms such as partnerships and networks, for example Healthy Communities, which involved professionals and bureaucrats more extensively in inter-agency consultation. Participation appeared to encompass professional and bureaucratic interests once again.

The emerging view of community participation as a partnership of organizations may have developed for a number of reasons. First, the 'empowerment approach' was not easily operationalized in a bureaucratic context of regulations, guidelines, and accountability mechanisms, especially when project monitoring was inconsistent and at considerable distance from regional offices. Second, an empowerment approach was conceptually attractive to elite federal and international planners, but presented political risks to the status quo, especially in a Conservative government intent on cutting funds to social programs. Third, building the capacity of small scale target group organizations was a risky venture for HPD because of the long-term support which they required.

An 'organizational partnership' approach to participation had a number of more attractive features. It acknowledged the need for community organizations to link together and economize efforts in a time of financial constraint. Also, networking was a transitory activity which was perhaps a better fit with the political decision-making process. Finally, organizing networks was closer to the traditional style of bureaucratic 'work' than basic community development activities.

In sum, the objectives of community participation in the HPCP were in transition from 1980-1991. After an initial dependence on professional and service organizations to implement health promotion with passive target groups, and a brief flirtation with grassroots empowerment and capacity building of organizations, there was an emerging emphasis on network development and partnership, which suggested a return to narrow forms of participation.

The tendency to conceptualize and implement different forms and purposes of participation was a recurring issue in the HPCP and was the source of ambivalence and contradictions in the implementation of the program. Target groups of disadvantaged persons in these cases will be shown to have had very different ideas about what participation meant. It also leads one to question the actual understanding and commitment of federal planners to the value of grassroots community participation in health promotion activities.

4.1.9 Summary

The Health Promotion Directorate appeared to be important in stimulating awareness and discussion of health promotion in Canada. Although HPD did not finance health promotion heavily, it supported some provincial and local health promotion initiatives and played a key role in knowledge development and dissemination, at least at the conceptual level. In the HPCP, the HPD attempted to demonstrate practically the value of health promotion and participation at a community level, albeit in a modest way. That it was unable, or unwilling, to evaluate the success or failure of HPCP projects is a loss for the health promotion knowledge base in general.

HPD's mandate and capacity in health promotion contribution funding was limited on economic, jurisdictional, administrative, and programmatic grounds. First, according to senior program managers, the HPD did not intend the HPCP to be a long term funder of local community health promotion activities due to the economic implications of funding an increasing number of projects as the idea became more popular. Long-term financial commitment to local health promotion was not a possibility in the contemporary economic environment. Secondly, federal bureaucrats and politicians were sensitive to provincial governments' responsibilities and jurisdictions in health and did not want to compete with them to fund local groups. Nonetheless, HPD wanted to demonstrate its new conceptual tools in health promotion. Thirdly, despite the reputation which HPD had for championing community participation in health promotion, there were a number of administrative barriers in its implementation of the strategy through the HPCP. The top-down hierarchy of the HPD and regional offices ensured that distant bureaucrats made the final decisions about project selection. The absence of formal priority setting for target groups ensured that HPD staff engaged in a constant lobbying process for groups to be priorized and funded. Although staff had experience and commitment to target groups, they appeared to have little expertise in project management, especially with respect to evaluation. Financial controls were tighter, but not readily adaptable to the needs of small organizations. Similarly, guidelines which suggested the incorporation of formal mechanisms for participation in local projects were promoted without regard for their feasibility or impact on project activities and participants.

Finally on a programmatic basis, the HPCP strategy for participation shifted continuously. The style of community participation promoted by the senior bureaucracy changed from professional management of target group participation, to grassroots empowerment and organizational development, to networks and partnerships over a ten year period. These shifts make the analysis of participation problematic since its intended purpose was frequently in transition.

In sum, the federal health promotion bureaucracy appeared to value the HPCP as a demonstration that the federal level could join the bandwagon of participation, and take initiative in an area of local health usually beyond its mandate, without many actual costs, risks, or ongoing responsibilities. This initiative and leadership may also have assisted their political positions in other, more predominant federal-provincial negotiations.

4.2 CASE: PREVENTION OF STDs AMONG STREET YOUTHS PROJECT

SPONSOR: INNER CITY YOUTH PROGRAM

4.2.1 Introduction

The Inner City Youth Program (ICYP) of Huntley Youth Services in Metropolitan Toronto operated a health promotion project from 1988 to 1992 that was concerned with the prevention of Sexually Transmitted Diseases (STDs) in urban street youths. Since there was a lack of appropriate information about STDs for this group, the ICYP project aimed to create and disseminate information and facilitate discussion among street youths about the STD problem. A variety of educational materials and videos were developed, tested, and distributed.

This first case study was selected for review on the basis that project documents indicated that community members had played prominent roles as employees. The sponsor claimed that it devoted considerable financial and personnel resources to utilize youth employees in its efforts to improve community participation.

In the case description, structural characteristics of the sponsor organization and project are described first. Subsequently, the chapter addresses how key structural factors influenced the process of community participation in the project - the types of participants, participatory strategies, project roles and activities, and the influence of community members.

Data sources for this case included six direct interviews, 16 project documents, and two educational videotapes created for the project. Interviews were conducted with the HPD program officer, an ICYP staff person who had worked in ICYP for four years, and the ICYP manager who had worked there for eleven years. Since many of the street youths in the STDs project had moved away and were not traceable, only three youths were interviewed. One older youth worked as an employee in the project, one served on the advisory committee, and one younger person volunteered occasionally in the production of educational materials.

4.2.2 Structural Characteristics of the ICYP Organization

History and Program Mandate

Huntley Youth Services (HYS) developed in the 1970's from the Big Sisters Association, a traditional charitable and service agency. HYS provided professional support services which the primarily voluntary membership of the Big Sisters Association could not provide to homeless young persons. However, HYS eventually realized this approach was inadequate, since there appeared to be little communication and understanding between professionals and street youths. The professional staff became frustrated in trying to counsel and support street youths who, in their view, did not want to accept a helper-client relationship or to be held accountable for their activities. For example, ICYP staff cited examples of youths who expected to be registered for welfare benefits without providing permanent addresses.

In response to these problems HYS formed the Inner City Youth Program in 1981 to provide direct social services for youths living apart from families in the inner city areas of Toronto. These non-professional services included counseling, information, and referrals for employment, housing, welfare and health concerns. In these early years, ICYP functioned primarily as a client-focused service agency although it also provided public education activities about homelessness, along with other agencies which serviced street youths.

Although Huntley Youth Services organized three other youth programs in Metro Toronto, the downtown ICYP program was the only one focused specifically on homeless youths. The program's inner city setting was considered an asset to its reputation by youths:

> ...the organization is at the perfect location for street youth. I can remember going to ICYP for counseling. They were really good to do it rather than some other government agency who wasn't involved in street youth. They were the closest to the source. (ICYP-6).

Youth respondents also reported that ICYP staff provided non-judgmental services which made the program a popular source of support. A youth volunteer noted that ICYP staff:

> ... are social workers for sure, total social workers. They make efforts to listen to opinions of the community that they are serving ...They still go by the book, but they do have their peer education programs, and the people who work there are easy to relate to on some level. (ICYP-2)

For their part, ICYP staff members perceived that the organization had gained a reputation among youth agencies by incorporating progressive ideals in a practical setting:

> ...it feels through the materials that we've been ground breaking in all these areas and people have noticed this ...When we're at conferences they say 'You're doing stuff we never thought we could do'. That feels progressive. (ICYP-1)

Finally, the Health Promotion Directorate recognized ICYP's leadership in working with street youths, particularly in developing educational products of high quality [DOC-02]. The HPD program officer reported:

> ...of all the organizations which work with this group they're definitely the leader and they're recognized as that nationally now. (ICYP-4)

Thus, historical, locational, and reputational factors appeared to facilitate ICYP's access to street youths. In particular, HYS and ICYP showed an ability to adapt their mandates to the changing needs of the target group. However, the intention of ICYP appeared to be to assist youths to survive on the streets, rather than to help them self-organize or work together in a community development context.

Target Group and Issue

The population of street youths presented a challenge to traditional social service agencies. Informal estimates of the number of street youths in Toronto varied from 4,000 in the late 1970's to 10,000 in the late 1980's (Crawford 1995). ICYP staff reported that the number of street youths had increased dramatically, in their estimation, due to family breakdown and the economic recession. The prevalence of STDs in the group was alarming and in 1991 the percentage of street youths in Toronto who were HIV positive was 2.2%, or 70 times the rate (0.03%) in the general population (Hall 1995).

The youths who used ICYP's services were a transient group who would drift in and out of the inner city area over time. They varied in age from 14 to 24 years, with a greater proportion of younger adolescents. Staff were particularly concerned about youths who were young and new to the streets or who came to Toronto from smaller communities, as they were believed to be particularly vulnerable to health and safety risks [DOC-02].

Reportedly, there were more males than females involved in the ICYP program, although the precise proportion is uncertain since gender statistics were not routinely recorded at the drop-in centre. However, during a two-month period in the STDs project, a Safer Sex Quiz was administered to 342 youths of whom 68% were males [DOC-05].

Staff members observed that youths in the ICYP program had diverse socioeconomic backgrounds, including those from suburban middle class neighbourhoods who were experimenting with street life, and those from working class backgrounds. Many youths from the suburbs had better educations, had the option of returning to their family homes when they wished, and did not have to face the insecurities of chronic homelessness. On the other hand, youths who originated from inner city areas had less education and were often completely without a home, family, or resources.

Staff noted that the majority of youths came from abusive family situations and were 'run-aways and throw-aways from their parental homes' (ICYP-1). Youth respondents shared this perception:

> You have a group of people who have basically been forgotten, abandoned, beaten up for most of their life. (ICYP-6)

In spite of these many systemic disadvantages, ICYP staff characterized street youths as a 'hard to service' group, who either resisted direction, abused services or were just 'ignorant of the resources available to them' (ICYP-1). ICYP staff noted a number of common patterns which made behavioral change difficult: transiency, preoccupation with looking for food, shelter or money, and use of drugs and alcohol. According to the ICYP manager, these behaviours made health education programs difficult to implement:

> Many street youth tend to be suspicious of adults and ignorant of the resources available to them ...due to the nature of their street lifestyle, they have little contact with reliable adults...they tend to believe they are immune to Sexually Transmitted Diseases and most of their understanding of sexual health concerns is gleaned from their often misinformed peers...they are reluctant to identify themselves as gay or as prostitutes or as intravenous drug users or as promiscuous... [DOC-01]

In other words, ICYP staff perceived that youths who denied being a member of certain sub-groups were most at risk of STDs. Overall, ICYP staff attitudes about youths did not seem as non-judgmental as the youths had perceived.

In contrast, youth respondents were not as pessimistic about their peer group and noted that street youths had their own distinctive culture which facilitated social support

> They have their own set of values, their own system of life and support of each other. There is support on the streets for the kids that is a subculture and a way of life. (ICYP-6).

For example, some youths lived in 'families' of their peers and relied on each other for income, shared housing and security. On the other hand, those of different sexual orientations (heterosexual - bisexual - homosexual) and popular style ('punk rock freak' - 'rock and roll') did not generally mix together.

In sum, the street youth target group was increasing in numbers and had a variety of systemic disadvantages and behavioral patterns which were perceived by ICYP staff to make service provision and behaviour change difficult. However, the group also had some characteristics which fostered cohesion

ICYP Program Linkages

ICYP's 'community' involved social service agencies as well as youths, since agency staff felt that street programs could only be effective through inter-agency collaboration. Even prior to the HPCP project, ICYP expended organizational effort and resources in developing and maintaining a network of agencies interested in street youths. These agencies included the Toronto Public Health Department, Hospital for Sick Children Teen Clinic, Hassle-free Clinic, AIDS Committee, Central Toronto Youth Services, Street Outreach Service, Toronto Street Youth Project, Covenant House, Street Health, YMCA House, Stop 86, and youth hostels. A youth volunteer noted that inter-agency linkages occurred through referrals, information sharing, joint project development, and serving on each other's project committees:

> Inner City is really well known and really well connected to the other agencies. Staff often sit on the advisory committees of different projects. I see them all over town at different workshops, displays and promotions. (ICYP-2)

Linkages between community service agencies were encouraged by funders as well. For example, government ministries coordinated service development conferences to bring agencies together for information exchange in specific STD areas, such as anonymous HIV testing [DOC-05].

Although community agencies were encouraged by ICYP to participate in STD prevention activities, this approach was not without problems. ICYP staff reported limitations to cooperation with respect to overlapping catchment areas of local agencies, divergent opinions on the root causes of the problems of street youths, and differing perspectives on morality. For example, a church-based agency for street youths refused to allow the screening of STD educational videos, nor would it distribute condoms to its clients. Instead, it promoted abstinence and self-control, which appeared to alienate some youths in the area and limited the agency's involvement in the STD project.

Resource Mobilization

ICYP received funding from a variety of municipal, provincial, and federal sponsors for their services and projects. HPD supplied $310,264 over four years to operate the STDs project under the HPCP. HPD also funded ICYP to conduct a number of projects related specifically to AIDS through the federal government's National Drug Strategy.

Resource mobilization was primarily affected by the top-down ICYP planning process. ICYP staff did not consult extensively with youths until after the project was funded. At this time it was decided that funding was required for youths to work as employees. As well, extra funds were needed to support newly identified expenses, such as honoraria, meeting costs, and video production costs which were not available from HPD after the budget had been approved. Staff wrote seven grant applications and 45 letters to secure extra resources from the Ontario Ministry of Community and Social Services and from a local cable television company. Thus, considerable staff and management time was spent in securing extra resources for youth participation in the project, primarily due to inadequate initial planning.

4.2.3 Characteristics of the STDs Project

In addition to the general characteristics of the ICYP organization, there were also specific structural characteristics of the STDs project.

Project Objectives

The original goal of the project was to prevent the transmission of STDs among street youths [DOC-01]. The objectives identified in the ICYP funding proposal were:

1. To identify the knowledge base of Toronto street youths regarding Sexually Transmitted Disease;
2. To develop effective and engaging materials which reflect street vernacular and the lifestyle and sexual practices of street youth;
3. To distribute and promote the materials in a manner which ensures their availability to street youth and their continued effectiveness beyond the duration of the project; and,
4. To influence the sexual practices of street youth in a manner which will reduce the incidence of Sexually Transmitted Diseases. [DOC-01]

These formal objectives were health educational in nature, intended to result in behavioral change in the youths, and reflected a lifestyle approach to health promotion.

From their experience with HPD, ICYP staff reported that federal funding was readily available for health promotion projects in which street youths received health information. However, youths also required resources for more basic needs, such as housing and food, in order to ensure their participation and receptivity. ICYP staff and management expressed frustration at HPD's calls for participation of indigent youth:

> Health and Welfare is speaking out of both sides of their mouth when they call for participation of youth who have nothing. (ICYP-3)

ICYP responded to this situation by proposing project activities which were consistent with the government priorities for AIDS education, while at the same time devoting some resources to address the immediate needs of youth. An ICYP staff member described their strategy:

> If we get a grant to do AIDS education or drug abuse prevention, you have to make sure that at least some component of what you're doing falls into that. Sometimes that's limiting because when working with people living on the street and using injection drugs, the issues that are most important are poverty or housing so we have to bend the rules to deal with problems properly. (ICYP-5)

For example, ICYP project staff spent time securing housing for individual youths so that they had a stable base from which to participate in the STDs project. The HPD program officer appeared to support these strategies by 'looking the other way'.

These acknowledgments of the importance of social determinants of health, however, were implemented within a traditional service philosophy wherein the ICYP staff 'provided' for the youths. Their concern for a social model of health did not consistently extend to their objectives for participation. In their proposal, ICYP suggested that youth participation was a priority since "the development of effective and applicable materials on Sexually Transmitted Diseases necessitates involvement and consultation with street youths at every step of the process." However, the project's formal objectives for youth participation were more limited:

1. To increase mutual aid and social support;
2. To impart new knowledge and safe sex practices to peers;
3. To seek and encourage others to seek medical aid when indicated. [DOC-01]

As well as these behavioural and instrumental aims of participation, the ICYP proposal envisioned that increasing the knowledge of youths would enable them to make better health choices and then "exercise greater control over their own sexual practices" [DOC-01]. This appeared to be the extent of any empowerment aim of participation.

The initial project workplan proposed that youths would participate in focus groups to assess and pilot test materials, and meet staff to plan and evaluate the project [DOC-01]. However, the plans did not include the establishment of an explicit organizational role for youths. Again, participation appeared to be conceptualized within a service agency mandate, rather than a community development model.

In sum, ICYP staff in the STDs project initially proposed objectives and activities at the health education end of the health promotion continuum. This approach, however, did not resemble a social structural approach to health promotion as it dealt only with the needs of youths for services which ICYP was accustomed to providing. Although staff realized that social and environmental conditions also needed to be addressed in order to facilitate youth participation, their capacity to openly deal with these beyond the individual level was limited by the objectives which they perceived were acceptable to the funder and by their own service philosophy.

Project Organizational Structure

The STDs project was incorporated into the HYS agency as follows:

1. The ICYP project utilized the Huntley Youth Services **board_of directors** which was composed of appointed social service professionals, clergy, municipal officials, politicians, and a few interested private citizens. Youths were not represented on the board. The board was responsible for the overall direction of HYS and occasionally board members would visit the ICYP drop-in centre where the STD project activities were organized. While there was no evidence that board members had direct involvement in project activities, they were kept informed through the ICYP **program manager** who reported directly to the board about STD project activities.

2. Initially, two ICYP **adult staff** were assigned to implement the project and evaluate the completion of project objectives. These staff members were part of the AIDS education department of ICYP and were supervised by the ICYP manager. They also organized the initial recruitment of youths, and developed and promoted STD educational materials. However, as will be demonstrated, conflict developed between the roles of staff members as social service 'gate-keepers' and as facilitators in the project. Later, four **youth employees** were hired as staff 'peer educators' with responsibilities for youth recruitment, education, and the production of educational materials.

3. A **project advisory committee** (Independent Steering and Evaluation Committee) was organized to give 'community input and direction' to the project staff. The invited committee included representatives from key street-based youths and health service agencies previously cited. Again, youths were not represented on the project advisory committee. The committee met quarterly with the following terms of reference: to review the project workplan and unexpected events; to provide guidance to staff and managers; and to evaluate the role of youths, the relevance and effectiveness of materials, and the

attainment of project objectives [DOC-05]. Since representation on the committee was by agency, different individuals from the same agency attended committee meetings according to their availability. There was no further information available from ICYP sources regarding the identity of individual committee members.

4. **Youth volunteers** also had input through focus groups at ICYP and other agencies which were used regularly throughout the project to provide feedback on the suitability of STD educational materials. Additionally, an informal **youth advisory group** of six to ten youths was formed during the first year to meet monthly with ICYP staff to review the project's process and to help evaluate and plan future activities. Video advisory committees were also formed to provide assistance and consultation during the development of videos on the risks of STDS in street youths [DOC-04, 05].

5. **Youth clients** of ICYP participated informally and periodically in video education sessions. These youths had no input to the project other than to receive and discuss the STD education materials.

Background and Roles of Other Participants

Staff - ICYP project staff and managers were men and women in their 20's and 30's with paraprofessional social work backgrounds. Over the course of the STD's project, two out of three staff were women, as was the program manager. Project staff all had experience in youth work and had other skills, for example visual arts training, which were used in the STD's project.

Professionals - The role of health and social professionals in the project was reported by staff and youths to be limited, as it was restricted to participation on the project advisory committee which gave general feedback to the staff about materials which were being developed.

Bureaucrats - The HPD program officer responsible for the ICYP project had worked previously in community development projects and had been in charge of youth initiatives in the Ontario office for a number of years. The program officer stated that she participated in the ICYP application review and monitoring process, but was not very involved in operational activities.

Thus the participants involved in the STD project included youths, ICYP agency staff, professionals, and the HPD program officer. (See Table 2). Participants were involved either directly, through project planning and implementation, or indirectly, through occasional technical, advisory, and resource assistance.

Table 2. Participants in STD Project of ICYP

PARTICIPANTS	
DIRECT	INDIRECT
ICYP Program Manager*	HPD Program Officer*
ICYP Staff*	HYS Board of Directors
Youth Employees*	Other Agencies: - youth - professionals
Youth Advisory Group*	Technical assistance: - Cable TV - acting
Project Advisory Committee	Other Funders
Youth Volunteers*	
Youth Clients	

* = Participants interviewed in this case study.

Leadership

Adult staff were responsible for the project but claimed that they shared direction and control of activities with youth employees. One ICYP staff member and one youth employee were mentioned most often by other respondents as initiators of ideas and activities in the project. Nonetheless, these individuals did not appear to take action independently from ICYP management.

Project Administration

ICYP's formal management systems for the project included employment records, financial accounts, and quarterly reports to HPD written by ICYP staff [DOC-03-15] These reports were in the form of unstructured narratives which listed project activities, numbers of participants, and the volume of STD education and prevention materials (e.g., condoms) distributed. While the reports provided an accounting of staff activities, there was virtually no emphasis on analyzing participation or on determining whether the project was meeting its major objective of creating a change in STD risk behaviours. The HPD program officer agreed that there were difficulties in determining whether behavioural changes among youths were actually occurring:

> Are they wearing condoms?.... Nobody knows, I mean you can't know ...
> We haven't done a study of that and I don't know how you would do it.
> (ICYP-4)

ICYP staff did prepare some internal evaluation reports, such as a Safer Sex Quiz, which focused on production, suitability, and sale of educational materials, as well as youth knowledge and behaviours regarding STDs, and youth attendance at discussions

[DOC-05]. However, an independent external evaluation which had been proposed was never implemented by the project advisory committee.

Summary of ICYP Structural Characteristics

HYS had a history of adapting its work with youths who were in difficulty and had gained a local reputation for responsive service provision, which was its priority. The street youth target group was transient and heterogeneous in many respects, with distinctive behavioural patterns which made working with them a challenge, especially in a sensitive area such as STDs. Youths perceived that in comparison to other agencies, ICYP provided non-judgmental delivery of services. This factor appeared to be instrumental in the development of youth interest in the STDs project. However, it was also evident that ICYP stakeholders had underlying attitudes toward youths which gave them a strong interest in maintaining control over the STDs project. Although there were attempts to make ICYP more accessible to street youths' lifestyle, HPD's preference for a health education approach to STDs also required ICYP to maintain a narrow project focus, in spite of the fact that staff realized that a broader structural approach was desirable.

Community program linkages were well established and resources were available for educational health promotion work, but the agency's inexperience in planning a participatory project was evident. The project structure was consistent with a traditional, hierarchical social service agency comprised of managers, paraprofessional staff and community workers, and direction was firmly in the hands of the service providers. Youths were not included in project management and only belatedly in staff positions. Thus, the youth target group did not formally share 'ownership' of the program. Finally, the ICYP project administration, apparently supported by a 'hands-off' HPD program officer, did not utilize many formal feedback mechanisms regarding youth participation or the achievement of project objectives. Many of these structural characteristics were important in the development of community participation in the project.

The next section describes how key structural factors in the ICYP organization and STDs project were associated with the type of community participants, the strategies which were used to obtain their involvement, and their roles, activities, and influence in the STDs project.

4.2.4 Types of Community Participants

Certain structural factors in the target group itself influenced the types of youths who participated in the STD's project.

Socio-demographic Status

ICYP staff reported that there was variation in the participation of youths in the STD's project based on educational and economic differences. Suburban, middle class youths used some ICYP services (employment and housing) for short periods but were not very involved in the STDs project. In contrast, inner city working class youths utilized additional ICYP services (health, welfare, counseling and drop-in centre) irregularly, but were reported to have had active involvement in the STD's project.

However, the participation of working class youths was not extensive or consistent. Youth respondents reported that planning a health promotion project was not a high priority for youths with little money:

> You have to remember that street youth who actually live on the street don't have a lot of time to sit around the table and talk about a video and get fed pizza once a week, because they get fed pizza at every drop-in the city. They've got to think about where they're going to sleep tonight, where

> they're going to get some cash to buy some drugs or some real food, where they're going to meet their friends so they can go and cause some party somewhere. (ICYP-2)

Thus, youths noted that time spent participating in a health promotion project was time away from earning income or meeting subsistence needs. From their perspectives, the immediacy of survival needs made consistent participation in the project unlikely without financial incentives. While this argument for non-participation is convincing, it is also possible that since lower SES youths spent more time than suburban youths in subsistence activities, such as panhandling and prostitution, they perceived that they were at a higher risk for STDs and should participate in the project. Regardless of the reasons, there was consensus that the socio-demographic range of youths who participated was narrow and did not include the entire clientele of ICYP.

Gender Dynamics

There was a lower proportion of females in ICYP's clientele, and gender dynamics appeared to affect the ability of young women to participate equally in the project. Female staff and youths reported that mixed gender groups in the project did not address young women's needs adequately since the young men tended to dominate group discussions and planning. Eventually, ICYP staff responded by forming a separate women's group to produce STD educational material from a woman's perspective. This action increased the number of young women in the project and had a positive influence on the gender range of youth participants.

Experience and Politicization

There were distinct differences in participation between those youths who were new to street life and those who had progressed to a more stable lifestyle. The majority of street youths in the area were young (14-18 years), inexperienced in living independently, and struggling to survive. Both ICYP staff and youths cited serious motivational problems in these youths which reflected both marginalization and a disregard for personal health:

> Well I'm probably dead already, I really don't think I'm going to live past this age, so I don't need to take care of my health right now because it's not an issue. (ICYP-6)

For these reasons, many young adolescents did not participate actively in STD project activities, although as high-risk clients of ICYP, they were the prime focus of educational materials.

A smaller number of older youths (18-24 years), who had lived longer on the street and achieved a more stable living situation, had more extensive involvement in the project. These youths had graduated into more secure environments and supported each other's involvement:

> In the end most of the people who ended up being in the project all knew each other from our previous street life ... Basically we came from a community of people on the street and a group of us really helped each other grow and get our shit together. (ICYP-5)

For example, a number of 'families' of youths, which formed temporarily for mutual support, participated together in the project.

From their street experience, older youths were quicker to perceive the health risks of living on the street and were concerned about younger persons:

> For most of us it was a very personal thing. We all had friends who had died from AIDS, friends who were HIV positive and we knew we were going to have more friends die from AIDS. (ICYP-6)

Finally, these older youths stated that they wanted to become involved in the STD project because it had potential for improving youth safety, for satisfying their own social needs, and for skill training and employment opportunities. For example, one older youth reported that she was actively involved in organizing new projects around youth issues such as AIDS, housing, and prostitution:

> Most of us were very political ...and had been very involved at a community level in a lot of projects, not just AIDS. I usually refer to myself as an activist slut. (ICYP-5)

In sum, the age range of youth participants was narrow and the majority of younger, high-risk youths were not active participants. More active participation occurred through a few older target group members who had the life experiences, confidence, resources, and skills necessary to participate in the project. These youths also had an activist political orientation which will be shown to be crucial in their developing influence in the project.

4.2.5 Sponsor Participation Strategies

The implementation of community participation in the STDs project by ICYP staff was influenced by factors of the target group and by availability of financial resources.

Marginalization and Distrust

ICYP's recruitment strategies were affected negatively by street youths' transience, marginalization, and suspicion of authorities. ICYP project organizers attempted to recruit youths for the project through direct approaches at the drop-in centre and on the street, and by referral from other agencies. News of the project was spread slowly by word of mouth, which was the primary method trusted by street youths. Media, public notices, and mailings were not used as staff believed they were less effective in reaching transient youth. A consequence of these factors was that few youths became involved in the project until their peers reported positively about the experience.

Dependence on Project Funding

Funding for the project served both to increase and decrease the opportunities for participation. Funding (from a provincial agency) allowed some participants to be paid as employees and thereby maintained their motivation. Limited material incentives for casual volunteer participation were also provided, such as transit tickets, food for meetings, and clothing

However, ICYP staff reported that uncertainty of funding diverted their attention from health promotion project activities, including the recruitment of youths. They stated that fundraising to pay youths directly reduced the time they could devote to involving other youths in the project.

Resource dependency also affected the participation of other community agencies serving street youths. In prosperous economic times, organizations were willing to send each other letters of support when applying for funding. However, a youth organizer noted that during the economic recession there was increased suspicion and competition for funding between the groups:

> It creates an atmosphere in which groups really don't want to work together because they perceive that each group is trying to take money or services away from each other...it does create certain hostilities in the various community projects. (ICYP-5).

Thus, the number of community groups which would work with ICHP may have been limited by uncertainty of funding.

Volunteer Payment

As noted earlier, provisions for payment of casual volunteers had not been incorporated into the ICYP budget, and they were not paid for their participation in the project. The issue of giving 'free advice' was a sensitive one and all three youth respondents reported that street youths resented providing free advice to staff and professionals:

> Street kids often get used that way - 'Oh come to this thing and put your input in and come and get involved' and nobody thinks about the fact that they're not getting paid ... but it looks good that there are actual street kids there. (ICYP-2)

On the other hand, the youths who were involved in video production were exposed to acting and technical skills which were valued in their culture and which provided sufficient practical experience and confidence for some of them to obtain other jobs For example, a youth employee noted:

> It gave me some really solid job experience which enabled me to go and get other work ...I've continued to do AIDS education and prevention work ever since then. (ICYP-5)

Overall, the youths' perceptions that resources could have been better allocated appeared to influence their participation negatively. Youths' views on payments for volunteers conflicted with traditional views of voluntary participation and will be addressed in more detail in the Discussion Section.

4.2.6 Participatory Roles and Activities

A number of organizational and project factors were associated with the roles of youths and the participatory activities which occurred. Youths played prominent roles as employees in the STD project, however, youths also participated as volunteers, clients, and youth advisory committee members. As noted previously, there were no street youths on the Huntley Youth Service board of directors, or ICYP advisory committee.

The roles of youth were associated with numerous structural factors such as ICYP's social service mandate, employment models, street youth experience, HPD requirements for advisory groups, and a shift to advocacy activities.

Social Service Mandate

Although project organizers had anticipated originally that ICYP staff would be the principal project workers, they soon realized that the staff did not have the legitimacy to gain the youth input that was necessary. Staff and youths reported that there was significant conflict between the staff members' primary roles as social service gatekeepers and advisors to youths, and their project roles in motivating and engaging youths in voluntary activities. A youth observed that partnerships between staff and youths were difficult to forge in the social service situation:

> Workers have a different relationship with youth, so trying to do this fun video project and at the same time they're this person that knows my problems ...it was difficult. (ICYP-2)

At the same time, staff observed that a change in relationship was vital for a more active partnership with the youths:

> They're the ones who have the information about what works for them ...unless that involvement is there, there isn't a sense of ownership. (ICYP-1)

As a solution, four older youths who had lengthy street experience were hired as 'peer educator' employees. They were responsible for coordinating the process of youth recruitment, for producing educational materials, and for promoting the project to other youth agencies The youth employees, along with other volunteers, also received training in technical video skills and learned group planning and interaction skills. Staff noted that participation of other youths increased when the youth employees were hired.

Thus, the presence of youth employees as intermediaries appeared to allow both staff and street youths to avoid the conflicts which made it difficult to work together on the project. In particular, the staff were able to maintain their primary service role without disruption. This strategy appeared to reflect the priority given to service by the agency as it also allowed the staff to maintain some distance in their relationship to youth clients. For example, one staff expressed concern about sharing project roles with youth:

> As open-minded and as non-judgmental as you would like to feel, what really puts it to the test is to see how OK we are with them sharing the same turf, the people we've been servicing. (ICYP-1)

Nonetheless, using street youths as employees appeared to break down some of ICYP's traditional role divisions between street youths and staff, such that one youth was hired permanently for office duties after the project. A staff member concluded that the change from a 'professional' model to a 'partnership' approach was positive:

> ...it feels like we're finally achieving working side by side involving the youth in a completely direct way in the service. (ICYP-1)

However, this partnership did not extend past a few employee positions. Overall, ICYP's mandate as a gatekeeper to social services was in conflict with the need to work with youths in a health promotion context. The youth employee strategy appeared to be a reasonable compromise for gaining youth cooperation, but also led to a number of power issues to be discussed later.

Employment Models

Two models of employment were used to facilitate youth participation in the program. Hiring youths as full-time employees was selected initially as a strategy since "that way there was more chance that they would actually show up because there was a pay cheque involved" (ICYP-4). The four youths who were hired had to meet the criteria of the Social Service Employment Program of the Ontario Ministry of Community and Social Services [DOC-04] which paid their salaries. One specific criterion, being on welfare with a permanent residence, perhaps fortuitously determined that older, more established youths would be in key youth employee positions. However, it also limited the scope of participation in the project of younger youths who were more transient and at higher risk.

During the production of the first STD video, youth employees were paid a regular salary. There were frequent work absences which disrupted the video production process and, as will be shown later, conflict often occurred around planning and implementing the project during this phase.

During the filming of the second video, ICYP changed its approach and paid youths $500 to act as 'consultants' and to be involved in particular scenes, rather than as full-time employees. Although youths had less continuity with the project under this consultation model, there were fewer conflicts reported and better attendance. This approach was perceived by ICYP staff to be more appropriate to the lifestyles of the transient youths. As well, staff reported that a system of 'pay for work completed' rather than 'pay for time spent' avoided the problem of full-time employment becoming a disincentive for youths to complete the project work.

However, while the consultant approach was perceived as more efficient, it may also have had a negative impact on the project itself. A youth noted that street youths had less input into the second video:

> It was a totally different kind of video, it was more like a documentary, just people in places talking. It comes across that the script was written. It wasn't the women involved who wrote the script. (ICYP-2)

In sum, ICYP moved from a system which granted formal term employee positions to youths to one which gave them only temporary status as consultants with less influence. It is unclear, however, whether the ICYP shifted to a less formal style of 'consultant' participation to avoid conflict in employee relationships or to improve efficiency in the production of materials.

Street Youth Transience

Traditional roles of the youths as clients at ICYP were to satisfy their personal needs for housing, welfare, food, and information. ICYP staff and youth employees recruited approximately twelve youths as unpaid volunteers to help plan and produce the informational videos and other educational material. However, the transient character of street youths proved to be a major obstacle to the consistency of their participation as volunteers:

> We found out as we went along that it was very difficult for people who didn't have a source of income or a place to stay to commit to the time it took to actually carry out the project to its end. Script development, acting workshops, videotaping and editing was a fairly lengthy project ...we ran into the reality that someone would be scheduled to show up on Friday for a meeting and it turns out that they're in jail instead, or they just don't bother showing up because they haven't eaten in 3 days. (ICYP-5)

Nonetheless, volunteering to work on project activities changed the nature of the youths' involvement in the centre. Youths observed that they now contributed to the centre's non-service goals and consequently were treated differently. A youth observed.

> I wasn't there chasing a worker around, I was there and they were having to respect me. I was more important than this brat who was screaming about a welfare cheque last week. (ICYP-2)

Thus, the nature of some youths' involvement in ICYP changed as a result of their new project roles. These roles challenged the ICYP organization and will also be shown to have influenced power dynamics in the project. It should be remembered, however, that while youth employees and volunteers were very active in the project, most youths were transient, still treated as clients of ICYP, and did not have major roles in the project other than in receiving STD information.

Youth Advisory Committee

At the suggestion of the HPD program officer, a group of 6-10 youths was invited by ICYP staff to be on a youth advisory committee to discuss the direction of the project and to devise new initiatives in STD education material. However, the committee consisted primarily of those youths (employees and volunteers) who had already shown a deeper interest in the project and did not include other ICYP client groups such as suburban or younger youths. The youth advisory committee consulted with staff and gained information from other street youths about the acceptance of the project, but it did not have any other clearly defined responsibilities.

The HPD program officer explained that the advisory committee "didn't always translate into what most people think of as an advisory committee" since it was very informal, had shifting 'membership', and met only periodically during the initial phase of the project. An explanation for this casual approach to the advisory process may be found in the underlying attitudes toward youth. For example, the HPD program officer observed that participation was a general problem with youth target groups:

> Children and youth are probably one of the hardest groups to get input from because they're not adults and they're not used to going to a traditional meeting to discuss issues and aren't usually into long range planning. (ICYP-4)

However, this attitude failed to acknowledge that some of these same youths were actively involved in organizing other community projects. The ICYP youth advisory committee appeared basically to be a response to HPD's expectation of a formal, yet token, mechanism for obtaining youth input, in spite of HPD concerns about the youths' capabilities.

Shift to Advocacy Activities

Street youth participation in project activities changed considerably over the three year term due to a shift in objectives from health education to advocacy. Initially, the STD project was consistent with a lifestyle health promotion focus. Most participatory activities, such as condom demonstrations and the development of safe sex information, were directed towards educating and supporting youths to make more informed choices about sexual and drug use behaviour. Very little emphasis was put on addressing social environmental conditions, other than on an individual basis, which made youths more vulnerable to STDs by being on the streets.

However, the participation of older youths with street experience as youth employees had consequences for this educational focus. As ICYP staff accepted these youths' proposals that conditions such as poverty and public health policies contributed to the STD problem, they gradually expanded the project to focus on advocacy activities with other community agencies. This was a significant shift in focus for ICYP which was a service oriented agency.

As the project progressed, increasing amounts of time were spent by ICYP staff and two youth employees on advocacy for policy changes regarding probation regulations, needle exchange programs, and prostitution which contributed to youth risks in living on the streets. Self-appointed 'councils' of youth agency managers and staff met with municipal, provincial and national politicians, bureaucrats, and law enforcement personnel to promote changes in legal, social, and health policies.

Although ICYP staff and youth employees reported that inter-agency activities were important, they also noted some negative aspects for participation. For example, staff reported that the amount of time devoted to meetings with other agencies was a problem.

> I could spend, and some people do, most of my time just going to meetings and talking with other social workers, other people with jobs like mine, and not actually serve the community. (ICYP-5)

Thus, the advocacy focus reportedly limited the staff and youth employees' efforts to recruit youths to actively participate in the project. Government sponsorship and facilitation of these advocacy activities appeared to reinforce a tendency towards participation of community organizations rather than street youths themselves.

In sum, participation of older, experienced youths led to an increased focus on structural causes of STDs and new project roles for a few youths, but at the same time, less participation by other youths in the project. Thus, a shift in focus to inter-agency planning and advocacy activities appeared to limit the participation of youths in the ICYP project.

4.2.7 Influence of Participants

Youth influence in the STDs project can be examined within the context of ICYP's service agency mandate and factors in the target group itself.

Service Provider Control

As a service agency, ICYP was accustomed to developing projects on its own, with little direct involvement of youths themselves. Only after the STDs project was funded did ICYP staff conduct a needs assessment regarding the types of STD issues and approaches which should be addressed in material development and dissemination. At this time, staff consulted with 15 other agencies, conducted five focus groups with youths and street workers, and attended eight external presentations and conferences. They also met and talked with individual youths who attended the ICYP drop-in centre [DOC-03].

Although ICYP collaborated with other community agencies in the development of the project proposal, there is no evidence that they consulted with youths as a group about the project idea until after the project was funded. Thus, the initial involvement of youths in decision-making in the project was not substantial.

ICYP's reputation for working with street youths appeared to substitute for their lack of consultation. The HPD program officer seemed to accept this over-confidence regarding youth participation:

> ...they were already interested in that and that's the way they worked so it wasn't as much of a concern that we had to be on top of them to make sure that the target population was involved. (ICYP-4)

This viewpoint indicated a very limited concept of participation, considering the exclusion of youths from significant organizational roles in the project. Eventually this exclusion had repercussions for the development of youth employee roles in the project, but it also influenced other conflicts in the project.

Street Youth Heterogeneity

Once the youths were invited to participate, individual, social, and political differences among them were claimed to be barriers to the development of consensus. For example, staff reported that there were differing opinions among youths regarding the inclusion of STD material related to homosexuality and male prostitution. ICYP staff perceived these disagreements to be due to personality issues and political allegiances among the youths:

> ... there were a multitude of problems - basically it was personalities - with the persons who were hired on the project. There were different kinds of allegiances within the group, politically and separately ...there was a definite collision and that made it very difficult to work on something as complex as a video where you had to have complete cooperation. (ICYP-1)

However, only one youth employee resigned his position due to these conflicts, and disagreements among the youths themselves were usually resolved with intensive discussion. Youths did not perceive a prolonged consensus process to be a burden:

> Decision-making can be difficult the larger the group ... I prefer to work in a collective, so I'm prepared to put up with that frustration to get all the views people do think. (ICYP-5)

Thus, differences between the youths may not have had as negative an effect on their participation as ICYP staff perceived. Conflict between youths was viewed as a ‘problem’ by staff rather than an ‘opportunity’. The next section will demonstrate the considerable influence that the youths developed in the operational activities through utilizing conflict strategies.

Street Youth Experience

ICYP staff and youths disagreed strongly on the subject of drug use while working or volunteering. ICYP's reputation as a non-judgmental service agency meant it accepted that youths used illegal drugs. However, in its new model of working with youths as employees in the health promotion project, ICYP had to face the possibility that overt drug behaviours would jeopardize the project itself. From the staff perspective, drug use made attendance and attention to project objectives less than optimal, and the legal ramifications for ICYP were a source of concern. However, youths insisted that drug use provided a strong experiential base for educating other youths about safe needle use.

Although the youth employees were not allowed to use drugs while working, volunteers were determined to continue. These youths decided to quit the project when told that they could not use drugs while volunteering:

> People would come into rehearsals stoned and nodding out on junk ...At one point Inner City said 'You guys can't be high while you're doing this.' So we said 'Fine, bye'. So then they said 'You can't be as high'. So everybody had to take smaller doses so we weren't falling asleep. (ICYP-2)

Staff and youth willingness to compromise on this behavioural issue allowed the project to proceed and the youths appeared to gain confidence in their ability to have some control in the project.

A second area of significant youth influence was reflected in direct conflicts over explicit video scenes which the youths felt were vital to the authenticity of the educational material. Responsibilities for planning educational materials were supposed to be shared among the youth volunteers, youth employees, and ICYP staff. Youths often proposed the use of slang language, which was usually accepted by the staff members after some discussion. However, the youths also proposed some controversial video scenes, for example displaying intravenous needle injection and putting on a condom, which were strongly opposed by the ICYP management who feared legal repercussions. ICYP also had concerns about alienating and embarrassing funders as well as offending various segments of the youth population and social service agencies. For example, the HPD officer observed that there was no formal acknowledgment of a link between the project and the federal department because of the fear of controversy:

> ...it doesn't say anywhere that it's funded by HPCP because it was requested by our then ADM [Assistant Deputy Minister] that it was too controversial and that our name shouldn't be on it. So we don't get credit for it. (ICYP-4)

The youths noted that it was the upper management staff of ICYP with whom they had conflicts:

> At one point things did get tense. We were given the impression that we had complete control over what we were doing. A guy came in and said 'Wait a minute, what are you doing?' and tried to take control away from the project. That may have something to do with the explicitness of the video. But that was gotten rid of pretty quickly because we were really angry. In the end because all of us were pretty self-empowered people to begin with, and felt really sure about what we were doing and all of us were really anti-censorship on a big level, we just said 'No way'. (ICYP-6)

After intense negotiations, during which the youths again threatened to abandon the project, the ICYP management relented and the video was completed. Subsequently, both staff and youths reported that relevant material was finally being produced which would be accepted by street youths. Youths reported that the process of keeping control over the explicit content of the video gave them great satisfaction:

> We actually succeeded, got our way and in the end I think it was really good we did that. Its one of the strongest positive comments I hear from people, 'Way to go. Glad you didn't use a banana'...I get feedback from people who use the video in their work and they all say it's accepted quite well by the audiences they show it to. There hasn't been anything that street level that I have seen.(ICYP-5)

There were a number of important elements which contributed to the assertiveness of the youths. First, many of the core group of older youths were independent and self-assured people with experience in dealing with project sponsors. Ideologically, they were opposed to censorship and control by professionals and were willing to withdraw from the project on these principles. Second, ICYP staff realized that the youths were correct in their assessment of the type of educational material which would be accepted by street youths. Third, ICYP management could not risk delaying or canceling the project if the youths withdrew, since they needed to maintain this successful participatory relationship with youths, for which they were becoming well known among other agencies. ICYP personnel also knew that replacing the youths would be no assurance that a more compliant group of youths could be formed.

In sum, a conflict between ICYP's traditional service values and its new health promotion project responsibilities provided a forum for youth influence to be expressed. ICYP conflict was ostensibly about the project's educational content and participants' behaviours, but there were also underlying tensions between the sponsor, as an agent of the social welfare system, and participants as clients. This tension appeared to exacerbate the conflicts even though staff tried to separate their social welfare roles from their project roles. In their traditional roles as clients, youths had very little control and threatening to withdraw from ICYP services would have had little effect on the staff. In the STD project, however, the youths knew that they could withhold something of value to the sponsor and were ready to use this threat to win their issue.

Numbers of Youth Participants

In contrast to the exact record-keeping required for ICYP's social welfare service programs, the HPCP project kept very informal estimates of the number of youth participants in the project. Project staff did not record the numbers of youths who volunteered or assisted in the development of materials as this was done on a 'drop-in' basis. Staff reported that street youths' suspicion and mistrust would have been raised if they had formally recorded the numbers or identities of participants. There is some credibility in this explanation.

Staff did record the approximate numbers of persons (without separating youth from staff) who attended public talks and demonstrations. They also recorded the number of written and phone requests that they received for materials. The following data are derived from quarterly project reports.

During the initial stages of project planning, production of STD education materials, and public education sessions, project reports cited approximately 14,000 contacts over a two year period. However, this figure included attendees at public meetings and distribution of STD materials to national and international agencies [DOC-03-10]. During the middle phase of the project (video production) only 500 contacts were reported [DOC-11-13]. During the final stages of the project, in which the second video was produced and advocacy networking was initiated, reported contacts rose again to approximately 1,600, largely through presentations of videos to student audiences [DOC-14-15].

In reality, these reported 'contacts' represented a wide variety of audiences other than the population of street youths, such as professionals and community workers. ICYP's inflated estimates of community member involvement appeared to be an attempt to demonstrate an impact of the project, in the absence of any other clear demonstrations of outcome. This point will be addressed in greater detail in the Discussion Section. Finally, it should be noted that the vast majority of project contacts were with youths as 'clients', or mere recipients of information. The number of youths active on the advisory committee

(10), women's advisory group (8), video committee (8-10), focus groups (~100), and as employees (4) was much more limited.

Post-Script

ICYP has continued to operate its social service programs and its AIDS education projects in collaboration with other agencies. Subsequent to the STD's project, other community groups, which were beginning to involve target groups more directly in the development of AIDS material, requested information on the ICYP approach to street youth participation. A ICYP youth employee observed:

> I can't say our video created the climate for all this to happen but certainly it was while we were opening that door the rest of the AIDS education community was also changing and developing. (ICYP-5)

Some of the more involved youths also continued in street youth work. For example, a youth volunteer reported that she participated in the development of an activist resource centre for young people:

> I'm part of a group trying to start an activist resource centre for young people so that we can give them access to equipment and information on how to start their own projects and grassroots organizations. If that happens it will be the first for Canada to have a place like that. (ICYP-6)

The fate of other youth participants is unknown.

4.2.8 Case Discussion

The ICYP case represents an example of community participation being used in its instrumental sense to assist a social service agency in developing STD educational material. Thus, a 'contribution' purpose to participation was evident, although some staff and youths attempted to transform client-agency roles for 'empowerment' purposes.

Numerous structural factors in the ICYP organization and target group, in particular, agency mandate, target group characteristics, resource restrictions, organizational structure, and a midstream change of objectives from health education to an advocacy approach were important. Some non-structural, individual motivational factors and interpersonal conflict factors also clearly influenced youth participation in the STDs project.

The mandate and history of ICYP as a social service agency for youths appeared to dominate the process of participation. The types of youths who were involved in the STDs project depended primarily on the needs and characteristics of the street youth group itself. The most active participants were older males from a lower SES with an activist orientation. More vulnerable younger youth did not participate actively since they were preoccupied with subsistence and participated primarily as clients of ICYP in receiving educational materials. Behavioural factors in the target group, such as transience, distrust, and drug use appeared to limit participation and may suggest that a different approach to participation is required for these youths than for more stable, mature target groups. Thus, a fundamental problem for participatory health promotion programs, which envisage disadvantaged target group members participating fully to change personal and social health conditions, remained unresolved in this project.

Participation was organized by ICYP using informal recruitment and communication methods which were suitable for a transient and distrustful target group. However, ICYP's inexperience in working collaboratively with youths limited the availability of financial support for youth participants who resented the inequities of working with paid project staff when the youths had so little. Finally, staff preoccupation with an insecure funding environment and with catch-up planning was responsible for reducing youth recruitment.

Over the course of the project, ICYP organizational structures changed with respect to youth involvement. Initially there was a broad based, informal participation of street youths as volunteers in focus groups and community agency representatives in advisory groups. Following early conflicts with staff roles and difficulties with casual youth participation, more formal roles were gradually created for youths as employees and on youth advisory committees. Later, however, employment was altered from formal employee to less formal consultant models which appeared to meet the needs of the project more than the needs of the youths.

This case was selected for study on the basis that community members were claimed to have had a principal role and influence as employees. The advancement of street youths to employee positions may have legitimated a client group, although not to the same level as regular staff members, and neither staff nor youths had real influence in the project. Involvement of the youths did not reflect a definition of participation from a structural perspective.

ICYP had a parallel conceptualization of youth service agencies as being a community of interest and established an advisory panel for input from this group as well. Thus, there was an attempt to counter the influence of youths with that of community service providers by utilizing separate advisory structures. Ultimately, this model allowed ICYP to provide service to clients, to receive assistance from youths, and to maintain credibility within the service agency community. Most important, the model maintained the ICYP agency in control of the project.

The process of working through problems with the youths became a major part of project activities and youths appeared to assert themselves well. Some youths had significant control over their personal behaviours and project content which was often exercised through processes of conflict. Although youths could be said to have seized control of various operational issues, their participation was still by invitation of the sponsor, rather than an established right. Youth control was exercised within a general framework of the sponsor's financial and organizational authority.

Later in the project, a shift from a health education focus to a policy advocacy approach, precipitated by older youths' experiences, eventually resulted in even fewer youth participants in active roles. In this case, coalitions and networks became a common method of involving the wider 'community' in the ICYP project. However, the advantage in participation of a wide variety of community agencies, which had potential to be listened to by policy makers, was offset by the time required to make coalitions work, by their occasional use by staff to avoid basic street work, and by their fragility in times of economic cutbacks. Coalition and advocacy work did not facilitate youth involvement in health promotion, although it may have had potential to improve the structural conditions responsible for their problems. This interpretation is consistent to that reported in other recent studies of coalitions in community-based AIDS services (Cain 1993).

Overall, the mandate of ICYP as a social service agency was a powerful force in the construction of participation in this project. ICYP staff handed over limited control of the project to youths, and did not allow them to formally participate in ICYP management. Neither youth employees, volunteers, nor the advisory committees were given explicit decision-making authority over the general objectives of the project, or over personnel and resource issues. Tensions between ICYP's service mandate and its new health promotion project mandate appeared to limit the influence of youths, except for a few operational decisions. Control in ICYP was in a state of transition from complete sponsor dominance to a state of negotiated influence with youths in certain project operations, but not in the principal decision-making structures of the organization. Except for a few short term employee positions, youth participation was informal and temporary, rather than formally embedded in the organization. Control of the health promotion project by a social service agency made strong participation by the youths unlikely. It is important to note, however, that these limited organizational changes, which were progressive for street youth agencies at the time, may have been acceptable to the youths because this target group was so limited in its ability to demand more.

4.3 CASE: DRUG & ALCOHOL ABUSE IN PERSONS WITH DISABILITIES

SPONSOR: PERSONS UNITED FOR SELF-HELP

4.3.1 Introduction

Persons United for Self-Help (PUSH) in Ontario organized a province-wide project from 1988 to 1994 to address the problem of substance abuse among persons with disabilities. Since there was little information available about drug and alcohol use by persons with disabilities, survey information was gathered initially on the circumstances of disability which affected the identification, treatment, and support of disabled persons with substance abuse problems. Educational materials, focus groups, conferences, and a speakers' bureau were then organized to initiate discussion of the issue by individuals, professionals, and health service providers. Advocacy activities with government and service agencies were also conducted.

This case was selected for review on the basis that project documents indicated that community members had played significant roles through participating on a board of directors. The sponsor claimed in its documentation that the PUSH board was the principal mechanism through which people with disabilities had input and influence in the substance abuse project.

Data sources for this case included six direct interviews, 12 project documents, and the report of an Addiction Research Foundation-PUSH research study (Tyas 1992). Interviews were conducted with the HPD program officer, an ARF researcher, the chairperson of the PUSH board, a former board director and volunteer, an able-bodied staff person, and a former staff person who had a physical disability.

4.3.2 Structural Characteristics of the PUSH Organization

History and Program Mandate

During the 1970's and 1980's, demographic increases in the number of ageing persons and trends toward de-institutionalization created a demand for appropriate public services for persons with disabilities in Canada. A survey conducted in 1988 estimated that 14% of the Ontario population had some type of disability which affected their lives (Ontario Ministry of Citizenship 1990). Concurrently, disabled persons in Canada began to organize self-help and political advocacy organizations, which were distinct from earlier organizations of disabled persons which focused on social and recreational needs (Driedger 1989).

PUSH (Ontario) was formed in 1981 as a consumer advocacy organization to promote self help and equal access to public services among physically disabled persons As a consumer organization, PUSH adapted the philosophy of the Independent Living (IL) movement in the United States which advocated that disabled consumers have control over the organizations and resources required for them to achieve maximal independence in their communities. Thus, the IL movement, and PUSH as an organization, arose from a growing militancy of persons with disability who rejected the control of professionals over their lives (Dejong 1979). Traditional service providers addressed disability by utilizing professional program staff, by providing services for 'clients', by emphasizing private charitable fundraising, and by focussing on individual types of disabilities. In contrast, PUSH emphasized what it termed 'consumer control', education and advocacy programs, government responsibility for program funding, and cross-disability representation, or involvement of persons with a wide variety of disabilities (MacEachen 1993).

PUSH worked for the full integration of persons with disabilities by advocating for policy changes within the areas of employment, transportation, income security, and accessibility. Since PUSH considered disability to be primarily a social issue and since its members had often experienced the domination of health care professionals, it was initially reluctant to focus its activities on health issues. Nonetheless, PUSH did organize a conference in 1986 on "Persons with Disabilities and the Health Care System" which provided some stimulus to the HPCP project [DOC 01].

During the late 1980's, disability organizations were high on the federal and provincial governments' social service priorities. Distinct bureaucratic structures within governments were established to organize disability policy and to fund community service groups, for example, the Ontario Office of Disability Issues and the Disabled Persons Unit within the federal Secretary of State.

PUSH was frequently called on by Ontario ministries to represent those with physical disabilities in the policy making process [DOC 01]. In this representation, PUSH acted as the provincial coordinating body, or umbrella group, for seven regional branches which mobilized local persons with disabilities around these policy issues. PUSH was also the provincial affiliate of a national advocacy organization, the Coalition of Provincial Organizations of the Handicapped (COPOH), now known as the Council of Canadians with Disabilities (CCD). Provincial affiliates appointed delegates to COPOH which elected an executive committee at its annual meeting. COPOH itself was funded primarily through the federal Secretary of State for Disabled Persons and supported its provincial affiliates such as PUSH through information exchange and lobbying for policy changes at the national level, for example, during the development of the Canadian Human Rights Act and the Charter of Rights and Freedoms (Driedger 1989). The PUSH links with COPOH were strong as the chairperson of the PUSH board of directors, who had major involvement in the drug and alcohol project, was subsequently elected chair of COPOH.

PUSH was a recipient of a number of grants since it was progressive in its proposals, vocal in its representations, and acted as an umbrella organization for a number of smaller disability groups. PUSH enlarged its central offices and staff repeatedly over a short period of time.

PUSH and the federal government appeared to have mutual interests in working together. As shown later, PUSH relied heavily on consistent Health and Welfare funding for financial assistance. PUSH sponsors perceived that, in turn, federal government officials claimed that they had genuine participation from the disability community in their health promotion programs:

> I don't think they view us as an attempt to get the community involved They view us as the community, probably for reasons of their own convenience. They can say PUSH was there. It has a stamp of some kind of legitimacy. Politically, they have to be able to say, 'Yes there is community input'. And because PUSH is a consumer organization they automatically have that. (PUSH-5)

From the HPD's view, however, there were few other alternatives at the policy level for disability consumer groups other than COPOH and its affiliates. PUSH was "the only disabled advocacy game in the province and... they've lasted for over a decade" (PUSH-4). It will be shown in this case study that PUSH's claim for 'representation' of disabled persons was a major source of their influence with HPD.

One of the potential dangers for HPD in funding an advocacy group such as PUSH was that it would criticize federal government policies. But since many of the health service issues being advocated by PUSH were provincial responsibilities, there was little chance that the federal government would be held up to criticism. PUSH staff suspected the federal government's interest in this possibility:

> In this second phase of the project, emphasizing advocacy, we've had good support [*from Health & Welfare Canada*] because I think they see it as

> something different and have an interest in it as a unique project approach and as a funding approach - would they fund an advocacy organization to yell and scream at a provincial government and agency?
> (PUSH-5)

While there was no direct evidence obtained from government bureaucrats to support this contention, the HPD may have encouraged PUSH's participation in the HPCP to advance its own position in inter-jurisdictional matters. Regardless, HPD's support of PUSH appeared to demonstrate the importance of disability on the political agenda, and this was based on the legitimacy of PUSH's claim for representation of the disability community.

Target Group and Issue

Although PUSH was supposed to be a cross-disability group, the heterogeneity of disability was not well reflected in the organization. PUSH respondents made distinctions between those who were disabled by congenital or traumatic causes, and those disabled by diseases such as diabetes or epilepsy. Persons with congenital and traumatic disabilities (estimated at 71% - Ontario Ministry of Citizenship 1990) were perceived to be primarily interested in integration, human rights, and equal social opportunities. Those with 'disease disabilities' (estimated at 29% - Ontario Ministry of Citizenship 1990), however, were believed to be searching for cures, which allied them to medical professionals rather than with other disabled persons. PUSH directors reported there was resentment that the 'disease disability' groups under its umbrella, which represented fewer persons, received more funding for services and research than did other groups.

Even within groups with congenital and traumatic disabilities, there were distinctions in PUSH. Those with a late onset of physical disabilities affecting mobility (35% - Environics 1989), such as spinal cord injuries, were reported by project staff to have higher public profiles, more involvement, and influence in PUSH than persons who had sensory disabilities (16%), psychiatric and developmental disabilities (10%), or were institutionalized (8%). Similar trends have been noted within the entire disability movement (Driedger 1989). Thus, PUSH primarily appeared to represent a 'functional elite' segment of the disability population.

During the course of their work, directors on the PUSH board became increasingly aware that some members had serious substance abuse problems. Not surprisingly, PUSH directors and staff viewed addiction from a sociopolitical perspective, which was consistent with the stance of the disability movement as a whole (MacEachen 1993). Addiction problems were believed to be caused by a combination of professional attitudes and societal influences. PUSH respondents suggested five reasons for addiction problems in persons with disabilities. First, persons with disabilities had heavy involvement with the medical profession, which avoided dealing with root causes of disability problems such as depression and pain by prescribing tranquillizers and sedatives, many of which interacted with even moderate alcohol use. Second, disabled persons were disadvantaged by physicians' attitudes that they were unlikely to drink alcohol, and thus not in need of information about drug and alcohol interactions. Third, the stigma of alcoholism and drug abuse, when combined with other attitudes regarding disability, made this a particularly sensitive issue for persons with disabilities and confidentiality was a major concern. Fourth, persons with disabilities had higher rates of unemployment which lowered self-esteem and made the usual incentives to control drinking, such as keeping one's job, less relevant. Finally, there were both physical and attitudinal obstacles in accessing the addiction treatment system, which discouraged persons with disabilities from seeking treatment [DOC-01].

Under these assumptions of social control, stigma and environmental barriers. PUSH respondents considered most addiction problems to be avoidable, yet at the same time, all persons with disabilities were considered at risk.

PUSH Program Linkages

Similar to other cases in this study, PUSH's community included many agencies and organizations. PUSH's claim for representation of 'thousands of consumers' in Ontario was principally through the membership of affiliated disability organizations for which it acted as an umbrella advocacy group. These organizations included the Ontario March of Dimes, the Ontario Head Injury Association, and Independent Living Centres [DOC-01]. A PUSH director emphasized the value of forging open alliances with other groups as well, such as seniors and employment equity advocates, to present a unified agenda for social change.

Although PUSH participated in joint projects with these organizations, an increasing number of disability groups in Ontario also applied for funding on their own. PUSH staff and directors reported that competition for funds had an adverse effect on the advancement of disability issues and chose to promote a more cooperative approach:

> There are some important areas which we just aren't able to get to. And we shouldn't. There should be a division of labour among different consumer organizations...But the chronic problem is lack of resources. (PUSH-5)

However, the HPD program officer noted that an expansion of funding opportunities fuelled this independence:

> There are so many different groups, and each group wants their own spokesperson, their own office, and their own chair. I don't know how strong is the ability to move together on issues in the province. (PUSH-4)

In fact, there was occasional dissension in the PUSH organization itself, as demonstrated when one regional group collapsed and then reconstituted itself into a separate advocacy group before returning to the PUSH umbrella. In sum, the disability organizations in Ontario appeared to both collaborate and compete with each other.

Resource Mobilization

Resource mobilization was given high priority by the PUSH board. This case illustrated a complex example of the various opportunities, pressures, and consequences for an advocacy organization in accepting public funds for the promotion of social change. There appeared to be two interacting factors affecting the ability of PUSH to secure resources. These factors can be termed 'bureaucratic policy' and 'political agenda'.

The 'bureaucratic policy' affecting PUSH decreed that provincial or federal core funding was available only to community groups which provided services to target groups. For disability groups, such services included transportation, housing, health education, and personal care. Core funding involved contractual agreements between community groups and government departments to provide services of a particular quality to eligible individuals over fixed periods of time. Satisfactory provision of services by the group resulted in continuation of funding.

All other funding, such as HPCP, was for short term projects demonstrating new service models, education, or research. Not surprisingly, HPCP funding was not officially available to groups which intended solely to criticize or promote change in government-funded services. A director observed that PUSH had no mechanism for legitimate funding of this core advocacy work and had to develop projects which also had a service or research component:

> PUSH is trapped like most advocacy groups since funding exists with the provision of service and if you want to get funding...you have to give the appearance of doing service. (PUSH-6)

In the PUSH case, 'service' referred to assistance to the broad population of persons with disabilities through information and education, rather than services for individuals.

PUSH complied with these funding requirements in the drug and alcohol project by developing educational materials, by holding information sessions with consumers and professionals, and by participating in studies of disability and addiction. At the same time it gathered support and research evidence for advocating changes in addiction treatment policy. These dual purposes were not hidden from funders but were accepted by them as a fair compromise. According to the HPD program officer this strategy was:

> a very traditional way that groups get their money... Indirectly we funded them for five years to keep their office open... without our money they wouldn't be around. (PUSH-4)

Thus, a 'political agenda' factor, which demanded that disability groups be given support during this time in Canada, appeared to contribute to this compromise (Driedger 1989).

The PUSH substance abuse project funding came in four stages. An initial pilot study, funded by the Addiction Research Foundation (ARF), provided survey data for use in the PUSH proposal to HPD. The project sponsors then received $285,917 over 57 months for project activities and subsequently two extension grants for additional activities were funded. Thus, HPCP grants ($326,000 over six years) for the substance abuse project provided 'indirect' core funding for PUSH

Through its strategy of developing a series of service projects in various areas, PUSH advanced its advocacy goals by obtaining resources to maintain personnel, programs, and visibility in the community even in times of economic cutbacks. Overall, PUSH's annual funding increased from $55,000 in 1982 to over $600,000 in 1992. Staffing also increased from four to fourteen positions from 1991 to 1993 (MacEachen 1993). PUSH staff recognized, however, that their position was fragile:

> Because we're on the government's agenda look what's happened. This is just unbelievable...but if there's a change in government or if the fiscal situation of the government gets worse then we could be facing the music too. (PUSH-5)

Both PUSH directors and the local HPD program officer recognized that there was significant pressure on the organization to redirect its goals to meet the priorities and opportunities which were being presented by funders. However, due to jurisdictional overlap in federal-provincial health and social responsibilities for disabled persons, PUSH organizers had the luxury of having both federal and provincial funders competing with each other to give grants. This strategy allowed PUSH to maintain a measure of independence over its goals and to challenge the funders' focus on service. PUSH respondents noted:

> ...its coming to a point where we're not going to deliver on what they would like to see delivered - produce a paper or product or kit or have an organization formed or have a project with a defined beginning and end. (PUSH-5)

> We constantly fight to say 'We're not going by your agenda. This is something we have to do. We want to find a way to fund it. If you won't, we'll find another way'. (PUSH-1)

Thus, PUSH was willing to be increasingly independent of particular funders if it could not achieve its objectives through their programs. As long as disability was on the political agenda, PUSH had options which allowed it to maintain its advocacy mandate.

4.3.3. Characteristics of the Drug and Alcohol Project

In addition to these general characteristics of the PUSH organization, there were also specific structural characteristics related to the design of the substance abuse project itself. The original purpose of the project was to increase accessibility to appropriate treatment services for persons with disabilities who had substance abuse problems [DOC-01].

Project Objectives

The formal, explicit goals of the project were to determine the extent of addiction problems in persons with disabilities, to assess the availability of treatment facilities, and to promote provision of appropriate education and services. The specific project objectives were to:

1. Identify issues related to substance abuse and develop connections between consumers and service providers;
2. Ascertain the extent of drug and alcohol addiction problems among disabled individuals in Ontario;
3. Encourage persons with disabilities who have drug and alcohol problems to utilize mainstream facilities, services, and support groups; and,
4. Work with facilities and services to make them aware of the need to accommodate persons with disability. [DOC-01]

PUSH proposed to address these problems directly through education of consumers, through sensitization of professionals, by increasing physical access to treatment facilities, and by encouraging appropriate consideration of the unique situations (for example, stigma) of persons with disabilities. Thus, the project was initially intended to include both health education and service planning components. However, the educational components did not focus on individual behavioural change as much as they focused on changing social-structural causes of addiction in persons with disabilities.

It must also be acknowledged that PUSH had other important implicit objectives in the project such as developing the organization's capacity to secure funding and to influence policy development in Ontario and national arenas.

Organizational Structure

Membership was an elusive concept in the PUSH organization. Although PUSH was legally incorporated, it resisted enforcing a formal set of criteria for membership. A volunteer reported that:

> PUSH has tried hard not to have a formal membership process where you have to pay so much money to be a member because for many that would mean that they couldn't join, particularly if you're on fixed income...it's very informal in that it's open to everybody and anybody can come and sit in on our meetings...There's no limit on who can attend. (PUSH-6)

However, membership was not completely open. PUSH developed guidelines for participation of able-bodied persons in the organization's meetings which called for:

> ... a minimal 80% to 20% weighting of consumers to professionals to allow for adequate consumer input and control of the proceedings. [DOC-01]

Similarly, a minimum of 51% of staff positions was to be held by persons with disabilities. Consumer membership was open to individuals having visible congenital, traumatic and disease disabilities, as well as to others who had less visible disabilities such as epilepsy and cancer.

It was difficult to determine the actual number of PUSH members. PUSH directors and staff often quoted a figure of 15% of Ontarians (approximately 1.5 million) as having disabilities and thus affected by the advocacy efforts of PUSH. However, the PUSH newsletter circulation had only 1000 listings, a number of which were institutions and community agencies (MacEachen 1993). Thus, the number of regional members actually supporting PUSH's political objectives, in contrast to the membership of other disability agencies in its umbrella group, was perhaps in the hundreds, rather than the thousands which were claimed.

Members from each of seven regions elected local boards, for example, PUSH North West and PUSH Central, which mobilized local advocacy activities. This general membership advised the PUSH board on the direction of the organization, on topic areas for development of new projects, and on new funding sources. See Figure 6.

The organizational structure of the substance abuse project within PUSH was as follows:

1. The project was managed by the PUSH **board of directors** which consisted of seven regionally appointed representatives and a six-member executive committee who were nominated and elected at an annual meeting of PUSH members. Directors consulted with local members in their regions and met together on a quarterly basis to develop organizational policies and project ideas, which were then ratified at the annual meeting. Resolutions from the floor were also used to give direction to the board for the subsequent year's activities. Finally, the executive committee of the board had a direct role in supervising the PUSH **executive director**.

2. A single project **employee** was hired to coordinate the HPCP project and report to the executive director. Depending on the availability of funding for other projects and the need to meet project deadlines, the employee often worked on more than one PUSH project at a time. This staff member was also responsible for drafting funding proposals and promoting the PUSH organization in public meetings.

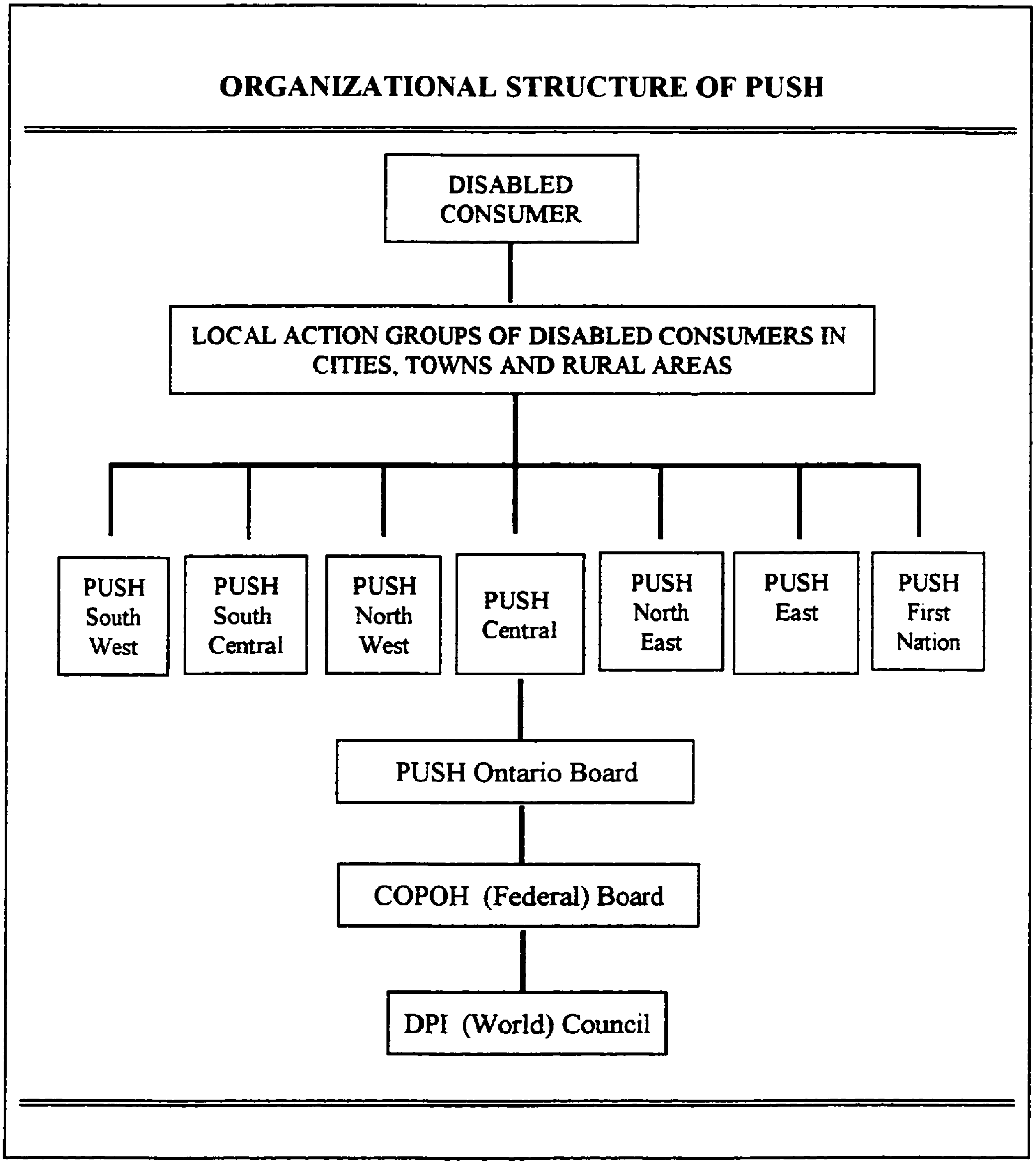


Figure 6. Organizational Structure of PUSH (from MacEachen 1993)

3. Although there was no formal advisory committee solely for the HPCP project, an **advisory committee** for another PUSH project provided intermittent advice to the board and staff. The advisory committee was composed of a majority of persons with disabilities, including representatives from other consumer and service organizations. Advisory committee members also did volunteer work in the project.

4. Local **volunteers** in the regions organized focus group meetings of **consumers** and administered survey questionnaires regarding substance abuse issues [DOC-04].

Background and Roles of Other Participants

Professionals - As an advocacy organization attempting to conduct 'service' projects , PUSH needed both political and technical support in the area of addictions. While health and social service professionals were portrayed by PUSH respondents as historical adversaries of the disability movement, in practice, they were involved at three key levels in the project - as political supporters, as technical resources, and as recipients of education about disability. PUSH and HPD considered the Addiction Research Foundation (ARF) to be a partner in the drug/alcohol project and it is unlikely that PUSH could have received HPCP project funding which involved research without ARF's political and technical support.

As of 1991, 340 different professionals had contact with the project, primarily through professional education sessions on disability awareness and substance abuse [DOC-11A]. However, only a few professionals actually worked closely with PUSH on project activities. An ARF researcher noted that poor professional attitudes were a factor in this apparent popular interest in disability, yet little in-depth collaboration:

> There has been a tendency for professionals to be very arrogant and to not really talk to the people they want to serve on a genuinely egalitarian basis.

> We tend to fall back on our technical understanding and our jargon as a way to distance ourselves from the problem. (PUSH-3)

However, this researcher also noted that professionals could change their attitudes over time as they began to understand the perspectives of disabled persons.

Bureaucrats - The program officer for disability issues at HPD was supportive of the PUSH organization and its attempts to create a more stable funding base. In accordance with HPD priorities, the program officer initially encouraged PUSH directors to submit a project proposal and advised them on its preferred format [DOC-02]. The program officer reported that subsequently she did not have an active role in the project, noting that PUSH preferred to be independent.

Nonetheless, provincial bureaucrats from the Office of Disability Issues (Ontario Ministry of Citizenship and Culture) supplied logistical support for group meetings and writing reports. PUSH staff perceived that sympathetic bureaucrats at both levels had roles in "advocating the consumer's viewpoint within government" (PUSH-5). Similarly, a PUSH director viewed bureaucrats' support as essential for the continuation of funding:

> With all government departments that are sponsoring projects, they need to have their people involved in the projects, if not directly, at least to be seen to be supporting it. (PUSH-1)

Thus, in addition to providing logistical and advisory support, bureaucrats were expected to facilitate the political agenda of the PUSH organization. Active participation of federal bureaucrat advocates at this level appeared to be crucial to PUSH's resource mobilization strategy.

Thus, a number of distinct groups participated in the drug and alcohol project. In addition to persons with disabilities who were board members, volunteers, or staff of

PUSH, there were also able bodied staff, professionals, and bureaucrats who participated. Participants were involved either directly, through project planning and implementation, or indirectly, through occasional advisory and technical consultation (Table 3).

Table 3. Participants in Drug/Alcohol Project of PUSH

PARTICIPANTS	
DIRECT	INDIRECT
PUSH Board of Directors **	HPD Program Officer *
PUSH Staff **	Addiction Agency Staff - ARF, AA
ARF Researcher *	MoH Representatives
Provincial Bureaucrats	Health Professionals
Regional Volunteers	Disability Organizations - CAILC, COPOH, etc.
Consumers in seven regions	

* = participant interviewed in this case study

Project Administration and Leadership

As is sometimes the case in small community organizations, formal organizational structures and processes were not always followed, and the actual administration of the substance abuse project was somewhat chaotic. For example, clearly delineated lines of authority were not maintained. The executive director shared supervisory responsibility for project staff with the board executive committee. This dual supervision was supposedly a means of reducing the executive director's workload, since PUSH had up to 10 projects in operation simultaneously. Project staff conducted most day to day project operations, under nominal supervision of the board executive committee, while board members attended important meetings with ARF and the Ministry of Health. Thus, board members had broad involvement in project activities and this occurred in other PUSH projects as well.

There was almost continuous turnover in both executive directors (3) and drug/alcohol project staff (6) over the six-year project period. For 18 months there was no executive director in PUSH and the board chairperson assumed this role (MacEachen 1993). Reasons reported for this rapid staff turnover included career mobility, retirement, and staff burnout [DOC-03,-11]. Gradually, with a complete board renewal every two years and frequent turnover of executive directors, responsibility for project management reverted to staff, who fit its activities in with their other responsibilities. The lack of stability and leadership within PUSH was evident.

In addition, effective evaluation mechanisms were missing, apart from quarterly reports to HPD. An internal 'evaluation committee' composed of board members was initially formed to monitor the project on a biannual basis. However, the committee met only twice early in the project term and, instead of monitoring project management, focused on reviewing a report from a 'Think Tank' on substance abuse. This further demonstrated a lack of interest and competency in management and evaluation in the PUSH organization.

In 1991, an external consultant was hired to evaluate the completion of project objectives, to present feedback from regional focus groups, and to assess the perceived impact of the project. Unfortunately, the consultant did not address how the project was being implemented or managed [DOC-11A]. The consultant concluded that since the project was more successful in raising awareness of the substance abuse issue among consumers than among professionals, it had not led to many changes in addiction service delivery practices. This conclusion is surprising considering the numbers of professionals who attended education sessions. It is also possible that professionals did not agree with the disability advocates' analysis of addiction causes and dynamics.

Summary of PUSH Structural Characteristics

PUSH became a major player in the disability field and grew quickly in its organization, resources, and program areas. Initially, the strength of the PUSH organization appeared to come from three factors - a board of directors and staff who shared a common vision and interest; success in mobilizing resources from multiple funders both to initiate new concepts and to respond to government needs; and the perceived legitimacy of a wide general membership through regional representation mechanisms.

However, rapid funding success and organizational growth created considerable internal strains within PUSH. Although PUSH directors considered their financial position to be quite strong, relatively easy funding from federal and provincial sources appeared to lull the organization into ignoring its own internal management. Board members had responsibility both for policy and for operational activities which will be shown to have had negative repercussions for participation.

Although PUSH claimed the role of an umbrella group representing virtually all disabled persons in the province, there were no mechanisms established to ensure that there was wide representation from all disability groups. Although membership in PUSH was claimed to be 'accessible' and based on shared experiences, it was actually informal, difficult to document, and not necessarily based on shared characteristics or values. In particular, a lack of formal corporate membership of other disability organizations, especially at the board level, meant that community groups had no particular responsibility for PUSH.

The following section presents how key structural factors in the PUSH organization were associated with the types of participants, participatory strategies, and participant roles, activities and influence in the substance abuse project.

4.3.4 Types of Community Participants

The types of participants in the PUSH project were influenced by a conflict between PUSH's disability mandate and its need for credible advocates, and by its non-adherence to organizational guidelines regarding staff positions.

Conflict in Target Group and Advocacy Mandates

As noted previously, although PUSH claimed that it had cross-disability representation, board members and staff reported that those with physical mobility disabilities were most frequently and intensively involved in the project. PUSH's mandate to advocate for access to mainstream public services appeared to lead it to an emphasis on those with less severe problems. For example, PUSH did not actively recruit severely disabled persons (15% of disabled population - Ontario Ministry of Citizenship 1990) for the project who were unable to leave their homes or institutional residences, although these persons may have had significant over-medication problems.

Furthermore, consumers who were intensively involved in the PUSH project did not appear to be representative of the socio-demographic range of persons with disabilities. For example, the PUSH board was composed of disabled persons who were primarily male (9/13), with physical mobility problems (12/13), and at least a secondary school education.

A staff member explained that consumers required significant skills and confidence to interact with professionals and bureaucrats on advocacy issues:

> On the whole the consumers who are involved are kind of an elite. There's a clear difference between consumers who have enough strength to work on issues like this and the bigger body of disabled people who for whatever reason don't get as involved and remain more confined to dependent lifestyles. (PUSH-5)

In sum, the community members who participated most intensively in the project were high functioning, privileged persons. This finding is similar to that in many other consumer organizations in the disability field (Driedger 1989).

Non-Adherence to Staffing Guidelines

HPCP funding allowed the creation of a full time staff position within PUSH for six years. PUSH guidelines required that it employ qualified persons with disabilities on a priority basis. Nonetheless, over the course of the project only three out of six staff were persons with disabilities. Two of these persons had never held full-time positions before and required up to six months of self-education before they were in a position to operate the project independently.

To compensate for the lack of staff members with disabilities, board members held disability awareness sessions for able-bodied staff to educate them on how to represent the consumer philosophy of PUSH. One able-bodied staff member was a recent university graduate and had a keen interest in the addictions field. His comments illustrate that awareness sessions were an effective strategy:

> ...I have tried as much as possible to get the consumer voice to the table where the policies are being made. I include myself in that even though I'm able bodied. I'm working under the control of a consumer organization. (PUSH-5)

Nonetheless, involvement in the PUSH project also had significant benefits for him:

> I feel like I've made a name for myself within the addictions field, no doubt about it. I got an appointment to the ARF board, one of the more bizarre things that's happened to me. (PUSH-5)

Overall, while PUSH's guidelines were supposed to support a degree of consumer influence in the project, disabled persons did not receive the preference intended.

4.3.5 Sponsor Strategies for Participation

This section discusses relationships between structural factors such as target group status, program linkages, and resource mobilization and the PUSH strategies which were used to encourage participation.

Addiction Stigma and Recruitment

Persons with disabilities were recruited for project activities in a variety of ways. Staff and volunteers used an established mailing list of PUSH members in the regions and made telephone calls to invite participation and to request that members in turn make invitations in their own communities. However, the stigma related to addiction was a major obstacle to participant recruitment when added to the power relationships which are inherent in disability. A PUSH director noted that many persons with disabilities relied on professional and bureaucratic staff for their needs:

> ...if you're a disabled person and you're relying on your attendant care or your public health nurse, you're not going to go to a workshop and start confessing about substance abuse problems... The people who had an alcohol problem were afraid that they would be thrown out of their housing or that their supports for medicine or equipment would be cancelled. (PUSH-1)

Thus, open participation in the substance abuse project meant a risk of personal exposure and further stigma for disabled persons.

Since privacy concerns were a major barrier to participation, organizers and volunteers spent considerable time reassuring members that confidentiality would be maintained and that they need not have a substance abuse problem in order to participate. In fact, organizers emphasized the issue of alcohol and medication interactions, rather than substance abuse, as a way of improving member participation.

To further address the issue of stigma, PUSH organizers decided that survey interviews that were conducted by volunteers with disabilities would be more acceptable to consumers than those conducted by able-bodied ARF researchers. The project staff also utilized anonymous telephone and written interviews to increase participation rates. Nonetheless, a PUSH director observed that many persons were anxious about confidentiality and withdrew from the pilot project:

> ...the researcher found about 20 who said they would do personal interviews. Then only about five would even discuss it face-to-face and they weren't the ones who had problems. (PUSH-1)

Finally, even though the addiction stigma issue created a need and opportunity for disabled persons to act as volunteers, PUSH staff turnover throughout the project prevented consistent volunteer recruitment and training.

Incompatible Mandates of Community Partners

Stigma concerning addiction also affected the participation of PUSH's own constituent groups. PUSH directors and staff asked for cooperation from other disability organizations such as the Canadian Association of Independent Living Centres (CAILC) and Disabled Peoples' International (DPI). However, in this case, many disability groups rejected the idea of acknowledging publicly that persons with disabilities might have substance abuse problems. A staff member interpreted this reluctance to be related to stigma:

> They didn't want to focus on this because they didn't want to admit that anybody had a problem, because it was tough enough being deaf and getting acceptance in the world...we were trying to get discussion groups at the Canadian Hearing Society for hard of hearing people, doing some focus groups or informal counselling and there was real resistance to that happening. (PUSH-2)

Problems were evident in collaboration with addiction groups as well. PUSH staff approached Alcoholics Anonymous (AA) to investigate the accessibility of their program to persons with disabilities. As a major self help program used by alcohol abusers, AA was considered to have a compatible philosophy with PUSH and thus was a possible ally. However, a PUSH staff member reported that contact was fruitless since the fundamental principles of self help and anonymity in the AA group limited their collaboration with anyone not having an alcohol problem:

> As I didn't have an alcohol problem I couldn't really go to an AA meeting. We couldn't get any official letters or phone calls, just couldn't get in. (PUSH-2)

PUSH's inability to make contact with AA may have reflected an incompatibility for collaboration between pure self help organizations offering confidentiality to members, and advocacy organizations requiring public presentations and possibly personal disclosure to effect change.

Limited Volunteer Honoraria

In this case, honoraria were available through the HPCP grant for assistance with some project activities. For example, this arrangement allowed volunteers who administered ten surveys to be paid a $50 honoraria [DOC-01]. However, in PUSH's service planning and advocacy activities, participation was reported to be limited by lack of payment to volunteers. A PUSH director noted that contributions of consumers and professionals working on the project were not equally valued:

> ...I sit around a table of 20 people and I'm the only one who isn't paid to be there and everybody is seeking my advice and taking what I use and distributing it around...everyone is getting paid good wages. They go home to have someone look after their house. Most disabled persons go home and look after themselves and do their own secretarial work. (PUSH-1)

Some members of PUSH who worked with professionals were starting to classify themselves as consultants and demanded payment accordingly when asked to attend official meetings with ARF. This tendency toward professionalization of volunteers appeared to further underscore the departure from a traditional voluntary role for disadvantaged target group members in health promotion activities.

4.3.6 Participatory Roles and Activities

A number of structural factors were associated with the roles of community members and the participatory activities which occurred. Persons with disabilities were involved in the substance abuse project in four ways - as members of the board of directors, as employees, as volunteers, and as recipients of information. A complex set of activities for participants were developed over the course of the project. The focus of these activities was a partnership with ARF.

Partnership with a Professional Organization

PUSH directors played major roles in planning and implementing the project. Initially, the chairperson of the PUSH board of directors approached the ARF president directly to request research about the addiction problems of disabled persons after the issue was raised at PUSH's annual meeting. However, the PUSH chairperson did not specifically request new programs for intervention at this time. This approach appeared to reflect an understanding of the sensitive nature of the addiction issue to disabled persons, as well as being part of a strategy for accumulating research evidence and allies before lobbying for improved treatment services.

PUSH board members and volunteers then worked together with an ARF researcher in Eastern Ontario to conduct a pilot study to provide baseline data about the incidence and prevalence of substance abuse in disabled persons (Tyas 1992). ARF staff provided technical resources for the study design, sample characteristics, and questionnaire. Local PUSH volunteers reviewed the survey material and identified potential respondents, of whom 60 persons agreed initially to participate. PUSH directors and ARF staff then jointly developed a funding proposal for the HPCP with significant input from the HPD program officer. This initial collaborative project was considered successful both by PUSH and ARF since it provided data for further project development. Of more importance, they reported that it demonstrated to their respective groups that there was mutual respect for each other's skills and knowledge. The perceived legitimacy of the PUSH organization as the voice of a sizeable minority in Ontario appeared to allow this partnership to develop on a somewhat equitable basis. The privileged status of key PUSH board members may also have helped in the acceptance of this partnership by a powerful service agency.

Leadership Gap

After funding was received from HPCP, persons with disabilities were hired as employees to coordinate project activities. However, employee attention was often diverted from the substance abuse project to manage other PUSH initiatives. In addition, disabled staff found that they were in high demand for work in other disability organizations, and especially in Ontario government disability offices. Staff turnover was rapid and caused disorganization within PUSH in its attempts to create regional interest groups and action around addiction issues. Thus, increased funding, loose project management, and personal employment opportunities led to work overload for staff and an inability to recruit adequately from the local regions. Finally, a PUSH director cautioned that those in leadership and staff positions were at risk of being co-opted:

> ...some disabled persons get hired to quiet them. If you have somebody who is very intelligent and vocal and knows the issues, they want them out of there real fast, and they get offered big money. The province of Ontario offered me $300 a day to work for them but once you work for them you can't speak against their programs anymore. (PUSH-1)

It was not clear whether any of the PUSH staff working on the drug and alcohol project were actually co-opted by offers of government employment, however, the leadership gap was clear.

Gendered Roles in Project Activities

Although there were equal numbers of men and women employed as staff in the project, a PUSH director reported that women tended to promote the self help and educational components of the project, while men tended to be involved in political advocacy activities. These differences may have reflected the priority which women and men gave to practical and political issues related to substance abuse. However, they also reflect the limitation on women to assume prestigious roles in this male dominated advocacy organization. Again, a finding of gendered roles is common among disability consumer organizations (Stone 1988, Driedger 1989).

Regional Volunteer Structure

Volunteers from the seven regions of PUSH Ontario were instrumental in providing local coordination of the project. Approximately eight persons in each region organized meetings, pilot tested survey questionnaires, and conducted small 'kitchen group' discussions in peoples' homes. Although records of these meetings were not kept, reportedly for reasons of confidentiality, staff noted that 'numerous' persons with disabilities participated in these information sessions and meetings. A volunteer reported that these activities were not only a form of self help but were also a method of project organization:

> The peer counselling is very important there. Where we really got to people was in the small kitchen groups where one disabled person who had been told all the facts and was eloquent in discussing and drawing information from people would go to a house and talk to four or five more. Those kinds of groups benefited and were more successful in gathering information. (PUSH-1)

Thus, ironically, the stigma related to the issue of drug and alcohol use stimulated the formation of a group of regional volunteers.

Progression to Advocacy Objectives

After two years, the PUSH board of directors advanced the project focus from research and health education to advocacy and service planning. A provincial commission had recently investigated the drug treatment system in Ontario. When asked to comment on the Martin Report (Government of Ontario 1990), PUSH noted that there was no mention of persons with disabilities or their particular needs. PUSH directors and staff then organized a provincial coalition of disability groups, addiction workers, and mental health professionals to propose changes to the addiction treatment system. PUSH also organized provincial conferences on the topic and invited ARF and Ministry of Health officials. Finally, PUSH directors proposed that persons with disabilities be included on Addiction Services Planning Committees which were to be formed by District Health Councils in the province. Eventually this recommendation was implemented after the project term was completed. PUSH's shift toward systemic advocacy parallelled the experience of addiction programs in other jurisdictions (Cherry 1993).

Eventually, PUSH staff entered into service planning discussions with ARF managers to revise treatment facilities and services which would integrate the needs of persons with disabilities, rather than provide separate addiction services for them. During this phase of the project, certain ARF staff and a few PUSH directors and staff members continued to work together. ARF staff provided technical support for communication links, speakers for joint meetings, and assistance in coordinating regional activities. ARF professionals also provided addiction service training for new PUSH project staff, resource materials, and publicity. Thus, ARF staff appeared to indirectly support the political advocacy work of PUSH.

There were mixed opinions about actual changes in the availability and suitability of addiction services for persons with disabilities. A PUSH director noted that some access problems were resolved:

> The major success there was in the native reserve at Moose River in northern Ontario which was made totally accessible at the detox centre...It would never have happened without the project. (PUSH-6)

However, apart from a few isolated instances, there were no systematic changes in access to treatment [DOC-11A]. As well, in some activities, there were accessibility barriers to the participation of disabled persons. For example, PUSH did not attend a federal-provincial consultation session on substance abuse problems as it was held in an inaccessible location [DOC-09].

PUSH directors considered this second phase of the project as both advocacy and 'community development', wherein the community of disability organizations under the PUSH banner was gaining influence and status in the social service environment. However, only a few PUSH staff and directors were involved in these activities.

The HPD program officer observed that awareness of the drugs and alcohol issue did not reach as wide a public audience as had been anticipated by HPD:

> I'm not sure this one has been a success for us. I think it has been a success for PUSH and their indirect goal...I think with many honest intentions they did try to access people but I don't know how successful they were. They were very good at accessing professionals which is kind of the focus of the organization in terms of their political mandate, and in dealing with ARF, and in dealing with the provincial government...I'm not so sure for disabled people themselves. (PUSH-4)

Thus, from this bureaucrat's perspective, PUSH's organizational objectives received priority over the addiction project objectives. Overall, the shift of project objectives from health education and research to advocacy and organizational development created more activities for staff and directors but required fewer participants from the PUSH regional groups.

4.3.7 Influence of Participants

Contrary to statements in project documents, PUSH staff members and directors stated that the principal mechanism for changes in addiction services was not through project roles and activities, but through PUSH's mandate as a consumer advocacy organization:

> There were a number of things like the advisory committee, but it's more the organization itself ... that's really been the principal influence...So not a lot of direct involvement but a whole lot of indirect influence. (PUSH-5)

This view suggested that the formal roles of individuals and committees in PUSH were not primary mechanisms for change as much as factors such as organizational reputations and mandate, and political alliances in countering professional dominance.

Advocacy Mandate

PUSH respondents reported that their organization had initiated the issue of addiction in disabled persons in Ontario. In contrast, ARF researchers reported that around the same time, they had also become interested in substance abuse in special groups such as women and persons with disabilities and intended to access provincial funding for research into these issues. However, when PUSH directors approached ARF for research assistance, PUSH claimed 'ownership' of the issue and demanded that PUSH be the lead partner in any studies or projects. Amazingly, ARF agreed that PUSH would be in charge of any mutual activities [DOC-01]. The ARF professional respondent perceived that ARF shared control of the project and took the leadership role as technical experts, once PUSH had sanctioned the issue to be addressed. According to the HPD program officer, PUSH was:

> pretty vocal and they didn't let ARF take control... instead of it becoming a disability issue for ARF, they were very much in partnership. (PUSH-4)

This appeared to be a considerable concession on the part of ARF, but it seemed to have its payoffs as well. The drug and alcohol abuse project facilitated the development of new knowledge about addiction and medication issues through the research components of the project. ARF professionals circulated publications based on these studies to 32 ARF offices and to many disability organizations throughout the province. Thus, ARF itself appeared to benefit from the initiation of a new focus area in the addictions field.

Overall, PUSH achieved acknowledgement by ARF and the provincial government that persons with disabilities were an important group to include in their programs, and that PUSH was a legitimate body for consumer representation. PUSH staff considered that they were now being listened to:

> We've definitely turned the heads of some bureaucrats and disability is now recognized as an equity group within the addictions field, whereas before that was not the case - the proof being the Martin Report which made no mention whatsoever of disability as recently as 1990. In government announcements now, disabilities are recognized as a group in need. (PUSH-5)

This influence was further demonstrated in the willingness of ARF to do extensive research in the area, and also in the appointment of the PUSH project coordinator to the ARF board of directors.

Professional Dominance

On a more subtle level, there were frequent conflicts between PUSH members and ARF professionals over the specific direction of the project. For example, PUSH members noted that issues of medication-alcohol interaction for people with physical disabilities were similar for people with psychiatric disorders. They asked ARF professionals to help organize a joint meeting of disability and psychiatric consumer groups to discuss the issue. However, according to PUSH staff:

> ARF wanted to keep physical disabilities separate from psychiatric because it's trendy in the drug-alcohol field to talk about dual disorders, or the coexistence of a substance abuse problem and a psychological problem...By bringing people with disabilities into it they think it messes it up. (PUSH-5)

The dominance of professional interests appeared to be in play. A staff member observed that some ARF researchers were patronizing in their resistance to the ideas of PUSH members:

> When you mentioned that you wanted these issues put in the research there was icy silence. Nobody actually said, 'We're throwing you out of the office' and it was tremendously polite. Disabled people don't encounter the same attitude, they're still polite to you, but nevertheless it's like you're asking for the moon and stars. (PUSH-2)

Thus, passive resistance, rather than open conflict, was used by some ARF researchers to manage the pace and direction of the project.

PUSH members were ultimately able to negotiate a significant role in the partnership due to the support of key ARF professionals. The board chairperson noted that:

> We were very fortunate that Dr. R. was sensitive - she was very keen to see that the needs of disabled people were attended to. (PUSH-1)

In sum, persons with disabilities seemed to maintain an equitable degree of influence and control in the project in partnership with a powerful professional service and research agency. This appeared to be due to a combination of key alliances with individual supportive ARF researchers, PUSH's current political profile, and its position that it would compromise on issues of technique and project design, but not on principles of 'consumer control'. PUSH's fundamental mandate as a political advocacy organization appeared to underlie many of these factors and allowed it to maintain influence in the addiction project. Its ability to do this was perhaps linked to the powerful emotive lever of disability which could be used to gain the cooperation of the HPD and ARF players in this project.

Numbers of Participants

A lack of adequate project monitoring systems hampered an accurate numerical recording of participants with disabilities in this case. From project documents, one can deduce that active participation involved 3-5 board members and 3 disabled staff members, approximately 50 local volunteers, and an unknown number of local consumers. In addition, approximately 50 per cent of a provincial 'Think Tank' (n=75) and regional focus groups (n=98) were consumers although this was less than PUSH's recommended (80 per cent) guideline [DOC-03]. Neither the external evaluator [DOC-11A] nor PUSH respondents could estimate the number of other persons with disabilities who were reached indirectly by media coverage or through the distribution of 50,000 brochures across the province. No records of member involvement in the project were kept and HPD did not appear to require them. This appeared to be a convenient omission since PUSH kept detailed records of the number of professional participants in the project. Failure to keep records of consumer participants may have served PUSH's public promotion of itself as representing a large number of Ontarians, when in fact, few were actively involved.

Post-Script

Although the following events occurred outside the study timeframe (1987-1991), they are crucial for interpreting the process of participation in the project. The provincial and federal governments increasingly recognized PUSH as the official representative of disabled persons' organizations in Ontario. PUSH received a variety of new project grants and their goal of organizational growth was met beyond their expectations, at least temporarily.

According to reports from board members, the PUSH organization began to undergo internal difficulties in 1994. Staff members, including a strong-willed executive director, began to take independent control of PUSH activities. Board members reported that they were excluded from decision-making on the pretence that contacting regional directors was too time consuming. In effect, there was a serious lack of communication between the regions, board, and executive director. At the same time, there were financial shortfalls when new project funding was delayed and existing funds were used to pay salaries and rent, with none left for project implementation.

The executive director was fired eventually by the board and then initiated a wrongful dismissal suit against PUSH. Three other staff members complained about their working conditions and initiated lawsuits also. At this point the board disintegrated and PUSH (Ontario) became inactive.

4.3.8 Case Discussion

Community participation was used by PUSH organizers for 'organizational' and 'empowerment' purposes, as both a means and an end. Ultimately, however, empowerment of the organization, rather than individual community members, was the goal. As a result, grassroots links were not developed sufficiently to ensure the survival of the organization in crisis.

The PUSH project operated within an emerging social, cultural, and political environment which encouraged new models of partnership of disabled persons with professionals and non-disabled persons (Shakespeare 1993). Consumer participation was primarily by a privileged group of physically disabled persons who were not really representative of a diverse and stigmatized target population. PUSH board members played key roles in the project which extended beyond their formal board responsibilities. Their status as board members appeared to facilitate collaboration with their powerful

ARF partner, however, their lack of attention to organizational responsibilities created problems in widening participation in the project to a larger number of consumers.

In developing community participation in this project, the PUSH board attempted simultaneously to protect a reluctant, stigmatized membership and to develop an equitable partnership with a powerful health and social service agency. That they were able to achieve this with even a small degree of success may have been due to their organization's position on the political agenda, which was achieved by a combination of rights and emotive levers. The influence and control of the board members in some project objectives was significant, especially given the status of their professional partner. However, the influence of grassroots members was minimal.

Overall, there was a narrow range of community participants as well. PUSH's organizational values of consumer control and community participation, which had evolved from the history of the disability movement, appeared to be overwhelmed by its needs for specific resources and technical expertise in this project. Furthermore, a wide active participation may have reduced the likelihood that ARF professionals would be closely involved.

The technical role of ARF professionals in the project was instrumental in providing objective information for supporting changes in policy. In turn, participation of sympathetic professionals and bureaucrats assisted with the development of PUSH's own organizational and resource mobilization strategies. Thus, PUSH's advocacy focus led it into alliances with professional and service groups rather than with grassroots self-help groups. The dilemma for PUSH was that focusing on wider participation may not have contributed to the principal issue which the project was intended to address - stimulating a change in the organization of addiction treatment services.

PUSH accepted the need for a strategic alliance with ARF to achieve its goals of public and professional awareness of the need for improved addiction treatment services. This relationship was very important in the legitimation of the PUSH agenda for improvement of addiction services in the province. ARF provided needed political support to PUSH since its scientifically-generated knowledge had credibility with funders. The use of professional partnerships to legitimize marginalized groups has been noted before in health promotion (Stacey 1988). This case also illustrated the potential for disadvantaged groups to utilize their own diminished status as an emotional rationale for gaining rights. These strategies appeared to be crucial in gaining an acceptance of disability as an important issue to funders and policy makers.

There were various claims of structural 'form' in the PUSH organization (wide membership, regional representation, guidelines for consumer control, available resources, community linkages) which indicated a potential for strong participation by disabled persons. However, the actual substance of community participation was symbolic and short-term for most members of PUSH. Factors such as leadership issues, and organizational management problems had much greater influence on actual community participation. More rigorous internal and external evaluation of the project may have improved achievement of its participation goals.

If HPD's real objective was to increase the organizational capacity of PUSH, then beyond a relatively brief phase of increased funding, projects, and attention, the project was a failure. HPD did not monitor or ensure that capacity building actually occurred in the organization. One of the problems with 'indirect' core funding may be that by not acknowledging capacity building to be a major objective, few specific plans are put into place for board development, staff selection and training, and membership recruitment.

4.4 CASE: ETHNIC YOUTH MENTAL HEALTH PROJECT SPONSOR: INTERCOMMUNITY HEALTH CENTRE

4.4.1 Introduction

The InterCultural HealthShare program of the London InterCommunity Health Centre (ICHC) conducted a project from 1988 to 1991 to address psychosocial adaptation needs of ethnic adolescents. A pilot study had indicated that intergenerational stress and acculturation difficulties were major problems of youths in ethnic communities. Project activities for youth focused on the development of self-expressive and coping strategies through the medium of art therapy. A 'Juggling Cultures' workshop, and videotapes which illustrated these therapy techniques were developed and presented throughout the community to a variety of ethnic groups and service agencies. This case was selected for review on the basis that project documents indicated that ethnic youths had participated primarily as clients in beneficiary roles.

Data sources for this case included seven direct interviews, excerpts of other interviews with 15 youths and four parents, 20 project documents (proposals and reports), and three videotapes and manuals created for the project workshop. Direct interviews were conducted with the HPD program officer, ICHC executive director and project coordinator, two ethnic youths (one male and one female), one parent, and a professional who was involved in the project.

4.4.2 Structural Characteristics of the ICHC Organization

History and Program Mandate

Early Canadian immigration was primarily from western European countries. In

1960's and 1970's, Canadian immigration regulations were expanded to include more non-European immigrants (Tepper 1994). The ICHC director noted the effect of these trends on the need for immigration services:

> Nobody thinks of the reality of the populations ...the immigration rules have changed and I have no problem with that. It's now third world and humanitarian aid, but that's different from the kind of immigration which came in 20 years ago which was white Anglo-Saxon. Unless you put in the resources for people who are culturally, religiously and linguistically so different, you're going to have an awful lot of trouble. (ICHC 2)

In addition, during the late 1980's, the demise of communist governments in eastern Europe resulted in increased numbers of well educated refugee applicants. Even though Canadian immigration policy was designed to select candidates from this area with the best chances of economic integration into Canada, there were not always suitable jobs available (Beiser 1988). Again, the ICHC director noted the effect on the mental health of immigrants in this situation:

> Because of the point system and its requirements we see people who are highly educated, especially from eastern Europe, and the level of frustration and unhappiness and mental problems is very, very high. (ICHC 2)

During this period, a variety of social services were developed for the absorption of immigrants with different languages and cultural values into Canada (Duffy 1993). In the London area, many services were supplied initially by voluntary organizations of individual ethnic groups. Gradually, ethnicity workers realized that assimilation into the Canadian culture was less successful if new immigrants were cloistered into groups. Some ethnic organizations began to create combined activities which would expose new Canadians to the similarities in experiences of immigrants, rather than accentuating cultural differences which could inhibit their integration.

The New Portuguese Centre was among the organizations which had taken this approach since 1977, under the leadership of two experienced community workers. This centre was initially successful in obtaining HPCP funding (1984-1987) for a project related to the needs of immigrant seniors in London. Since a major finding of that project was that seniors were concerned about their relationships with adolescent grandchildren, the community workers then developed and received HPCP funding for a new project to address the needs of youths.

When provincial base funding became available for a new InterCommunity Health Centre for ethnic low income families, the HPCP project funding was transferred to InterCultural Health Share, a program within the health centre which operated limited term projects such as literacy, English as a Second Language (ESL), and women's support groups. The health centre was perceived by HPD staff to be a more suitable location for the ethnic youth project not only because of the centre's focus on immigrants' mental health issues and its multicultural representation, but also because of the presence of the two community workers who had obtained management positions there.

ICHC as an organization was a relative newcomer to the multicultural area. However, the individuals working for ICHC had a history of involvement in ethnic issues and a reputation in HPD for sensitivity and tact. For example, the HPD program officer noted that the ICHC staff demonstrated a deep concern for community members:

> That was a real strength they had...just really caring for the people and not letting other bureaucracy or any other rules get in their way of getting to what really needs to be done...'OK, here's the problem. How are we going to get around it to get where we need to be to meet the needs of the kids?' (ICHC 4)

Finally, the HPD program officer for youth issues observed that the physical setting of the community health centre provided a common neutral meeting area for different ethnic groups:

> ...there was a space for a group of young people to come together from the different ethno-cultural backgrounds, rather than the Portuguese youth group at the church and the Vietnamese youth group somewhere else. It provided an opportunity for the intermingling of cultures rather than everybody going off in their own separate youth groups. (ICHC-4)

The location of the youth project in a multicultural health centre was convenient and may have provided a cohesive force. However, it will be shown that this setting reinforced the therapeutic approach taken with the target group in the project.

Finally, ICHC staff realized that political priorities regarding multiculturalism were changing. In contrast to previous years under the Ontario Liberal government, the 1990 priorities of the New Democrat Ministry of Health did not include multicultural issues (Gamlin 1994). Ministry references to ethnicity now included the concept of anti-racism, along with multiculturalism. The ICHC director complained that politicians viewed multicultural issues to be 'in the mainstream' and therefore seemingly of less importance.

Target Group and Issue

Although the general needs of new immigrants were not perceived by ICHC to be on the political agenda, issues related to the health of a particular subgroup, such as ethnic adolescents, did receive attention from funders. Project organizers defined ethnic adolescents as "those persons, aged between 12 and 21, who come from families where English is not the first language, and in which traditional values are strong". [DOC-01] They particularly emphasized the need to include older youths with refugee status who had no family support systems in Canada.

ICHC considered that its youth clientele came from over 20 ethnic groups which were involved in the health centre [DOC-01-10]. A great deal of effort was reportedly spent by ICHC staff in developing consensus **within** these communities, although little effort or progress appeared to be made in gaining cooperation **across** the groups. The ICHC executive director noted that many ethnic groups had their own community centres for activities, and differences in language and customs kept groups apart:

> If we were working with the Portuguese community we would have meetings with them, but we didn't bother bringing the Arabic people there because they would have nothing to do with that. (ICHC 2)

Youth respondents themselves were also doubtful of the prospects for consensus with other groups. However, one girl noted that understanding between groups could be improved:

> Different people react differently. Portuguese people are brought up differently from Polish people. They have different opinions and values and cultures and customs. So we could talk about all these things. Like abortion where some people think it's OK and others think that it's a sin, and we could talk about it. (ICHC 1)

The HPD project officer also remarked that there were differences between ethnic groups which affected inter-group participation:

> The ethnic aspect changed how they organized...often what happens is that different ethnic organizations get set up to serve their own communities...some want to cooperate more than others and it takes some time to look at what are the values of cooperation and how can we be stronger together. (ICHC 4)

Overall, study respondents believed that new immigrants faced significant social-cultural barriers in working together closely.

The position of youths in ethnic families appeared to be a controversial issue. On one hand, interview excerpts from ethnic parents indicated that their primary concerns were for the youths' well-being. Parents noted that the difficulties experienced by youths were principally due to a conflict between Canadian cultural values and established ethnic family values. On the other hand, the ICHC project coordinator observed that, in some ethnic families, the youths were not the first priority:

> In actuality, the young people do not come first on the list, but are 'dead last'. Their views and opinions are discounted. They are never allowed an opportunity within the family to express themselves. They are forced to leave school at sixteen, put to work in low level job situations and then expected to turn over full wages to their parents. This then lays the foundation for family discord and strife as these young people see their mainstream peers pushing on with school, spending money, free to express themselves and able to come and go with their friends. (ICHC 3)

While this characterization may be an over-generalization, both perspectives acknowledged that internal family conflicts were the prime cause of youths' problems. Staff believed that helping youths to understand and cope with conflict, without also addressing parental attitudes, was fruitless and only accentuated tension in the home. Thus, ICHC also began programs for parents, not only to alleviate fears about the purpose and content of the youth project, but to educate parents about potential stressful situations in their homes.

In addition to perceived differences in family dynamics, there were also varied socio-political interests. ICHC staff reported pressure from some ethnic groups to include anti-racism programs in the health centre. The ICHC director discounted the importance of the issue of racism in the community, although staff and youth reported that overt attacks on ethnic minorities had occurred in the area. The executive director stated that a political interpretation of ethnic problems was counter-productive to the health centre's programs:

> I have a real fear that as the politicians, through the pressure of Toronto [ethnic groups], get into this anti-racism business all of the good work we've

> done such as the Juggling Cultures program is going to suffer...A lot of people are feeling alienated. They don't relate to the anti-racism strategy. They might relate to discrimination and prejudice but even so it's not so much that, it's the whole question of access. This whole political thrust is disturbing things. (ICHC 2)

In sum, there were not only differences between health centre staff and some families on the source of youth mental health problems, but also differences on political issues.

ICHC Program Linkages

ICHC staff noted that there was a cooperative atmosphere among health and social service agencies in the local area. Health centre personnel worked closely with ethnic community groups to pool resources and create combined programs. For example, a neighbourhood team of agencies including ICHC jointly planned programs for low income, alcoholic, and ex-psychiatric clients in the inner city area.

The ICHC group also formed alliances with other city groups concerned with health and ethnicity, such as hospitals, school boards, mental health centres and physicians, the university, adult education facilities, public health units, and the District Health Council [DOC 03-06]. The purpose of these alliances appeared to be to share information and resources as well as to gain political support for project initiatives.

Finally, the project organizers formed an informal 'partnership' with the London Multicultural Youth Association (LMYA) over a six month period early in the ethnic youth project. As will be shown, this youth association had potential for meaningful participation in the project which was never fully realized.

Resource Mobilization

As a service organization, the InterCommunity Health Centre did not have as many difficulties in mobilizing funding as did the PUSH or ICYP groups. The health centre clearly offered services and programs which fitted the requirements of both provincial and federal funders. In addition to its base funding from the Ontario Ministry of Health, the health centre was funded by seven other ministries with differing priorities, reporting, and payment periods.

ICHC received $275,720 from HPD over 38 months for the ethnic youth project. ICHC had funding for staff salaries and expenses to conduct workshops with youths but, similar to ICYP, also required and received extra funds from the Ontario Ministry of Citizenship and Culture to develop educational videotapes and manuals. Additional funds, again from other sources, were obtained to provide honoraria for youth volunteers and teachers who assisted with school-based workshop sessions. Office resources were shared initially with agencies such as the Multicultural Youth Association.

As with other voluntary organizations in this study, ICHC resource mobilization may have been affected by the general economic climate. The ICHC executive director noted that the economic recession had an impact on the ability of the health centre to create new programs in multicultural health:

> Two years ago we were looking at real growth. That has gone. It's much tighter and we won't be able to expand from two people four years ago to 27 now. That's the speed at which we were growing. It's not going to happen anymore to that extent and we're not going to be able to take on as many new initiatives. (ICHC 2)

Although ICHC had been successful in obtaining funding for its health projects, staff observed that little funding was currently available for general immigration needs in the community. The executive director perceived that governments attempted to cut back immigration and multicultural programs during the recession by designating ethnic issues as 'mainstream' and not requiring additional resources. She rejected this rationale for cutbacks:

> So it's not mainstream by any means because no resources are going into it...There isn't any provision here for translation. The language programs are being cut down. There are no re-training opportunities. (ICHC 2)

General financial restraint was not the only limiting factor to the growth of ICHC programs. As noted earlier, the 'political agenda' regarding multicultural issues was also changing. Consequently, ICHC staff incorporated objectives which would address racism in their funding proposals, even when they felt this was not the major issue affecting ethnic groups in their geographic area:

> I know that if I write a proposal I have to throw the word 'anti-racism' in. It annoys me because that's not my thrust and it isn't the thrust of any of this city so much as it is in Toronto. We're getting swamped by the priorities over there. (ICHC 2)

In sum, ICHC was able to obtain resources easily for its multicultural and immigration programs during the late 1980's. By 1990, the economic recession and a change in political agenda appeared to affect its ability to expand or maintain its programs without shifting its focus to other issues which were then in vogue.

4.4.3 Characteristics of the Ethnic Youth Project

Project Objectives

ICHC staff identified that health issues of all types - physical, social and emotional - were important to the ethnic communities. The HPCP project objectives were:

1. To explore cultural values and norms affecting both adolescents in stress and parents of families in conflict;

2. To maintain a health support network of health oriented and social service workers to assist in material development;
3. To develop an increased ability on the part of both the adolescent and the parent to adapt and utilize their native problem solving techniques and skills;
4. To identify and train ethnic peer counsellors to facilitate group or individual sessions; and,
5. To design two handbooks for use by peer counsellors of parent groups and youth groups. [DOC 01]

The health promotion project was intended to focus on improving self esteem, inter-ethnic acceptance, and family relationships through group social activities and discussion. Thus, the project was to include health education, self help, and mutual aid components of health promotion.

Although ICHC staff acknowledged that mental health problems of ethnic youth were associated with societal attitudes, cultural differences, and economic disparities, the ICHC approach focused principally on an interactional, family systems perspective (Back 1981, Kurian 1986). For example, the project identified five principal psychosocial issues - depression, alienation, family break-up, dislocation, and sibling conflict - which were consistent with an individualistic approach to mental health problems [DOC-08]. By exposing youths and families to the commonalities of different cultures and to the similarities of their experiences in adapting to Canadian culture, staff expected that youths could learn to cope with their difficulties and improve relationships with their families. Little emphasis was placed on addressing social structural determinants of stress in youths in the project, such as poverty, and this made it unique among the cases in this study.

The ICHC staff insisted that their focus on group dynamics and their interest in psychosocial issues in mental health was a different approach than that taken by medical professionals. Nonetheless, the concepts reflected in the phrases that were commonly used by staff, such as 'presenting problems', 'multi-problem youth', and 'art therapy' appeared to represent a model of psycho-behavioural interventions for personal problems using a therapeutic group milieu [DOC-01]. This approach may also have been more acceptable to conservative ethnic groups which had respect for professional programs.

Interestingly, the original proposal did not focus specifically on art therapy as a technique, nor on the production of educational videotapes. However, the ICHC project organizers did propose that there would be extensive participation of the youth target group

> ...youth from all these communities will be included in all stages of the project and integrally involved in all aspects of the project including planning and implementation...[DOC-01]

The organizational structure of the project however, did not reflect these participatory ideals.

Organizational Structure

1. After being transferred from the New Portuguese Centre in its second year, the project was managed by the London InterCommunity Health Centre's **board of directors**. This board included academics, medical personnel, and ethnic community leaders. In 1991, eight of the eleven board members were professionals of Anglo-Saxon background who worked for local institutions such as the university, community college, hospitals, and health unit. The three ethnic community members of the board were not recent immigrants to Canada. Directors were nominated by an internal board process, although

they were elected at the centre's annual business meeting. The board did not appear to have major involvement in the project and was kept informed of activities by the health centre **executive director** who had initiated the project and was responsible for funding applications.

2. The InterCultural Health Share **program director**, who had also initiated the project, participated in program development and liaisons with community groups until she resigned in the final year of the project. A **staff project coordinator** was responsible for coordinating day-to-day activities of the project, meeting with community groups, recruiting youths, and conducting group art therapy sessions.

3. Separate **informal advisory groups** were established in each of six ethnic communities which had been identified by the health centre staff. These advisory groups of six to eight ethnic persons included clergy, community centre directors, professional service providers, teachers, parents, and youths and were selected by ethnic community leaders and ICHC staff.

4. A **formal advisory committee** selected by ICHC staff was composed of six representatives from the informal advisory groups, some of whom were parents of youths. There were also seven professional service providers and a provincial government bureaucrat on the committee, but no youths. There were no written terms of reference for this committee. The roles of these participants will be discussed in more detail later.

Background and Roles of Other Participants

Professionals - ICHC had a mandate to deliver health and social services to the ethnic community and it was not surprising that there were a variety of professionals involved in the project. Initially, professionals associated with the health centre's clinical operations gave advice to staff about the needs of ethnic youths and the treatment of mental health problems. Professionals were also utilized as consultants by ICHC staff for youths who were subject to abuse or who had more serious psychiatric problems. Some of these professionals had ethnic origins and were invited to participate on the advisory committees since their work positions brought them into contact with ethnic youths and community leaders. Professional service providers were reported by staff to be interested particularly in the development of educational materials which they could use in their own settings.

Bureaucrats - The HPD program officer for the ICHC youth project had been involved with the immigrant senior's project which had been developed previously by the New Portuguese Centre. However, her involvement in the ICHC youth project was limited to routine review and monitoring activities. See Table 4.

Table 4. Participants in Ethnic Youth Project of ICHC

PARTICIPANTS	
DIRECT	INDIRECT
ICHC Executive Director *	HPD Program Officer *
ICHC Program Director	Other Funders
Informal Advisory Groups (6) - ethnic leaders/parents* - professionals - youths	Formal Advisory Committee - ethnic leaders/parents - professionals - bureaucrats
ICHC Project Coordinator *	Parents/Family Members
Professional Art Therapist *	University Researcher
Volunteer Youths *	Other Professionals
Ethnic Youth Clients *	Video Technicians

* = participant interviewed in this case study.

Project Administration and Leadership

A number of persons played key leadership roles in the ICHC project. The executive director of the health centre supervised the overall project with the program director and they initially played the lead roles. They were well known in the local community and had strong ties to various ethnic, service providers, and university groups. The HPD program officer reported that ICHC staff utilized their personal political connections to mobilize support from influential groups outside the community:

> S. is on the board of Senate at Western...so she could start making inroads from quite a high level in terms of the kinds of need for involvement from the university which has been traditionally isolated from the community. (ICHC 4)

These connections with professional groups were important for the development of research support which documented the need for the centre's programs.

Leadership shifted when the staff project coordinator was hired and assumed major responsibilities for conducting and promoting the project. The new project coordinator was also a member of the ethnic community and had credentials in four languages and art media. The ICHC executive director observed that she was instrumental in providing a therapeutic focus and skills in the project:

> We did all this social stuff and then we were fortunate to hire W. who had a specific skill. She came in just as an artist and at that point was not thinking art therapy at all. She just ran another recreational program we were trying out. Somehow we picked wonderfully. Whether you are male or female, across groups, art is something that is a non-threatening kind of medium...The art seemed to work. (ICHC 2)

During the second year of the project, leadership became more dependent on professional involvement. The project coordinator enroled in a university diploma program in art therapy to further develop her counselling skills. During the course of the project, the coordinator developed and tested new therapy techniques with ethnic youths and reported on these in her art therapy training program. She was also able to use her job experience as credit for practicum requirements and to substitute articles she had written about the ICHC project for course papers. This led to the involvement of a university professor, a certified art therapist, who closely supervised the project coordinator regarding the development and application of the art therapy approach during eight of the youth workshop sessions [DOC-08].

Finally, ethnic community leaders on advisory committees, primarily clergy, played minor leadership roles by approving the project's activities and actively encouraging ethnic parents to allow their children to participate.

Project monitoring and reporting occurred through quarterly reports to HPD by the project coordinator and program director. There was no external review of the project and evaluation was limited to informal assessments by staff of the suitability of workshops and training materials [DOC-16]. This lack of rigorous formal evaluation did not appear to detract from ICHC's ability to obtain a provincial grant to expand the project in 1991.

Summary of ICHC Structural Characteristics

A combination of increased immigration and multicultural policies led to the establishment of immigration services, including mental health counselling, in this community. The ICHC emerged as a specialized service agency for ethnic groups and developed a positive reputation for its work. The HPCP project focus was on ethnic youths who experienced conflicts between their traditional family values and the dominant Canadian adolescent culture and was oriented toward individual and family behavioral change. This therapeutically based counseling approach to youth's problems appeared to derive from the project's setting in a community health facility managed by health professionals who served a diverse, conservative ethnic population. ICHC resource mobilization strategies, which had previously been successful in the multicultural field, were reluctantly adjusted to include an anti-racism focus.

Organizational mechanisms for project management involved major stakeholders in the ethnic and professional communities, but did not facilitate their meeting together to discuss the project or community needs. Ethnic representation in ICHC management was primarily by community leaders, bypassing the target group and their parents. Organizers rationalized this approach by claiming that ethnic parent groups would not work together and had little time for active involvement in the project. However, due to the isolation of the board and advisory committees from each other, this approach ultimately left direction of the project in the hands of ICHC staff and failed to involve the youth target group in any project positions carrying responsibility.

The following descriptions will show how key structural factors in the ICHC organization and project were associated with the process of community participation.

4.4.4 Types of Participants

The ethnic youths who participated intensively in the ICHC project had diverse backgrounds. Although participant records were not available for confidentiality reasons, ICHC staff reported that of 24 actively involved youths, only four had been born in Canada while the rest were recent immigrants. The latter's length of residence in Canada varied from three months to five years. Most youths were in their middle or late adolescence (16-21 years) although there were a few as young as twelve years. Youths' educational and literacy levels varied, with some enroled in university and others who were in basic ESL high school programs. Socioeconomic status also varied considerably depending on the length of time that youths had been in Canada and on their backgrounds (Sawicki 1991).

Although there were no reports of differences in youth participation based on these characteristics, other structural factors appeared to influence the types of participants.

Sponsor History

ICHC organizers claimed that they chose groups to participate in the ethnic youth project "for their various traits, current level of identifiable demonstrated needs, length of time in Canada, and demographic characteristics" as determined through discussions with key informants [DOC-01]. However, the previous experience of ICHC staff with five ethnic groups (Portuguese, Vietnamese, Chinese, Hispanic, Greek) in the immigrant seniors project appeared to be more influential in their selection, as these were the principal groups chosen. Later, Polish and Arabic groups were invited to join since new project staff were conversant in their languages. Overall, staff familiarity and working relationships appeared to determine which groups were included.

There did not appear to be an attempt to include all twenty ethnic groups which utilized the health centre. For example, ICHC staff did not include ethnic groups with which they did not have strong ties, such as Africans, Caribbeans, and Indians. The HPD officer claimed that the lack of black groups in the project was purely due to demographics:

> People who watched the video comment that there aren't a lot of blacks in the group. Toronto groups particularly would say, 'Where are the Jamaicans?' Well, there aren't that many Jamaicans in London, but there are Africans. That makes it a different kind of group than if you had a Toronto based group. (ICHC 4)

However, the organizers' negative views on the need for anti-racism programs in the community could also explain the relative absence of some ethnic groups in the project.

It is important to note that, although there were seven major ethnic parent groups involved in the organization of the project, individual youths from other cultures also attended workshop sessions.

Gender Discrimination

ICHC staff reported that some young women were prevented from attendance due to parental concerns about the 'safeness' of the mixed gender programs. However, an older brother also explained that young ethnic girls had more family responsibilities which limited their involvement:

> I think women play a great role in our country, that is to take care of the house. So I was surprised when I came to Canada and I saw all these girls hanging around downtown...but then you wonder if their parents are getting help from their daughters. So when we came here, we make sure that my little sister doesn't change like that. We just make sure that she doesn't go out. (ICHC-A)

ICHC responded to these restrictions by conducting a separate young women's support group and by providing chaperones for mixed social events. Eventually, half of the most active youths were female, including some from conservative ethnic groups [DOC-07].

4.4.5 Sponsor Strategies for Participation

The following section describes how factors such as perceived ethnic differences and program linkages affected ICHC's recruitment strategies for ethnic youths and parent groups.

Ethnic Diversity

ICHC organizers tailored their recruitment approach to each ethnic group. The project coordinator reported that local leaders were approached individually and invited to publicize the project:

> For the Portuguese we announced it through the church because the endorsement of the priest was vital to participation...We went to the Arabic mosque and asked the leaders there...we went to the Chinese community centre and to a couple of physicians who were seen as leaders of the community and asked for their support. (ICHC 2)

Separate meetings were then held with the different ethnic groups to allow parents to express their concerns about their children's involvement without having to cope with a variety of cultural styles and expressions [DOC-04]. However, while this strategy may have facilitated the initial entry of a number of ethnic groups, it also prevented groups from having significant interaction except with each other at infrequent formal advisory committee meetings or social events.

In defense of their strategy, the staff acknowledged that the cloistered, hierarchical structure of the project did not really resemble the community participation philosophy of the Health Promotion Directorate. ICHC staff complained that they were frustrated with suggestions from bureaucrats for the use of egalitarian organizational strategies for community participation, such as coalitions, since these did not consider individual ethnic community differences:

> ...they don't understand the difficulties of working with special populations and that each one has to be innovatively developed...if you start from a standard model, you get nowhere. So they will tell you to have community participation, but you have to go back and say 'This model doesn't work'. (ICHC 2)

Thus, ICHC used its past experiences with ethnic groups as a rationale for organizing participation on its own terms. However, this approach is in stark contrast to methods used by other ethnicity workers involved in anti-racism coalition work in Ontario (Hernandez 1988). An alternate explanation for the ICHC approach may lie in the project's professional orientation and reluctance to yield control to community groups.

Limited Partnership with Youth Organization

At first, ICHC used a cooperative arrangement with the London Multicultural Youth Association (LMYA) to attract youths to the workshops. ICHC staff claimed that they were particularly interested in attracting 'model youths' who had time and interest for involvement, first hand knowledge of youth frustrations, and an interest in furthering their own leadership as peer counsellors. The ICHC coordinator noted that LMYA organizers:

> ... didn't have anyone to deal directly with programming. They had a lot of people coming in for specific things or to ask questions but no one to do programming. So it was like a symbiotic relationship. I could supply the programming, they could supply the target group. (ICHC 3)

This 'partnership' resulted in increased participation from youth association members. However, the LMYA role was not further developed and it never became a full partner in the project, even though its adult director was appointed to the ICHC project advisory committee. The incentive for partnership with the youth organization appeared to dissolve once the project moved to the ICHC.

4.4.6 Participatory Roles and Activities

Ethnic community members were involved in the youth mental health project in three ways - as clients, as volunteers, and in advisory groups. Initially, ICHC staff conducted social and recreational events for youths, acted as chaperones, and invited parents to join them on outings. These activities were intended to attract the interest of the communities, to demonstrate the interest and trustworthiness of ICHC organizers. and to create opportunities for informal mixing of ethnic groups [DOC-06].

The discussion now focuses on how the ICHC program mandate, a shift in project objectives, and the advisory committee structure affected the roles of ethnic participants in project activities.

Professional Orientation and the Client Role

ICHC's mandate as a community health centre oriented toward therapeutic health services appeared to influence its approach to ethnic youths and families. In contrast to an original project objective which emphasized family and youth involvement as peer counsellors, the actual project activities became oriented toward art therapy mediated by professionals. Nonetheless, these activities appeared to be valued. For example, a mother reported that her daughter developed new coping skills:

> When we first arrived my daughter was really depressed at school and it took her a long time to adjust. Now she just goes in her room and draws and after three or for days she is better. (ICHC B)

Some youths reported that they formed new friendships with other ethnic students, increased their participation in community activities, and gained prestige with Canadian peers who had viewed the youths in the 'Juggling Cultures' videotapes:

> Meeting other people from other cultures was tremendous for me...it made me look to myself and say, 'Hey Joe, you don't really have it that bad. Appreciate what you've got'. (ICHC J)

A second generation youth reported positive changes in his ethnic identity:

> When I was a kid I used to say 'Dad, I wish I was white'...After the video I was proud to be Chinese, felt like I wanted to go to Chinese school and learn Mandarin. I can speak Cantonese fluently now. (ICHC 5)

However, ICHC staff reported that youths were not interested in a project which was oriented therapeutically:

> Nobody would have come if we had said, 'Tell us about your traumatic past' or 'Come to a mental health workshop'. You have to conceal your ultimate objective with a smokescreen and build some other ways of achieving that participation. (ICHC 2)

Even so, youths did not appear to view themselves as having major problems since they attended an average of only four sessions out of seven [DOC-16].

Although the organizers made efforts to attract youths who were in difficulty, they were not prepared to accept all types of youths. For example, after initial experiences in working with youths who used illegal drugs or were in trouble with the law, project staff decided they did not have the necessary expertise to deal with anti-social youths who disrupted the group therapy milieu. They referred these clients to professional counsellors. However, the project coordinator did welcome some specific youths as a challenge to her therapeutic skills:

> The profs in my psychology department would say 'I wouldn't touch that client with a 10 foot pole'. I thought, 'Who is going to touch them? Who is going to work with them?' People are afraid. If I have the languages and the initiative and the understanding to do it, well I'll do it. (ICHC 3)

This combination of professional overconfidence and personalized selection made project recruitment quite inconsistent.

Although the professional art therapy strategy appeared to facilitate ethnic mixing and organizers reported no differences in participation in the seven ethnic groups, it may not have met the needs of all ethnic youths equally. For example, youths in some ethnic groups may have benefited from individual counselling, or other forms of artistic expression such as music, dance, or story-telling (Sue 1981). Finally, ICHC's focus on group therapy may have limited the number of youths who could be actively involved. Only 25-30 youths (8-10 young women, 6-20 young men) participated initially in the workshop activities.

Shift to Production of Education Materials

Initial project objectives which emphasized parent/youth coping skills and training professional and peer counsellors appeared intended to contribute to development of the ethnic community. In fact, ICHC did work briefly with LMYA to sponsor youth leadership training sessions. However, the peer counsellor facet of the program was not developed further, apparently due to the emphasis on a more 'professional' counseling approach.

The interest and capabilities of the project coordinator, as a professional art therapist in-training, seemed to divert the project from its original objective of promoting self help in the ethnic communities. ICHC staff raised extra funds and shifted the focus of the project to the production of three videotapes of the art therapy process (entitled: I. Culture Shock; II. Prejudice, Racism, and Alienation; III. Freedom - Keeping the Balance). For these activities, staff selected 24 youths as volunteers in filming videos, producing manuals, and reviewing their content. These youths were primarily from the Portuguese, Polish, and Hispanic groups, although volunteers from other groups were also included [DOC-06]. Project staff noted that this shift was agreed upon by HPD, the advisory committee, and ICHC management since it would produce educational materials which could be utilized by a wider clientele than could be reached by the single staff person.

Ultimately, however, this shift of objectives limited the roles which youths could play in the project to mere recipients of counselling and temporary volunteers, rather than as peer counsellors. Overall, the shift reduced the ongoing involvement of the ethnic youths, while increasing the opportunities for the coordinator to present the educational materials to professional audiences.

Token Advisory Groups

In addition to participating as clients and volunteers, youth and adult members of ethnic communities were involved in the project through a system of informal and formal advisory groups. ICHC staff reported that approximately 50-60 adults participated in these advisory groups, although only a few youths were involved.

Informal advisory groups in each target community identified youth needs and provided practical supports in terms of locations for youth group meetings and refreshments. However, the project coordinator reported that these groups did not have significant input to the development of the actual project activities:

> They didn't have time to sit around and develop a program. They wanted to have a program given to them...They didn't have time to research all this or talk to other people and that's where our job came in. (ICHC 3)

Staff's claim of responsibility for development and management of the project appeared to be facilitated by the professional orientation of the sponsor organization and by its clinical approach to the youths' problems.

Since the formal advisory group of ethnic leaders and professionals met only twice during the project's three year term, it did not appear initially to have a significant role in the project. Minutes from these meetings indicated that the committee focused on the need for, and suitability of, specific educational materials developed in the project [DOC 20].

This focus on educational material products may have reflected the HPD funder's interest in producing concrete outputs for the project, but also may have indicated ICHC staffs' desire to disseminate their project model to other groups and professionals.

Interestingly, when the project received a six month extension from HPD to finish production of the workshop videotape, the formal advisory committee suddenly became more active (with four meetings in three months). The committee applied for and received funding from the Ontario Ministry of Citizenship and Culture (Anti-Racism Secretariat) to produce yet another video for teaching health professional students about culture and health [DOC-18]. The advisory committee's interest appeared to be revived suddenly by the potential for direct application of the project to professional constituencies.

Overall, the advisory committees had inconsistent input and were ineffective in giving ethnic community members, especially youths, substantial involvement in project management or decision-making. Although the committees involved a cross-section of the ethnic community, their primary usefulness appeared to be in meeting professional interests and in identifying needs of a passive target group which did not take a great interest in the project.

4.4.7 Influence of Participants

The day-to-day expression of influence in the ICHC project was ambiguous. Although there were few overt disagreements reported among youths, elders, and project staff, two youth respondents had differing perceptions of who actually controlled the project. One youth noted that the project coordinator organized everything for the youths. The other reported that she always asked youths what they wanted to do and talk about. The coordinator herself reported that the ICHC had "given her control" in the project. She noted that she continually consulted the community leaders about changes in the project and negotiated new ideas with the youths. She asserted that she did not abuse this control since she knew that the success of the project depended both on the satisfaction of the youths and the ethnic communities. It should be noted that, generally, youth respondents stated that they were satisfied with their involvement. Nonetheless, power issues were evident in the process of initiating the project and in the pervasive influence of professionals.

Paternalistic Attitudes Toward Youth

The project organizers, professionals, and ethnic leaders were the predominant initiators and decision-makers in the project. For example, the ICHC executive director initially mobilized members of the local academic community to conduct an assessment of youth needs and to support the funding application for the project. ICHC organizers also solicited input of professionals concerning attitudes toward adolescents, intergenerational relationships, youth attitudes, program ideas, and identification of clients and potential peer counsellors [DOC-01]. Youths themselves were not asked to identify specific mental health problems prior to the project, although in interviews they too expressed concerns about how youths were coping in the Canadian culture.

Thus, paternalistic attitudes of adults toward the capabilities of youths appeared to underlie their exclusion. The HPD program officer noted that youths were not familiar with planning activities:

> There were some problems in helping them to identify, and to do some long range planning, because kids don't think about long term things. Usually it's 'What are we doing tonight?' They realized right away that the traditional committee format doesn't work with kids because they don't want to commit to something for that length of time. (ICHC 4)

This assumption of youth preoccupation, however, did not inhibit youths in the LMYA and local student councils from planning other community activities. The desire of health centre staff to direct the project solely with parental and professional input appeared to be an alternate explanation for the lack of youth participation in the initial planning process.

Professional Power Dynamics

The service mandate of the ICHC and professional orientation of the mental health project appeared to strongly affect the influence of community members in two ways. At the individual client level, power dynamics were expressed in subtle ways through the medium of 'therapeutic relationships'. The professional art therapist who consulted to ICHC staff noted that a subtle power relationship was necessary for successful treatment in the therapeutic milieu:

> ...if I am seeking some help then I am going to go to somebody that I can give status to, some power. He or she must have some power to be of help to me, some strength. That is a necessary component. The other side is that there has to be a recognition that we are all with some frailties and share that human base. You have to have both. (ICHC 6)

Thus, health promotion principles of self-help and target group empowerment were contradicted by the therapeutic approach taken in this case.

On an organizational level, the therapist rejected the possibilities of community control and proposed that a balance between professional and community influences in local projects was necessary:

> If our goal is to have as much interaction as possible and as much community awareness as possible, then the role of the professional eventually has to disappear. If they were part of the community themselves, it would mean taking on equal status with the community and I can't see that happening...That's at the base really. If the community can do what I'm doing for them as a professional, and I'm being paid to do it and getting the recognition and the status, and the community is out there and they can do

> it, then I'm going to feel rejected. I'll suspect the community of not being able to do what I can as a professional. I think there would be great resistance to allowing the community to take that leadership. Professionals will protect their turf. (ICC 6)

Interviews and observations of her interaction with the project coordinator indicated that this professional strongly influenced the direction which the project took with the youths.

Numbers of Community Participants

In addition to numbers cited previously, project documents indicated that over the course of the project approximately 1,000 people, including school groups, ethnic adults, and those from professional groups, participated in workshop sessions which utilized the 'Juggling Cultures' video. Although detailed documentation for this claim was not available, at least half of these participants viewed the videotapes only in a presentation format and did not actually participate in art therapy sessions [DOC-16]. Once again, documentation of youth participation in the project did not receive much attention.

Post Script

Subsequent to the HPCP project, the ICHC organization was recognized increasingly by other professionals, ethnic groups, and provincial bureaucracies for its expertise in the area of ethnic mental health. For example, the organization was requested frequently to provide advice to various provincial ministries regarding race relations and multicultural issues. ICHC also received funding for another project to develop videos addressing ethnic-professional interactions for the purpose of sensitizing student health professionals [DOC 19]. This new project appeared to underscore the organization's interest in professional roles in community health.

Finally, the success of the ICHC project led eventually to a permanently funded position for the project coordinator in the community health centre:

> ...because of all the work done during the project and .offshoots of the project...now my position is a secure funded position. It's only three days a week but it is permanent for art therapy. I think it is one of the first positions like that in a community health centre. That's really substantial and significant. (ICHC 3)

4.4.8 Case Discussion

Involvement of ethnic youths in the ICHC case could scarcely be termed 'participation' as defined in this thesis. Ethnic adult involvement was somewhat more substantial, although it appeared primarily to be for the purpose of 'contribution' to ICHC's professional agenda.

Structural factors such as the ICHC history and staff members' idealization of professional roles and knowledge appeared to strongly influence community participation. Health and social welfare professionals participated significantly as support persons to the program due to the project's leadership and clinical setting. A diverse set of youths in terms of age, education, and socio-economic status participated in the project. However, the seven principal ethnic groups chosen by project organizers appeared to be determined by their previous history with project organizers, and perhaps sociopolitical views regarding racism.

Cooperative participation of ethnic groups in the project was claimed to be impossible due to differences among the ethnic communities. However, participation strategies appeared to derive as much from a desire to control the project as from ethnic diversity. Advisory group structures seemed to be important in a political sense to gain approval of the project, but were mostly token in terms of actual operations. Neither youths nor parents had significant decision-making roles in the project, although some ethnic leaders appeared to have some influence.

The objective of developing self-help skills within the youth ethnic group did not appear to be met. Furthermore, a change in project objectives seemed to decrease the opportunities for community member roles in the project and left them dependent on professional mediation. Unlike the previous ICYP and PUSH cases, the ICHC service providers did not advocate for systemic or policy changes which could affect the ethnic youth mental health issue. Consequently, public involvement did not decrease later in the project, but in fact, expanded to involve greater numbers of people, albeit only as recipients of information at workshops.

The ICHC case provides an example of client participation in a health promotion project which had very limited demonstration of community control. A conservative, family-centered target group was not given any real opportunity to assert itself against a professionally organized health centre. Nonetheless, there was little conflict apparent in the project which might have indicated dissatisfaction on the part of the youths. The roles of sponsors and professional providers did not appear to overwhelm the participants, although analysis revealed more subtle influences in power relationships.

Overall, structural factors related to the sponsor and project design, which emphasized a professional therapeutic approach, were predominant. The therapeutic approach taken with the youths, which emphasized individual problems and professional knowledge, did not lend itself to community members' actively sharing information, much less control of the project. However, these conclusions must also be interpreted in light of the community members' satisfaction with participation and by a lack of overt conflict. Perhaps, similar to the ICYP case, low expectations of participation were inevitable in this youthful ethnic target group.

4.5 CASE: INDEPENDENT LIVING CENTRE PROJECT SPONSOR: HANDICAPPED ACTION GROUP INCORPORATED

4.5.1 Introduction

The Handicapped Action Group Incorporated (HAGI) in Thunder Bay received HPCP funding from 1988-1991 to provide support services for persons with disabilities living in community settings. An Independent Living Centre (ILC) was developed to provide activities which focused on personal advocacy and peer interaction, provision of information, skill development, and increasing community awareness of the needs of persons with disabilities. The ILC was linked to a national network of disability centres. all of which provided this core set of activities.

This case was selected for study since project documents indicated that community members had participated primarily as volunteers. A complex organizational structure was used to manage these volunteer roles.

Data sources for this case included eight direct interviews, excerpts of interviews with 23 other project participants, and 19 project documents (proposals, reports, evaluation). Interview respondents included the HPD program officer for disability projects, the HAGI executive director and the ILC project administrator. The five community respondents included two men and three women. Three persons were between 25-35 years of age and two persons were from 35-50 years of age. All respondents from the ILC had primary physical disabilities although one respondent also had a developmental disability.

4.5.2 Structural Characteristics of the HAGI Organization

History and Program Mandate

Over the past 25 years, major changes in residential care for persons with disabilities in North America were prompted by economic constraints as well as by humanitarian and civil rights concerns (Driedger 1989). Long term care facilities and rehabilitation institutions decreased in size as persons with disabilities were discharged into community settings. Although providing community care was more expensive than originally planned, the total amount saved on institutional services was not spent on community support services (Zola 1983).

Numerous volunteer based self help groups of persons with disabilities formed to address the needs of living in community settings. For example, during the 1970's and early 1980's organizations in Canada and the United States began to form Independent Living Centres (ILC) in response to these trends towards de-institutionalization, rejection of the medical model of rehabilitation, concepts of normalization, and disability consumerism (Boschen 1992).

During the International Year of Disabled Persons (1981), the Canadian federal government funded a Special Parliamentary Committee on the Disabled and Handicapped to prepare a series of reports entitled Obstacles (Canada 1981). One of the committee's recommendations, the establishment of ILCs, provided a basis from which consumer groups could negotiate legitimately with the government for funding (Lord 1987).

Also in 1981, the Council of Provincial Organizations of the Handicapped (COPOH - now known as the Council of Canadians with Disabilities - CCD) established an Independent Living committee. Valentine (1994) notes that "a key development from this committee was the conscious separation of individual vis-a-vis collective advocacy" (p.37). Unlike the American Independent Living movement which combined these elements, Canadian disability advocacy groups such as COPOH took a lead role in policy and legislative activities, while ILCs focused on assisting individuals in developing their personal skills, by providing information, and by negotiating services for individuals.

In 1986, the Canadian Association of Independent Living Centres (CAILC) was formed to promote ILCs. In Canada, the Independent Living philosophy has been to "promote and enable the progress and process of citizens with disabilities to take responsibility for the development and management of personal and community resources" (CAILC 1989a)(p.3). ILCs are intended to address local issues, be cross-disability in representation, be non-profit, and promote integration and full participation of persons with disabilities in society (DOC-01, CAILC 1992). Currently there are 21 ILCs in Canada having a common set of programs (CAILC 1992) and structures (CAILC 1989b) which make them eligible for government funding.

Early in the process of disability consumer group development, the Handicapped Action Group Incorporated (HAGI) was formed in 1972 by a group of physically disabled adults in the Thunder Bay area. The group worked initially with the Lakehead Social Planning Council to make changes in community services to allow for improved quality of life for persons with disabilities. For example, by the late 1970's, HAGI had established a transitional living centre to provide centralized living accommodations, attendant care, and training in life skills to persons with severe disabilities who were being de-institutionalized. HAGI also established a wheelchair bus transportation system, an accessible housing unit project, and community recreation programs for persons with disabilities. The HPD program officer noted that Thunder Bay was a progressive community for disability issues in comparison to other areas:

> I don't think that I've ever seen as many disabled people in one city. When I think of Toronto I hardly ever see anybody in a wheelchair. But HAGI in Thunder Bay was a whole different world. (HAGI 5)

Overall, HPD bureaucrats noted that HAGI had an excellent reputation with funders for advocating the interests of persons with disabilities, as well as for providing information and efficient services.

In 1987, HAGI conducted a needs assessment and then established an ILC project following the model established in other Canadian locations. However, there was one important difference. Other ILCs in Canada were started by consumer organizations which were formed expressly for the purpose of developing community services in their areas. Because HAGI had already established numerous services, it was the only Canadian group to form an ILC as a project, rather than as a separate organization. It will be shown that this history of the development of disability services and organizations in the Thunder Bay area made the organization of HAGI's ILC project somewhat different than other ILCs in CAILC.

Target Group and Issue

Prior to the establishment of the ILC, HAGI's mandate and experience had been solely in work with physically disabled persons. However, the Independent Living approach promoted a cross-disability focus which recognized the common problems and the need for generic services for persons with physical, developmental, and psychiatric disabilities (CAILC 1989b). This broader focus required that the ILC include persons from other disability groups in its planning and programs, although HAGI, its parent organization, did not have this requirement.

In addition to diverse interests based on disability status, there were also differing socio-political interests in the ILC membership. An ILC consumer noted that disability was not in itself a unifying factor:

> ...we aren't a coherent community at all. There are a bunch of individuals grouped together because they happen to have a disability. Within that there's a huge range of types of disabilities...for instance, the only thing I have in common with a lot of other spinal cord injured people is my injury. I don't have any political viewpoints, social viewpoints, any of those things in common so I get the sense the same is true of the disabled community. I think the number of people who have showed up at meetings over the years is a real indication of that lack of coherence. (HAGI 1)

This distinction along socio-political lines was further evident in the fact that not all disability groups in the area wanted to be included in the project. For example, the Thunder Bay region had a concentration of aboriginal persons with disabilities, yet they organized their own disability services, rather than being absorbed into the HAGI disability service system [DOC-10,18].

In spite of these disability group divisions, HAGI and ILC staff agreed that the issues of persons with disabilities were best understood from a social structural perspective, rather than from a medical rehabilitation perspective, which focused primarily on abilities and problems within individuals (Bickenbach 1993). In particular, the proponents of Independent Living suggested that social and environmental barriers were sources of stress, and were critical in determining an individual's ability to cope with a disability (DeJong 1979, Lord 1987). HAGI organizers viewed factors such as stigma, societal attitudes, socioeconomic status, limited access to educational and recreational facilities, unavailability of transportation, and lack of family and interpersonal support as significant barriers to living independently in the Thunder Bay community [DOC-01].

While HAGI identified social barriers as the major issue, it noted that individuals' lack of skills and confidence were also problems. HAGI staff perceived that persons with chronic disabilities who lived in community settings faced a number of restrictions in their everyday activities which were related to their personal capacities. In order to enjoy the freedom associated with community living, they also required a number of physical and social supports. In addition, some individuals required extensive assistance to begin to identify these needs for support. Thus, HAGI staff recognized the need for individual consumer training and skill development as part of the solution which an ILC could provide [DOC-01].

In sum, an approach was needed to address both structural barriers to integration as well as individual adaptation problems. HAGI's efforts to meet both these needs within a single organization will be shown to be problematic for participation.

HAGI Program Linkages

Early in the ILC project, HAGI staff contacted other local disability service organizations to inform them of the ILC plans and to enlist their support. This process was viewed by staff as crucial for general community acceptance:

> It's very important for a centre which is getting established to go out and talk to groups and let them know what you're trying to develop so they don't feel like you are duplicating services, so the role you will have will be different from their role and then you can work together. (HAGI 6)

In addition to linkages based on services, HAGI also participated in advocacy coalitions which promoted disability policy and legislative reform. In particular, HAGI was a member of PUSH North West, a regional organization of PUSH Ontario. Thus, HAGI, the parent organization, was involved heavily in advocacy while its ILC was not allowed to do so.

ILC project staff participated in an Ontario Network of ILCs (ONILC) and CAILC, the national coordinating body of Independent Living centres. However, the ILC's unique position within HAGI, which prevented its complete autonomy, was occasionally a barrier to its involvement in decision- making in the national association. As will be seen, these sets of program linkages provided the basis for a number of conflicts between HAGI and ILC members in the project.

Resource Mobilization

Internal conflicts, however, did not appear to hamper HAGI'S ability to secure funding, an indication of the position of disability organizations on the political agenda of the time. HAGI used an incremental approach, similar to that of PUSH, to secure funding for its programs. In the area of community services, HAGI was funded initially through the Ontario Ministry of Community and Social Services to operate the transitional living centre. In 1987, HAGI secured federal Secretary of State funds for the community needs assessment and then received a three year (1988-91) HPCP grant of $242,342 to develop the ILC core programs with two part time staff and volunteers. This funding provided a basis for initial ILC organization but was insufficient to operate the full spectrum of programs expected by CAILC.

ILC project staff then applied for further funds from 15 public and 64 private sources. Eventually, with funding from six new sources, the organization was able to support additional project components (for example, Family Violence, Literacy) with increased staff. However, this incremental approach also resulted in lapses between funding periods which threatened the continuity of staff positions. The ILC organizers observed that they were able to manage these intervals only through their unique relationship with the parent HAGI organization:

> When we are going through periods when a project may be over and we haven't got funding to sustain us, or we've been approved but the dollars haven't come in, HAGI has been able to carry us. So we are really fortunate and the other ILCs don't have that. (HAGI 6)

In another way, the organizational relationship with HAGI limited the ILC's ability to mobilize resources. HAGI's policy was to use the proceeds of private fundraising only for capital costs, with the strategic expectation that essential operating costs should be a responsibility of public funders. However, the ILC was not eligible for the secure provincial funding which HAGI received for its housing, transportation and attendant care services. Thus, the ILC needed to fundraise privately for its operational costs as well. This dilemma put the ILC fundraising scheme into conflict with HAGI policy. Eventually, in 1990, the separate incorporation of the ILC allowed the project staff to raise funds privately without negating the strategic policy of the parent organization.

In 1988, and then again in 1993, CAILC negotiated block public funding for ILCs in a unique relationship with two federal departments which sponsored programs related to disability. The ILC administrator noted that this provided security of funding for the core programs of the Thunder Bay project:

> At the same time our national association was in the process of being formed in Ottawa. The work began with the Secretary of State (Disabled Persons' Participation Program) and Health and Welfare (Disabled Persons' Unit) federally in a tri-party agreement that allows the centre to receive core funding for a five year period. That allowed us to bring the full staff complement on. (HAGI 6)

This arrangement also meant that the ILC was funded through two separate federal mechanisms (CAILC and HPD), which had implications for programming. The CAILC funding agreement (Canada 1992) and CAILC's internal criteria for ILCs (CAILC 1989b) specified that ILCs were not to engage in legislative advocacy or public lobbying, these being activities reserved for advocacy organizations such as PUSH and CCD:

> Staff at ILCs do not advocate for the individual consumer - rather they provide the advice and tools necessary for each person to advocate on their own behalf. (CAILC 1989b)

However, neither HPD funding (as shown in the PUSH case), nor HAGI had any such restriction on advocacy, which resulted in confusion about HAGI's traditional lobbying activities vis-a-vis the ILC mandate. This confusion was complicated by the dependent organizational relationship between HAGI and the ILC. The effects on community participation will be discussed later.

4.5.3 Characteristics of the ILC Project

The overall goal of the ILC project was to improve the knowledge of disabled community members so that they could take advantage of opportunities and supports for living independently in the community [DOC-01].

Project Objectives

The HAGI proposal for an ILC identified many structural impediments to integration, yet in practice, it focused mostly on supporting individuals to act on their own behalf. Based on the 1987 needs assessment, the ILC project objectives were primarily in health education, self help, and mutual aid. The four core objectives and programs required under the CAILC mandate were intended:

1. to provide training, information, and support in problem solving for individuals with disabilities. The Individual Advocacy program helped individuals to obtain government disability benefits, accessible housing, transportation, etc.

2. to assist consumers to establish social support networks among peers. The Peer Interaction program developed nine peer support groups (for example, multiple sclerosis, schizophrenia) and one to one peer relationships.
3. to direct consumers to appropriate community services. The Information and Referral program operated a resource library, telephone information, and referral services to disabled persons, agencies, and the public.
4. to create new disability programs and resources particular to the needs of the Thunder Bay community. For example, the Research and Development program received funds for programs such as employment equity and substance abuse. In addition, the Thunder Bay ILC also promoted the concept of IL within the region via a Regional Independent Living Workshop Series. [DOC-01]

Except for the latter workshops, these objectives and programs were similar to those developed in all ILCs funded under the CAILC-federal government agreement. Thus, the ILC project was intended to provide specialized support for individual persons with disabilities, as well as help them gain access to public services, including the services which HAGI coordinated. However, these dual mandates of service provision and advocacy were sometimes in conflict within the HAGI-ILC project and will be shown to be the basis of ongoing problems for community participation in the project.

Organizational Structure

HAGI claimed that its representation of disabled persons was strengthened by its emphasis on consumer participation in decision-making [DOC-02]. The HAGI executive director reported that 'consumer control' was reflected in bylaws outlining the composition of the HAGI board, staff, committees, and membership. These bylaws were compatible with those of CAILC:

> Consumer control denotes that the people receiving the services are also the people offering them. Canadian ILCs have mandated in their bylaws that 51% of the Board of Directors at each Centre are people with disabilities. (CAILC 1988b)

Persons with a physical disability became members of HAGI by application with a token fee, which was often waived, to cover costs of a newsletter. This membership allowed full involvement in all HAGI activities. Although only 60-100 members participated in HAGI annual general meetings, they were open to all physically disabled persons in the region, a practice similar to that of the PUSH case.

However, this focus on physical disability meant that the ILC project could not technically be a cross-disability program, in contravention of CAILC rules. In practice, those with non-physical disabilities who wanted to participate in ILC programs were recorded on mailing lists, but were not 'members' of HAGI, and could only be involved at lower levels of the ILC organizational structure. See Figure 7 & Figure 8.

1. The ILC project was managed initially by the HAGI **board of directors**. Although HAGI bylaws stated that the board of directors had to include at least 51% disabled persons to ensure consumer control of the organization, it was only since the mid-1980's that this policy had been followed. In 1988, all eight board members were physically disabled persons who were nominated and elected by ballot at the HAGI annual general meeting.

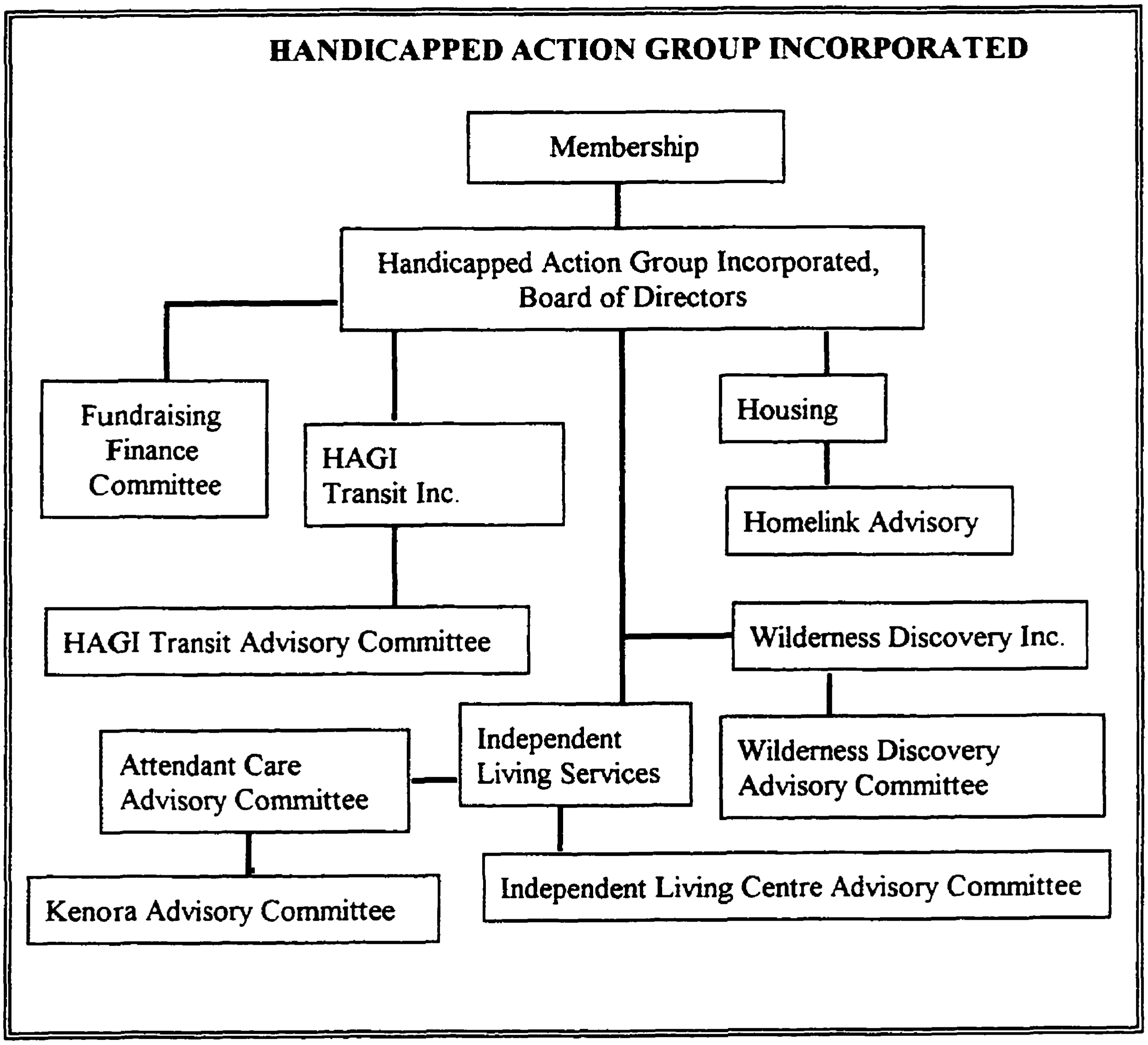


Figure 7. Organizational Structure of HAGI (from HAGI Doc-19)

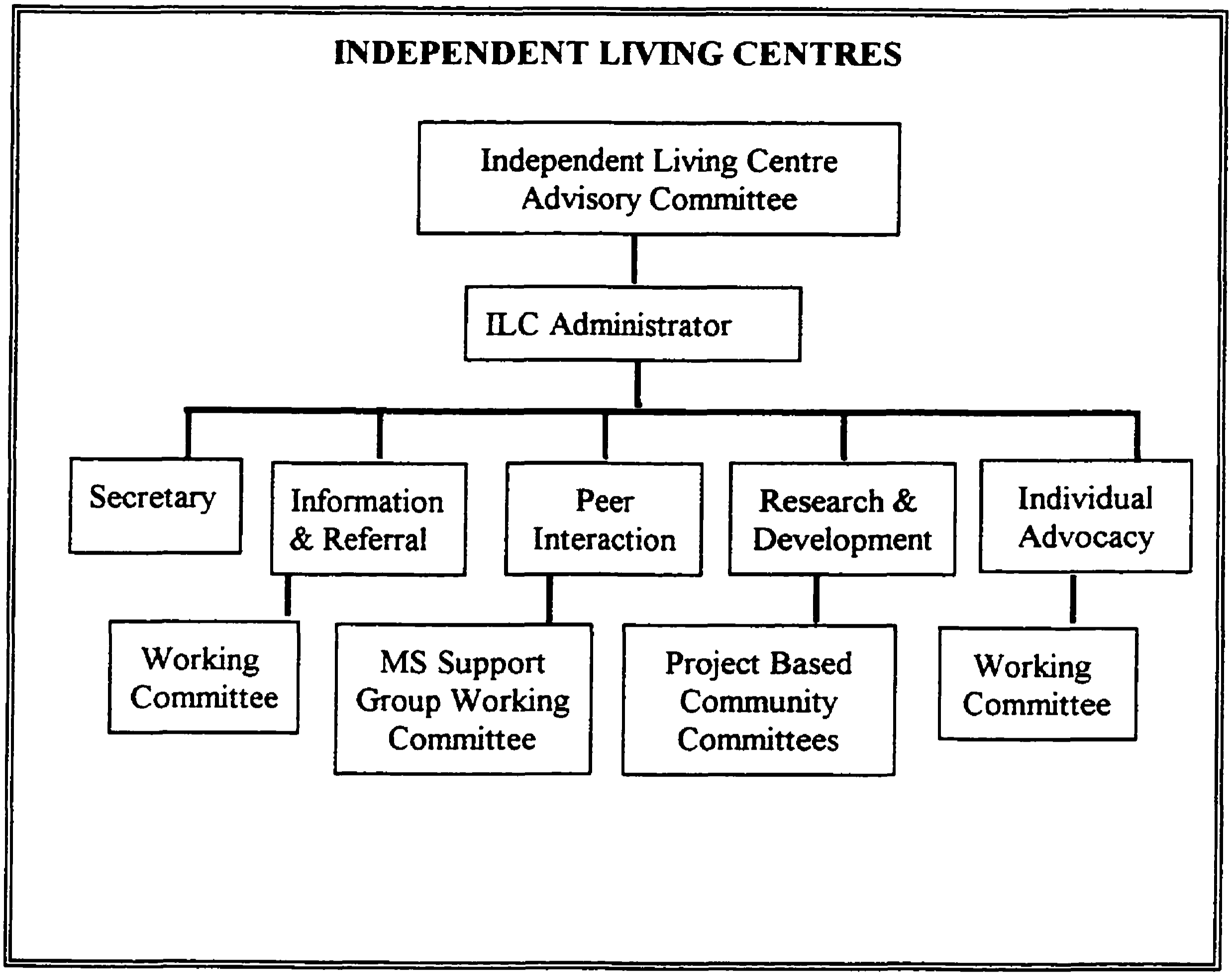


Figure 8. Organizational Structure of ILC (from HAGI Doc-19)

In 1987, the HPD program officer recommended that a separate ILC organization be established to allow cross-disability membership with an independent board of directors. This strategy would also separate those providing HAGI services from those in the ILC who were helping individuals to access these services. As well, CAILC had developed eligibility criteria which required ILCs to be incorporated separately to ensure their independence (CAILC 1989b). Finally in 1990, towards the end of HPCP funding, a new corporate entity, HAGI-ILC Services was formed, but with the same board members as the HAGI organization [DOC-19].

2. Two persons were hired initially as ILC staff - a **project administrator** and a secretary. Subsequently, five other **employees** were hired when additional funding for specific program areas became available. Able-bodied staff had training in social work or developmental disabilities. Staff were not hired unless they agreed to support and promote the ILC organization values. The project administrator reported directly to the HAGI executive director.

3. Initially, an advisory committee which HAGI had formed for its attendant care program was utilized to monitor the ILC project. However, this committee, which was composed of service providers, municipal authorities, consumer group representatives, and HAGI board members, was reported by the executive director to be too involved with attendant care issues to address the ILC needs adequately. Subsequently, an ILC **advisory committee** was appointed in 1989, the second year of operation, also at the request of the HPD program officer [DOC-06,19]. The advisory committee's terms of reference were to advise the HAGI board on the operations of the ILC project and to recommend staff for employment. However, the advisory committee of nine persons included not only the HAGI executive director but also three members of the HAGI board [DOC-12,16]. Thus, the independence of the advisory committee from the board itself was questionable.

The advisory committee reported to the board on a monthly basis, however attendance at advisory committee meetings was poor, with considerable turnover in membership. Staff reported that this inconsistency was primarily for personal reasons, although advisory committee respondents reported that more cross-disability participation was needed to improve the committee's representativeness and relevance [DOC-19].

4. Persons with disabilities acted as project **volunteers** assisting with clerical tasks and participating in the ILC core programs through a complex committee structure. Each of the four core programs had a standing committee composed of ILC staff and 5-6 volunteers, board directors, and service agency representatives. These standing committees advised the ILC project administrator on the operation of each program. Some volunteers reported that they served on several standing committees [DOC-19].

There were also working committees for each of the four core programs. These were supposed to be composed entirely of persons with disabilities, although an exception was made for an employment equity committee of the Research and Development Program which had a majority of able bodied community and business representatives. Working committees were intended to provide opportunities for volunteers to conduct planning prior to approaching staff for logistical assistance. They were also to provide training for volunteers for further committee work. At least one volunteer had progressed through the ILC committee system and served on the HAGI-ILC board of directors.

Working committees met sporadically and each committee had its minutes and plans 'approved' at the next level. Thus, decision-making was slow, with five stages required for approval of new project ideas.

5. **Clients with disabilities,** or consumers, participated through receiving services in the ILC core programs, such as support groups or individual advocacy services.

Background and Roles of Other Participants

Professionals - Guidelines for consumer control in the ILC were used to manage professional involvement. ILC staff appeared to make a distinction between the involvement of health professionals and professionals from other backgrounds. Due to the personal experiences of many persons with disabilities, rehabilitation professionals were viewed as potentially dominating and not suitable for involvement in the consumer organization. The HPD officer observed:

> HAGI probably wouldn't let a professional cross the path. They're very strong and that's the whole focus of IL...In terms of that classic rehab professional I suspect there aren't a lot of people involved there. (HAGI 5)

However, professionals from the fields of social services, law, and education were involved frequently on the ILC and advisory committees:

> ...we had to have an advisory committee so there were a few doctors and lawyers on it. It was great because you got the input that was needed...They knew the system so we could all work together. It helped us because we showed them our point of view and they showed us their point of view. (HAGI 3)

ILC staff and consumers viewed these latter professionals' participation as important, not only in facilitating changes in services, but also as a strategy for educating service providers about the issues and expertise of persons with disabilities. As will be shown, however, even these professionals did not treat people with disabilities as their equals.

Bureaucrats - Federal, provincial, and local bureaucrats had varying involvement in the ILC project. The HPD program officer for disability had frequent contact with HAGI during initial development of the project proposal. For example, she visited four times annually in the early years of the project, encouraged the establishment of an advisory committee and an independent ILC board, and thus was involved in developing the organizational structure. This contact decreased over the term of the project.

Provincial bureaucrats who had regional offices in the Thunder Bay area also had frequent contact and participated with ILC members on HAGI service planning committees, such as housing and employment, or attended annual HAGI meetings.

Municipal bureaucrats had less active involvement in the ILC even though some disability services were under their direct jurisdiction, for example, accessible housing. Occasionally, municipal staff participated on ILC standing committees, but more frequently their involvement was in managing requests from ILC staff for individual consumers' access to social services. Some bureaucrats were perceived by staff to have little interest in cooperating with the ILC as an agency, and to prefer to deal only with disabled clients as individuals.

In sum, persons with disabilities were involved at all levels of this consumer project. Able bodied persons also were involved directly as staff, as professionals, and as bureaucrats. See Table 5.

Table 5. Participants in ILC Project of HAGI

PARTICIPANTS	
DIRECT	INDIRECT
Board of Directors	Other Funders - provincial
HAGI Executive Director *	Agency Professionals
HPD Program Officer *	External Evaluation Consultant
ILC Project Administrator *	
Volunteer Committees: -Advisory Committee * -Standing Committees ***(4) -Working Committees (8)	Disability Groups - CAILC - DAWN - DAN
Able Bodied Volunteers -college students -other persons	
Clients with Disabilities*	

* = participant interviewed in this case study

Project Administration and Leadership

The ILC project administrator was a key leader in the project. The administrator organized all ILC funding proposals, negotiated block funding with CAILC, and managed the ILC relationship with HAGI. She also developed the volunteer program for the ILC and advocated for its independence as an autonomous organization.

The ILC administrator supervised the other employees and volunteers and was responsible for financial and program reports to HPD, as well as to CAILC and its federal funders. An Evaluation Committee composed of HAGI board directors, ILC staff, advisory committee members, and volunteers organized a three year evaluation plan with the assistance of an external consultant hired through project funds [DOC-05]. Reports for each year and a final evaluation (1991) were generated and then reviewed by the board of directors and funders [DOC-19]. These reports identified a number of concerns about the HAGI-ILC organizational structure and mandate. Nonetheless, the project was approved to continue with CAILC-H&W-Secretary of State funding until 1996.

Summary of HAGI Structural Characteristics

HAGI was one of the earliest disability consumer organizations in Canada. It developed new programs in an atmosphere of changing public attitudes and evolving concepts of disability. Many of its activities were initiated to meet identified community needs and were operationalized when suitable public funding became available. A diverse disability community and clear needs to provide support for dependent target group members provided the rationale for HAGI's broad approach which included both service provision and public advocacy. However, differing program and target group mandates for HAGI and the ILC provided numerous problems in the ILC operation.

The ILC project was only semi-autonomous and this made it unusual for Canadian ILCs which were coordinated through a national organization. A restricted HAGI membership and a complex organizational structure raised problems of representation and community member influence which will be addressed later.

Through its ILC project, HAGI proclaimed strong organizational values of cross-disability representation, consumer control, and a public focus on structural barriers to integration. However, there were also contradictions to each of these values stemming from internal organizational factors, the practical needs of consumers, differing disability and socio-political interests, and a restrictive funding agreement. Many of these characteristics affected the process of community participation in the HAGI project.

4.5.4 Types of Participants

Precise records on the characteristics of community members who had been involved in the ILC over the three year project term were not kept. The ILC administrator reported, however, that the majority of community participants were females in early to middle adulthood (20-50 years), although some seniors and young adults also participated. Most participants were reported to be unemployed and on disability pensions. Persons who were employed tended to participate in the management and direction of the centre rather than volunteering in its daytime core programs. Structural factors such as HAGI's target group mandate, gender differences, and staffing guidelines influenced participation in the project.

Bias Toward Physical Disability

HAGI's mandate and history as a disability organization affected the types of participants in the project. In spite of the cross-disability principle under which ILCs were supposed to operate, persons with mobility impairments were reported to be much more involved than persons with sensory, developmental, or psychiatric disabilities [DOC-19]. Persons with less visible disease disabilities such as diabetes, epilepsy and cardiovascular diseases also participated, but even less frequently [DOC-08].

Although all ILC participants (physical and non-physical disabilities) were eligible to serve on the ILC advisory committee, six of the initial advisory committee members had physical disabilities, with the remaining three being representatives from service organizations. Cross-disability representation did not seem to be a high priority in practice. Despite being raised as an issue by evaluators and bureaucrats a number of times since 1988, the HAGI board did not take formal steps to open up its membership to those with non-physical disabilities until 1991. HAGI's continuing emphasis on physical disabilities may also have reflected problems in using a self help Independent Living model with persons with developmental and psychiatric disabilities, who may have required professional support that was not available through their peers. Overall, the ILC's limited success at achieving a cross-disability membership raises concerns about the range of disability groups in the project.

Gender Differences

Many respondents noted the effect of gender on the range of participants in the ILC. As noted previously, more women than men participated in the ILC project, although this was not the case in other HAGI programs such as transportation, housing, and recreation. Women respondents noted that disabled men appeared to have little interest in a self help Independent Living approach which focused on social support and counseling:

> Even though it's geared to both genders I see more women...I don't know why. Perhaps the men don't feel they need the help. They feel more intimidated. Men with disabilities don't seem to feel comfortable in asking for help. (HAGI 4)

The project evaluator also noted that since few of the disabled women held jobs in the community, they had time available for ILC activities [DOC-19]. Similarly, since all but one of the staff members were women, gender imbalance may have affected the recruitment of men to the project. Thus, men's lack of participation may have been influenced by their employment status, as well as by their personal needs and preferences for volunteering in non-emotive programs.

Non-compliance with Staffing Guidelines

ILC guidelines specified that 51% of all ILC groups (board, staff, committees) should be persons with disabilities. In 1991, however, only three of seven employees were disabled, although one of these was the project administrator. The consequence of this practice is unclear, however, there is evidence that staff characteristics may have affected the participation of community members. For example, utilization of the ILC by people with visual impairments apparently increased with the employment of a person who was blind [DOC-19].

4.5.5 Sponsor Strategies for Participation

The ILC attempted a number of recruitment strategies (media, letters, word of mouth) to attract disabled persons to attend meetings, workshops, and support groups. The

HAGI director noted that public response was not heavy and that use of personal contacts was the most successful strategy to motivate participation:

> We can send out letters but the secret has been word of mouth. You have to go out and talk to people and invite them. Even with major conferences you have to contact them personally...We've tried to just send out notices but you don't get the turnout as if you had called and invited them with a personal invitation. (HAGI 7)

Similar to other cases involving disadvantaged groups, personal recruitment methods required a great deal of time and reinforced the role for community volunteers in the project. This section illustrates how target group marginalization, program linkages, and limits on resource mobilization were associated with strategies for the encouragement of participation.

Marginalization of Disabled Persons

According to both staff and volunteer respondents, the majority of persons with disabilities who participated in the ILC became involved when they were in states of personal crisis or depression. These persons had led quiet, sheltered lives for many years and had not been involved in many community activities. Upon finishing school and realizing gradually that they were unlikely to fit easily into employment settings and personal relationships, they often experienced depression and anxiety about their futures. Personal crises such as loss of housing or disability benefits, parental death, or physical deterioration then led them to seek out help. The ILC administrator noted that many persons attended only if an event or program addressed their personal concern:

> We tend to see the same people all the time unless it's an issue that is really going to affect their lives. Like, 'My attendant care is going to be cut off and if we don't do something about it I'm not going to be able to survive independently' - then people come out. HAGI 6)

Staff respondents also noted that the social and organizational skills of consumers were not well developed. The ILC administrator observed that there were limitations to the speed at which consumers could develop and that ongoing support was required for independence:

> ...staff gets really frustrated because you want to see the change take place quickly. For someone becoming independent, if you've never had that opportunity before and you've never had to make decisions or choices, it takes a long time and is a long process. (HAGI 6)

In contrast, community respondents reported that initially they felt they wouldn't be allowed to influence the ILC programs, and thus only participated in events which were of high personal interest. A young woman observed that these patterns seemed to be particular to persons with disabilities:

> It seems that in the disabled community there is a lack of motivation. There are a few people that do all the work. It is really hard to get people out. People feel that their voice won't count. (HAGI 3)

Thus, long term socialization of disabled persons to be dependent, and previous experiences in disempowering situations, appeared to result in significant motivational problems for community participants. The tendency to view the ILC organization as a problem solving agency, rather than as a self help mechanism, may also have contributed towards this situational participation.

Community Agency Cooperation

Interestingly, the recruitment of community agencies for ILC program planning was more successful. Respondents noted that organizational participation was common in the Thunder Bay area and this support extended to disability issues:

> The Thunder Bay community has a very strong network and historically if there is an issue to be dealt with, or a project to be taken on, everyone gets together as a team rather than trying to divide the pie...In that sense we are really lucky. (HAGI 6)

Thus, past experiences in working together on HAGI projects appeared to facilitate agency involvement in the ILC. The source of this community support may have been due to the isolation of the region and the need for inter-dependence, as well as the relative homogeneity of the population compared to multicultural southern Ontario.

Resource Limitations

Although funding for seven staff persons was secured eventually from different agencies, ILC respondents perceived that lack of financial resources had a number of impacts on recruitment of persons with disabilities. First, staff were unable to advertise widely and promote the centre's services through television and radio advertising. Second, short term staff were pre-occupied with job security which impeded long range organizational planning for consumer involvement [DOC-19]. Third, there were few opportunities for remuneration for disabled persons in the project. Occasionally, funds to pay persons undergoing pre-employment training were available from short term project grants. These training positions were highly valued but rarely led to further employment. One volunteer reported that more actual job placement was needed:

> ...my job training wasn't really training. It wasn't going to get me a job. It was just experience. Social Services hasn't got me a job in the 12 years I have been in Thunder Bay. This is as close as I have got to a real job. (HAGI 2)

Thus, community members who viewed participation in the ILC principally as a strategy for employment were often disappointed and stopped attending. A number of ILC respondents expressed great interest in securing permanent paid positions as staff members within the centre. The ILC's failure to employ more disabled persons as staff did not help the situation.

Interestingly, in contrast to other cases in this study, compensation for attending volunteer meetings was not raised as an issue by ILC respondents. This may have been due to the perception that disabled participants were the primary beneficiaries of the project and that others, specifically professionals and bureaucrats, did not benefit significantly from their involvement.

Participation was also constrained by a lack of resources which affected physical accessibility of the ILC. Since the ILC had limited funds available for specialized adaptive devices, interested persons with communication impairments were unable to participate. Similarly, disabled persons with jobs had priority for accessible transportation provided by HAGI. Unemployed ILC members frequently mentioned this as a barrier to their own participation in daytime volunteer meetings [DOC 19]. Finally, physical accessibility was limited to the main floor of the ILC building when a grant to install an elevator was not received. While the ILC's acceptance of these restrictions on access appeared incongruous with its philosophy, one needs to remember that it had to raise funds privately for basic infrastructure and capital costs since these were not included in the CAILC funding agreement.

4.5.6 Participatory Roles and Activities

Persons with disabilities, who made up to 60 requests per month for information, participated initially in the project as clients, or consumers of ILC services, not as formal members of the organization [DOC-03,04,10]. If clients had ongoing needs, the ILC staff then either referred them to an appropriate external source, enroled them in a centre program, or encouraged them to visit the ILC to meet other consumers. At any one time, approximately 50 consumers were enroled in individual programs to help them deal with their problems or to gain access to disability services [DOC-19]. For example, one consumer reported gaining self-confidence and developing new inter-personal relationships:

> I've received a lot of support. If it wasn't for the ILC I wouldn't be where I am today...I've tried to be widely involved and give my input whenever possible. I am still somewhat shy but for me it will take some time but I have come a long ways. (HAGI 4)

A smaller group (approximately 20 at any one time) of community members advanced to participate as unpaid volunteers assisting with programs and secretarial tasks The project administrator reported examples of volunteers who achieved independent living in the community:

> One individual started volunteering here doing computer work and eventually we were able to get her a project grant where she developed a computer bulletin board for us. She had been living at home for 35 years with her parents and had never thought of living on her own. Just last year she finally, with a lot of support of the staff, got her first apartment in 35 years. (HAGI 6)

As noted previously, a few persons were also paid to attend training programs. One community member reported that she developed organizational skills and employment experience which allowed her to secure her first job:

> The job I got last year on violence was how I got the PUSH job. I'll be working as a frontline worker at a crisis centre for battered women. It's led to more and more. It opened doors. This one is a paid job! (HAGI 3)

Thus, the majority of disabled community members who participated in the ILC did so as clients with needs for specific programs which could help them live more independently in the community. A smaller number actually participated in ILC planning through the volunteer committee structure. This trend was determined largely by the target group's needs for services.

This section describes how structural factors (advisory structures, leadership, program mandates) in the HAGI organization and ILC project affected the actual roles of community participants in project activities.

Complex Advisory Structure

There were expectations from both provincial (NDP) and federal (Conservative) funders that local community members be involved in the ILC management. The HAGI director noted that at the provincial level:

> They look in your proposal for funding about whether your structure and organization heavily involves the consumers of the service you are proposing. (HAGI 7)

while at the federal level:

> I call them the 'consultation Conservatives' - they don't do anything without consulting first...They ask 'Have you consulted with whoever you are going to provide services for?' (HAGI 7)

In addition, CAILC reviewed each ILC bi-annually to ensure consumer involvement before forwarding a funding recommendation to the government. These external requirements appeared to be influential in HAGI's establishment of the ILC advisory committee structure.

The complex committee structure with five levels (Figure 7 & 8) appeared to be designed to give every volunteer participant a formal role in the project, yet without real decision-making power. For example, the ILC administrator noted that 'volunteer development' was a major focus of the project and was facilitated by the working committees:

> Although they don't have any particular authority in terms of directing staff, they can give staff guidance...The purpose is twofold. One it gives staff an opportunity to talk with consumers involved in their programs on a regular

> basis rather than trying to meet them all individually...Also to use it as a tool for consumers to develop skills in sitting on committees and giving input. (HAGI 6)

Volunteers also served on the advisory committees of other community groups and thus represented the ILC in a variety of community programs. However, staff were concerned about over-working too few active volunteers:

> Things tend to meld together in people's minds and they are unclear of whose committee meeting is what and the different purposes of things. [DOC-19]

Lower level program committees were oriented largely towards training and 'advising' higher levels of the organization. However, the minutes, or recommendations, of each committee were 'approved' by the next level. Thus, the time between the initial advice and guidance of the working committees and final decision-making of the HAGI-ILC board was extensive.

Even the formal ILC advisory committee, which was created after the project had been operational for two years, did not have the potential to negotiate significant changes in any of the core objectives or programs, which were mandated by the CAILC funding agreement. This lack of real influence may explain the inconsistency of members' attendance at advisory committee meetings.

Overall, this complex organizational structure appeared to have some merit in terms of giving positions and activities to every volunteer. However, as noted earlier, HAGI membership restrictions (only physically disabled persons) also meant that not all ILC participants had equal opportunities for involvement at the board level. Although the entire process could be said to be consumer controlled, this was not by a broad range of consumers nor was it very direct.

Staff Leadership

The position of the ILC administrator was a crucial one. The administrator carried out planning, public relations, and project management roles, but also gave leadership to the IL movement provincially, nationally, and even internationally. A staff member commented on the administrator's importance to the project:

> Since the administrator is very effective in almost every area, the present structure works. But it depends almost entirely on her. HAGI is uninvolved and yet ultimately in control. The advisory committee is detached. The ILC is another top heavy hierarchical organization which works because of the administrator, but without her who knows? [DOC-19]

Although ILC staff claimed that they did not plan or develop new programs without the participation of community volunteers, staff did in fact initiate program ideas for volunteers to consider, based on the practices of other ILCs. When volunteers originated program ideas themselves, staff decided whether these fitted into the centre's mandate and resources. Thus, staff members acted as intermediaries between volunteers and the advisory committee and board.

In sum, staff members played central roles in coordinating programs which had been nominally planned and developed by volunteers. While this meant that some staff persons with disabilities had influence, they also served as buffers between general community members and those who actually made decisions.

Advocacy versus Service Mandates

The ILC focus on advocacy created problems for participation in two areas. First, many of the ILC activities which supported individuals in securing housing, employment training, and social support were termed 'individual advocacy'. However, community member participation in these programs was problematic due to the ILC's relationship with

HAGI, a major service provider. For example, ILC staff members attempted to assist disabled clients in negotiating an increase in transportation services from HAGI. When HAGI staff declared that the clients had lower priority since they were unemployed, some community members perceived that ILC staff would not advocate against their own parent organization. Additionally, they feared losing the transit service in retaliation and did not pursue the issue further [DOC-02,19]. Thus, the ILC's inability to effectively advocate against HAGI led to a decrease in the numbers of participants in the individual advocacy program, as well as in its scope of activities.

Secondly, problems arose when members of ILC committees were involved in service planning with other stakeholders such as professionals and social service agency staff. Issues of physical accessibility, employment equity, and housing were addressed in these group planning discussions. However, more politically oriented actions, such as public demonstrations or letter writing campaigns, were termed 'group advocacy' and were disallowed by the ILC administrator and HAGI directors on the basis of the tri-party funding agreement with CAILC and the federal government [DOC-01,02]. Thus, activities which were openly critical of federal and provincial disability policies were discouraged, while activities which were more cooperative and perhaps co-optive in nature, such as participation in government sponsored meetings, were encouraged. This approach frustrated a number of consumers with strong political views on disability:

> ...the centre was not allowed to act as an advocate for people. It always had to act in terms of supporting people in their own advocacy and as a result it was quite stymied, paralysed in a lot of its activities ...unless persons with disabilities take on their own issues the centre won't do it either...the federal funder thinks that's a conflict of interest and in my opinion its a real deterrent to getting people involved. (HAGI 1)

Staff members were divided on the issue of group advocacy. The project evaluator noted that some staff supported the official ILC position, while others were more critical:

> We would be better to facilitate consumers' development of political lobbying skills...We should reevaluate our mandate to avoid political action. [DOC-19]

Overall, CAILC's policy on advocacy restricted political lobbying by the ILC, and appeared to negate the Independent Living movement's socio-political foundations. The policy also failed to acknowledge that group advocacy could be conducted by organizations in areas outside of their own operations, for example, by advocating generally for increased funding for disability services, or by promoting changes in human rights' legislation.

Interestingly, HPD policies on advocacy were more liberal than in other federal departments, such as the Disabled Persons' Unit of Health & Welfare Canada and Secretary of State Disabled Persons' Participation Program. Thus, there was conflict between CAILC's rules, which assigned the mandate for advocacy to politically oriented organizations such as the Council of Canadians with Disabilities, and HPD's relative openness about supporting health promotion projects which conducted advocacy. Receiving funding from both sources appeared to complicate the matter for the ILC.

In sum, the inability of ILC staff and consumers to participate actively and openly in individual and group advocacy reflected a fragmented approach to the problems of disabled persons in the region. The participation of local community members in a cohesive plan to promote disability concerns appeared to be impaired by a confusing mix of federal policies and organizational mandates of HAGI and the ILC.

4.5.7 Influence of Participants

Power dynamics were expressed directly through the HAGI - ILC organizational structure and indirectly through stigma.

Board Monopoly

The development of the ILC project within HAGI, an organization with similar views on disability but a different membership and mandate, illustrated numerous power issues. Initially, the HAGI board of directors reassured the HPD funders that, although the ILC would need close support from the parent organization, HAGI's:

> ...experience and credibility over the last 10 years as a **consumer-controlled organization** for persons with disabilities would prevent any problems regarding the organizational independence of the (IL) centre. [DOC-02]

HAGI expected that its history and philosophy would ensure active consumer influence and it implemented a complex organizational structure to achieve this goal. However, it was evident to all that the committee approach did not work. Under pressure from HPD, CAILC, and the ILC staff, the HAGI directors proposed a compromise in 1991 to allow greater ILC independence:

> We made a new organization called the HAGI-IL Services Inc. Under that corporation, which has a common board with HAGI, they operate both the ILC and the personal assistance program...Mostly we'll have four board meetings in the same night. (HAGI 7)

The new HAGI-ILC board was responsible for approving all ILC committee plans and thus had great control in the project. In theory, this new organization was supposed to achieve the separation of HAGI and the ILC and allow independent action by control of the ILC. However, true independence from HAGI must be questioned considering that the two boards shared the same persons as directors. This manoeuvre allowed the HAGI directors to maintain control in the ILC project, despite concerns about the need for separating service (HAGI) and individual advocacy (ILC) functions. Additionally, ILC independence was undermined at the level of the ILC advisory committee which contained three HAGI board members and the HAGI executive director. In this case, issues of organizational independence and conflict of interest appeared to be treated by board members as technical problems which were manipulated easily.

While ILC staff noted that these manoeuvres restricted their independence ("The ILC tends to be swallowed up with HAGI" [DOC-19].), they did not appear to have an effect on the actual ILC project activities. However, they did affect who approved them. Two volunteers observed that consumer control in the operational decisions of the project was not a reality:

> I don't know if we have a heck of a lot of influence but we sure have a lot of opinions! (HAGI 8)
>
> Right from the start it didn't work out well. Then it was more what we wanted to happen and now it's slowly becoming more controlled. The consumers are becoming more controlled. We don't have much of a say anymore. (HAGI 4)

The reputation of the HAGI parent organization appeared to have a great effect on its ability to restructure the board and advisory committee as it wished. HAGI board members rationalized that since HAGI was 'consumer controlled' there was no concern about whether the organization met the needs of disabled persons [DOC-02]. However, the mere fact that HAGI directors had physical disabilities did not make the ILC 'controlled' by the average consumer. These views appeared to confuse consumer representation, albeit primarily by physically disabled persons, and consumer control in the organization.

Stigma Towards Disabled Persons

HAGI-ILC members were aware of the potential for powerful external interests to divert the project from its consumer focus. By structuring their organization to ensure control of persons with disabilities over staff and board management, there was little opportunity for professionals, bureaucrats, or able-bodied staff to dominate.

Regardless of these controls, able-bodied persons expressed their influence in subtle ways. Volunteers observed that some professionals and bureaucrats who served on committees with ILC members did not give the project their full attention:

> ...they're in and out and they're there in name only...I don't think they really give a damn one way or another, but it's a committee and they can use it in resumes. They come into the meeting and say 'We have to leave in twenty minutes'. Well, what did you come for? (HAGI 8)

Another volunteer noted how able-bodied participants were disrespectful of the intellectual capacities of persons with disabilities:

> Somehow there is still an attitude out there that if you're disabled you don't really have it up here... When I was working with police and lawyers I found it the most...even in the women's groups I run into it once in awhile. (HAGI 3)

In sum, there were subtle social stigmatizing control mechanisms between consumers and able bodied participants regardless of HAGI's efforts to structure the project.

Number of Community Participants

The number of disabled community members who were active in the ILC over the term of the study was approximately 150 persons, including consumer clients [DOC-19]. This number included 8 board members, 3 staff, 3 advisory committee members, and 20 committee volunteers.

Post Script

As an organization, HAGI gained credibility among funders for its ability to develop the ILC project which led to grants for other activities [DOC-04,07]. However, nine years of funding through CAILC (1988-1996) did not signify an ongoing commitment to ILCs by government because of financial constraints and federal restrictions on long term support for community programs which could be considered under provincial jurisdiction. Currently, the federal government is phasing out its funding to this national set of ILCs by 1999.

4.5.8 Case Discussion

The HAGI case represented a mixture of participation styles, being both instrumental and transformational, as well as having purposes of both 'organization' and 'empowerment'. However, the transformational and empowerment aspects were conceived narrowly and appeared to benefit only a few staff and board members. Other consumers had to settle for the achievement of personal goals and were not able to access real influence in the project.

HAGI had a unique reputation among disability organizations due to its longevity, its promotion of a progressive consumer philosophy, its successful funding strategy, and its complex organization. However, the ILC project focus on health education, community development, and service planning was never allowed to include group advocacy issues, which were implicit in HAGI's organizational values and philosophy. Both individual and group advocacy, as crucial components of a response to a social model of disability, were confounded by policies, roles, conflicts of interest, and internal manoeuvres by board members and management to maintain influence. This led to an ambiguous position in the

ILC on acceptable activities which could be undertaken by members, and limited participation of those persons who were interested in more external political action

The development of community members' participation was certainly affected by the service needs of a marginalized target group. However, the organizational structure also seemed to be an influential factor which affected not only who participated and what roles they played, but which also was a key element in the power dynamics of the project. The complex committee structure may have allowed skill building by community members but was controlled ultimately by HAGI board members in the upper levels of the organization. The ILC project advisory committee had the potential to be powerful but was limited in that it was a) organized after the ILC programs were firmly in place; b) composed partially of HAGI board members; and c) answerable to a HAGI board which was not fully representative of ILC consumers.

While these organizational decisions were made in the name of 'consumer control', perhaps in reaction against a history of professional control over the lives of persons with disabilities, there appeared to be considerable manipulation by certain levels of the HAGI organization. Although there was no evidence of personal gain, the effect was to seriously contradict the organizational philosophy of consumer control of the project and cross-disability representation. A lesson learned is that organizational structures which facilitate participation need to be developed to fit minority group needs as well as legal incorporation requirements (Jenkinson 1993).

The HAGI-ILC organization as a whole managed to assert control in its dealings with funders, local professionals, and other disability organizations. However, community participation in this project did not strongly represent a grassroots model. While volunteers were claimed to be the backbone of the ILC, in reality, the staff and board of directors held most of the power. When a community organization is composed of target group members, as in this case, it may be the opportunity for mobility of grassroots members within the organization which is important for participation, as much as the organization's success in its relationship with external groups.

4.6 CASE: HEALTH AND DISABLED WOMEN PROJECT
SPONSOR: DISABLED WOMEN'S NETWORK (TORONTO)

4.6.1 Introduction

In 1990, the DisAbled Women's Network (DAWN) in Toronto began a three year project to address disabled women's health issues. The organizers planned to use the interest raised in this topic to establish a new provincial network (DAWN Ontario) of women with disabilities which would address a broader range of disability issues and also contribute to the national organization, DAWN Canada.

Local self help groups in five regions were established with varying degrees of financial and logistical support from DAWN Toronto. These groups organized a series of regional workshops which were intended to increase awareness about disabled women's health, to identify health care needs, and to develop skills and strategies for improving access to health services. Information materials on disabled women's health were also developed and disseminated. Finally, a provincial coordinating body was organized at a symposium of disabled women, health professionals, and bureaucrats.

The DAWN project model was different from that used in other cases as it was decentralized, with multiple sites acting semi-independently, but with cooperation in some areas. However, the DAWN project was similar to the PUSH and HAGI cases in that organizational development was an intended goal, and in this case was explicit.

This case was selected for review on the basis that project proposals and documents indicated that community persons had played prominent roles as advisory committee members. These committee members were intended to be instrumental in the initiation and development of local DAWN chapters and also in the formation of the provincial network [DOC-01b].

Data sources for this case included seven direct interviews, 19 project documents, and two papers written by participants about the project. Interviews were conducted with the HPD program officer for disability issues, the DAWN project coordinator, and a rehabilitation professional who was involved with a local self-help group. Three community respondents were 30-40 years old and the fourth was 50-60 years old. All community respondents were women with physical disabilities.

4.6.2 Structural Characteristics of the DAWN Organization

History and Program Mandate

DAWN Canada was a feminist organization concerned with women's issues in the disability movement and with disability issues in the women's movement. The DAWN organization developed initially from the failure of disability groups and womens' groups to include disabled women adequately in their planning and management (Stone 1988). In the early 1980's, feminist women in the Coalition of Provincial Organizations of the Handicapped (COPOH) and Disabled Peoples' International (DPI) became frustrated with these groups' lack of response to women's concerns. Specifically, disabled women did not feel included in disability organizations which were dominated by men and which did not support an equal role for women in these organizations. Similarly, disabled women felt excluded from feminist organizations which did not provide accessible meeting places or adaptive services for those with visual and communication impairments. The disabled women's response to this perceived marginalization was to organize separate groups which would focus on disabled women's life issues.

In 1985, a meeting of disabled women in Ottawa founded DAWN Canada, with financial and advisory support from the Secretary of State Women's Program. In the next few years, the efforts of a small number of women led to the formation of provincial and local DAWN groups across Canada. However, these national, provincial, and local bodies were not sustained uniformly due to lack of funding, poor communications, and an over-dependence on individual volunteers. For example, an initial effort to establish a DAWN organization in Ontario in 1986 was unsuccessful due to an over-reliance on two women, and a lack of strategic planning and organization (Stone 1988).

These early groups operated as informal collectives rather than as formal organizations. Stone (1988) reports that DAWN members recognized gradually that a collective organizational structure resulted in 'hidden leadership' and a lack of accountability and responsibility. Subsequently, more formal organizational structures, with elected leaders and bylaws, were initiated at the provincial and national levels. However, grassroots collective organizations continued to be used as mechanisms to mobilize local women.

In 1987, another national meeting was held to elect a new DAWN Canada board of directors, with individuals attending from all of the provinces and territories. At this point, though, there were only a few formally constituted provincial bodies (British Columbia, Saskatchewan, Newfoundland) and local chapters (Toronto, Whitehorse, Quebec City) which could send elected representatives to the national meeting. Other 'representatives' were acting individually and unofficially. For example, in Ontario at this time, contacts had been established with a small number (10-15) of individual women in different cities, but there were no local organizations or networks of disabled women. The national meeting concluded that local chapters and an Ontario provincial network were needed.

In 1988, DAWN Toronto, the sole chapter in Ontario, began to establish a network of local DAWN groups to consolidate a provincial organization and contribute to DAWN Canada. DAWN Toronto decided to utilize a focus on disabled women's health issues to facilitate this goal and applied successfully to HPD for funding [DOC-01a,b]. During the course of this HPCP project, interested women organized local DAWN chapters in Ottawa, Kitchener/Waterloo, Thunder Bay (1991) and in St. Catharines and Kingston (1992). At the end of the HPCP project a DAWN Ontario organization was formally established.

Thus, the DAWN organizations, a nested set of local, provincial, and national bodies, developed slowly and with a variety of organizational forms over a 10 year period. This extended developmental period seemed to be necessary, not only for the evolution of a core group of interested women with disabilities, but also for them to experience community organizing, to develop sufficient confidence and organizational skills, and to decide how they could best interact and function. The HPD program officer noted that:

> Sometimes organizations move as quickly as the people involved can move...(By 1987) certainly there was a stronger sense of 'Yes, it's time for this group to be formed and we're important and let's do it.' (DAWN-4)

The tentative development of DAWN appeared to have been rooted in the life experiences of the target group itself.

Target Group and Issue

As an explicitly feminist organization, DAWN organizers subscribed to the view that disabled women were doubly oppressed. As disabled people, DAWN respondents perceived that they were denied access to public services such as transportation and had few employment opportunities. In support of this view, a 1987 survey of DAWN members in Ontario reported that 74% had annual incomes of less than $11,000 and 50% received less than $5000 annually (Doucette 1987). Disabled women as a group in Ontario also had an 81% unemployment rate (Pal D 1993).

As women, DAWN members perceived they were also oppressed by a sexist society, including men with disabilities. A number of authors writing about women with disabilities support this view and report that the principal experiences of disabled women have been marginalization and exclusion from normal social life, including participation in disability organizations (Doucette 1987, Ellerington 1990).

DAWN's principles appeared designed to counter these experiences of exclusion. In its promotional material, the DAWN Toronto group advocated for the inclusion of marginalized disabled women. For example, DAWN had an explicit goal to make women's services accessible, to recruit disabled women regardless of race and sexual orientation, and to be 'the voice of disabled women'. Other DAWN goals emphasized values of peer education through role modeling for disabled girls, and of providing information on disabled women's concerns. Finally, DAWN valued collaboration in working with other groups, such as social justice coalitions, and bridging the gap between disabled consumer groups and the women's movement (DisAbled Womens Network 1990).

Other less explicit values were also demonstrated in DAWN project activities. Among the most obvious was the value in supporting individual women's development through self help support groups. The DAWN organizers recognized that personal growth was necessary before organizational growth could occur. Finally, DAWN respondents appeared to value organizational independence by working in areas which had been neglected by other groups. For example, the DAWN coordinator noted that, in spite of strong feelings about the medicalization of disability and over-protecting attitudes of professionals, there was a general reluctance among cross-disability consumer organizations to focus on clinical health issues:

> ...it is an issue a lot of disabled people tend to avoid because the last thing you want is to be in hospital or involved very heavily in the health care system since it has tended to be very oppressive. Because we have taken this on and used it as a vehicle... it has taken it up a lot in the community's eyes and for people with disabilities. (DAWN 6)

By addressing health issues explicitly, DAWN members perceived that they gained respect from other organizations and developed expertise in an area which other cross-disability groups did not claim.

At the initial DAWN Canada organizational meeting in 1985, disabled women identified six broad issues of concern: 1) accessibility to the women's movement and women's services; 2) violence against disabled women; 3) affirmative action; 4) assertiveness, awareness, and self-image; 5) sexuality; and 6) parenting and child care (Pelletier 1985). Many of these concerns were associated with health and the health care system. Specific gender and health concerns among the disabled women included pregnancy, availability of Pap tests, and the impact of reproductive technologies on disability. For example, the DAWN Toronto project coordinator noted that child bearing and parenting were particularly problematic due to a lack of knowledge and support services for disabled mothers:

> The health care system hasn't really recognized that we are female, that we have children, that we should be going for Pap tests every year. They haven't realized that we are the same as other women and have all those needs plus the disability on top of that. (DAWN-6)

Disabled women respondents reported that physicians were reluctant to accommodate women with disabilities in their practices due to these professionals' lack of information and to prejudice regarding gender and disability. Similar to the HAGI and

PUSH cases, DAWN members considered themselves to be at a significant disadvantage in their dealings with health professionals. For example, one woman noted that passivity was the expected role in relation to professionals:

> ...many women with disabilities feel so disempowered in their interactions with health care professionals they don't have the confidence to begin even finding a common language. (DAWN 2)

This perceived power imbalance between disabled women and health professionals has been reported previously (Altman 1985, McComas 1993).

However, the expression of these gender-health-disability concerns were complicated by a variety of socio-political interests in the DAWN organization itself. Stone (1988) notes that the history of DAWN Toronto was marked by the delineation of differences between women with disabilities, especially on the role of feminism in disabled women's lives. An interesting example of this tension was on the issue of abortion. While some disabled women supported the feminist principle to the right of reproductive choice, other women questioned this right when it involved the termination of a pregnancy in which there was a risk that a foetus had a developmental impairment. These women suggested that abortion for this purpose devalued people with disabilities.

In spite of DAWN's goal of inclusion, there were also differences in views over the involvement of even more marginalized groups, such as lesbian disabled women. The HPD program officer reported that over time more women in DAWN accepted the importance of including all disabled women:

> ...there's been a shift to looking at oneself with a more empowering kind of light...Even to say the word 'feminist' in 1987 was to be too heavy. (DAWN 4)

Nonetheless, even with a common acceptance of the importance of a feminist analysis, there were significant differences reported by DAWN staff and organizers between women who were interested in personal empowerment and self help, and those who were interested in advocacy and political action.

In sum, disabled women in DAWN felt stereotyped and ignored by women's organizations, by disability consumer organizations, and by health professionals. They had common experiences of marginalization and concerns with access to public services, especially with health care. However, there also were socio-political differences between DAWN members based on feminist and disability perspectives. Overall, a diversity of differences in values and interests did not appear to impede DAWN in securing resources for its work, perhaps because there was little competition from other groups of disabled women in Canada.

DAWN Program Linkages

Since DAWN organizations were formed initially as an alternative to traditional disability and women's organizations, their early links with other community programs were minimal. However, there was one exception to this pattern. The Canadian Association of Independent Living Centres (CAILC) network was a source of both practical and motivational support. The DAWN project coordinator noted that disabled women's health had become a shared concern since both local DAWN groups and ILCs focused on grassroots issues:

> ILC's have disabled women as clients and are getting these questions and have to work with them and they're finding out how bad the system is too. A lot of the ILCs haven't worked on the issue of health so that is new to them. (DAWN 6)

All five of the initial chapters in the DAWN Ontario network were established in cities with ILCs. While local DAWN volunteers supplied the initial motivation and developed project ideas, ILC staff provided organizational and logistical assistance. For example, ILC staff helped DAWN members to contact potential members, to advertise meetings and workshops, to make local transportation arrangements, and provided secretarial and clerical services. Some disabled women employed in ILCs were also allowed to work on DAWN project activities as part of their job responsibilities.

Resource Mobilization

DAWN projects across Canada received funding from various public sources at the provincial and federal levels, from private foundations, and from labour unions. Similar to the PUSH case, which received funding from both disability and addiction sources, the DAWN groups received funding from both disability and women's programs in government. In 1990, the HPD awarded $325,059 to DAWN Toronto for their three year health promotion project which was ongoing at the time of this research.

Although the central DAWN Toronto group received funding to facilitate the development of a network and the initiation of local DAWN chapters, these local groups were also expected to fundraise for ongoing costs or special events. The HPD program officer informed local women's groups that start-up money was readily available from the Secretary of State Disabled Persons' Participation Program:

> We send out the bylaws and encourage them to contact Secretary of State which has been waiting for groups to evolve to help them with seed money. Once they are ready they can get money fairly easily. (DAWN 4)

Thus, HPCP funding was not intended to support operational costs of local programs beyond the program initiation phase. As will be seen, however, few local chapters maintained their fundraising efforts after their initial proposals and expected ongoing financial support from the HPCP project funds. This difference in perspective created considerable conflict within the project and will be discussed later.

Overall, the position of disabled women's groups appeared enviable with respect to funding opportunities. Interestingly, the DAWN organizations were able to develop in a time of social funding cutbacks, including those to other women's groups (Phillips 1992). Being able to span the political agenda with respect to disability and womens' issues appeared to be important in DAWN's early funding successes.

4.6.3 Characteristics of the Health and Disabled Women Project

The overall goals of the DAWN project were to organize a self help network and to inform professionals about disabled women's health concerns [DOC-01b]

Project Objectives

The DAWN project objectives were in the health promotion areas of health education, community development, and health planning and advocacy. The specific objectives as outlined in the final project proposal were:

1) to help women with disabilities meet together to identify common health care concerns and ways of improving their own health;

2) to build a self help network throughout Ontario to provide ongoing support to each other, to share information, and to advocate at the individual and group level for a more accessible health care system;

3) to create practical public education tools; and,

4) to establish sources of funding to ensure the ongoing work of the network [DOC-01b].

In contrast to the PUSH and HAGI disability cases, the DAWN Toronto group emphasized organizational development as an explicit objective. An unstated, yet implicit objective was to involve health professionals in the project as advisors [DOC-01b,04].

Organizational Structure

DAWN Toronto had approximately 60 active members at the time that the HPCP project began. Membership in DAWN chapters was claimed for any disabled woman who attended meetings on a regular basis or who volunteered to help plan activities. Both able-bodied and disabled women were eligible to join the group, although informal guidelines concerning 'consumer control' were in practice. An annual general meeting of members was convened to elect a board of directors and approve DAWN program plans. The DAWN Toronto organization was transformed from an informal association to a formally incorporated organization during the course of this project.

1) A five member DAWN Toronto **board of directors** was elected at the annual general meeting and had a 2 year term. It developed the HPCP project proposal under the leadership of the founding chairperson of DAWN Canada who was a board member. Officially, the board had responsibility for project administration and reporting to HPD, however, in practice it delegated its responsibilities for the project to staff members.

2) The board hired three **employees** for the project. The aforementioned chairperson resigned her board position to take the **project coordinator** role which reported to the board on a monthly basis. The project coordinator and an assistant coordinator managed the project activities with the help of a part time bookkeeper.

3) In 1990, the first year of the project, a group of five women from across Ontario formed a **provincial advisory_committee**. These committee members (1 able bodied and 4 disabled women) were appointed informally by local DAWN chapters for a three year

term. Two of the five committee members were from the parent DAWN Toronto membership, and one of these was a board member. The committee was to meet twice a year in Toronto and reported officially to the DAWN board through the project coordinator. Over the course of the project, the advisory committee membership increased from five to eight persons as new chapters were formed. The advisory committee members helped plan provincial events, developed educational materials, contributed to fund-raising efforts, and promoted the DAWN project in their home communities. Eventually, this committee disbanded when the DAWN Ontario organization was formed in 1992, with most of its members being elected to the new DAWN Ontario board of directors.

4) **Volunteers** in each of the five participating communities took responsibility for development of local membership and group activities. These women were recruited by their local advisory committee member.

5) **Consumers** in each community attended workshops and self-help groups.

Background and Roles of Other Participants

Professionals - There were specific attempts to increase professionals' interest in disabled women's health [DOC-01b]. The HPD program officer recommended the involvement of professionals on the advisory committee, and eventually on the provincial board of DAWN, to ensure the support of other health care providers:

> ...we will need to include people from these (professional) fields at the beginning of the project if we are to be successful in the longer term and at the community level...without it, there could potentially be problems in reaching health care providers and bringing them along with the project. [DOC-18]

However, while representation of health service providers on the advisory committee was proposed as a means for DAWN to gain credibility and acceptance in the longer term, professionals' participation was primarily at the local level. There was only one professional involved on the eight member advisory committee in 1992. Professionals such as doctors, nurses, university professors, and organizations such as the Association of Ontario Health Care Centers, the Canadian Red Cross, and District Health Councils were involved in various other activities. During the project, some professionals attended local workshops to discuss women's health concerns. Others attended a provincial symposium along with policy makers and planners. Professionals also reviewed the educational material and brochures which DAWN staff produced for distribution to health care providers. Finally, disability awareness training was provided by DAWN volunteers for professionals who worked in health care centres.

Further information regarding the numbers and characteristics of professionals in the project was not collected by the sponsor. However, a DAWN survey of 101 health professionals and organizations across Ontario indicated that, although 49% of the 61 respondents wanted to be involved in the project, few actually participated [DOC-13]. Many of the professionals in the project worked for community health organizations, rather than institutions, and were accustomed to working cooperatively with community members. Also, many of the women professionals who participated were reported to express an interest in a feminist analysis of health issues (McComas 1993).

In sum, the professionals who did participate appeared to be sympathetic to the goals and values of the DAWN organization. However, the DAWN goal of developing widespread interest of professionals in disabled women's health issues did not appear to be met.

Bureaucrats - The HPD program officer for disability projects appeared to be instrumental in initiating the DAWN project. She contacted DAWN leaders repeatedly over a three year period proposing that a project could be funded. She then reviewed their proposal [DOC-01a] and negotiated substantial changes which made it acceptable to others in the Health and Welfare bureaucracy [DOC-01b,3,4]. One member of DAWN noted that the bureaucrat had:

> stretched the rules to the n^{th} degree...she's done a fantastic job in funding some of the things she's got funded... (DAWN 2)

After the project was funded, the project officer continued this type of strategic assistance on a bimonthly basis for the first year and then reduced her involvement, reportedly due to other HPD pressures on her time. This personal support appeared intended to lend practical support to the central project and also to influence the bureaucracies of Health and Welfare and the Secretary of State in funding groups of disabled women. As a result, bureaucrats from other federal and provincial agencies participated in local workshops and the symposium.

In sum, women with disabilities participated as advisory committee members, and as staff, board members, and local volunteers. In addition, able-bodied women health professionals and bureaucrats were involved strategically in the project. (See Table 6)

Table 6. Participants in DAWN Health Project

PARTICIPANTS	
DIRECT	INIDIRECT
Advisory Committee ***	Board of Directors
HPD Program Officer *	Other Funders, Unions
DAWN Project Coordinator *	Service Agencies - DHCs
DAWN Staff	Health Professionals
Volunteers (5 communities)*	External Evaluator
Health Professionals *	Local Womens' Groups
ILC Staff	Disability Groups - PUSH - COPOH - CAILC
Consumers/women with disabilities	

* = participant interviewed in this case study

Project Administration and Leadership

The project coordinator was a key participant and acted as an organizer, facilitator, and manager. As mentioned previously, the project coordinator had extensive experience in both women's organizations and disability groups. She had earlier facilitated the development of both DAWN Canada and DAWN Toronto, had a strong personality, and was frequently mentioned by other community, professional, and bureaucrat respondents as being the driving force behind the project. The project coordinator wrote the project proposal, managed its implementation, coordinated and trained local DAWN members to organize, and convened the advisory committee.

Advisory committee members acted as local leaders and coordinated regional meetings, maintained communication with central project staff, and motivated other local women. Some committee members had sufficient leadership skills to organize local groups independently from the coordinator. For example, a disabled bureaucrat, who had experience in funding ILCs through CAILC, was a key organizer in one city.

The DAWN project was intended to be decentralized, with local chapters having autonomy in defining health issues and projects in their own communities. Although local chapters were encouraged to work closely with the project coordinator to develop their activities, they were not bound to do so. However, central project funds were allocated to local groups only if they developed activities anticipated in the funding proposal, for example, organizing educational workshops. Chapters which utilized other mechanisms, such as self help groups, did not receive the same degree of planning or financial support for their expenses. Most of the HPCP funding was devoted to staffing, consultants' fees, and central activities such as organizing the provincial symposium, advisory committee meetings, developing educational materials, and networking with other organizations. In sum, the central DAWN managers had relatively tight control over project resources.

DAWN staff claimed that evaluation of the project occurred in two ways. During the first year, the project coordinator sent needs assessment questionnaires to women with disabilities regarding their health attitudes and practices, and to health agencies regarding the availability of specialized services for disabled women. Although these surveys did not evaluate the project per se, the information was used eventually to develop educational materials [DOC-07b].

Secondly, an external consultant was hired to conduct an evaluation, in conjunction with the project coordinator, at the end of each project year. Evaluation information which they identified as being relevant to community participation included membership characteristics, numbers of women, reasons for joining, benefits, and roles of professionals [DOC-11]. However, evaluation reports for years I and II were not sent to HPD, supposedly due to delays in developing the evaluation plan. Furthermore, an external evaluation was not filed with DAWN's final report to HPD.

Summary of DAWN Structural Characteristics

DAWN had a complex set of structural characteristics which included both strengths and weaknesses. Among its principal strengths was the support of the federal bureaucracy both formally, in terms of funding programs, and informally through the advocacy of interested bureaucrats. DAWN also had supportive links with other community disability organizations (ILCs) which facilitated the development of a network of semi-independent local chapters. Finally, in contrast to other cases, the DAWN project objectives explicitly included organizational development which allowed resources to be channeled legitimately in this direction.

However, DAWN also had a number of characteristics which had the potential for impeding its progress. Disabled women perceived that they had been excluded systematically from other social movements and frequently had to fight to have their issues addressed in disability and women's organizations. Socio-political differences between the disabled women compounded this problem and the project's focus on contentious health issues and professional interactions was a risky venture. A reliance on key leaders such as the project coordinator appeared to be necessary for motivational purposes, however, clear accountability and attention to administrative monitoring were lacking. These were particular weaknesses in light of the need to develop a sustainable organizational structure for a new DAWN Ontario network. The next sections present evidence of links between many of these structural factors and the community participation process.

4.6.4 Types of Participants

Women in the DAWN project were reported by DAWN staff to have similar characteristics to participants in other cases related to disability, although again detailed records were not kept. Respondents noted that the majority of women were 30-50 years old and not employed at regular jobs, although some were enroled in educational and re-training programs. Most project participants were reported to be on disability pensions, had casual jobs, or were supported by their family or spouse. Thus, the DAWN project group appeared similar to the population of disabled women in Ontario with low incomes. As in other disability cases in this study, there was a narrow range of participants in the DAWN organization. Most women in DAWN were reported to have physical mobility or visual impairments, while few women with psychiatric, developmental, or hearing disabilities were involved in the organization. In addition, although ethnic women were involved in some locations, few DAWN groups were reported to include aboriginal women. The types of participants in the DAWN project were influenced by marginalization of the target group and by bureaucrat conflict of interest guidelines.

Marginalization Experiences

Respondents reported that women who were recently disabled or who had led sheltered lives were prime targets for recruitment. However, these women were also reported to have problems with depression, fatigue, and inertia which reduced their participation. A local organizer noted:

> Disabled women around here just sit back and they wait for everything to be done for them. You have to push them all the time, get them out, get them doing things so they're not vegetating in their homes. Give them something to live for, let them know that there are people who are doing a lot more than them, give them some self-esteem. (DAWN 5)

Women with such problems attended self help groups and occasional public meetings, but were not active in the organization of the project.

As women gained experience in the DAWN project, some became highly motivated, articulate, and encouraged others to join. For example, one woman who had been involved in DAWN for a longer period of time reported that her motivation was to achieve changes in accessibility and political recognition of women's needs:

> We are not going to roll over and die. We are not giving up...I'm willing to go to jail. We're going to let people know what we think. I'm willing to have a police record to get change. (DAWN 5)

However, even when highly motivated, participation was limited. Women reported that they were often too busy with health problems, family responsibilities and other community activities, including meetings of other disability groups. Women were also intimidated by public or formal gatherings even when the subject was of concern to them. One advisory committee member summarized the personal factors which limited her participation:

> From my own situation I know it's probably energy, politicization, and powerlessness, like nothing is going to make a difference. (DAWN 3)

Finally, some women were prevented from participating by service providers. A volunteer described how professional dominance restricted DAWN organizers' access to disabled women:

> The difficulty for us was in getting by the gatekeepers because many of them don't want us to meet the women, particularly where you have institutions and group homes where attendant care is provided. They

> certainly don't want them talking to us and telling us they are unhappy with attendant care. (DAWN 2)

In sum, disabled women's marginalization seemed to be a potent factor in inhibiting their participation.

Bureaucratic Boundaries

In one region, a few disabled women bureaucrats were also members of DAWN. According to one respondent, who had been employed in a ministry which funded disability programs, government employees were cautioned by their superiors about being too involved with federally funded consumer organizations for risk of being in a 'conflict of interest'. Presumably this involvement might influence bureaucrats' abilities to judge the merit of disability projects objectively. This caution inhibited her own participation in DAWN until she left the bureaucracy, at which time she became more involved [DOC-18a].

Overall, the presence of sympathetic bureaucrats and target group members on the inside of government decision making circles appeared to facilitate the priority of DAWN groups on the political agenda, their ability to get funding, and thus the involvement of disabled women in health promotion activities. While this support may be criticized as being a potential conflict of interest for bureaucrats, it appeared common and inevitable in an era of government funding of special interest groups such as women, ethnic minorities, and disabled persons, all of whom populated the bureaucracy.

4.6.5 Sponsor Strategies for Participation

DAWN staff, advisory committee members, and local volunteers recruited women with disabilities in ways similar to the approaches used by other disability organizations.

Primarily, personal contacts were made by project staff with key local women. In turn, these local leaders contacted other disabled women as well as women's groups and disability organizations. In addition, project staff sent mailings to health centres, Independent Living Centres, housing co-operatives and other community agencies. DAWN staff also made presentations to conferences and published articles and interviews in the media. Referrals to local DAWN chapters were requested from professionals and agencies such as Vocational Rehabilitation Services. Finally, one local group was fortunate to have a driver for the local bus for the handicapped inform disabled women about the DAWN project in their community. Thus, personal contacts were crucial in recruitment of marginalized women with few resources and little motivation.

In this section, DAWN organizational factors, such as leadership, program linkages, and resource availability are shown to have influenced strategies for the encouragement of participation.

Leadership

The project coordinator's leadership skills and experience appeared to facilitate community participation since she had contacts in many Ontario cities which facilitated the development of local DAWN groups. In four communities, the DAWN project coordinator played an active role in advising women how to organize initial workshops on health issues and self help groups. Respondents from local communities noted that her role was crucial in their efforts to stimulate local DAWN activities.

ILC Linkages

Women from only certain regions of Ontario were recruited in the project and provided an example of how program linkages influenced who could be involved. The project coordinator and local respondents reported that volunteers could not organize a DAWN chapter without ILC logistical support. Thus, women who lived in regions without ILCs and inquired about the project were not actively organized, but were only put on mailing lists to receive information about conferences and resource materials. Although these ILC linkages appeared to facilitate the recruitment of participants, they also limited the geographic range of the project.

Centralized Resource Administration

As previously discussed, most resources were allocated to central project activities which were deemed by the project initiators to be crucial in the development of a DAWN Ontario organization. As a result, local DAWN volunteers complained that they had insufficient funds to adequately address the needs in local areas. For example, they reported that lack of local project funds limited local DAWN groups' expansion of self help and advocacy programs into residential care facilities.

However, local chapters were not very aggressive in seeking their own funding. It was not clear that the DAWN organizers' decision to spend resources centrally had a major effect on participation in emerging local groups. None of the local groups appeared ready to expand their activities during the time frame of this study. For example, by mid-1992, DAWN chapters were established in only four of five target regions. Centralization of resources could have potentially inhibited recruitment and enhancement of local participation, but in this case it did not seem that the local chapters were able to take advantage of these resources. They appeared to need centrally based direction in order to gain enough experience, confidence, and skills necessary to progress further on their own. Thus, a bottom-up decentralized management process with extremely marginalized women may not have been effective in promoting long term participation. Nonetheless, the perception that central priorities dominated local concerns appeared to contribute to conflict between the groups which will be described later.

Limited Funds for Access and Compensation

Finally, local DAWN respondents observed numerous logistical and financial constraints on the organization of participation in both local and provincial activities. At the local level, transportation systems for people with disabilities required booking far in advance which prevented last minute changes in meeting times. Even when arranged, lack of sufficient accessible transportation was a major constraint when 8-10 women all required transportation at the same time to reach a meeting.

At the provincial level, inter-city meetings for advisory committee members, especially for those from northern Ontario, were complicated by inaccessible transportation and accommodations, special diet requirements, and the need for attendant care [DOC-16]. At both levels, there was insufficient child care and a lack of suitable communication facilities for visually and hearing impaired women. Local DAWN organizers perceived that these logistical constraints on participation could have been relieved by including adequate funds in the project proposal for access services, however, this was not done.

Similar to other projects in this study, women in the DAWN case felt that lack of compensation for their time and advice to professionals and bureaucrats was a barrier to their full participation:

> People sometimes resent that they're asked to do something as volunteers when others are being paid $1000 a day and then come back and pick your brain. They say, 'I'm giving all the information but I'm not getting paid'. People feel that their expertise is very valid but it is not seen as valid because it's not paid for. (DAWN 3)

Women did not feel they should be paid for organizational development activities such as fundraising for the organization, but should be paid to participate in a focus group or to help conduct a workshop with professionals as part of the project's health education mandate. None of these avenues for compensation were included in the project proposal negotiated between the project coordinator and HPD program officer.

4.6.6 Participatory Roles and Activities

DAWN members implemented a variety of project activities to address their objectives, beginning with basic health education and support of individual disabled women. Local volunteers organized workshops, in conjunction with ILCs, at which women expressed their experiences in trying to access and receive adequate professional care. At these workshops, women practiced the assertiveness skills which they needed to improve their interactions with professionals. For example, women developed and practiced specific questions on topics such as Pap tests which they could ask professionals. Later, DAWN project staff and advisory committee members produced information booklets which outlined these issues and distributed them to disability and women's organizations.

The DAWN sponsors recognized that individual awareness and skill development, achieved through health education programs, were not sufficient to prepare women with disabilities for negotiating with health care providers. Group support was also necessary and was achieved through the DAWN network of local chapters. This community development process involved local group formation in the five communities, communication links between groups, and a 'Speaker's Bureau' of women willing to address public and professional audiences.

Factors such as DAWN's board and advisory structures, professional involvement, project objectives, and program linkages affected the roles of community participants in project activities.

Lack of Board Involvement

The original roles of DAWN Toronto board members, the advisory committee, and project coordinator were developed during negotiations on the original proposal by the HPD officer and board representatives, including the future project coordinator. The initial proposal to HPCP contained no references to roles for the board members [DOC-01]. External reviewers raised questions over this omission and they suggested having an advisory committee composed of board members only [DOC-03]. Subsequently, the HPD officer suggested that an advisory committee, including women from other cities as well as one board member, be organized to provide local stimulation to chapters as well as be a source of future board members for DAWN Ontario. She also recommended that other DAWN Toronto board members have some involvement on project subcommittees: "Basically this would ensure some board connection and thus, hopefully, no surprises for all" [DOC-04]. This bureaucrat's input appeared to influence the project direction as both these recommendations were presented in the final proposal [DOC-01b].

In practice, the DAWN Toronto board appeared to have minimal involvement in the project from 1990-1992 other than to approve the project reports to HPD. However, as individuals, the new chairperson of the board participated in fundraising meetings with local politicians and one other board member served on the project advisory committee [DOC-16]. Other Toronto board members took a less active role. At least three reasons are possible for this hands-off stance and the lack of a clear role for the board in the project.

First, board members may have felt that the formation of an Ontario DAWN network should be supervised by a provincially based group, such as the advisory committee, which would have more legitimacy. A history of informal collective decision-making in DAWN may have inhibited the boards' involvement, which may not have wanted to usurp the advisory committee's rights to organize its own network. Second, the project coordinator, as a founding chairperson of DAWN Canada and as a DAWN Toronto board member prior to her employment on the project, may have been perceived to represent the board's interests adequately in the project. Third, the DAWN Toronto board was itself going through the process of incorporation and was inexperienced in organizational governance. Eventually in 1992, with the election of a DAWN Ontario board which represented members in the five local chapters, formal responsibility for the project passed from the DAWN Toronto board.

Limited Advisory Committee Mandate

The project advisory committee included experienced women from local groups who advocated a political action approach. According to the final project proposal [DOC-016], the advisory committee was intended to be of central importance, however, the eventual terms of reference of the advisory committee were restrictive and indicated that committee members were to be 'advisory' to staff, rather than to the board. Furthermore, the advisory committee was only to 'provide input', to 'assist in the development of literature', and 'assist in creating a provincial network' [DOC-16], which indicated its secondary importance. The central role of the advisory committee appeared to have been diminished.

As noted earlier, it was not until late in 1992, in the last year of the HPCP project, that most members of the advisory committee were formally elected to a board of directors for DAWN Ontario. One woman was appointed subsequently to the board of the DAWN Canada organization.

In combination with a board of directors which did not assert organizational direction for the project, and an advisory committee which did not have the mandate to direct it either, the project staff were in a position to greatly influence the project's operational decisions. The HPD program officer expressed doubts about the durability of this organization which relied so heavily on a few key articulate leaders:

> I'm not sure the skill development stuff got done as much as the health stuff...Someone is going to have to take some time, sort of talking and helping them and listening and doing those kinds of things, to bring up their level of competence. (DAWN 4)

However, the HPD officer, who had been involved heavily in the early stages, did not appear to monitor the development of roles in the project:

> Because I haven't been able to keep up with the information, I really quite frankly have not had a sense of whether things are working out or not. My sense is that they are OK now, and sometimes I hear otherwise, and I think maybe my intuition is off base here [DAWN-4]

This statement indicates that project evaluation by HPD was virtually non-existent once the project was implemented.

Overall, there appeared to be two purposes of the advisory committee - to advise and assist in a limited way in the health project, and to gain organizational skills to become members of provincial and national boards of directors. Although the advisory committee structure allowed the development of new positions for a small number of local women leaders, their actual participation in this project appeared to be hampered by the lack of a clear mandate and by the absence of any evaluation efforts.

Fear of Professional Dominance

DAWN held regional workshops to sensitize professionals to the needs of women with disabilities. According to one woman, the purpose of sensitization was to:

> ...educate the doctors so that they will become more modernized. A simple thing like having a table that lowers so that people can get onto it, really simple things that they should have thought about by now. You wouldn't think a doctor would have an office you couldn't even get into. (DAWN 5)

A DAWN volunteer reflected on the need for interacting with professionals:

> It was really important to have both consumers and health professionals if the end result was to educate, to change the health care women with disabilities were getting. If we had health care providers involved from the beginning, we would sensitize those individuals and also they would provide connections to their spheres of work and information. (DAWN 1)

However, project objectives which emphasized interactions between marginalized disabled women and health professionals may have limited the numbers of participants. Overall, the focus on professionals made women hesitant to participate since they feared being ignored, patronized, or at risk of repercussions to their personal care.

Generally, local DAWN members expressed caution about professionals and wanted them to play supportive, rather than leadership, roles in the project:

> ...it needs to be consumer focused. If women without disabilities from a professional group came in and took some strong leadership roles in trying to get the group to go where it doesn't want to go, that would create some problems. We're the ones with the disabilities. We know where our issues are. (DAWN 3)

Some local groups developed their own approaches which would maintain their control. For example, in one region, women compiled a list of health care professionals whom they felt were competent in dealing with disabled women's health. In another region, ten disabled women formed a mixed consumer-professional group to discuss health issues (McComas 1994). Thus, some disabled women participated with professionals only if the process was managed to allow women an element of control.

Shift From Health Education to Advocacy Objectives

As the project progressed, DAWN participants utilized planning and advocacy strategies to influence changes in local health facilities. DAWN members held local meetings to which physicians, nurses, and therapists were invited to discuss issues of service accessibility and appropriateness of health care. Two advisory committee members also participated on District Health Councils in their communities.

Finally, the DAWN staff and advisory committee planned a provincial symposium in 1992 for women, health professionals, and health care planners from institutions and government agencies. The provincial symposium was used to discuss professional training curricula, as well as policies and programs to increase accessibility to health services. This symposium also culminated in the election of a founding board of directors for DAWN Ontario. The organizers selected 'delegates' from DAWN chapters based on criteria which included disability type, geography, age, aboriginal and ethnic background, and 'other factors' which appeared to refer to sexual orientation [DOC-17].

In contrast to other cases in this study, participation at the provincial advocacy level was not restricted to a few privileged DAWN leaders and appeared to involve a broader range of community members. Additionally, the move from health education to advocacy did not reduce the number of community members who were involved.

However, there were some negative aspects for community participation at the local level in this shift of objectives. A DAWN advisory committee member noted problems with having both personal growth and political advocacy objectives:

> The difficulty with a DAWN group in many areas of the country is that you have a number of women who are at a stage of their development where they really want a consciousness raising support group. There are a few others like myself who have been involved in a lot of other things, who are into political action. When you try to put those two together at the grassroots level there's often conflict. (DAWN 2)

Thus, internal struggles between disabled women surfaced locally on the issue of participation for personal support versus public advocacy.

Linkages with Advocacy Groups

As noted previously, the early development of DAWN chapters was facilitated by their linkages with ILCs. As part of the advocacy program in the later stages of the project, the DAWN Ontario central group also formed alliances with other groups of women with mental/emotional (e.g., Psychiatric Survivors) and physical disabilities (e.g., Women Living Independently with Disabilities - WILD). In addition, DAWN advisory committee members met with able bodied women's health groups and women's groups against violence. A committee member noted that as the DAWN groups became more visible, the interest of other women's groups increased:

> ...Women's Services (Secretary of State) didn't see disability as something they wanted to get involved in. They only moved since DAWN Canada has done extensive work for them on violence against women with disabilities. Since then a number of local groups through ILCs started to do some work and on that level start to see women with disabilities as part of their community. (DAWN 2)

In contrast to their earlier history of exclusion from active involvement in disability organizations, DAWN was invited to conduct advocacy activities in partnership with consumer organizations such as PUSH and COPOH. For example, the project coordinator represented DAWN on a variety of initiatives addressing drug and alcohol addictions, sexual abuse by professionals, reproductive technologies, and community health centres [DOC-10].

However, DAWN's advocacy activities with other groups were restricted largely to issues and participants at the provincial level. Members of local DAWN chapters were not involved heavily in advocacy because of their close links with ILCs, which were prohibited in their federal funding arrangements from doing so. Fortuitously, the division of the DAWN project into distinct central and local groups allowed some disabled women's participation in provincial advocacy activities to occur.

4.6.7 Influence of Participants

Power dynamics in the DAWN project were reported between the project staff and local groups as well as between disabled women and professionals. Leadership factors appeared to have both negative and positive effects on the influence of community participants.

Central Leadership

There were a number of conflicts reported between local groups and the project coordinator in the areas of resource management and governance. The project coordinator herself claimed that regional DAWN groups had autonomy in their local management:

> Usually I would be the only person coming from the outside. We wanted it to be women working on their own, so they would have control. (DAWN 6)

However, in practice, there were negative consequences to local groups' attempts to assert independence. Women in one community resisted suggestions from DAWN staff to hold workshops with pre-determined topics as a means of forming a DAWN group:

> ...it made no sense to me at all in terms of an information workshop that would be talking at women, showing a film, and having what I thought were silly workshops where women wouldn't have a chance to talk and involve themselves. (DAWN 1)

Instead, this group organized a consumer-professional group, which did not follow a standard format, but consequently received less support and financial assistance. This caused resentment among the women who knew of the resources which other groups were receiving:

> ...I was quite frustrated that we weren't getting some, or more, of this money from the provincial project. It's a real strain to have this project and not be acknowledged that it's going well. (DAWN 1)

A DAWN organizer in another city stated that she was not even aware that resources might be available from the central project for local activities.

A second example of power dynamics involved the advisory committee. The project coordinator and advisory committee members were supposed to plan the project's central activities together, using data from surveys of workshop participants which identified consumers' concerns [DOC-12,13,14]. Advisory committee respondents noted, however, that the project coordinator maintained control over the process of central project planning. For example, requests to include more local (i.e., outside Toronto) representatives on the advisory committee, and to have the committee meet occasionally in other cities, were rejected [DOC-15,16]. Paradoxically, the coordinator herself remarked that over-reliance on one person was undesirable:

> If the leader dominates a group too much some people may stay away...Sometimes they don't get the community involved as much. (DAWN 6)

Thus, with the leadership of a powerful project coordinator who did not acknowledge her own control, a restricted advisory committee mandate, and the hands off approach of the board of directors, the DAWN coordinator appeared to hold most of the power in the central project. As the former chair of DAWN Canada, the project coordinator was able to initiate the project, resign her DAWN Toronto board position to take a project staff position, and then direct the project virtually unimpeded. This manoeuvre may technically have been a conflict of interest, however neither the HPD officer nor DAWN Toronto board members appear to have challenged it.

Experienced Grassroots Leadership

In contrast to this example of central control, another dimension of power dynamics was observed in the interaction between a local group of disabled women and health professionals. These disabled women, who were experienced in community organizing, determined the basic conditions under which they would be involved in a mixed consumer-professional group. One of the conditions was that "the planning, implementation of activities and decision making for the committee was to be controlled by women with disabilities" [DOC-19]. Other conditions which the women suggested appeared to reflect the marginalized experiences which had dominated the women's lives:

> It started off as basic as 'You can't wear a white coat'. That tells you a lot about how people perceived how health care professionals were going to interact with them. We sifted out some of that stuff, got it down to a basic,

> 'We make the decisions. This is what we expect from you and the bottom line being that if we don't like you we can ask you to leave.' (DAWN 2)

Thus, the group was to have a majority of consumers and be able to withdraw the membership of professionals if there was serious disagreement.

The women developed a contract with these terms and conditions and sent letters of invitation to 53 local health organizations requesting written responses to a set of questions. The responses from women professionals made a significant impact on the group:

> We got 11 replies which was really astounding. That was the most empowering meeting. When I arrived at the meeting with the 11 replies people were astounded, excited, shocked, amazed that somebody actually agreed to these conditions to work with us. (DAWN 2)

After interviews, five health professionals were selected to join the group of ten women. Mixed groups of disabled and professional women then sought out approximately 50 women with disabilities living in institutions and in community settings to discuss their concerns with the health care system. Some of these women then participated in other meetings and workshops, thus establishing a local DAWN chapter.

In spite of these rules and safeguards, one professional was selected with reservations, which ultimately resulted in a conflict with the group:

> We chose another woman who we really didn't want. We made the decision to accept her, not because of what she said, but because (of where she worked). We felt that was a key position to have...in retrospect we all think we may have made the wrong decision...We get the sense she's there because her boss told her she should be there. She's not really bought into the process in the same way the others have. The challenge we face is whether we stand up to our contract and ask her to leave. (DAWN 2)

Thus, even with explicit consumer control guidelines defined in advance by the local DAWN group, there were structural aspects of professional influence, such as employment position, which could not be controlled by the disabled women. Overall, however, these local DAWN members maintained considerable control in their project activities.

However, the benefits did not just accrue to disabled women. A professional respondent reported that she benefitted personally from involvement in the local consumer-professional group since she learned both about disability from a woman's perspective and about gender issues from a disability perspective. Other health professionals supported the aims of the DAWN project and introduced the topic of disabled women's health into their clinical practices and classrooms (McComas 1994).

Number of Participants

It was difficult once again to determine the number of active participants in the DAWN project. Organizers estimated that approximately 500 women participated in some aspect of the project during the time frame of this research. However, this estimate included women who merely attended local workshops as consumers and had no other active involvement in the project. DAWN organizers estimated the number of active participants to vary from 10 to 30 women in each of five local groups, although detailed records were not available. This information indicated a relatively small number (perhaps 100-150) of active participants in this new provincial organization.

An indicator of low interest in participation was gained from a survey of disabled women across the province early in the project. Of 520 questionnaires circulated to disabled women, only 94 (18%) were returned. Of these respondents, only 49 (52%) offered to actively volunteer in the project workshops, while 56 (60%) offered to distribute information [DOC-12]. These low estimates of active participants should cause some concern in health promotion funding agencies which might believe projects' claims to have a broad based impact.

Post Script

DAWN groups were established initially in five Ontario cities by local project volunteers, with a further two groups (Sudbury, Hamilton) which obtained other funding to begin activities in 1993. One local DAWN chapter disbanded in 1993 due to internal struggles which were related to ideological differences on advocacy.

Beginning in 1992, DAWN Toronto received funding from the Ontario Ministry of Citizenship and Culture (Office for Disabled Persons and Ontario Women's Directorate) for a variety of new short term projects. However, with subsequent provincial cutbacks to funding, DAWN Toronto dissolved in 1995. DAWN Ontario, on the other hand, continues with funding from the federal Department of Human Resource Development.

4.6.8 Case Discussion

This project had complex goals for individual improvement as well as organizational development. Thus, participation had both 'empowerment' and 'organization' purposes. That these goals and purposes for participation were only achieved partially appeared to be largely due to a lack of effective organizational structure and the reticence of a marginalized target group.

Nonetheless, in the face of discrimination and attitudinal barriers based on both gender and disability, the ability of disabled women to develop local, provincial, and national organizations was remarkable. The emergence of these organizations was in reaction to, but also depended on, the feminist and disability movements since they allowed some key leaders to gain skills, experience, and self-confidence in organizing. However, DAWN Ontario did not develop from the grassroots but from a top-down, HPD-dependent group.

There appeared to be two major groups in this case - the dominant, educated, experienced board members, staff, advisory committee members and bureaucrats who directed and supported the project; and the more numerous local disabled women who had minimal involvement in the organization. The community members who were involved in the DAWN health project were primarily low income women with disabilities and reflected the target group's general characteristics, especially in terms of marginalization, poverty, and unemployment.

A number of structural factors appeared to be important in participation. HPD staff, playing what appeared to be accepted as internal bureaucratic advocacy roles, were influential in securing funding for disabled womens' projects. However, there were also bureaucratic policy guidelines which limited the roles and numbers of disabled bureaucrats who could be personally involved. The HPD program officer was highly supportive of the project, if not partisan, and could be faulted for allowing DAWN to develop unchecked after her initial intensive activity.

The DAWN organizations were clearly in transition. DAWN Toronto's strategy of having both central and local organizational structures and activities was intended to simultaneously develop grassroots and central capacities of the new DAWN Ontario. Having an autonomous organization with standard governance structures such as a board of directors, however, was not a guarantee that community member recruitment or empowerment would occur. Powerful individual staff and an unusual project goal (i.e., coordination of the establishment of a provincial network by a single Ontario chapter) appeared to complicate the role of a hands-off board in this project.

Overall, leadership was the key structural factor in determining the participation of women with disabilities in the DAWN project. Leadership by the board of directors was clearly lacking, although the reasons for this are not completely clear. Leadership by the provincial advisory committee, which had been proposed as the principal mechanism for disabled women's control of the project, was never fully realized. The advisory committee structure appeared to be under-utilized, being only a mechanism to stimulate the establishment of local groups, to develop educational materials, and, perhaps to build skills for future board members. These purposes are not inconsistent with a well-managed project, however in this case, there was little voice for grassroots members. In spite of convincing examples of leadership potential in some local activities, it is apparent that control of the central project was assumed by a single DAWN staff person with considerable experience, energy, and charisma.

One could argue that strong central leadership was essential if the project was to achieve two of its formidable objectives: re-education and planning with powerful health professionals and developing a provincial network of disabled women. Indeed, the project made modest gains in both of these areas, while involving a similarly modest number of disabled women. Thus, central leadership allowed the DAWN Ontario organization to develop in contrast to its earlier (1985-86) efforts (Stone 1988).

Grassroots autonomy was absent, perhaps justifiably so, considering the need for central management to prevent a second failure of the organization. However, the facilitation of a strong ongoing provincial network may also have been hampered by this example of centralized control. Overall, DAWN's strategies for organizational development, requiring a high degree of leadership, were in conflict with its goals for personal empowerment, which required a more inclusive decision-making process.

4.7 CASE COMPARISON

The cases studied have provided illustrations of how structural factors in health promotion organizations are associated with particular components of community participation processes. Through a comparison of these cases, this chapter focuses on developing an understanding of how, when, and why these specific factors influence participation in local projects. Rather than develop a typology of cases based on structural characteristics, which is not appropriate because the cases are few and often similar in structure, each principal structural factor is analyzed showing its relationship not only to community participation, but its connection to other structural factors as well. This approach sets the stage for elaboration of issues related to key findings and their significance to health promotion and community participation in the Discussion Chapter.

The principal structural factors which were identified in the case studies are grouped conceptually into the three dimensions of structure. See Table 7.

Table 7. Principal Structural Factors in the Community Participation Process

POLITICAL-LEGAL-ECONOMIC DIMENSION	SOCIAL-CULTURAL DIMENSION	ORGANIZATIONAL DIMENSION
HPCP Funding Policies - limited federal resource commitment - selection of preferred groups - shift to partnership Administrative Practices - inconsistent payment of costs - inappropriate guidelines - inadequate evaluation HPD Staff Involvement	Socio-demographic Characteristics Target Group Stigma	Technical & Ideological Reputations Service & Advocacy Mandates Restrictive Target Group Mandates Advocacy Objectives Preoccupation with Resource Mobilization Instrumental & Political Program Linkages Governance Model - effect on participant positions - effect on power dynamics Type of Leadership Professional Involvement

In this comparative analysis, the evidence for influence of political-legal-economic factors in the HPD bureaucracy and community participation are discussed first, as these are common across all cases. Next, social-cultural factors which are associated with participation of disadvantaged persons in the cases are reviewed. Finally, the chapter presents the organizational factors which affected the participation process.

4.7.1 The Political-Legal-Economic Dimension of Structure

As defined earlier, the political-legal-economic dimension includes ideology, political entities, legislation, and economic systems which facilitate or limit community participation. The political-legal-economic dimension also includes policy decisions to include or exclude certain groups from participatory programs. Participation in the five cases was influenced by several common factors in the political-bureaucratic milieu, specifically, HPCP funding policies, overly directive administrative guidelines coupled with a loose management style, and the performance of HPD bureaucrats.

HPCP Funding Policies

Target group funding policies and practices in HPD strongly influenced who actually participated in the program in three ways. First, limited federal resource commitments to HPCP are discussed. Second, the effects of the HPD priorization process, the project solicitation process, and bureaucrats' advocacy on selection of certain groups are presented. Thirdly, the influence of a policy shift to partnership funding is described.

a) Limited Federal Resource Commitment to HPCP

At a macro level, political priorities always influence participation through the allocation of resources to particular sectors. A former HPD manager noted that, in a general sense, federal health promotion funding policies influenced the selection of target groups, and therefore the involvement of specific constituencies:

> If the government says the priorities are in drugs and there are only monies available to work in those areas, then the community participation will be limited to those people who see these as important issues, or are desperate enough for money that they'll do anything to get it. (E-9)

Health and Welfare respondents and documents asserted that the HPCP was a showpiece for demonstrating the importance of community participation projects for disadvantaged groups. However, a number of contradictions undermined this claim. First, there were few resources allocated to the HPCP in comparison to centrally-controlled operational projects and to professionally-controlled target issue projects. This inevitably limited the participation of disadvantaged groups.

Second, even though a key strategic focus of the HPCP was to facilitate organizational capacity building of local community organizations, funding terms were brief (32 month average for 16 projects in Ontario). The government's short term funding of demonstration projects warrants comment. Longer term funding would be necessary if the strategic goal was actually to achieve solid community priority-setting, staff training, and development of viable community management structures. Clearly, this was not the case in the HPD. Instead, short term funding resulted in dependency on HPD and unrealistic expectations being placed on small community organizations, a number of which (PUSH, DAWN) did not survive after federal funding was terminated.

Third, project renewal policies were conducted in an ad-hoc manner. Extension of projects was supposed to be based on performance, however, there were no effective evaluation mechanisms utilized by HPD nor sponsors. Instead, some organizations (PUSH, ICHC, DAWN) were flooded with requests from federal and provincial funders to submit additional funding proposals. For example, one sponsor (PUSH) was essentially granted core funding under HPCP, which was contrary to Health and Welfare policy. By funding a succession of projects to PUSH over an extended 5 year period, HPCP supported an organization which conducted public advocacy activities for a priority target group. This appeared to indicate the importance attached to the political support of certain organizations which were in the position of being allies, or alternately, of being critical of the government (Pal L 1993).

The impact of these policies was that, rather than providing an opportunity for community organizations to fully develop themselves to do health promotion work, the HPCP was a loosely conceived 'demonstration' that federal health promotion funding could be inserted at the local level.

b) Selection of Preferred Groups for Participation

A second policy-related influence on target group participation was the HPD priorization, solicitation, and selection process. According to senior HPD respondents, the five target groups in the HPCP from 1987-1991 were identified as disadvantaged groups which had been supported traditionally through Health and Welfare's programs. However, the groups did not have a sufficiently high profile (in contrast to seniors and persons with AIDS) to merit their inclusion in the priority target issue stream. Thus, although these groups were of lower priority, they still merited attention due to their disadvantaged position (children/youth), or to their emerging political influence (women, persons with disabilities).

A priorization process, conducted on an annual basis, was intended to rank the groups in order of their preference for HPCP funding. In practice, certain biases could be detected. For example, Health and Welfare Canada's own internal evaluation had recommended that children, youth, and low income persons should be assigned the highest priority in the HPCP. Disability groups were considered to have lower priority since their needs could be met by provincial and local community funding programs (Health & Welfare Canada 1989). Nonetheless, of the 16 Ontario region projects reviewed in this study, eight projects involved disabled persons while only three involved youths, and only one specifically addressed low income persons (Appendix B). Projects which addressed poverty as a principal focus were rarely funded and bureaucrats claimed that identifying community organizations which were interested in the needs of people with low income was difficult. However, the failure by senior bureaucrats to designate an Ontario staff member to facilitate project proposals specifically with this target group may have been of greater importance.

A second bias appeared to occur in the project solicitation process. When the HPCP was widely publicized in the early years (1982-83), 700 project applications were received annually while only 100 could be approved for funding (Health & Welfare Canada 1985). To reduce this demand in future years, HPD staff solicited proposals only periodically, and primarily from groups which they knew directly, in preference to mass public mailings. However, they also sent application forms to other eligible organizations on request. By 1987, HPD still received five times as many applications as could be funded (Health & Welfare Canada 1989), indicating that the restricted solicitation strategy was only partially effective. In sum, target group priorization and project solicitation, which ultimately determined which target groups and what types of community members would be involved in the program, became narrowly controlled.

HPD respondents claimed that the failure to formally establish long term priority target groups, as had been done for the target issue stream of HPCP, was due to the desire of HPD staff, external interest groups, and political staff to influence the annual process of priority setting. However, there was no clear evidence that the latter two groups influenced priority setting in the HPCP. On the other hand, program officers, with their community development experience and personal links to target groups, advocated that specific organizations be placed on the HPCP funding agenda. For example, the priorization of women with disabilities as a target group occurred because program officers in different regions mounted a campaign to inform colleagues about the particular needs of this group, which were not being met by either disability or women's groups. Thus, the legitimacy of the new group was established gradually through internal promotion by program officers in conjunction with external pressure from disability consumer groups, such as DAWN and CAILC. In this situation, there were so few disabled women's groups in Canada that priorizing this target group meant selecting DAWN for funding.

Senior HPD respondents acknowledged that target group identification was not a neutral activity, but an example of political priority setting. Lobbying practices were accepted by senior HPD staff, as long this did not appear to represent the personal interests of program officers. However, with government staff occasionally being part of target groups, such as women and persons with disabilities, it was difficult to maintain neutrality and a conflict of interest situation may have occurred for one or more staff members.

What was the actual impact of this narrow target group priorization, solicitation, and selection process on community participation? One important effect appeared to be the overweighting of disability projects in the Ontario region. Based on this study of 16 projects, it is difficult to conclude why disability groups received higher priority. However, the persuasive character of the HPD program officer for disability may have been responsible. Bewley (1994) has noted that consumer organizations may be fostered to meet the needs of bureaucrats to be involved with target group communities in order to consolidate their influence within government. While it is not possible to attribute this motive to the HPD program officers, their lack of ongoing involvement in most projects, after their initial intense activity, supports the view that they primarily gained credibility within HPD for stimulating new organizations. In such cases, HPD follow-up and support for the highly valued 'organizational capacity development' was lacking, to the ultimate detriment of these temporary star projects.

c) Shift to Partnership Forms of Health Promotion

A third major influence of HPD policies on local community participation was the increasing emphasis that was placed on funding partnerships. The motivation of senior HPD staff towards partnership participation appeared to be influenced by legitimate concerns about federal fiscal limitations, the lack of representativeness of membership in target group organizations, the low impact of small scale projects, and sponsors' inabilities to develop viable organizations.

The new funding focus within HPD was on partnerships of local community groups with professionals, academics, and bureaucrats which would focus on special target issues. One bureaucrat noted:

> With Healthy Communities there was an attempt to bring the players together. It was different from looking at projects, to look at infrastructures. That is the work of program officers, directors and bureaucrats to see the connections between projects, ideas and infrastructures. (E-5)

Thus, with the advent of funding to community-wide intersectoral programs such as Healthy Communities and Strengthening Community Health, the HPD focus appeared to support participation of community organizations, rather than community members.

Although HPCP projects continued to address their target groups' needs, they were influenced by this shift since their activity plans were approved on a year-to-year basis and they were encouraged to increase partnership and networking activities. As noted previously, this shift to partnership was also supported by local agency staff since it assisted the development of advocacy activities which they felt were important.

The policy of funding collaborative issue-based projects was clearly distinct from funding target groups. On a conceptual level, the new approach of fostering infrastructures, such as community coordinating committees, supported a neo-corporatist model of consultation with community groups, government, and service providers. However, consumer groups had concerns that non-target group members were being brought in as partners and that consumers would lose the control to which they had become accustomed during the 'empowerment' phase of the HPCP.

In the area of disability, for example, the original funding strategy of Health & Welfare Canada focused on supporting individual grassroots organizations (Phillips 1994). During the late 1980's and early 1990's, however, this emphasis shifted gradually to funding partnerships among organizations of persons with disabilities and non-disabled professionals, academics, labour, and business persons. A DAWN member, who was also an ex-bureaucrat, observed that the shift:

> ...is very dis-empowering to disabled persons because it hasn't built in enough safeguards to ensure that we maintain control over the process. And the feds don't want us to have that control. It's too problematic to work through the process. (DAWN-2)

Even a former HPD manager noted that community influence was reduced:

> (The community) had a fair amount of influence at the beginning when it was more open-ended. As the government mandates became imposed on the programs, they had less influence. (E-9)

Community respondents feared that this trend was shifting planning and organization back to a professionally-dominated model which was perceived by HPD to be more efficient and capable of achieving broader health effects. While it could be argued that infrastructure development and networking were functions with which federal level bureaucrats should have been more familiar and capable, this model of participation had the potential for loss of target group influence, in spite of formalization of the participation process.

Finally, community members expressed concern that these partnerships and networks were becoming vehicles to promote federal government political issues, rather than target group needs. A disabled woman commented that a networking strategy was believed to be more visible politically and appealing to the general public than funding small local projects:

> ... they like to see people say they're doing a great thing ... National Access Week, Independence '92, all of that stuff is built on the premise that we in Canada have done a marvelous job ... My sense was that really what they're into is a move to a lot of glitz and glamour in government funding with very little substance. (DAWN-2)

The danger of community organizations being coopted through partnership strategies to support current political priorities was perceived by some community members as a real problem.

Thus, the early target group approach had allowed community members the potential to gain limited control of their projects. This approach generally followed the philosophy of organizational capacity building and the purpose of participation as 'organization' and 'empowerment'. However, when organizational difficulties and the minimal rate of return of these projects became evident, the bureaucracy returned to a target issue approach with which it was more familiar. The evidence suggests that HPD's policy shift to target issues and partnerships at least partly contributed to the redirection of HPCP projects, and thus community members' roles and activities.

In sum, the funding policies of the HPD shifted over time away from a target group approach which supported a narrow range of favoured groups and community organizations, and which also had limited capacity to implement health promotion over the long term. Networking and coordination of activities between agencies began to be encouraged, but new partnership strategies seemed to preempt community member control of their own health promotion activities.

HPCP Administrative Practices

A second major political-bureaucratic factor involved administrative practices within the HPCP. Three aspects of this administration affected the ability of community organizations to implement participation programs. First, the influence of inconsistent payment for participant costs, including volunteer honoraria, is described. Second, the appropriateness of guidelines for participatory structures is discussed. Thirdly, the effect of a lack of evaluation is presented.

a) Inconsistency in Payment of Participant Costs

Paying target group members to participate in projects as volunteers, advisory committee, or board members was a controversial strategy. Financial incentives for individuals' participation were not supported readily by HPD guidelines on allowable expenditures. HPCP allowed volunteer honoraria only for certain discrete volunteer activities which resulted in a product (e.g., collecting survey data in the PUSH project) rather than for attendance at organizational meetings. However, all sponsors recognized the value of material incentives and believed that these increased the numbers of participants and the consistency of their participation. Some agencies (ICHC, ICYP, HAGI) secured limited resources from other funders to pay a small number of community members as volunteers. This practice appeared to have a symbolic value in encouraging the participation of others who aspired to these positions in the future. Completely 'voluntary' projects may have had even less potential for securing individuals' participation.

However, the policy which dictated that volunteers were not to be compensated neglected the issues of opportunity costs of participation (i.e., by participating, a person gave up the opportunity of earning income elsewhere), and created inequity between well-paid sponsor and professional participants and unpaid community volunteers. For example, in the ICYP street youth project, staff tried to achieve long term commitment of the youths by paying them for their time and advice. However, this strategy was at odds with the HPD view that the project activities themselves were intended to benefit the youths and they should not be compensated for volunteering. This disagreement illustrates an incompatibility between health promotion programs which assume an inherent value in community participation versus disadvantaged community members' perceptions of their own needs.

Overall, HPD guidelines governing honoraria for volunteers caused considerable resentment between sponsors and community members and negatively affected the ability of sponsors to organize community volunteers in most of the projects (ICYP, PUSH, HAGI, DAWN). However, the inability to interview non-participants in projects limits the conclusions that can be reached as to the importance of financial incentives. Studies in other provincial jurisdictions have reported that restrictions on volunteer honoraria in health promotion planning had similar negative effects on participation (Yazdanmehr 1994). The important issue of providing compensation for voluntary contributions by disadvantaged persons in health promotion will be explored further in the Discussion Chapter.

Lack of funding for direct participation costs was also a problem. Initially, it appeared to the researcher that HPD rules were being applied inequitably to projects since a few groups received some participant support costs (child care, transportation, accessibility) while others complained that they did not. There seemed to be three reasons for this discrepancy. First, HPD project officers may not have offered consistent advice to applicants on this issue due to their preoccupation with networking and other bureaucratic work. Second, community project sponsors may not have been adept in estimating the costs of participation. It was evident that projects which applied initially for participant support costs received some funding as long as details were completely specified. This strategy, however, was not always feasible for grassroots groups which had yet to develop detailed action plans that required consultation with community members who had not yet been recruited (DAWN, ICYP). Third, the HPD administrative system may have been inflexible and unresponsive to the needs of target group participation. Groups which applied to HPD after project approval to change their budgets were less successful in their efforts, since HPD utilized a rigorous budgetary approval procedure that allowed only internal budget changes on an annual review basis. At this time, requests for extra budget resources could not be approved

In sum, disagreement on the need for volunteer honoraria, incompatibility with a federal budget approval system, HPD staff inconsistency, and the inexperience of community agencies appeared to contribute to sponsor difficulties in securing support costs for participation. These problems further illustrate the contradiction in HPD's emphasis on organizational capacity building as the focus of the HPCP, versus the actual operation of the program.

b) Inappropriate Guidelines for Participation

A second HPD administrative influence involved a variety of guidelines to manage the participation process. HPD promoted the formalization of community participation in local projects through mechanisms such as incorporation and the formation of advisory committees. However, few projects had specific operational objectives in this regard and thus had limited resources for development of organizational structures. Projects which had monies available for organizational development could spend time developing their organizations (DAWN), while others had to borrow time from other project goals (HAGI, PUSH, ICHC, ICYP). Some projects were already part of incorporated organizations (ICYP, PUSH, ICHC). Other projects (DAWN, HAGI), in complying with HPD advice to become more formalized, seemed to follow the letter of the incorporation law, but not its spirit.

In addition, guidelines for participation did not fit each target group equally well. As seen in the ICYP and ICHC cases, youth participation was not easy to achieve on the same basis as adult participation, due in part to the necessity of having adults manage the project finances. Similar problems were documented in other Ontario HPCP projects involving persons with developmental and neurological disabilities and women ex-offenders with substance abuse problems. These problems seemed to represent contradictions between a formal, uniform approach to participation guidelines and implementation realities in specific target groups.

Even in adult projects (DAWN, HAGI, ICYP), community respondents noted that participatory mechanisms suggested by bureaucrats, such as community coordinating committees, inhibited the participation of grassroots members who did not have experience in these venues. Community members complained that excessive time was devoted to organizing committee functions and interactions with each other, rather than in addressing health and social concerns of the target group. Thus, federal directives to develop participation structures at the community level did not attract widespread public interest or support, although the individual sponsors who were directly involved in these formal structures appeared to have an interest in them.

Finally, although formal incorporation requirements often delayed the initial implementation of projects, they were supported generally by local groups as the price to pay for HPCP funding. However, this focus on organizational capacity building, public accountability, and representative decision-making, which HPD staff respondents specified as one of their primary goals for participation, was not matched by necessary resources or planning. Again, HPD principles which emphasized local capacity building and community development appeared to be beyond its own capacity.

Overall, the effect of HPD's administrative guidelines for community participation was less clear than in other jurisdictions which have set formal legislative mandates for participation (Gittell 1983, Green 1994). A comparative study would be informative to determine the relative importance of this factor to participation.

c) Inadequate Evaluation Practices

A third aspect of HPD administrative practices which influenced participation was its focus on evaluation. HPD's lack of evaluation and monitoring appeared to decrease the amount of information about participation strategies which was available to project sponsors. Within the entire HPCP funding program, HPD collected little information specifically about community participation, except for a brief general rating of participation by a sample of 100 funded projects (Health & Welfare Canada 1989). As noted previously, evaluation ratings indicated only a moderate degree of public participation in project planning, implementation, and evaluation. Although this evaluation was an in-house activity, and would not be expected to offer a negative view of the program, the evaluators were still critical of the reported degree of community participation.

A further review of project reports and correspondence in these cases indicated that a lack of interest in evaluation at the government level filtered down to local projects. In the sponsors' quarterly reports to HPCP, financial matters were reported in detail, but other information about projects was given less attention. Changes in HPD reporting formats appeared to influence this minimal presentation of information. Early (pre-1991) quarterly reports were in the form of narratives in which sponsors described current project objectives, activities, and plans for the future. The focus on community participants was primarily in terms of reported benefits. At this time, sponsors limited their evaluation of the process of community participation to reporting the number of target group members at public events or the number of people who received educational materials. In efforts to document the participatory nature of their projects, some sponsors even claimed that less active members of groups, such as those on mailing lists, were actively involved in the decision-making process. For example, a disabled woman in Thunder Bay was simultaneously counted as an active member of the HAGI, PUSH, and DAWN projects.

By 1991, HPCP required projects to submit their reports on standardized forms to ensure a more consistent and readable reporting format. Ironically, this new requirement drastically reduced the volume and detail of information which project sponsors reported, including information about participation of target group members. As a result, little was actually reported about participation in the projects and HPD staff had little information on which to give feedback. In two study cases (PUSH, HAGI), a more complete internal evaluation was performed, partly to meet a requirement for the extension of funding. However, even in these detailed evaluations there was virtually no attempt to determine the quality, depth, or effectiveness of participation [HAGI DOC-19, PUSH DOC-11A].

HPD respondents explained these findings by noting that initially there were difficulties in identifying and implementing appropriate evaluation indicators regarding community project processes, and this has some validity. Subsequently, however, HPD staff developed indicators for 'increasing public participation' and 'strengthening community groups', but did not apply them to actual projects. Again, this appeared to reflect the actual importance of community participation to the bureaucracy, apart from its symbolic value. By failing to model good evaluation practices, by not demanding local evaluation reports, and by utilizing monitoring mechanisms which limited the amount of useful information, HPD ensured that feedback was limited, particularly concerning the range and influence of participants. This in turn allowed sponsors to develop widely divergent styles of community participation according to their own ideas.

HPD Staff Involvement

The third major political-bureaucratic factor affecting participation concerned HPD staff involvement in the projects. By 1987, regional HPD staff were responsible for administering HPCP target group projects, for coordinating local target issues projects and regional aspects of national projects, and for consulting with provincial health promotion authorities. While the HPCP budget for target group projects remained relatively constant ($4 million), the total number of HPCP projects (target group and target issue) across Canada increased from 108 in 1986-87 to 240 in 1987-88. National level programs increased simultaneously. Since staff levels in regional offices increased by only 15% during this time period, all HPD respondents claimed that program officers had increased responsibilities in other program areas, with less direct contact with HPCP projects and less time for target group development. These changes in workload also coincided with the perception of regional staff persons that they experienced a loss of influence over setting HPCP target group priorities.

Bureaucrats seemed to play mediating roles between community members, professionals, and the broader bureaucracy to facilitate the involvement of multiple interests in projects, rather than focussing specifically on target group member participation. For example, HPD staff were instrumental in recruiting bureaucrats from other federal and provincial ministries to be involved on project advisory committees, although this was achieved with mixed success. HPD program officers also helped in community member recruitment in some disability projects (PUSH, HAGI, DAWN) by arranging links between community groups.

Although individual bureaucrats provided support for strategic planning in some disability projects (PUSH, DAWN), direct involvement of program officers in local projects varied greatly. This appeared to be due to personal working styles of bureaucrats, to the needs of specific project groups, and to the availability of bureaucrats' time. Generally, HPD staff involvement was heaviest at the beginning of projects and declined later. Thus, HPD staff were not very involved in the development of project advocacy activities, which usually emerged later in the projects.

By 1992, the principal roles of program officers had shifted from the stimulation, planning, and monitoring of individual projects to being sources of information about funding and about other groups working in the area. This role change also coincided with the HPD's shift in focus to networks and partnerships through the HPCP. However, this shift presented a dilemma to Ontario program officers who expressed concern that some sponsor organizations did not yet share their idealistic ‘empowerment’ vision of participation, nor have sufficient organizational skills to implement participatory strategies on their own. Consequently, some HPD program officers continued to contribute significantly to the design of local projects (HAGI, DAWN), including the development of strategies for involving community members. Over the time frame of this study, however, there was decreasing bureaucratic support and monitoring of the development of local participation.

Overall, the supervisory process may have compromised government accountability principles. Certain program officers appeared to take the side of community groups over the government by accepting inflated estimates of local community participants and by neglecting evaluation requirements. However, in the context of the HPD and its ever-shifting approach to target group health promotion, this loose performance seemed to be tolerated since the interests of the senior HPD bureaucracy had moved on to more exciting ventures. There was little pressure on program officers to monitor small HPCP projects closely. To the degree that this was a politically motivated funding program for target groups, HPD staff performance did not contradict this overarching purpose. In addition, senior HPD staff recognized that the political benefits of the program far outweighed the costs of its loose administration.

Pal (1993) notes that during the 1970's a similar phenomenon occurred in the Women's Program of the Secretary of State, whose administrators held themselves accountable to the women's movement rather than to government priorities. Pal also notes that women bureaucrats were able to do this due to the relative invisibility of the Women's Program within the bureaucracy. This invisibility may have been similar for those HPD staff who were involved in small local projects, especially after new high profile target issue and national health promotion programs were put in place. Regardless of the question of internal accountability, however, the impact of minimal supervision by distant bureaucrats on local project participation appeared to be significant. It may be important to study whether the sustainability of community organizations is directly related to project support and supervision, especially for small target group organizations. The interplay of bureaucrats' personal advocacy for target groups and their preferred style of work may also be an important element in the study of publicly funded participation programs.

This section shows that political-legal-economic factors had major effects on the selection, support, and management of HPCP local projects. These factors indirectly determined the types of participants in HPCP projects and the organizational strategies which sponsors used to mobilize community members.

In sum, rhetorical suggestions that government funding programs could enable community participation and capacity building served to motivate local agencies. As well, individual bureaucrats were critical in stimulating local community organizations to apply for funding. However, funding policies for target group programs were developed inconsistently and were influenced by HPD staff preferences. Furthermore, bureaucratic follow-up was neglected, due in part to a lack of clear plans for policy implementation in the HPCP. Restrictive administrative practices concerning project financial guidelines and organizational structures also seemed inappropriate for small scale agencies. Projects' geographic remoteness from support in Toronto and Ottawa complicated the matter. The consequences for local projects were expectations by HPD of empowerment and participation, but without practical support.

Overall, the claimed agenda of the HPCP, to support grassroots participatory health promotion organizations, was limited principally by its strategy of short term funding. A lack of long term commitment was accompanied by a policy shift to funding partnerships and networks which emphasized macro level planning and information sharing, rather than micro level project management. Consumer organizations, which were less willing and able to adapt than traditional service agencies, fragmented and began to disappear. Thus, HPCP provided opportunity structures for local agencies to develop temporary participatory projects, but simultaneously provided little overall support or direction. The fit between federal expectations of sophisticated project implementation and the realities of disadvantaged fragile organizations was poor. Overall, one can conclude that a political function of the HPCP was evident, in a time of general support for social interest groups.

4.7.2 The Social-Cultural Dimension of Structure

As defined earlier, the social-cultural dimension of structure includes influences (attitudes, norms, values) from social relationships which have developed historically, such as dependency and marginalization of minority groups and women. The social-cultural dimension also includes the socio-economic nature and interests of various groups. The target groups being addressed in these five cases were persons with disabilities, youth, and women, all of whom experienced poverty, marginalization, and discrimination. These groups were selected for attention in the HPCP with the assumption, based on an 'empowerment' understanding of participation, that in addition to the practical needs which could be addressed by health promotion, the groups had a right to programming which could improve their individual conditions. In addition, the groups had a right to participate collectively in joint activities. This participation, however, was inhibited by two key factors in the social-cultural dimension of structure - sociodemographic characteristics and target group stigma.

Sociodemographic Gradients in Participation

A gradient of participation occurred across a number of basic sociodemographic factors. Although a variety of ages were represented in the cases, there were few seniors (older than 50 years) and young children (under 13 years). Youth projects (ICYP, ICHC) included those 13-22 years of age, while other projects (PUSH, HAGI, DAWN) included persons primarily 30-50 years old. No youths were involved in the disability consumer organizations. The minimum age necessary to be a member (16 years) or director (18 years) of an incorporated agency in Ontario may have limited the involvement of youth in these membership-based projects. This restriction on youths' participation in management illustrates an incompatibility between goals of youth involvement and self-managed projects as the preferred forms of community organizations for health promotion funding.

There were generally equivalent numbers of men and women reported by staff to be involved in projects, except in HAGI and DAWN where women predominated. Women's lower workforce participation was cited in only one case (HAGI) as a reason for the higher involvement of women. Project objectives also influenced gender ratios, since there was some evidence (PUSH, HAGI) that advocacy activities were preferred by men over social support and self-help activities. In addition, there were significant attitudinal barriers to women's participation noted in two projects (ICYP, ICHC), which eventually required the formation of separate women's groups.

According to case respondents, there were few aboriginal participants in the projects. This imbalance was also reflected in the lack of aboriginal projects (1 of 16) in the Ontario region. Ethnic community members were evident only in the ICHC and DAWN projects. Finally, community members with very low incomes or educational levels were reported to have low involvement. They usually participated as clients and volunteers, rather than in more responsible project management positions.

Age, gender, income, and educational levels have been reported previously to be related to community participation (Sills 1968, Cohen 1980, Godbout 1981, Eakin 1984). However, the mechanisms by which sociodemographic status affects participation are complex and contentious. Persons who have to concentrate on meeting their basic living 'needs' may not participate as extensively (Widmer 1987). This explanation is supported in these cases by the virtually unanimous desire for financial compensation for volunteer participation. However, an 'incentive' explanation for non-participation also seemed to be relevant, in that many disadvantaged community members were reported to disbelieve that there would be valued benefits for their participation efforts. Similarly, the 'civic culture' of participation in mainstream health promotion activities may not have been relevant for those from ethnic and aboriginal groups. Finally, sponsors noted in these cases that it was particularly difficult to combine individuals from different income groups in the same activities, since lower income members felt labelled negatively and not welcomed as equal participants. This may explain the common finding that project benefits accrue to more privileged community members (Sills 1968, Watt 1988).

As a counterpoint to these explanations based on sociodemographic differences, Cohen (1980) and Wandersman (1981) suggest that fixed elements of target group status may be less important to participation than non-structural factors such as the immediacy of the issue to target group members and their length of residence, stability, and experience in the community. In these cases, participation of many target group members seemed to be limited fundamentally by their slow personal progress in self-help activities. Inexperienced target group members were not generally interested in managing health promotion projects and required significant staff support for administrative tasks which required financial accountability and reporting skills (HAGI, ICYP). These limitations may reflect the degree of powerlessness in disadvantaged target groups and the time required for personal changes to occur (Wallerstein 1992).

Overall, the particular target groups selected by the HPD had a number of sociodemographic disadvantages which have been reported to be associated with low levels of community participation in other areas of public health (Godbout 1981, O'Neill 1992, Sullivan 1995). Although planners expected some difficulties in recruiting participants, they did not appear to have anticipated the narrow range of participants in most projects, and HPD staff expressed concern about 'representativeness' of the groups. Ultimately, however, HPD's focus on funding separate target groups in the HPCP seemed to reinforce these exclusions, rather than bringing diverse sociodemographic groups together.

Stigma Toward Target Groups

Stigma is defined as a personal attribute which detracts from the character or reputation of a group (Neufeldt 1988). However, in a sociological sense, stigma is also a social relationship marked by exclusionary attitudes towards general conditions such as poverty or disability. In these study cases, attitudes toward marginalized target group members by sponsors, professionals, and bureaucrats were reported to affect participation significantly (ICYP, PUSH, ICHC, HAGI). Some professionals and bureaucrats patronized community members or discounted their abilities to make rational decisions. Other professionals reportedly exercised subtle power dynamics by intellectualizing discussions, by inattention to community member views, and by limiting the time spent in meetings with community participants. Furthermore, marginalizing tactics were directed usually at the target group as a whole, rather than at specific individuals with whom professionals were interacting. This supports the conclusion that a general stigma was associated with the status of being in a target group. Interestingly, this dynamic was repeated within target groups themselves (e.g., stigma regarding gay youth, developmentally disabled persons, and lesbian women).

HPD's target group funding policy and lobbying by bureaucrats for the inclusion of particular interest groups (e.g., disabled women, ethnic youth) was intended to support 'at risk' groups which supposedly had issues in common. However, these strategies may also have reinforced the exclusion of other subgroups which were not specified, such as institutionalized disabled persons and gay and lesbian street youth who were even more marginalized. Guidelines for target group inclusion were not specified clearly by HPCP and each project appeared to use its own criteria to form compatible groups. Consequently, the representativeness of these small organizations, especially those which were organizing province-wide advocacy activities with a small number of active participants (PUSH, DAWN), could clearly be questioned.

Thus, internally and externally derived stigma seemed to have a limiting effect on community participation. Woelk (1992) has suggested that those who have limitations imposed by their social environment (e.g., stigma, lack of opportunities) may not believe that they have the right to participate. This viewpoint has been demonstrated in the literature on powerlessness, learned helplessness, and empowerment (Wallerstein 1992, Rappaport 1987). Wallerstein (1992) and Woelk (1992) further suggest that marginalized groups are both excluded actively and fragmented internally and thus are unable to organize. As a consequence, disadvantaged persons may develop a world view that open participation with non-marginalized persons will not be productive for their survival.

This section on social-cultural structural factors illustrates an important issue. Ultimately, participatory programs are intended to decrease differences in status, in resources, and in opportunities on the philosophical principle of equity. Although target group members had the right to participate, they often did not do so because of sociodemographic factors, which reflected a variety of inhibiting mechanisms, and stigmatizing attitudes of other participants. Thus, subtle social closure mechanisms were operative which resisted the dominant rhetoric of participation (Scott 1990). The choice of particular groups of disadvantaged persons may indirectly determine a low level of participation which is both inherent in their disadvantaging condition (e.g., poverty, disability) and also reinforced by systematic exclusion through stigma.

4.7.3 The Organizational Dimension of Structure

As defined previously, the organizational dimension of structure includes administrative networks, procedures, and attitudes of planners which shape the decision-making process. Organizational structural factors affecting participation in these five cases are presented in three groups. The first group consists of factors which reflected the reputations and responsibilities of the sponsor agencies. Specifically, sponsor agencies' histories, their program and target group mandates, and specific project objectives influenced the types of participants and the strategies which agencies used for recruitment.

Technical and Ideological Reputations

Sponsor organizations were all pre-existing community voluntary associations which operated other community health and social service activities for which they were known in their communities. The history of most sponsor groups (ICYP, PUSH, HAGI, ICHC) in organizing projects was a powerful motivator in attracting target group members to health promotion activities. For example, ICHC staff gradually developed a public reputation among ethnic leaders for their compassion, interest, and competence in ethnic health issues. This reputation gave it a 'technical expertise' in certain activities and services which attracted ethnic participants. Similarly, the ideological positions of some sponsors (HAGI, PUSH) gave them a 'moral authority', which attracted participants. For example, PUSH developed a reputation as a promoter of disability rights in the province and was able to mobilize consumer interest in the HPCP project based on this position.

Sponsor organizations which worked with transient groups (ICYP), or groups with internal divisions (DAWN), had more difficulties in using their reputations to attract participants. Drake (1992) notes that a common history of struggle will mobilize a group but that this can be difficult to institutionalize and sustain, especially if the group has low internal cohesion. An interesting proposition for further study is the extent to which the stability and cohesion of a group affects participation in social movements.

Service and Advocacy Program Mandates

Program responsibilities were related to these reputational factors. Sponsor organizations had 'program mandates' (their position on a service-advocacy continuum) and 'target group mandates' (the particular target group being addressed).

All of the consumer organizations (PUSH, HAGI, DAWN) had overall goals to advance the positions of disadvantaged persons through advocacy and/or to meet the specific needs of members through service (HAGI, DAWN). The remaining agencies (ICYP, ICHC) had program mandates to provide health and social services to high risk groups (street youths, ethnic families). Advocacy activities were secondary priorities on the whole for service agencies, although ICYP did shift in this direction later in its STD project.

An emphasis on service mandates tended to restrict the roles and influence of community members since, in these cases, sponsor staff were accustomed to working with target group members as passive clients rather than active partners. Many services involved hierarchical provider/client relationships, rather than self-help or mutual aid interactions, which assume more equal status between organizers and community members. Although power dynamics were evident in service projects, it was difficult to distinguish their effects from the dynamics of adult-youth relationships. Overall, service agencies seemed to view the service to individuals as a sufficient benefit in itself. More active participation of target group members in project management was perceived by these sponsors as a potential conflict of interest for target group members who might increase their personal benefits at the expense of others.

Organizations with advocacy mandates tended to focus on public benefits, for example, policy changes and promotion of the organization as a legitimate player in the field. Advocacy roles in projects were assumed generally by a few community members with more experience in the organization. The influence of community members in these groups was facilitated since advocacy was in opposition to external interests such as professionals, who were perceived as a threat (PUSH, HAGI, DAWN). In some projects (HAGI, DAWN Central), however, an advocacy mandate did not give individual community members much influence within their organization and only masked expressions of internally focussed power.

One can ask why individual community member influence was lacking in these advocacy organizations. Although advocacy style organizations tend generally to have members who are ideologically-oriented and who make strong commitments to participation (Sills 1968), this may not be the case in organizations of disadvantaged persons who rely on others to speak for them. The relative differences in status and experience between leaders and other more marginalized target group members may ensure that leaders assume control in order to achieve the public benefit goals of the organization. A study of leadership and member characteristics in advocacy organizations versus service agencies, in both disadvantaged and general community populations, may be helpful in delineating the effects of program mandates, leadership, and disadvantaged status on participation.

Restrictive Target Group Mandates

A third organizational factor related to agency responsibilities involved their target group mandates, or their bias towards particular disadvantaged groups. Limited target group mandates in these cases appeared to restrict the range of community members who were involved. Most agencies used a narrow approach to target group definition (HAGI, PUSH, ICHC, DAWN) such that particular groups (e.g., persons with developmental and psychiatric disabilities, Afro-Caribbeans, aboriginals) were not included readily. Fears of being overwhelmed with complex issues of disability stigma and racial tension may have been factors underlying this restriction.

In these projects, target group mandates appeared to be set by the particular history and ideology of the agencies, however, it should be noted that they were also influenced by funding criteria established by a variety of bodies (Ministry of Health, Health & Welfare Canada, CAILC, Secretary of State) which required specific target group identification for funding eligibility. HPD staff encouraged some agencies (HAGI, DAWN) to broaden their focus to be more inclusive yet at the same time, appeared to support a narrow view in its own selection of projects. For example, in the Ontario HPD office, records indicate that there was over-selection of agencies with mandates in physical disability (versus developmental and psychiatric disabilities) and in child and women's agencies (versus low income and aboriginal agencies).

The agencies in this study recognized their narrow ranges of participation and attempted to redress situations by encouraging individuals from excluded groups to participate, but only as individuals, not as representatives of excluded organizations, and not at project management levels. Similar problems with narrow ranges of participants have been noted in other Canadian studies (Stone 1988, Lord 1988). However, the literature also suggests that certain ideologies, such as feminism and Marxism, can overcome concerns about group heterogeneity in community development projects (Litwin 1986). It may be useful to examine whether or not there is a broader range of participants in health promotion projects which utilize these ideologies.

Advocacy Objectives Limit Grassroots Involvement

Actual project objectives, their source, and their shift over time were a fourth organizational factor related to agency responsibilities which influenced participation. The five HPCP projects differed in their project objectives but generally followed the lifestyle (ICYP, ICHC) and social structural (DAWN, PUSH) streams of health promotion. These objectives generally fitted the service-advocacy mandate dichotomy previously mentioned. One project (HAGI) incorporated both approaches. Few projects had explicit participation objectives and most appeared to view community participation as a process, or strategy, to implement projects rather than as an outcome, or end in itself. This appeared to contrast significantly with HPD views of participation.

Service projects with lifestyle objectives (ICYP, ICHC) put primary emphasis initially on direct contact with target group members. Gradually, however, organizers used general education and the media to contact the public and considered that dissemination of the program and materials to a wide variety of audiences constituted community participation. However, these latter participants were largely passive recipients of information.

In advocacy projects with social structural objectives (PUSH, DAWN), a small number of participants with considerable depth of involvement undertook advocacy work. These groups placed little emphasis on the dissemination of health education materials, yet also claimed that inactive, or infrequently active, target group members were represented in the project as participants. These participants could be considered to be passive recipients of increased status and influence through their affiliation with the organization.

A project with a mixed focus (HAGI) attempted to have community participants support each other in peer groups as well as participate in negotiations with providers to improve access to services. There was a wide range of participants in this project - from those acquiring basic life skills to those participating in advocacy and lobbying. However, this dual focus also required the sponsor to establish mechanisms for participant transition from basic to more advanced project information and advocacy activities. Community members were considered to be 'potential participants' benefiting both from public information and advocacy activities.

It has been reported elsewhere that the number of participants depends on whether project goals are selected by staff or by community members (Wandersman 1981). In the study cases, project objectives were largely set by staff in consultation with HPD bureaucrats. In three cases (ICYP, HAGI, DAWN) community members had nominal opportunities for suggesting changes in project direction, but these were implemented rarely. These findings correspond with Wandersman (1981) who noted that participants in community programs generally have little effect on the instrumental goals of programs. He attributes this lack of impact to a failure of organization, rather than to the process of community participation itself, although the findings in this study demonstrate their tight linkage.

In the HPCP projects, community participation appeared to be affected particularly by changes in project objectives. There was a gradual trend in most projects (except ICHC) to move from promoting activities for personal change to promoting activities for structural change. Some shifts to advocacy in these cases were planned (PUSH, DAWN), but others came about in response to community member (ICYP) or board (HAGI) pressure. Some sponsors (ICYP, PUSH) may also have shifted their attention to advocacy objectives, at least partly, since this approach was less demanding on their resources. This trend toward advocacy is consistent with findings in other community development settings (Jackson 1989).

A shift in objectives from health education to advocacy in three projects (ICYP, PUSH, HAGI) increased activities for a few individual community members, but decreased the overall numbers involved in the projects. Only in one project (DAWN) did a larger number of participants become involved through the shift to advocacy - but this may have been due to the stage of development of the project and its strategic mandate to develop a women's network.

There are a number of possible explanations for these findings. An absence of concrete tasks and outcomes in advocacy work may explain community member inactivity (Sills 1968). Godbout (1981) has also noted that consumers are more interested in goals related to adaptation of conditions (e.g., access and expansion of addiction services in PUSH), than in technical innovations (e.g., art therapy techniques in ICHC), or transformation of relationships (e.g., DAWN and HAGI). If true, this consumer interest in changing social conditions presumably would have led to increased participation in advocacy activities rather than less, as was observed in these cases. Perhaps since service needs were still being met (ICYP), and since addiction was a stigmatizing issue (PUSH), community member participation in advocacy was less likely to occur. Again, the issue of disadvantage appeared to be important.

HPD's lack of project monitoring complicated the problem. Except for one case (HAGI), there was little feedback to agencies on how a shift towards advocacy in their project objectives affected participation. HPD staff may also have been reluctant to question funded groups too closely in the event that this might interfere with project completion or embarrass the HPD. Finally, HPD's own policy shift from a target group approach to target issues, community networks, and partnerships supported, and perhaps instigated, some of the projects' changes in objectives. Shifts to advocacy and service planning networks not only fit the emerging health promotion ideology, but were closer to preferred styles of bureaucratic work and gave the impression that program impact was much larger.

Thus, there were serious implications of a shift toward advocacy in these disadvantaged grassroots groups. Advocacy work required reframing target group issues into political terms in order to address structural conditions of health. However, this strategy had the concomitant risk of alienation over time from grassroots groups which had continuing service needs. For example, PUSH utilized its regional membership only early in the drug and alcohol project. As the project received a number of funding extensions, there was less activity at the grassroots level and community members had their needs met through local ILC's. However, the PUSH advocacy group was not well linked to the coalition of Independent Living Centres. This was due as much to a perceived divergence of goals between the organizations as to the COPOH-CAILC policy, supported by federal funders, to separate individual advocacy from collective advocacy in the disability movement. Ultimately, this separation of advocacy interests and service interests left PUSH without political and practical support during an organizational crisis. Further implications of a shift toward advocacy activities on community participation in disadvantaged groups will be elaborated upon in the Discussion Chapter, as this is a key health promotion strategy.

This section illustrates that reputational and programmatic factors were important in the ability of sponsors to attract community members. Factors such as agency history, program and target group mandates, and project objectives were related directly to community members' motivations to participate in projects. Reputational mechanisms provided a degree of self-identity and autonomy to the agencies which facilitated target group member confidence and involvement. Thus, some social movement characteristics were operative (Castells 1983, Touraine 1981). However, agencies were also very dependent on state funding and maintenance of the reputations of agencies among funders required frequent innovation in project responsibilities. Frequent changes in project mandates, objectives, and activities had serious implications for grassroots participation.

A service approach was important for satisfying some of the instrumental problems of disadvantaged persons, but ultimately limited the influence of target group members due to traditional service and professional hierarchies. On the other hand, shifts to an advocacy approach allowed a more direct focus on social change objectives, yet inhibited grassroots participation. Thus, neither approach directly facilitated individual empowerment. In sum, there seemed to be a fundamental tension between the rhetorical promotion of participation as a cure-all strategy and its practical application as a means to achieve health promotion project objectives.

A second group of organizational structural factors reflected resource management issues which influenced the agencies' abilities to recruit participants. This set of factors included sponsors' resource mobilization strategies and linkages with other community programs. Both factors appeared to be strongly affected by HPD policies and practices and illustrated an influence of the political-legal-economic dimension on participation dynamics at the organizational level.

Sponsor Pre-occupation with Mobilizing Resources

All project sponsors and many community respondents claimed that there were insufficient federal financial resources to operate the projects adequately, and in particular to support community member recruitment and participatory activities. Nonetheless, sponsors managed to complete most project objectives, although usually with only a moderate degree of public involvement. Claims of insufficient funding appeared to have validity in those cases in which activities were focused on community members' immediate needs (HAGI, ICHC, ICYP), the volume of which were difficult to predict. On the other hand, funding appeared to be adequate in cases in which activities were focused primarily on networking and advocacy (PUSH, DAWN).

While each case in this study had a secure project budget for its funding term, all project sponsors claimed that they had few options to obtain supplemental funding for projects. However, it also appeared that sponsors and the HPD failed to plan the project proposals adequately. This must be considered a serious administrative shortcoming which affected participation negatively. For example, lack of financial resources decreased community participation directly by limiting transportation, child care, and special access devices for target group members. The effects of inadequate resources on participation have also been reported recently in other health promotion projects (Farrant 1991) and in community care planning for people with disabilities (Bewley 1994).

At the organizational level, project sponsors responded to the challenges of limited resources with one or more strategies which had repercussions on community participation:

1. The 'efficiency' response (co-funding, using private resources, cutbacks, collaborative ventures with allies) which led to less staff time being spent with community participants (primary strategy in ICYP, HAGI, and DAWN);

2. The 'co-optation' response (altering the project focus to match the current political agenda and/or the inclusion of currently popular groups) which led to expansion of the sponsor's network and new linkages between community groups (primary strategy in ICHC); and,
3. The 'empowerment' response (lobbying with allies for increased shares of social programs) which led to increased sponsor-to-sponsor contact and less contact with grassroots community groups (primary strategy in PUSH).

In sum, the findings of these case studies show that the availability of state funding for health promotion projects may have limited the numbers of community participants for three reasons. First, community members may not have been needed to contribute to the survival of the organization and therefore assumed more marginal roles. Second, the sponsors' time spent in securing grants may have restricted their abilities to recruit community participants. Third, organizations had to service the funder's requirements for accountability once they were funded. Administrative systems were set up to support the project grant, but extra resources were also required to support the new administrative structures. A study of community-based AIDS services described similar problems:

> We needed a source of funding to get things going, but once we got that money we were supposed to be a community-based group. We were supposed to be putting our roots into the community. We never had a membership drive. I swear I don't think we have 60 members. (Cain 1993, p. 677)

Thus, goal displacement can occur and community participation may be relegated to a back burner. As shown elsewhere (McCarthy 1987), the adaptation which was required for resource mobilization in these agencies directly limited participation of community members.

Phillips (1992) noted that, beginning in the 1989 federal budget, funding to social special interest groups in Canada decreased dramatically. This uncertain economic environment may have decreased community participation indirectly in two ways. First, as noted previously, sponsors diverted their attention to resource mobilization activities, rather than supporting activities necessary to promote community participation. Secondly, lack of resources created organizational instability and insecurity of staff positions, which decreased staff effectiveness in recruiting participants.

Both of these direct and indirect mechanisms are consistent with existing literature on resource requirements in community organizations (Ng 1990, Shragge 1990). It would be useful to determine whether resource effects on participation are linked to other structural factors such as program mandate, program linkages, and leadership as predicted in resource mobilization (McCarthy 1987) and new social movement theories (Scott 1990).

Instrumental and Political Program Linkages

A second resource-based organizational factor in local agencies was linkages between programs. This was conceptualized as 'community group participation' by both sponsors and HPD. Projects used extensive linkages with other agencies for information sharing, project coordination, referrals, and occasionally joint funding initiatives. Sponsor staff and professionals were involved primarily in these networking activities, but community members on advisory committees or boards of directors were also included occasionally.

Linkages with other community groups were used both for instrumental and political purposes. A common instrumental purpose was to increase sponsor organizations' access to new community members (ICYP, HAGI, DAWN, ICHC). The need for this strategy reinforces the impression that the potential target group populations were not large, or at least were widely dispersed. Occasionally, linkages allowed the project to be expanded to new target groups. For example, the ICHC project eventually expanded from youth to women through its links with other ethnic organizations. As noted previously, agencies also linked with each other to develop joint funding proposals. However, the time spent in establishing networks and alliances between organizations for resource mobilization also meant that staff had less time for direct participant contact and recruitment.

In addition, when the focus of network activity was to conduct political advocacy work (PUSH, HAGI, DAWN), contact was made principally with other advocacy groups, bureacrats, and professionals, none of whom facilitated community participation directly. Nonetheless, there were some positive effects of this networking which had indirect effects on participation, such as the increased influence of coalitions in securing funding (for example, HAGI and CAILC, PUSH and ARF), and strategic information sharing and coordination (ICYP, DAWN).

Subsequent to 1991, the sponsors' use of program linkages in these cases appeared to be stimulated by HPD strategies to create networks and partnerships in health promotion organizations. The intention of these federal strategies seemed to be to build the capacity of local organizations through sharing scarce community resources, to make use of the skills of professionals and community development specialists, to allow increased influence of health promotion bureaucrats, and to improve the viability of projects in light of decreasing HPD staff involvement and financial resources.

Informal coalitions of organizations were stimulated by factors, such as scarcity of resources and the presence of a catalyst organization, which are reported commonly in the literature (Butterfoss 1993). However, coalitions were also stimulated by a need to locate and recruit target group participants. This instrumental purpose of program linkages may be unique to health promotion projects for disadvantaged groups and again illustrates the fragility of community participation in this context.

Social movement theory suggests that coalitions of groups of disadvantaged persons may have difficultly in mobilizing resources due to their lack of associational contacts with those who control resources (Knoke 1990). However, the strength of political group identity achieved in such coalitions or social movements may compensate for this instrumental shortcoming (Touraine 1981). As health promotion programs move toward a networking approach, it may be important to study the relative advantages of the networking strategy for disadvantaged groups in comparison to other mainstream community groups.

This section shows that sponsors' resource mobilization strategies had powerful effects, both directly and indirectly, on community participation in local health promotion projects. The short term HPD funding program ensured that agencies were constantly pre-occupied with resource mobilization activities. Staff expertise was necessary to raise extra funds, and this dependency created inconsistent efforts for community recruitment. Similar efforts to secure payment for community participants were largely unsuccessful, which further inhibited their participation.

Program linkages with other agencies were pursued as one means of countering the resource problems, however, these links required even more staff time for their maintenance. Only a few target group members in each project were able to substitute for staff in their fundraising and networking activities. Overall, federal funding policies and promotion of partnership strategies appeared to play significant roles in influencing how sponsors managed their resources which, in turn, affected the participation process.

A final group of structural factors in the organizational dimension affected the actual activities of community members in projects. Participants' formal positions, informal roles, and power dynamics were affected by structural factors which included governance, leadership, and professional involvement.

Governance Model

Governance appeared to be a key distinction between projects in relation to the organizational dimension of structure. The HPD claimed to show a preference for projects controlled by target group members. However, of the 16 Ontario projects reviewed originally in this study, only eight were nominally consumer-controlled, without professionals or service providers holding the majority of board and advisory positions (Appendix C). The three disability organizations in this study (PUSH, HAGI, DAWN) had various forms of target group 'membership' in their governance structure, while the youth service agencies (ICYP, ICHC) did not. Membership for target group members in consumer organizations was largely ascriptive and through self-identification as physically disabled persons. Membership was open technically to both target group members and others, however, majority membership guidelines were in place to ensure control by target group members. Other membership regulations concerning fees, registration of personal information, and attendance at meetings were applied inconsistently. Membership in consumer organizations appeared to serve a legitimation function, both to provide credibility in advocacy activities and to secure funding. Governance models affected participant positions in projects as well as power dynamics.

a) Effect of Governance Model on Participant Positions

In compliance with HFD guidelines, all sponsor agencies in this study were, or became, legally incorporated during the project period. There were five major modes for the involvement of community participants in these incorporated structures (board of directors, advisory committees, staff, volunteers, clients/consumers). This general categorization was remarkably similar across the cases and reflects traditional positions in contemporary voluntary organizations. Governance, or membership status (consumer organization versus service agency), was a key factor in how community members were involved in these organizational positions.

Boards of Directors

Target group members were not represented on boards of service agencies (ICYP, ICHC). However, target group members did participate on boards of consumer organizations (DAWN, HAGI, PUSH) and far exceeded the minimum proportion (51%) set out in their organizational bylaws and guidelines. Target group board members were primarily individuals with lengthy experience in the organization and were elected, rather than appointed, to their positions. While the board nomination process was sometimes by invitation (HAGI), it was more open in the cross-provincial projects of PUSH and DAWN Ontario.

Members of boards of directors had legal positions of responsibility and control yet, contingent upon sponsor membership status, they were involved to varying degrees in project management. Boards in service agencies were relatively uninvolved in projects and left this responsibility to staff persons who reported periodically to them. In contrast, consumer agency boards were usually more directly involved in projects. One board was closely involved in supervision of project staff (PUSH), although this overlapped directly with the executive director's responsibilities. Another board (HAGI) kept strict control over project activities, even so far as to duplicate itself as the new board in a semi-autonomous ILC group. Finally, one board (DAWN) differed in that it had little direct involvement in the HPCP project due to conflicting organizational responsibilities with the advisory committee, and the unusual situation of a powerful ex-board member being project coordinator. In all consumer cases, however, individual board members also contributed to projects as advisory committee members or as volunteers - indicating a closer link between board members and health promotion projects than in service agencies. The status of consumer board directors as target group members also may have facilitated their interest and legitimacy in playing these informal roles.

Some expert respondents observed that participation on boards of voluntary organizations has been an important tradition in North America. Others suggested that expecting community members to participate in administrative aspects of health promotion projects was naive and would attract only certain types of participants, such as those with advanced skills and self-confidence. One ex-community development worker respondent observed:

> There's a mythology that's developed in the health sector which says that unless citizens are involved in program planning, objectives setting, funding, personnel decision making, accounting, etc., then it's not truly a health promotion project. As if relatively powerless or marginal people . . . are going to experience a profound sense of empowerment by having to prepare next year's budget, write this policy report, or sit on this hiring committee interminably. [E-3]

These cases suggest, however, that more experienced target group members were readily available to take these positions, as long as expectations of accountable performance were minimized.

The finding that consumer agency board members had more direct involvement in projects has a possible explanation. Many other studies have found that board members in voluntary associations traditionally play roles in policy development, monitoring, and accountability to external funders (Sills 1968). As such, voluntary associations usually maintain a hierarchical separation between decision-making and operational responsibilities. This separation prevents an over-identification of board members with the target group which may otherwise make decision-making subject to bias. The service agency projects in this study generally followed this pattern. However, in consumer agencies in which board directors are also target group members, directors may not separate these functions, due perhaps to emotive links with the target group. Board directors may see themselves as both representing the interests of the target group and being responsible for project implementation. This dual identification may create situations in which role confusion occurs, traditional accountability mechanisms are ignored, and credibility eventually is compromised. These effects have been noted previously in studies of anti-poverty projects (Green 1994).

Health promotion projects which aim to enlist target group members to boards of directors need to consider the role problems which may emerge. The iron law of oligarchy (Michels 1959) may be of particular concern in situations where target group members on boards are able to use their ascriptive legitimacy to monopolize projects. An even narrower hierarchy may result, even though there is a semblance of 'community control'. It may be interesting to further study the power dynamics of such projects in which target groups members play both policy and program roles.

Advisory Committees

Advisory committees in these cases varied in terms of form and functions. In all of the projects, advisory committee members had official duties, but no formal accountability to the sponsor or the funder. Committee members had varying involvement with project tasks, meetings, and decision-making and were often involved with other projects of the sponsor, which facilitated intra-program linkages. Again, the distinction between advisory committees in service agency and consumer organizations is informative with respect to participation.

In service agencies (ICYP, ICHC), which did not have target group member participation on boards of directors, an advisory committee was the most advanced structure through which community members could exert influence. However, both of these cases also utilized additional 'unofficial' advisory committees to solicit advice from community agencies and professionals which worked with the target groups in other settings. These separate advisory committees appeared to be used to counter the input and influence of the primary target group members. In neither case did the official and unofficial advisory committees meet together, thus negating the possibility of real dialogue.

In the case of consumer organizations, HPD guidelines for participation complicated the issue by not actually requiring advisory committees. In one case (HAGI), a cumbersome advisory system composed of staff and consumers was used to improve consumer skills in meetings and to prepare plans for ultimate decision-making by a hands-on board. In another consumer organization (DAWN), restrictive terms of reference for the advisory committee left its input to be drawn upon at the discretion of staff. Finally, a third consumer organization (PUSH) did not assemble a specific advisory committee for its project as the board of directors was perceived to already represent the target group. Professionals were included on advisory committees in all these consumer organizations.

Thus, although service agencies and consumer organizations constructed advisory committees in different ways, community members on these committees did not appear to have significant involvement in the five projects. The terms of reference of advisory committees were developed largely by the agencies themselves, rather than being specified in the project proposal for review by HPD, which itself had no specific guidelines on committee formation or responsibilities. Furthermore, committees were not used as mechanisms to ensure the balanced involvement of target group members or other interested parties, nor as arenas in which differences could be aired and resolved. Advisory committees in this study seemed to be token bodies required by HPD for funding, which health promotion agencies then used to represent community participation symbolically. Overall, the reliance on advisory committees as a mechanism to involve community members seemed inadequate due to a lack of recognized rights and responsibilities in these positions.

There is little comparative literature available on target group member participation in advisory committees. This represents an important gap which should be studied further since advisory committees are utilized commonly as mechanisms for participation of disadvantaged groups in health promotion projects.

Employees

Sponsor staff had key roles in all projects, and were responsible for organization of daily activities, supervision of other staff, and reporting to boards of directors. They also played major roles in identifying and modifying the focus of the projects.

The staff in projects based in a single community (ICYP, ICHC, HAGI) were supervised directly by boards of directors and managers. In contrast, the staff of multi-community projects (PUSH, DAWN), although technically responsible to a board of directors, were more autonomous due to their projects' geographic range and apparent lack of organizational accountability.

Staff persons tended to be comparatively young men and women with previous project experience and at least some post-secondary education. Target group members were hired as employees in most projects (except ICHC), in both supervisory (PUSH, HAGI, DAWN) and staff positions (PUSH, ICYP, HAGI, DAWN). Target group members were often hired only for the specific project term (ICYP, DAWN), but occasionally were long term employees supported by a number of funding sources (HAGI, PUSH).

All groups claiming to be consumer organizations had affirmative action guidelines in place for employing target group members. These guidelines appeared to be elicited by

HPD's explicit preference for project proposals from consumer organizations, as well as by consumer organizations' own philosophies (CAILC 1989b). However, the guidelines were actually followed in only one group (DAWN) which had few (3) employees. In other consumer organizations (PUSH, HAGI), the guidelines appeared to be primarily symbolic, to reinforce an image of the organization as being self-managed.

Noncompliance with employment guidelines resulted in fewer target group members gaining skills in project management and otherwise benefitting from employment. The sponsors' explanations for noncompliance, which focused on a lack of qualified persons, were not really credible considering the number of community members who reportedly vied for staff positions. The needs of project management appeared to be of primary concern to the sponsors, and skill development among target group members seemed secondary. Sponsors also did not appear to be ready to cope with the problems inherent in expecting marginalized, inexperienced target group members to participate actively in project management.

For example, in one service agency (ICYP), street youths were hired as temporary employees as an afterthought, but were replaced subsequently with others on more manageable contract conditions. This shift appeared to be due to concerns over youth employee performance as well as a strategy to avoid having a consistent cadre of street youths in positions from which they could challenge service providers' decisions. In the other service agency (ICHC), the plan for hiring ethnic youths as peer counsellors never materialized. In contrast, target group employees in consumer agencies had much more latitude than their service agency counterparts. In some situations, they virtually ran the project (DAWN) or were key leaders (HAGI).

Overall in these cases, there appeared to be more opportunities for employment of target group members in consumer agencies, although few projects lived up to their own expectations in this regard. Consequently, a number of agencies secured funding on the basis of having affirmative action employment guidelines which were mainly ignored and HPD did not criticize this practice seriously. Of even more importance, few resources were available for staff training and project activities often ground to a halt while new target group staff gradually learned their jobs (PUSH, ICYP). This, in turn, reduced recruitment of other community members, an effect which has been reported elsewhere (Crump 1996). The expectation that disadvantaged target group members can assume responsible staff positions without significant training and support may represent a contradiction in the vision of health promotion planners and funders which merits further study.

Volunteers

Volunteers in these cases were usually stable target group members who were directed by project staff to assist with recruitment, planning, and implementation of activities. Volunteer positions in the projects were considered to be purely operational and did not involve any formal decision-making roles. The HAGI case is a nominal exception to this observation as all volunteers were automatically on advisory committees.

Volunteer activities were not problematic except in the case (ICYP) where youth volunteers' new responsibilities in providing feedback and direction on the production of STD education materials conflicted with their traditional client roles of receiving housing and financial support. In all cases, volunteers clearly identified themselves as such and appeared to value their positions and responsibilities. This finding concurs with Oakley's (1991) observation that formalization of organizational structure and function maintains the interest of participants in community projects.

While there were no major differences noted between volunteers' actual roles and influence in consumer organizations versus service agencies, there may have been an important motivational difference. In service agencies, there were no mechanisms for advancement of target group members from volunteer positions to permanent staff or board positions. However, in consumer agencies, one's status as a target group member allowed role mobility to other positions and there were examples cited of volunteers who had achieved higher positions. Thus, the potential for long term volunteers in consumer agencies appeared to be brighter than for those in service agencies.

Clients

Target group members participated in all projects as clients by identifying group needs, by receiving information, and by providing feedback on educational materials, and by being involved in peer support groups. Again, there were few concrete differences between the ways clients were involved in service agencies versus consumer organizations. Nonetheless, the manner in which the contribution of clients was conceptualized by project organizers seemed to vary significantly.

In service agencies (ICYP, ICHC), target group members who were not assisting or directing the project (i.e., acting as clients) were perceived by sponsors to have a stake in the project primarily as individuals in addressing their particular needs and circumstances. Clients were valued as individual beneficiaries of services and as participants in group support for others.

In contrast, clients in consumer organizations were also viewed as formal members of the organization with an interest in its development (PUSH, DAWN), or at least as potential members if they could be persuaded to become more involved (HAGI). Thus, clients were perceived by these organizers as gaining benefits, such as developing target group identity, through their association with the project. This may have been one reason that consumer organizations in these cases inflated membership figures optimistically - to assist the consumer identity formation process and thus validate their legitimacy as interest groups. This key point will be examined further in the Discussion Section.

b) Effect of Governance Model on Power Dynamics

A second major effect of governance was on power dynamics. The case studies have shown that power in these health promotion projects was exercised primarily by staff, bureaucrats, and professionals. Except for a few instances of community members being able to exercise persuasional influence in operational areas, there were no examples of community members obtaining control over the fundamental conditions of their projects. The closest that grassroots community members came to achieving 'community control' was in one of the local DAWN groups, which for a short period reversed the traditional power relationships between consumers and professionals.

Influence in the community projects also appeared clearly to vary with governance and membership status. Of prime importance, target group members initiated projects only in the consumer organizations (PUSH, HAGI, DAWN). Projects which were located in service agencies (ICHC, ICYP) were initiated by agency staff and then negotiated with target group members. Apart from this important demonstration of influence the two types of organizations also revealed differences in the expression of power.

Service Agencies

These two projects (ICYP, ICHC) illustrated traditional hierarchical and paternalistic models of service provider-client relationships. In neither case were target group members involved in project management or direction. The influence of street youths was limited by the social values, mores, and censorship attempts of the sponsor, although there were some adaptations to meet the social needs and participatory styles of street youths. In Luke's (1974) conceptualization of power, ICYP managers attempted to use 'force and authority' in their conflicts with youths. However, the youths' willingness to use similar threats, such as withdrawal from the project, countered the agency's efforts. Youth experience, independence, and the sponsors' fear of project loss were the major factors enabling youths to achieve some limited control in the project. The youth's willingness to engage in conflict, both between themselves and with the sponsor, also had a positive outcome in that innovative STD education materials were distributed. The youths also gained status in their community for their stance.

In a less combative environment, ICHC project staff utilized a therapeutic milieu as the fundamental strategy for diverting conflict. Staff and professionals had some sensitivity to complex power issues which bordered on 'hegemony' in the provider-client relationship (Lukes 1974). While this therapeutic strategy limited ethnic youth participation essentially to passive roles, it provided some social benefits to them as well.

Extremes of decision making styles were observed in the service agency projects: from confrontation and negotiations (ICYP) to participant passivity and paternalism (ICHC). Both styles illustrated a zero-sum power situation (Arnstein 1969). Overall, these cases had only minimal to limited influence of target group members, even considering the adult-youth dynamic.

Consumer Organizations

In consumer agencies, the influence of external, non-target group participants was more easily neutralized by those in leadership positions. Internally, there was little basis for ideological conflict, yet there was significant conflict based on struggles between those in various organizational positions. The iron law of oligarchy (Michels 1959) seemed to prevail even in these member-based projects.

Hierarchical organizational structures were used in all consumer cases, even though they were maintained inconsistently in some projects (PUSH, DAWN). It was surprising that alternate 'horizontal' decision-making structures, such as collectives, were not utilized, especially considering the emphasis on target group member empowerment and the experience of disabled persons with professional hierarchies. Nonetheless, there was no evidence that consumer organizations attempted to structure themselves differently.

Minor conflicts in consumer organizations often occurred between community volunteers and those in more privileged positions (staff, board members). The latter groups used 'non-decision' forms of power (Lukes 1974) and referred matters to the authority of boards of directors which were either remote (DAWN) or shielded by staff from conflict (HAGI). While lack of target group cohesion (Drake 1992) may have been partly responsible for the inability of volunteers to assert themselves, ultimately they were managed out of decision-making by the projects' formal organizational structures.

Decision-making within consumer organizations varied from zero-sum paternalism (HAGI, DAWN-Central) to non-zero sum consensus styles (PUSH, DAWN-Local) (Arnstein 1969, Susskind 1983). However, in these consumer agencies, target group members in the lower echelons still had only limited to moderate influence. These findings are supported by Wandersman (1981) who reports that consumer organizations can achieve influence over professional and bureaucratic groups, but that the individuals within them do not share in this influence. The implications of these findings for health promotion programs, which encourage both professional involvement and consumer-directed organizations, will be further addressed in the Discussion Chapter.

Overall, governance models emphasizing membership in health promotion organizations had significant effects on community member positions, activities, and power dynamics in these cases. The HPD strongly promoted organizational incorporation as a method for improved performance and accountability. However, HPD did not similarly insist that a membership governance structure, which may have facilitated empowerment, be mandatory.

Type of Leadership

A second organizational dimension factor related to participant activities and power dynamics was the type of leadership in projects. In three of the five cases (ICHC, DAWN, HAGI), staff persons took clear leadership for the health promotion project. These leaders were also members of the target group (although the ICHC staff person was not a youth, she had an ethnic background) which contributed to their charisma and credibility with target group members. Some groups also had strong (charismatic, influential, competent) leadership at the board level (PUSH, DAWN) at certain stages of the project. Hence, leaders tended to come from both staff and board levels and represented an example of how analytic attempts to differentiate the influence of board from staff in small organizations may be artificial (Checkoway 1985).

What was the effect of this leadership on community participation? Leaders were crucial to the operations of their projects, however, their respective roles and influence on participation were quite different. One leader had virtual control of management (DAWN), and another leader (HAGI) acted as an intermediary between a dominant board and passive community members. One other strong leader (ICHC) assumed most of the responsibilities in the project, but her activities affected participation primarily by mobilizing parents and professionals, rather than the youth target group. Strong leadership by staff in these three projects seemed to attract community members through their management of various incentives for participation (Knoke 1985). Those projects without strong leadership (ICYP, PUSH) had inconsistent involvement of target group members and turned relatively quickly to advocacy activities which involved fewer participants.

The development of leaders was supported by HPD staff who fostered personal contacts with key individuals in the projects. HPD staff may have valued consistency in project leadership at least partly because their own ability to support groups was so limited.

This study's findings of the influence of leadership on participation are supported by studies of the empowerment process in disadvantaged groups (Wandersman 1981). Similarly, Balcazar (1994) has reported that leaders in advocacy organizations of persons with disabilities markedly affect the issues raised, the actions taken, and the outcomes achieved in advocacy.

Some literature suggests that leadership is not always important to the involvement of community members (Wilson 1973, Butterfoss 1996). Furthermore, leadership characteristics such as specialized skills, available time, and personality have been identified as facilitating organizational management, yet limiting member influence in voluntary associations (Sills 1968). However, in these cases which attempted to mobilize marginalized target group members, the skills of leaders appeared to be crucial.

Professional Involvement

A final factor in the organizational dimension related to participant activities and power dynamics was the degree of professional involvement in projects. As noted previously, half of the sixteen projects reviewed utilized professionals heavily in management activities. Even in the consumer cases, professionals from within the target group population began to replace external health professionals on project advisory committees (DAWN, HAGI), thus blurring the lines between target group members and professionals. This appeared to have an effect similar to that of board members working as volunteers - an increase in personal influence of those with dual interests.

Professionals had key positions in those health promotion projects (PUSH, DAWN, ICHC) which had clear objectives to work with professional groups. In other projects (ICYP, HAGI), professionals participated indirectly as advisors and consultants either individually or as representatives of their agencies. However, professional involvement was not perceived to be completely altruistic. In all projects, sponsors reported that professionals were very interested in securing relevant educational materials and access to target group members for research purposes, and not merely in contributing to the projects' goals.

The predominant view of professional respondents on their roles in community health promotion projects was that of being in partnerships with communities. A number of expert respondents noted a tendency for professionals to be assigned a subsidiary role in providing information and advice, and to not have any real influence in decision-making in health promotion projects. One academic respondent felt that this tendency was contradictory to the purpose of a professional having expert knowledge:

> I don't believe in opening my mouth and letting the community pop the flies in. I think as a professional I have a contribution to make. Equally, I don't think I'm always right. I think it's a dialogue, a recognition of mutual capabilities and inputs. [E-1]

However, this view does not acknowledge structural advantages to professionals in their participation, such as specialized training, valued expertise, and access to bureaucracy.

There was always discussion by the project organizers about the relative risks and benefits in recruiting professionals. Consumer organizations (PUSH, HAGI, DAWN) made professional involvement a policy issue, using guidelines to restrict their involvement to minority positions on boards and committees, while service agencies (ICHC, ICYP) accepted professionals more readily as an essential part of their operations.

In their external activities, even some consumer organizations (PUSH, DAWN) made key strategic alliances with professionals as partners. In these situations, even though individual professionals were willing to concede power to community members, their formal status as professionals prevented them from being on a completely equitable basis with community participants. As a counterpoint, a decrease in the status of professionals may have diminished their value to the projects since they were often important in securing resources and recognition for the groups. Interaction between these partner groups usually resembled 'negotiation and co-production' processes with both consumers and professionals sharing power and achieving at least some of their goals (Susskind 1983).

The operational question seemed to be how to develop such partnerships among essentially unequal partners. Overall, professionals were an essential constituency in these cases for both strategic and instrumental reasons. Even though senior HPD respondents claimed that they preferred target group approaches to avoid over-professionalization of health promotion projects, all HPD officers encouraged the strategic involvement of professionals. There was also common recognition by sponsors that professional skills were necessary, and even consumer groups acknowledged their strategic need for professionals, although there was distrust of professional motivations and attitudes. These views raise serious questions about the viability of health promotion programs which are based on idealistic concepts of de-professionalized community management of health issues. As health promotion projects involving disadvantaged groups shift to advocacy and enter the era of partnership funding, it may be important to study the impact of partnership with professionals on community influence, especially when professional and consumer lines become blurred.

In summary, organizational factors such as governance, leadership, and professional involvement utilized mechanisms of control and status to affect activities and power dynamics in the participatory process in these cases. These results coincide to some degree with O'Neill's (1992) report that factors such as adequate information, community user mandates, strong personalities, and community consultation mechanisms were important in securing effective community participation in Quebec's community health system (Centre Local de Services Communautaires - CLSC).

The standard incorporated organizational structure gave a variety of formal positions, but not necessarily roles and influence, to community members. Ultimately, this distinction depended on the membership status of the organization. When agencies were controlled by professionals and service providers, no matter how well intentioned they were and how much rhetoric they promoted, the actual opportunities, concrete positions, and influence of target group members were limited. In these instances, the self interests of service providers predominated. In contrast, when organizations were controlled by target group members themselves, even when managed autocratically, there was at least the potential for individual target group members to participate meaningfully. In Oakley's (1991) terminology, a leadership opportunity structure, or potential access to positions of power, was available, even for community members acting as volunteers or clients. This opportunity structure seemed to be instrumental in motivating community members to participate in consumer organization projects. Membership status and governance are useful distinctions upon which to compare the effect of organizational factors on community member participation and will be elaborated upon in the Discussion Chapter.

Simultaneously, leaders were crucial in mobilizing reluctant target group members who had to be persuaded to participate in project organization. Leaders acted as intermediaries between bureaucrats, who had visions of an 'empowerment' participation, and disadvantaged persons. Professional and bureaucratic groups also exerted pressure continually to shape the health promotion agenda in projects and were successfully countered only in member-driven agencies.

4.7.4 Overview of How Structural Factors Affect Participation

On many counts, egalitarian community participation was not fully realized in the HPCP. The response of the federal government to calls for community participation in health promotion initially reflected the ideologically rooted desire by lower bureaucratic staff for an emancipatory participation. At the same time, this was combined with a preference by senior bureaucrats and government politicians for devolution of responsibility for health onto the individual, community, and other levels of government. However, these facilitative influences on participation were countered by a disinclination to support 'strong' initiatives of participation financially. At the federal level, the HPD devoted little real monies or staff to the program, nor consistent thought to the differences between grassroots participation, organizational capacity-building, and infrastructure development. This resulted in a short-term funding program and a failure to evaluate participation adequately. Encouragement of participatory strategies at the grassroots level by HPD bureaucrats increased gradually for a time, then decreased markedly as political priorities changed. The bureaucracy began to support a neo-corporatist model of participation in decision-making through the inclusion of community organizations in partnerships with government and other interest groups. The initial efforts of the federal HPD in its conceptual work were eclipsed gradually by provincial and municipal programs in health promotion which had more long term functional relationships with community groups. On balance, only a modest effect on participation in the health promotion field was achieved from federal government support to the HPCP.

At the community level, the HPCP projects provided foci of social support for disadvantaged persons, some changes in public awareness of community health issues, and local bases of organizational skills which could be utilized for other community development activities. Thus, the primary effect of the projects appeared to be in initiating the process of participant involvement in the organization of community activities.

The results of the study demonstrate four trends in the community participation process. These include: low numbers and ranges of active participants; difficulty in recruiting participants; decreasing participation over time; and limited target group influence and power. The direct influence of the organizational dimension of structure on community participation was predominant in all cases. In particular, advocacy mandates and objectives limited the numbers and type of community participants. Furthermore, resource mobilization priorities limited the efforts made to recruit and maintain community members. Finally, governance models for membership control increased the numbers of community members in management, and board positions, as well as their influence over other actors. However, membership models did not prevent internal power dynamics based on traditional organizational roles.

The evidence for direct influence of political-legal-economic and social-cultural dimensions of structure was less clear and there may be a variety of reasons for this. First, these other dimensions may not be as important to participation of disadvantaged persons in local health promotion projects. Second, other dimensions may not be conceptualized as easily as the organizational dimension, which is more concrete and observable at the community project level. Respondents may not perceive the direct influence of social-cultural and political-legal-economic factors which operate in the background, or at a macro level. Third, other these dimensions of structure may be operative through the organizational dimension. For example, factors such as governance models and resource mobilization strategies, which respondents identified as being related strongly to participation, may in turn be influenced by the political, legal, and economic milieu. In support of this third explanation, there were numerous influences observed of the HPD bureaucracy, such as partnership initiatives, participation guidelines, and HPD staff involvement, on structural factors in the organizational dimension. Similarly, structural factors in the social-cultural dimension, such as target group stigma, indirectly influenced organizational dimension factors such as target group mandate. Thus, social-cultural and political-legal-economic dimensions of structure had significant background effects on organizational factors which in turn influenced the participation of disadvantaged groups more directly.

In contrast to organizational and political-legal-economic factors which appear to operate through clear causal mechanisms, social-cultural factors may reflect a different order of structure. The latter factors are tied to characteristics of the participants themselves, and to prevailing relations with dominant groups and thus are closely linked to agency. As such, causal explanations for the effect of social-cultural factors on participation become recursive and it is difficult to identify a structural source of participation problems.

In reviewing these cases, it is clear that structural factors were not the only factors affecting community participation. All projects included interesting examples of personal and interactional factors which appeared to influence the process of participation significantly. For example, disadvantaged groups which had their personal needs met in projects often developed a more general awareness of target group needs and rights which then facilitated their further participation. Thus, the experience of participating itself was a powerful influence. As well, there were personality conflicts reported occasionally between community members which resulted in persons withdrawing from, or reputedly not joining, projects. These non-structural factors were not fully investigated in this study but must be considered to be potentially important elements in a comprehensive analysis of the participation process.

Overall, the mechanisms by which structural factors influenced community participation in these cases were restrictive rather than facilitative. The underlying conditions of target group marginalization, the HPD policy agenda, and unimaginative organizational practices confounded well-intentioned efforts to involve community members in the projects. The next chapter uses the community participation literature to discuss some of the key issues raised by these findings.

CHAPTER 5

DISCUSSION

In this chapter, there are two major streams of discussion. First, the discussion reviews some key issues in the literature which assist in explaining the observed relationships between structural factors and participation in health promotion projects. Specifically, four issues are addressed:

1. Variable purposes for participation;
2. Effect of advocacy objectives;
3. Financial incentives and volunteerism; and,
4. Preconditions for target influence and power.

The discussion focuses on how these issues contribute to structural barriers to participation and the implications for health promotion programming.

Second, the methodological advantages and disadvantages of using a case study approach to study the phenomenon of community participation in health promotion are discussed. This discussion focuses on issues of generalizability, case and respondent selection, and the adequacy of data regarding structural factors and participation.

5.1 Issues in the Relationship between Structure and Participation

Links between structure and agency in numerous areas of the health promotion participation process have been illustrated in the Results Chapter. To focus further on the mechanisms of these relationships, four key issues are discussed. These particular issues have been selected for discussion as they are recurrent themes in the literature on community participation; they have particular relevance to participation of disadvantaged groups in health promotion; and they provide opportunities to discuss the interaction mechanisms between structure and agency.

a) Variable Purposes of Participation

A major finding in the study was the low number and range of community members and how these were influenced by narrow funding policies, restrictive agency mandates, pre-occupation of staff with resource mobilization, and target group disadvantages and stigma. The number of community 'participants' in these cases was generally low, even considering the expectations one may have of 'Self-Help and Advocacy' projects. All sponsors submitted inflated and poorly documented estimates of participant numbers to HPD which, in turn, appeared to accept them. Nonetheless, it was patently obvious that in many cases, the number of actively involved community members was quite limited. Fundamentally, this appears to call into question the actual impact of the HPCP target group funding stream, although this study was not designed to address this concern.

Another question emerges, however, which is important to this thesis. Under the assumption that target group members actually existed in the areas and that sponsors did try to recruit them, why, apart from some concerns which were expressed by HPD evaluators, did both sponsors and funders ignore this apparent lack of participation?

A plausible explanation is that the funder and the sponsors had purposes for participation, other than target group impact, which were intended to be satisfied in the HPCP. The numbers of participants were not a priority for either group.

As noted earlier, the literature describes three general purposes for community participation as 'contribution, or efficiency', 'organization', and 'empowerment'. During the study period, HPD was interested primarily in organizational capacity building and viewed these local health promotion projects as a mechanism, or means, to help achieve this goal. Bureaucrats tended to take a 'technical' approach to participation with an emphasis on incorporated organizational structures and guidelines. The HPD focus was on the availability of positions for individuals in the organizations, rather than an emphasis on mass participation. Thus, an 'organization' purpose of participation was evident for the funder.

Furthermore, the projects were intended to act as pilot 'demonstrations' to other provincial, municipal, and international health promotion agencies in which the development of technical models to reflect 'Achieving Health For All' concepts was a priority (Pinder 1994). For example, HPD's focus reflected a concern for a pluralist balance of interests in decision-making, which was exemplified eventually in their promotion of partnerships as a model for participatory health promotion.

For their part, sponsors were interested primarily in organizational survival, through resource mobilization and program linkage strategies, and in focussing their program mandates to meet the needs of disadvantaged persons. In order to meet these goals, all sponsors needed to develop their external legitimacy with funders and policy makers and their internal legitimacy with target group members.

Sponsors which were service agencies demonstrated internal legitimacy by meeting the direct service needs of youthful target groups, which did not require their active participation. These sponsors appeared more interested in project activities, service coverage of client needs, and program linkages, than in the actual number of active and involved participants. This represented the purpose of participation as 'contribution and efficiency'.

In the case of consumer organization sponsors, internal and external legitimacy was met primarily through membership status. The emerging purpose of these community organizations was advocacy (participation as 'agency empowerment'), which did not require mass active participation in order to be effective, but did require nominal membership. Social movement organizations, such as PUSH, may not be concerned about the number of active members at any one time since they can often mobilize a broader pool of supporters from other organizations when necessary (Phillips 1994).

In contrast to sponsors and funders, individual community members identified an additional social purpose for their participation. Community members noted the beneficial affects of participation on their personal confidence and self-esteem. Thus, participation as 'involvement, or social therapy' (Weingert 1976) may also be an important purpose, for both privileged and disadvantaged groups. In the disability field, for example, Lord (1994) reports that the expansion of social networks and social support is an important purpose of partnerships for organizations of disabled persons. While one can argue that this purpose of participation is also important for the general population, disadvantaged groups often have less access to organizational resources which allow this social purpose to be fulfilled.

Thus, diverging purposes for participation led both HPD and sponsors to a decreased emphasis on participant numbers. Was this reasonable? While common sense would argue that the more participants who are involved in community projects the better, there are situations in which this may not be so. First, the optimal number of participants may depend on specific project target groups and objectives. For example, the numbers of community members who would be involved, at least as recipients of information, would be lower in health promotion projects which focussed on very specific target groups (e.g., mothers of disabled children) or target issues which affected only a few (e.g., safe drinking water). Similarly, the numbers of community members who could be involved directly in development of educational materials or public lobbying and service planning may be few. Alternately, the numbers who could be involved in mass mobilization projects such as Participaction or Healthy Communities would be greater. In each case, however, it would be desirable that the proportion of eligible participants be high.

Second, the optimal number of participants may also depend on the stage of project development, especially in those projects which are intended to build organizational capacity. For example, at an early stage, most projects require key leaders to consolidate organizational efforts, and to consult with grassroots groups. At an intermediate stage, projects might expect to have significant numbers of community members involved in activities and in the diffusion of the project to new areas. Finally, there may be a concluding stage with devolution of program responsibility to caretakers, or a dissolution of the project once its health promotion goals are achieved. Both of these options would require fewer participants.

Thus, low numbers of active participants should not have been particularly threatening to either the funder or the sponsors. Nonetheless all sponsors inflated their estimates of participant numbers, and HPD staff accepted them, perhaps partly as a lingering desire to demonstrate broad program impact for federal political purposes. Furthermore, in the context of social service cutbacks, both sponsors and bureaucrats may also have inflated estimates to maintain or justify the continuation of program funding and staff jobs.

Overall, HPD's and sponsors' acceptance of low numbers of active project participants recognized that the HPCP was a mechanism for supporting small community organizations, and not a mechanism for mass participation. From an organizational capacity development perspective, which appeared to be the over-arching goal of the

HPCP, the 'political' size of the organization was much more important to both the sponsors and the bureaucracy than a mere technical counting of participants. Senior HPD bureaucrats did not appear to want to question seriously the premises, rhetoric, or performance of their flagship participatory program. Overall, the political character of the HPCP can be considered as a plausible explanation for low numbers and loose reporting practices.

Although the parties in these cases appeared to agree on the low importance of participant numbers, they disagreed on the ideal range of participants. Generally, a broad range of participants is important due to the common non-involvement of marginalized groups in community projects. This non-involvement may occur both for exclusionary reasons of intolerance and stigma, as well as for reasons concerning individuals' personal capacities to participate at the same intensity as others. However, the optimum range of community participants in health promotion activities may also depend on the project's goals. For example, target issue projects (e.g., safety, addiction) are often intended to address a broad range of participants. Target group projects (e.g., low income women, physically disabled adults) are intended to address a medium range of participants. Network development projects are intended to affect broad communities but may only include a narrow range of compatible organizations (e.g., Healthy Communities).

In these cases, HPD respondents perceived that health promotion organizations should be 'representative', and thus legitimate as a public interest group for federal political purposes. This view entailed having a broad range of sub-groups involved in the projects, even if their absolute numbers were very low. Sponsors, on the other hand, perceived that their organizations should have 'representation' in decision-making, especially in community partnerships. This view did not require a broad range of sub-groups to be actively involved.

An underlying theoretical distinction, identified earlier in the literature review of social change theories and participation, is valuable in this discussion. Representative democratic principles of liberalism and free choice within a neutralist state can be contrasted with participatory democratic principles of equity and community interests within a social welfare state. Plausible explanations for the effect of purpose on the participation process will be influenced by these views of democracy.

'Representativeness' and 'representation' have become important, but different, issues in the participation literature. Representativeness of an organization indicates whether there is participation from the entire range of individuals who could be involved. This approach derives from the politics of consumerism and market welfare, and is the prime interest of funders and government in their relationship with community organizations which are providing service. Representativeness utilizes formal administrative structures, based on notions of representative democracy, which also acknowledge that there may be problems with interest groups getting heard. Democratic theory presumes that there will be inequities in economic power, and thus inequity in the ability of disadvantaged groups to participate (Held 1987). Under a system of representative democracy, the average member of the organization is relatively remote from the real exercise of power. Other concerns centre around the elite roles created by representative systems. Representatives often develop vested interests in their functions which may conflict with those of the members who selected them (Dachler 1978, Sadler 1979). The HAGI project provided examples of this vested interest exercise of power.

On the other hand, representation of a collective organization is quite different and indicates whether an organization is included in the decision-making process. This approach derives from the politics of liberation, inclusion, and equal opportunities, and is the prime interest of community organizations which attempt to form a collective identity based on shared experiences and ethical, rather than material, motives (Jenson 1994). The PUSH project illustrated this concept of representation in the drug and alcohol field. Representation uses informal power structures and is based on notions of participatory democracy (Held 1987). However, even if there is representation by community groups in decision-making it does not guarantee organizational influence, due to the presence of power hierarchies, to lack of access to information, and to disparities in administrative skills (Eakin 1984, Sullivan 1995).

Representative legitimacy is rife with contradiction. On the one hand, when citizens demand participation, bureaucrats challenge them with "Who do you represent anyway?" This challenge may reflect either a power struggle or a conflict between representative and participatory democratic principles. On the other hand, when bureaucrats select citizens from particular groups for participation there is often a requirement that citizens are not to act as representatives of those groups, but are only to participate as individuals. This again may reflect either a power struggle or a fear that representatives will seek approval continually from their constituent group, in ways that are time consuming (Lucas 1978).

Similar to the findings of this study, Beresford (1994) and Bewley (1994) note that consumer organizations of persons with disabilities have been criticized for not being representative, or inclusive, of the broad population of disabled persons who are service users. However, Godbout (1981) argues that consumer leaders have often evolved from passive service users to active advocates for change. In this way, the representation of collective experiences in a consumer group may be broader than the representativeness of its members. Regardless, there is an increasing realization that target group members must not act individually, but as true, informed, and legitimated representatives. However, for this to happen there must also be organizational support in the form of training and physical, informational, and temporal forms of access (Drake 1992).

For example, in the disability field, consumer groups attempt to achieve 'representativeness' by focussing on a broad range of activities which persons can access, rather than formally recruiting a broad range of people to participate. This strategy was noteworthy in the HAGI-ILC project. For a community organization to involve all subgroups in health promotion projects, for example by ethnicity, sexual orientation, and disability status, significant external supports would be required.

In sum, variable purposes for participation appear to explain key findings of low numbers and range of participants. Sponsors and government bureaucrats agreed that large numbers of active participants were not needed in the projects to meet 'organization' and 'agency empowerment' purposes. Nonetheless, they exaggerated participant estimates apparently for political and self-security reasons. In contrast, different conceptualizations of representativeness and representation between funders and sponsors, which reflect various views of democracy, were responsible for differences on the ideal range of community members. Fundamental differences in program mandates underlie these differences and illustrate significant barriers to concepts of broad-based participation in health promotion projects for these populations.

b) Effect of Advocacy on Participation

A second major finding in this study was that, over time, there was a decrease in local community member participation and an increase in the roles and influence of staff and community leaders. This trend appeared to be influenced by a shift in project objectives from education and self-help for target group members to advocacy and lobbying with other agencies for changes in public policies and programs.

General shifts in project objectives, or goal displacement, have been noted previously to have varying effects on participation (Sills 1968, Klandermans 1984). However, the intention here is to discuss how advocacy activities in particular are associated with low levels of participation.

Neufeld (1991) identifies six levels of advocacy for disadvantaged persons, varying from a focus on the individual and family (self-advocacy, family advocacy, one-to-one advocacy), to a focus on society (legal advocacy, system advocacy, public advocacy). It is the latter types of advocacy which appeared to create changes in participation patterns in the study cases.

There are two views of the effect of advocacy activities on participation. The instrumental view assumes that fewer community members are actually needed to conduct advocacy activities. This view will later be used to explain organizations' strategic decisions to shift to advocacy and the resultant effect on participation. On the other hand, the motivational view assumes that fewer community members are interested in advocacy and most decline to participate. The motivational view helps explain the tendency for more advantaged members, who have fewer needs for material benefits, to predominate in advocacy. These persons are not as preoccupied with survival needs and may instead desire the status that can be achieved through participation in an advocacy campaign (Hermann 1991).

The specific focus, or orientation, of the advocacy activity is important in this motivational view. Turner (1987) describes three action orientations of advocacy campaigns as:

1. a participation orientation, or orientation toward the personal benefits of participation;
2. a power orientation, or orientation toward acquiring and exerting influence; and

3. a value orientation, or orientation toward the goals and ideology of the movement.

From the motivational view, Klandermans (1984) utilizes this typology to hypothesize that organizations with a power orientation must convince potential participants that the advocacy campaign will be successful, or persons will not participate since there is little direct material benefit to the individual. Paradoxically, however, once the organization convinces individuals of its effectiveness, the more attractive it is for individuals to take a free ride, and thus have less reason to participate (Olson 1968). If an organization has a value orientation as well, this problem of non-participation is reduced since the individual may participate for the achievement of an ideological goal. Thus, Klandermans' analysis predicts that 'pure' advocacy organizations, without additional material, ideological, or identity formation benefits, are unlikely to have significant participation. None of the cases in this study appeared to have a single action orientation for advocacy and it is difficult to explain the findings from the motivational view alone.

Alternately, an instrumental perspective on advocacy is useful in explaining the emergence of these organizations' advocacy strategies. Shakespeare (1993) notes that organizations may shift their focus to advocacy in an effort to increase their legitimacy and resources. As such, they may oppose the funding of new groups claiming to represent the same interests. In this research, decisions made by disability advocacy groups and government to exclude emerging ILC organizations from system and public advocacy activities appeared to be an example of this dynamic, which reflects a power orientation.

Phillips (1994) notes the instrumental difficulties which are faced by community organizations involved in advocacy in trying to balance the need for representation through lobbying and the need for participation through collective action. Offe (1985) and Melucci (1988) note a similar distinction between representation (indirect, deferred goal satisfaction, by leaders) and participation (direct, immediate, large investment of time) which are both necessary in social movements. However, these strategies require different resources, types of knowledge, and organizational processes, and are difficult to balance. If a social movement organization chooses to pursue advocacy primarily through attendance at meetings, the conduct of research, and fund raising, it runs the risk of losing touch with the grounded passion and participation of its constituency. On the other hand, an advocacy strategy focused principally on public participation and collective protest brings the dangers of diminishing effectiveness, credibility of representation, and alienation of more moderate supporters.

The literature suggests that organizations do not necessarily choose one option over the other, but develop strategies to allow them both a place. For example, national organizations may leave participatory advocacy to local groups which can quickly mobilize public interest. However, there is a danger that lack of connection between these levels may divide issues into national and local responsibilities, resulting in a loss of influence. An alternate approach is to share responsibility for advocacy strategies in order to address the same issues at national and regional levels. This approach recognizes that political opportunity structures are operative as well (Tarrow 1989). For example, government interest, funding sources, alliances with other organizations, and existing structures of gender, class, and race relations may vary in a country and should be addressed at different levels of the organization according to the context. This intersection of structure (invitations and opportunities provided by existing conditions) and the agency of organizations (choices and opportunities which are made) is a major focus of new social movement theory.

The disability organizations in this study had similar values and goals for disabled persons and could be termed part of the disability movement in Canada. Klandermans (1984) provides a structural typology of social movement organizations which leads to explanations regarding their reliance on local participants. An 'isolated' social movement organization has no branches and relies on direct contact with its members. In its early days, HAGI was an example of this type of organization. In contrast, a 'federal' structure has local branches and can interact with these in one of three different ways. A loosely coupled 'network' structure (e.g., DAWN), which often results from a merger of preexisting organizations, may have good coordination within a community. A 'pyramid' structure (e.g., PUSH) has weak links between levels with higher level organizations providing services, giving advice, and defining common goals, all of which promote the unity and legitimacy of the movement. Local organizations in pyramid structures are relatively autonomous, diverse, and spontaneous. In 'centralized' federal movement structures (e.g., HAGI-ILC in CAILC), local organizations are coordinated by a highly centralized national organization.

Klandermans suggests that federal structures may be able to make use of local chapters, but there is no guarantee that local chapter officers will be able to mobilize local members, especially in loosely coupled network structures (DAWN). Movements with a pyramid (PUSH) or centralized structure (HAGI-CAILC) are more likely to be able to mobilize local officers, however, if they cannot do so they are worse off than a movement with an isolated structure, because the movement is cut off from its local constituencies and may face extinction (PUSH).

Thus, advocacy organizations which utilize a loose network structure may rely on grassroots mobilization in times of crisis. Those which utilize pyramid and centralized federal structures, which may be better for managing opportunities and claiming legitimacy of group goals, may be less responsive and much more risky in the context of a rapidly changing funding environment.

In sum, instrumental views of advocacy appear to be more useful in explaining why the development of an advocacy focus may influence the decline of active community participation in health promotion projects. Furthermore, structural links between associated programs may be important in predicting their ability to mobilize participants.

Overall, a shift towards advocacy objectives may be inevitable in a field such as health promotion which claims to address issues from the micro to macro levels. However, the structural barriers to active participation in such a shift should be recognized and plans made to minimize the potential consequences of loss of grassroots support.

c) Financial Incentives and Volunteerism

A third recurrent finding in this study was the difficulty in initiating and sustaining the involvement of community members. Both project sponsors and target group members reported that the lack of financial compensation for the participation of individuals was often responsible. This was the case especially for those acting in 'advisory' and 'volunteer' project positions. Although there appeared to be some honoraria available for participant payment, these were not offered openly by the bureaucracy, nor negotiated skilfully by the sponsors. Target group members did not expect compensation for involvement in self-help activities, but lack of financial incentives was claimed to have been a barrier to participation in project activities which were intended to develop the organization, to produce educational products, and especially for joint planning with professionals and bureaucrats.

Explanations for the relationship between financial incentives and participation have roots in Olson's (1968) social exchange theory of collective action. Research utilizing this economic analogy identifies the personal, or opportunity, costs of participation in terms of expending scarce resources. Social exchange theory has been used to explain why persons may demand volunteer pay in compensation for personal costs of participation such as time, expenditures for child care expenses, and safety risks (Prestby 1990).

Research has also focused on incentive management to increase participation in voluntary organizations (Prestby 1990). In the ideal situation, a sense of individual empowerment is influenced by a 'good' person-environment fit, whereby organizations provide sufficiently varied and valuable benefits to offset the relatively low costs of participation. Members then actively participate and become more empowered as a result. However, if the fit is 'bad', members either receive too few benefits, benefits of too little value, or they experience too many costs and thus participate minimally, which inhibits the empowerment process. Disadvantaged community members who expected payment in the study cases reflected a poor person-environment fit.

These findings and literature lead one to ask whether purely voluntary action (that is, without a financial exchange) is relevant for general society, for health promotion organizations, and for disadvantaged persons.

The scope and responsibility of altruistic voluntary community activity have been generally maintained in Canada over the past few decades. In addition, contemporary welfare systems, which were initiated to express ‘second generation human rights’, have become highly professionalized and expensive public service industries (Howell 1987). In turn, there have been calls for community participation as a necessary corrective response both for economic reasons, as well as to achieve increased equity and social cohesiveness (Midgeley 1986).

However, the symbolic import of financial payment for valued work in our society cannot be underestimated, especially in times of high unemployment. Thus, the individual’s ability to achieve payment for ‘voluntary’ activities may be seen as a substitute for employment, and may hold significant motivational importance beyond its dollar value. Additionally, concepts of community participation and public compensation have been linked recently in trends toward 'workfare', in which welfare recipients are expected to provide labour in public community services (termed the 'Community Participation' component of Ontario Welfare reform) in exchange for benefits. A voluntary aspect of workfare has also been promoted so that welfare recipients may even suggest where they would like to work in the community (Kitchener-Waterloo Record, 1996). That others, who provide volunteer labour in similar settings, should also expect compensation is not surprising. Thus, volunteerism in certain socio-economic segments of society may decline without adequate incentives.

Pure volunteerism is also at risk in health promotion organizations for a number of reasons. First, as the purpose of community participation shifts from 'contribution', and 'organization' and representativeness, to 'empowerment' and representation, the emphasis changes from community members' responsibilities, for which they should volunteer, to community members' rights. Thus, the onus shifts to the organization and the state to secure participation, and this may be done at least partly through financial incentives.

A second structural dynamic affecting volunteerism in this context is related to the rapid development of health promotion organizations due to increased funding opportunities. In this situation, there is little advantage in establishing set organizational roles and structures which may be difficult to change (Checkoway 1985). Especially in consumer organizations, where role mobility is a feasible and necessary motivational feature, target group members may start as volunteers and learn by experience, before taking paid jobs in the organization. Requesting pay for valued voluntary activities prior to assuming a formal staff role does not seem contrary to either the developmental needs of the organization or to current concepts of community development. Thus, evolution in the purpose of participation in health promotion and in its structural organization may predict a decline in volunteerism.

Finally, with respect to participation of disadvantaged groups, there have been historic lines of inquiry concerning class differences in volunteerism. Veblen (1899) initially introduced the theory of the leisure class which held that a conspicuous display of leisure, for example, through charitable philanthropy, was a direct way of proving one's wealth and position in the social class. In the Canadian context, Porter (1965) further explained charitable philanthropy by the wealthy in terms of historic Christian moral concepts of responsibility towards the less fortunate. Porter also noted that wealthy persons participate in charitable work conducted by private foundations as a way of preventing the extension of publicly financed programs into issues of social welfare. However, in the era of state-financed health promotion programs since the 1970's, the latter motivation appears to have been unsuccessful.

Explaining the implications of a lack of financial incentives on the participation of disadvantaged target group members requires the use of other perspectives. The first utilizes social exchange theory to examine incentives and costs. Research on motivations for general participation in voluntary neighbourhood associations reveals that purposive and solidary incentives, rather than material incentives, are important to the average person. In contrast, there have been few studies investigating incentives for participation in community health activities by disadvantaged persons. However, one study of mentally ill persons in self-help groups shows that personal and material incentives, such as financial payment, were also important in decisions to participate (Norton 1993).

Overall, the poor have few resources to spare for endeavours which do not promise a concrete benefit, as is often the case in health promotion projects which focus on organizational development and agency empowerment. However, disadvantaged persons are often willing to invest their personal resources and participate in social action organizations when others have provided the initial investment and there appears to be a promising opportunity (Herman 1983). Thus, the reputation and mandate of the organization, as illustrated in the ICYP and PUSH cases, may modify an initial reluctance to participate, even without payment.

From a second perspective, Schreader (1990) explains the lack of payment to disadvantaged persons for voluntary labour in ideological terms. The traditional altruistic ‘civic culture’ perspective, which extends the leisure class theory, has been that the process of developing one’s full potential as a citizen, beyond one’s participation in the workforce, requires the self-sacrifice inherent in performing voluntary activity (Widmer 1987). However, this expectation ignores certain target groups’ structural disadvantages in relationship to paid labour, which excludes them from wage earning. By expecting these groups to volunteer in health promotion projects, the state reinforces the ideology that their labour is to be unpaid. This explanation appears particularly relevant to the cases involving disabled persons in this study. Thus, traditional concepts of volunteerism may not apply to disadvantaged persons' participation, even in self-help activities, especially if more privileged persons are perceived to benefit by their participation (e.g., professionals being paid to attend meetings). Interestingly, other federal departments are now formally recognizing the need for volunteer honoraria in research initiatives which focus on disabled persons (SSHRC-HRDC 1994).

Overall, the lack of financial compensation for disadvantaged community members was an inhibiting factor but did not absolutely restrict participation in these cases. Furthermore, the inability to interview non-participants in projects about their reasons for not participating limits the conclusions that can be reached. Nonetheless, there appear to be some symbolic and organizational reasons which help to explain why pure volunteerism in health promotion projects for disadvantaged groups may be difficult to achieve. These findings may qualify the general literature on volunteerism and the need for financial incentives to secure participation in certain groups.

d) Preconditions for Power

A fourth finding in this study was the uniformly low level of influence of ordinary community members in project decision-making. Organizational factors related to participation roles (governance models, leadership, professional involvement) were of key importance in this dynamic. This illustrates the fundamental importance of power, or relations of dominance between groups, in these participatory settings.

As a background to discussing the influence of these structural factors on the expression of power, it is useful to clarify certain power typologies. Contemporary power theories assume that power is relational rather than unidimensional (Lukes 1974, Foucault 1979, Alford 1985). When one actor dominates in a situation, other actors can resist the process in ways which may aid other goals such as identify formation. In this sense, power is not zero-sum and absolute, but relative and negotiable through processes of conflict and co-production (Susskind 1983).

Alford (1985) suggests that pluralist, managerial, and class perspectives on power are distinct from each other as they entail different levels (individual-group, organizational, societal) of influence. Alford also states that each perspective on power predicts different forms of participation. A pluralist perspective, which is used to analyse power relationships between individuals or groups, arises from a functionalist interpretation of interest groups and rests on an assumption of accepted norms and values. Power is situational and measured by influence over the outcomes of conflict. A pluralist perspective expects participation to be widespread, but controlled through concepts of 'representativeness'. Alternate styles of participation, such as mass protests, indicate failure of pluralist political institutions.

A managerial perspective on power, which is used to analyse power relations between organizations, arises from Weberian views of elite vested interests. Power is structural and measured by the capacity of state and corporate interests to dominate each other. This perspective expects elite domination to protect the organization from unorganized participation. Such unofficial participation indicates the breakdown of protective structures of organizations, for example, their hierarchical nature.

Finally, a class perspective on power, which is used to analyse power relations at the societal level, arises from Marxist views of social stratification. Power is systemic and inferred from relations of dominance between groups, for example, between social classes or between industrialized and developing countries. In contrast to the pluralist and managerial perspectives, Alford suggests that a class perspective expects mass participation to occur, which will expose contradictions of stratified systems such as capital and labour.

Alford does not attempt to reconcile these various perspectives, as they are conceptualized at different levels of analysis and each view rejects or reinterprets the others. However, their common reliance on structure (in all of its dimensions) indicates that some reconciliation may be possible. Lukes (1974) and Foucault (1979) suggest that different power processes can coexist at the same level of analysis. In particular, Lukes' analysis of power processes suggests that, in any setting, a dominant group may exert control over a subordinate group in three ways:

1. Force/authority - Dominant groups may take active measures to prevent others from occupying influential or authoritative positions;

2. Non-decision - Dominant groups may fail to act, thus leaving in place obstacles and barriers which prevent others from exercising power; and,
3. Hegemony - Dominant groups may construct and reinforce a reality in which it is the norm for them to exercise power, and for subordinate groups to be passive recipients of benefits. This dynamic can occur in any realm of class, race, disability, or gender.

Furthermore, assuming that power is relational, a particular resistive participatory response may occur. However, Drake (1992) notes that certain pre-conditions are necessary for non-dominant participants to exercise such power. This study has also identified certain structural factors which are associated with these pre-conditions. First, consumers must develop the personal 'capacity' to actually resist power, especially in situations of force and authority. Structural factors which limit this capacity include target group marginalization and stigma which impede progress beyond meeting the immediate needs of individuals. Second, disadvantaged groups must occupy organizational 'positions' in which power can be exercised; they must have authority to counteract non-decision. Structural factors which facilitate the achievement of these positions include suitable organizational structures such as membership models, role mobility, leadership development, and various forms of access. Third, disadvantaged groups' organizational positions must be situated within 'norms and networks' such that the exercise of power is effective and achieves its purpose, especially in hegemonic situations. Structural factors which facilitate the effective development of norms and networks include legitimate organizational mandates for 'representation', resources, political priority, and a managed role for professionals.

Drake (1992) states that participant power cannot be expressed if any of these pre-conditions are absent. However, these case studies suggest that the extent to which structural factors limit or facilitate these pre-conditions determines the nature and degree of participation as a response to the exercise of power. This background leads to a discussion of why three key structural factors were important in the expression of power in the cases.

First, the control of projects through membership in sponsor organizations was a key factor which positively affected the influence of disadvantaged persons in this research. According to Drake (1992), such 'positions' are crucial to developing situations in which participants can exercise power. He notes that, given the opportunity, target group members choose to run their own agencies rather than be subject to the governance of others who may predominate in a pluralist setting. The importance of project governance and membership was highlighted in the HPCP by its encouragement of organizational guidelines to control the participation of non-consumers in projects.

A board of directors structure is often cited as a factor which can lead to consumer control in the area of public health planning. There has also been ongoing debate about whether boards of directors control, or are controlled by, the organizations they are intended to govern (Tucker 1980). However, in this study there was mixed evidence of the influence of board participation by consumers on control in health promotion projects. Service agency boards had no target group representatives at all. However, certain target group members on consumer organization boards had both policy and implementation roles in projects.

Most studies of disadvantaged persons' influence through board membership have occurred in formal organizational settings. For example, Godbout (1981) reports that individual consumers require a guaranteed number of elected seats to be able to exercise any influence in CLSCs in Quebec. In contrast, Eakin (1984) reports that, in Quebec hospitals, democratization of board membership beyond elites was ineffective in transferring control to community interest groups. Sullivan (1995) also notes that individuals with disabilities who had membership on health policy boards in Nova Scotia had no increase in decision-making authority. These studies indicate that the status quo was maintained because of the traditional power hierarchy, the lack of individuals' ties to formal consumer organizations, and consumers' inadequate knowledge base and skill levels which were required to participate on an equal basis with professionals and elites. The importance of formal board structures in smaller grassroots organizations is less clear, although there appear to be some parallels.

Finally, standard organizational practices in decision-making venues may affect power opportunity structures. For example, a lack of 'access' may be perpetuated by inviting directors to serve on boards rather than by open elections (Shakespeare 1992). Alford (1975) also notes that inter-agency planning committees which include target group members may operate under rules which require a consensus, and thus are doomed to failure. He argues that the inclusion of a wide range of community members to make community groups 'representative' ensures that consensus will not be reached within the community, much less with professional and bureaucratic participants. Thus, a 'veto group' process leads to stalemate and perpetuation of the status quo. The present study indicates that target groups' inabilities to overcome differences due to their socio-demographic characteristics can also affect their 'capacity' to exercise power under these rules of consensus.

Overall, these problems lead to questions as to whether or not a board structure is sufficient to increase community member influence in small scale health promotion projects. Since this study did not include agencies which used other forms of organizational structure, it is not possible to conclude that boards are, or are not, important in the empowerment of community members. Nonetheless, target group membership in project governance appeared to be an influential factor in the expression of power in this study. It should be noted as well that not all target group members can effectively assume positions of influence in a membership-based organization and that significant mediation by other actors may be necessary.

A second factor in the expression of power in these cases was the strong influence of project staff members and this may be explained partly in terms of broader trends in participation. Katan (1986) explains that emerging worker participation dynamics are also in effect in community development projects, and that staff are not as subservient to managers and boards of directors as they were previously. In service agencies, in which staff have a mandate of professional autonomy and responsibility, Katan predicts conflict between increased staff participation and consumer participation since agencies are trying to manage a dual threat to the status quo. In this study, for example, service agency staff interests predominated over consumer interests.

In consumer organizations, on the other hand, the dynamic is less clear since staff are often target group members themselves. For example, the assignment of target group staff members to increased responsibility and influence in advocacy activities may be explained merely as a move toward efficiency of personnel utilization. Alternately, it may be viewed as a co-optation of target group interests, depending on the perceived threat to the agencies involved. This latter explanation, however, may be complicated when staff are target group members, who then may have additional legitimacy in advocacy activities due to their consumer status.

Overall, the utilization of target group members in non-traditional positions, such as employees in both service and consumer agencies, appears to increase their opportunities to exercise influence. In addition, it may change the organization's negative perceptions of target group members' 'capacities', which previously reinforced agency expressions of benign hegemonic power.

Finally, a third factor in the expression of power was professional influence. This influence was pervasive in cases studied, although it was managed to a greater degree in the consumer organizations. Stewart (1995) has shown that partnerships between health professionals and self-help groups are likely to develop and may be beneficial, but need special supports. These supports are necessary to manage the change in traditional service provider-user relationships and include: professional re-education, coordination of projects by consumer organizations, and social role clarification. These elements of new 'norms and networks' were well demonstrated only in the DAWN consumer-professional project which attempted to balance power relations before beginning the process of partnership with professionals.

In conclusion, a number of links have been shown between the expression of power, structural factors of governance, staff and professional involvement, and participants' abilities to respond, which help to explain the limited target group influence in these cases. The discussion also indicates that if community participation is perceived only in terms of traditional organizational structures and negotiation of roles with staff and professionals, then tokenism may prevail. However, if a redistribution of power is also considered to be important in community participation, then voluntary agencies may require significant re-configuration. A necessary change in the definition of such agencies would include governance and control by the target group in question.

This discussion has examined some underlying mechanisms of significant barriers to an inclusive, broad-based form of community participation in health promotion. Various social structural theories of representation, advocacy in social movements, incentives in volunteerism, and relational power have been used to explain key findings concerning the relationship between structure and participation in the cases. However, before making conclusions in the final chapter, qualifications should be made regarding methodological limitations of the study.

5.2 Methodological Issues in the Case Study Approach

This study intentionally focused on a particular problem in health promotion--the participation of disadvantaged groups. Certain methodological decisions were made to optimize the information which could be assembled about participation in this situation. These decisions affected the types of organizations studied, the types of respondents interviewed, and the forms of data which were collected. In turn, certain methodological limitations were evident.

a) Generalizability

The multiple case study methodology selected for this research had a number of positive and negative points. The use of in-depth studies of health promotion projects was valuable for the clarification of conceptual issues in participation through the use of open-ended questions and cross-checking information between respondents. Use of study sites which were linked by a single funding program was also valuable as it allowed the detection of common structural factors and their influences on participation. Specifically, bureaucratic structural factors in the political-legal-economic dimension could be compared across cases as sponsors operated under common guidelines for conducting the projects.

However, there were also a number of limitations to generalizability in this multiple case study. Findings were restricted to the local target group projects within the Ontario HPCP context. Generalization to other situations and populations is precluded by the small number of cases and also by the exclusion of Francophone projects. Finally, the study findings did not apply to national level projects, nor to those related specifically to target issues such as AIDS or impaired driving. Thus, it was not possible to conclude from this study whether the location, size, or organizational sophistication of community sponsors influences the expression of participation.

b) Case and Respondent Selection

The selection of projects for in-depth study and the choice of key informants could have influenced the findings of the study even though selection criteria were specified to minimize these potential biases. It had been expected originally that community participation in the cases would differ significantly, based on the principal mode of community participation being utilized, as identified from document analysis. However, the most common or active participant roles were not identified accurately in the project documents and community members were involved in multiple positions in each case. In retrospect, the selection of cases at the beginning of the study could have been based on other observable organizational factors such as mandate (service or advocacy) or governance of the organizations. In the end, the range of selected cases was useful for discerning general mechanisms of structural influences, although not for developing detailed typologies of particular structural factors with respect to participation.

The number of community respondents interviewed in each case achieved the levels which were anticipated in the pilot study. However, the representativeness of these respondents to the other case participants could not be ensured. Sponsor staff contacted potential respondents directly for both ethical and practical reasons, and recruitment of respondents was slow. A variety of reasons for recruitment problems are possible, including sponsor reluctance to facilitate interviews, community members' transience, and community member disinterest in participating in a university research study.

Disadvantaged persons in some cases (ICYP, PUSH, HAGI) may have been suspicious of attempts to gather personal information about volunteer activities if they perceived that welfare and disability benefits would be at risk. Similarly, this type of fear may have precluded their participation in the projects. They may have been concerned that welfare officers would assume that they were not available to work, or were actually able to work, in the case of persons on disability benefits or workers' compensation. In either case, volunteering in health promotion projects may have been viewed as activities which they did not want made public. Overall, difficulties in respondent recruitment for this study seemed to validate sponsors' claims that enlisting disadvantaged community members was a challenge.

c) Data Completeness and Quality

The interview guide, which was developed through a literature review and pilot testing, was satisfactory for eliciting respondent perceptions of the association of organizational dimension structural factors with the participation process. Information regarding the influence of other structural dimensions (social-cultural, political-legal-economic), however, was not obtained easily. For example, most community respondents did not comment on how political decision-making structures and the economic climate affected participation. Expert respondents, on the other and, reported these issues from their experiences, although they were not always able to offer concrete evidence related to the HPCP. Nonetheless, many community respondents did refer to the prevailing atmosphere, or normative ideology, of participation in Canada as an important positive influence. Many also referred frequently to the negative influence of disadvantaging social conditions on participation. Again, concrete examples, or rationales for these relationships were offered rarely- as if the vocabulary for links between these structural influences and participation was not available. This inability to verbally express these relationships may have biased the weight of evidence towards the influence of the organizational dimension on participation.

Similarly, respondents prefaced their remarks frequently with a caution that the dynamics of the participation process, and its value, depended on the 'purpose' of participation. Cohen (1980) cautions, however, that purposes of participation are difficult to assess since they are implicit, subjectively held, may be discovered over time, or may change with experience. This view demonstrates that it may be difficult to evaluate participation in projects against a standard purpose, since this ultimately depends on the subjective intentions of different types of participants. In sum, the methodological decision to study structural factors through individual reports of experience may be useful in exploring potential relationships, but is ultimately limiting in authenticating data or confirming hypotheses.

Finally, respondents of all types provided detailed information about participation in project activities, however, this could not always be confirmed by secondary sources or records. Furthermore, the quality of document data that could be obtained about individual cases was difficult to ascertain, since some project sponsors appeared to have tailored their reports to meet HPD priorities and expectations.

A recurrent problem in data collection was the apparent lack of detailed credible information about the numbers and characteristics of participants. Apart from the sponsors' and HPD's low priorities for evaluation, which have been discussed, target group members may also have been reluctant to divulge personal information to project staff. Consequently, interview data were given priority in the analysis, as the researcher had opportunities to probe for clarifications and inconsistencies.

In sum, methodological issues in program and case selection limit the generalizability of conclusions which can be drawn. Similarly, the use of semi-structured questions to elicit respondent reports of their experiences and perceptions of causal mechanisms limits the explanations which can be developed. As previously discussed (Chapter 3), however, these are well-known limitations of the qualitative case study method and do not preclude the fulfilment of the primary intent of the thesis--to explore relationships between structural factors and the process of participation.

CHAPTER 6

CONCLUSIONS

In this concluding chapter, the principal findings are first presented to answer the research questions which were posed in the study. Hypotheses for future study which are related to these findings are also summarized. Second, key conceptual issues concerning the concepts of target groups in communities and the ends/means of participation are discussed. Third, in light of these conclusions, recommendations are advanced for health promotion participation policy. Finally, the usefulness of a structural perspective on community participation is reviewed and directions for future research are proposed.

6.1 The Relationship of Structural Factors to Community Participation in the HPCP Case

Four aspects of the process of participation in these cases were influenced by key factors which reflected the broad array of structures conceptualized in this study.

a) Who was involved in projects?

The number and range, or types of participants, were modest in these cases. HPD's target group policy and HPD staff's promotion of certain groups fostered participation of a narrow range of marginalized community members. These restrictions were supported by local agency mandates to work with preferred sub-groups in the target group populations and over time, to focus on advocacy work. Local leadership was responsible for efforts which increased the total numbers of casual participants, but leaders were less effective in attracting active long term participants. Participation hypotheses which arise from these findings concern target group cohesion, bureaucratic commitment, and leadership in service/advocacy programs.

b) How was participation organized?

Sponsors used participation strategies both for project organization and for project recruitment. A standard incorporated structure, which was mandated by HPD, encouraged hierarchical responsibilities. Some organizations used a membership governance model effectively, but this was not mandatory. Strategies for participant recruitment, which were largely dependent on personal contacts, were implemented by project staff and by volunteer initiatives. These strategies were seriously impeded by federal policies on short term funding, which affected staff security, and on financial incentives, which affected volunteer motivation. In particular, the pre-occupation of staff with fundraising limited their roles in participant recruitment and community health promotion activities. In compensation, program linkages were used increasingly by staff to expand the participation of other community agencies in the projects. Hypotheses which are related to this question concern the effects of participation guidelines, bureaucratic supervision, and the degree to which resource mobilization strategies are related to program linkages.

c) What roles and activities were taken?

The majority of community participants were limited to volunteer and client positions in self-help and health education activities and had little mobility in their roles. A minority had board, staff, and advisory committee positions which involved planning and management activities. Target group membership in the governance structure appeared to be a key factor which distinguished the activities of those in various types of agencies. Finally, shifts in project objectives from health education to advocacy increased the variety of participant roles and activities, but only for a few community members. Participation hypotheses which are relevant to this question include the role of community members on advisory committees and the relative advantage of networking and advocacy approaches in mainstream versus target group health promotion programs.

d) What was the balance of power?

The influence of community members was moderate in these cases, with membership status again being a key distinction. Overall, marginalized community members did not have the degree of independence or control envisioned in an egalitarian view of community participation, and they relied heavily on the cooperation of other more powerful participant groups, such as staff and professionals. Professional involvement was pervasive and varied from overt manipulation to key instrumental and political support. Increasing formalization of local project structures and reporting requirements required disadvantaged community members to collaborate with these groups which had the necessary skills to manage projects. However, disadvantaged groups' lack of power due to social marginalization was occasionally countered by individuals' experiences in group participation which allowed them to assert their demands. Thus, non-structural factors of agency were intricately involved in issues of power. Hypotheses which are related to power dynamics and participation concern the impact of partnership with professionals and the consequences of consumer board members playing both policy and program roles in projects.

The lessons learned from this study are clear. The concepts and ideals of community participation of disadvantaged groups can be used in health promotion to rally considerable bureaucratic and sponsor support. However, there are important structural influences, from both federal and local levels, in the implementation of participatory processes. Although bureaucratic support may be key in developing funding programs and in fostering the initiation of participatory projects, subsequent administrative practices and lack of evaluative follow-up can detract significantly from their execution. Thus, the bureaucracy's role in local health promotion programming can be vital, but can be effective only if participation is given sufficient political priority. Local project governance which emphasizes target group membership may be a necessary prerequisite to assure that community participation is not token. Even so, attention to managing excessive professional involvement and achieving flatter organizational structures is crucial. Factors in the organizational dimension of structure may have the most immediate and direct effect on participation. This is fortuitous since it is factors in this dimension which can perhaps be adjusted by community agencies most easily .

Ultimately, this research concludes that community participation in the HPCP did not meet its rhetorical goals, yet perhaps these ideals are not achievable. These cases show that, when working with disadvantaged groups, capacity building is a relevant goal. However, participation of disadvantaged persons can only be facilitated over the long term, and not imposed. Consequently, secure funding, bureaucratic commitment, and group readiness to act are obvious pre-conditions to achieving these ideals.

6.2 Conceptual Issues in Participation

Two key conceptual issues are relevant to these conclusions. These issues concern the identity of target groups in communities and the 'ends/means' distinction in participation.

a) Target Groups in Health Promotion

In addressing the concept of community, it is useful to discuss the issue of disadvantaged groups, how they fit into health promotion ideology, and the resulting implications for participation. Many authors have blamed ‘failures’ in community participation projects in health promotion on lack of clarity in spelling out what was meant by the concept of ‘community’ (Tesh 1988, Farrant 1991, Nilsen 1996). Traditionally, meanings of 'community' have been based on geographic and affinity groupings, both of which incorporate aggregational and relational notions. However, in the area of public health, other concepts of community are evident (Rifkin 1981). ‘Communities of interest' reflect organizations which have self-identified their interests and are willing to work on current health concerns, for example, AIDS or anti-smoking coalitions. Target issue organizations funded under HPD are examples of 'interest' communities which attempt to access resources through public funding.

In contrast, 'at risk' communities are target groups which are identified by others as potentially at risk of poor health. The target groups in this study, which were identified and priorized by HPD staff, demonstrate the latter type of community.

Lefebvre (1993) notes common barriers to participation within health promotion organizations which take a target group, or 'at risk', approach. Many of these barriers to participation were evident in the study cases:

1. no clear definition of mission and objectives due to lack of assessment of consumer needs and lack of organizational consensus;
2. poor identification of key target audiences, including subgroups at highest risk;
3. placement of political and professional objectives above consumer needs;
4. biases toward expert opinions;
5. influence of staff intermediaries between target group members and planners; and,

6. scenarios of urgency which result in short project time lines.

Lack of control by the target group underlies many of these barriers and suggests that the top-down, 'at risk' target group approach to community has fundamental limitations for participation. Participation may be effective with general community populations (of geographic and affinity groupings). Similarly, communities of self-identified interests or target issue groups may have potential for strong participation. However, 'at risk' target group communities, which require significant external stimulation and support, may not be suitable for expectations of strong participation, especially if required to self-organize and achieve 'empowerment'. The notion of 'disadvantage' may itself be the ultimate structural barrier to participation. This tempts the conclusion that the participation of disadvantaged and marginalized groups may be significantly different from participation of mainstream community members in terms of motivation, constraints, and strategies which are necessary to make it meaningful and effective. This finding should be further explored.

b) Ends/Means of Participation

A second conceptual issue, the distinction of participation as a means as well as a valued end, creates significant confusion in practical applications. This problem was noted in this study in the HPD's frequent shifts in goals for the HPCP. To restate the issue, people's receipt of benefits on a broad and increasing basis is the goal of most human service programs which assume there is a need to address special problems and inequitable situations. Doyle (1990) emphasizes the priority of participation as a means to achieving this goal. Instrumental participation in decision-making, planning, and implementation is necessary and useful in increasing this access to benefits.

Transformational participation as an end in itself is also believed to be important, but as an adjunct to this basic goal of benefits. However, if an organization's primary focus is on ‘representation’, or achievement of status in decision-making circles, then the potential for members’ interests to be met is necessarily delayed and indirect. Keeping members involved and supportive may be difficult unless they perceive a concrete benefit to themselves beyond the solidary and purposive benefits which are likely in an advocacy organization.

Most analysis in this field tends to emphasize the contradictions in participation and aims at an “either/or” understanding of instrumental and transformational forms. In both forms, however, there is an expectation that participation can be controlled and predictable. Neither form in itself appreciates participation to be a complex “learning process by which outcomes are the result of adapting to change as change occurs” (Rifkin 1996, p. 87).

In an early attempt to reconcile these concepts, Cohen (1980) notes that participation is an intermediate, instrumental goal, analogous to concepts such as 'employment' and 'education', wherein there is both a valued process and a benefit. Recently, there have been calls to incorporate a dialectical “both/and” approach in health promotion (Eakin 1996) and community participation research (Uphoff 1992, Rifkin 1996). This approach utilizes multiple frames of reference (e.g., micro-macro, instrumental-transformational) which support and reproduce, rather than contradict, each other. Uphoff (1992) suggests that “several positions that are inconsistent within a single frame of reference can reasonably be held if more than one frame is applied, according to mutually agreed criteria such as utility and coherence” (p.309).

Rifkin (1996) notes the implications of accepting the “both/and” approach for participation research. Professionals would need to accept the validity of views of lay persons and allow new ideas to be examined. Planners would need to recognize that community participation is a set of views and activities which reflect local solutions to specific circumstances, and which may or may not have any universal aspects. Finally, planners would need to cease expecting that community participation tied to a single frame of reference will lead to program success.

The "both/and" approach to conceptualizing participation may be a valuable development in general participation research. The experience of these cases indicates that participation as an end, or strategy for organizational capacity building for disadvantaged groups, may be useful, but only insofar as it is successful in building an organization which can meet its members' immediate needs. Current health promotion philosophy suggests that it is desirable to achieve both instrumental and transformational goals of disadvantaged persons' participation simultaneously. However, the resources required for this goal are significant. This presents very real difficulties for planners, which are unlikely to be resolved in times of dwindling support for public funding of social interest groups.

6.3 Implications for Policy Development

In spite of the limited extent of community participation in these cases, this researcher was impressed by the receptiveness shown by respondents to the study and their interest in learning more about participation. Ideals were still strong although the respondents expressed concerns about how to implement participatory programs properly, and how to prevent their co-optation. In light of this interest in modifying practice, a number of practical recommendations for strengthening community participation in health promotion can be suggested which coincide with certain structural factors identified in this study:

a) Resource Allocation

If health promotion is intended to address the needs of disadvantaged groups, it must be realized that this is a long term task. Funding policies must allow sufficient resources and project terms to increase the actual participation of grassroots community members and to maintain community organizations' viability over prolonged periods of time. Such an approach however, runs counter to the short term commitment of government funding in this area. Thus, one can predict that this impasse will not only continue, but will likely become exacerbated in the future.

b) Target Group Orientation

If health promotion programs continue to use a target group approach which focuses on marginalized individuals who have few organizational skills, there must be special supports provided to enhance their effective participation. Provision of training in group participation and management skills for community members should be a priority, in addition to developing leadership skills. Volunteer costs should be treated as legitimate expenses of participation, but the need should be documented clearly and implementation should be evaluated fully.

c) Roles of Professionals

Cooperation between community members and other actors may be fundamental in health promotion projects which are affected significantly by professional, bureaucratic, and service agency priorities. Some health professionals demonstrate that they have a genuine interest in community participation in health programs. Considering the prevailing influence of professionals in the health promotion field, which is likely to persist, professionals should be encouraged and trained to enhance local project activities, rather than to direct them.

d) Program Links and Advocacy

If changes in health conditions are actually desired by policy makers, there should be an increased emphasis on the use of alliances and networks in health promotion to focus on the social-structural determinants of health. This strategy may, however, reduce the emphasis on grassroots involvement unless a parallel strategy is implemented to satisfy the instrumental needs of disadvantaged community members. Advocacy should be treated as a legitimate activity in health promotion, but an adequate identification of supporters should be required.

e) Organizational Structures and Control

If equal representation of community members is to be a fundamental condition of fora for public participation, then the current emphasis on organizational structures which promote accountability and representativeness over representation should be revised. Project control by consumers through membership-based governance models should be a condition of funding. A broader range of organizational structures, including non-board structures, should be encouraged.

f) Participation Coordination

If laurels for the conceptual development of health promotion are to go to federal planners, then darts should go as well for their failure to develop concepts of participation adequately. HPD staff attempted, but did not produce a coherent grassroots participation strategy. This was perhaps an unrealistic expectation of a centralized federal body.

However, the potential for success in this venture was present in the efforts of experienced program staff with origins in community work. Unfortunately, the lack of importance of the participation issue at the federal level was ultimately reflected in its loose administration and devolvement to bureaucratic preferences. The Canadian federal form of governance is intended to provide some coordination of national health strategies, although this may decrease with a diminishing fiscal responsibility in the area. Increased efforts should be made to understand and coordinate participatory structures and processes at each level of government that addresses health and social development issues.

An era of financial restraint in government spending may spell the demise of small health promotion projects with marginalized groups, since little funding is available for the organizational or personal support required in these populations. This demise may presage a return to a service orientation in public health. Such an orientation tends to invest in professionals, who then become resources to those in need, rather than to improve the conditions and capabilities of target group members directly through programming. Alternatively, marginalized groups may be left to fend for themselves. In the absence of the ideal, it appears that a focus on skill training within small, highly focussed and consumer-operated health promotion projects would allow progress on group health goals without being side-tracked by the panacea of participation.

6.4 Future Research from a Structural Perspective

This study has utilized the sociological perspective of structuralism in studying the complex phenomenon of community participation. The broad view of structure which was taken in this study proved to be relevant as it allowed the exposure of important structural barriers which were not evident in the literature. There was ample information available in the HPCP cases about structural conditions for participation, much of which was received unsolicited from respondents, although it was difficult at times to substantiate these data. Simultaneously, community members offered views on participation which could be interpreted from personal empowerment and group interaction perspectives, although these were not investigated. A comprehensive study of structural and non-structural factors in participation would be useful to further examine the links between structure and agency.

Cohen and Uphoff's framework provided a useful starting point for analysis of community participation in these cases. In particular, it identified key questions about the participation process and the range of structural factors which may influence this process. However, the framework did not clearly separate the structural elements from the participation process. Furthermore, the incorporation of analytic elements from social change theory was necessary for elaborating the framework for the health promotion context of this thesis.

This research has advanced the conceptualization of structure in community participation. In particular, this study has: identified key observable parameters (numbers, range, roles, influence) in the participation process; delineated major categories or dimensions of structural factors which affect these parameters; identified the organizational dimension of structure as being predominant in its effect on participation in a selection of health promotion cases; and explored a variety of issues in health promotion which suggest that the participation process in disadvantaged groups may be unique.

At this time, the development of a structural model of participation is needed to assist further studies in exploring practical and theoretical issues in this field. A number of preliminary hypotheses have been proposed which can be elaborated through social change theories and inserted in the model. This model may then be used for the prediction of project success and to inform the development of new participatory mechanisms.

Although a case study approach was useful in identifying structural factors in participation, it was limiting in its inability to demonstrate causal relationships in a generalizable manner. It is important that future research on participation be conducted with methodologies which are generalizable to a variety of settings and which can thus provide fuller theoretical explanations. Finally, it is crucial that the social change outcomes, or long term effects, of participatory projects be examined through longitudinal studies. This academic research agenda for community participation will require both qualitative methods and valid and reliable survey instruments, some of which may be developed from the factors identified in this study.

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APPENDIX A

INTERVIEW GUIDE AND RATIONALE

An interview guide of approximately thirty-five questions is used along with further probe questions. Respondents are asked questions appropriate to their background.

BACKGROUND (ALL)

What has been your involvement with Health & Welfare, the HPCP or the project?

- Determine respondent interest group affiliation.
- Determine role in project.
- Determine reasons for involvement.

COMMUNITY MEMBERS, SPONSOR STAFF, HEALTH & WELFARE STAFF

What was the purpose of the project?

- Determine the purpose and objectives of the project, i.e., health service planning, health education, environmental education, public policy, community development.

Was community participation important in the project?

- Determine the purpose of participation

What type of participation was used in the project?
How was this participation organized?
How were participants initially involved?
How were participants subsequently involved?
Was this approach to participation successful?
Were there any difficulties in involving participants?

- Determine the mode of participation, i.e., client, employee, volunteer, advisory committee, board of directors
- Determine recruitment strategies

What degree of influence did the community have in the project?

- Determine the process of participation, i.e., non-participation, tokenism, citizen power.

What changes (personal or social conditions) have occurred due to the project?
How were these changes documented?

- * Determine effects of participation and how participation is evaluated

How did the organization develop its relationship with the community?
What resources did the organization use to achieve its goals?

- * Determine origins and development of the community relationship and resource mobilization.

What were the strengths of the organization (or community)?
What type of changes did the organization (or community) believe that it was possible to make?
How did the organization (or community) view its role in the community?
Was the organization (or community) allied with other groups working in the community?

- * Determine social movement characteristics.

What type of community individuals participated in the project?

- * Determine the key community persons in the project.
- * Determine participant characteristics.

What other groups had a part in the project?
What were the roles of professionals, bureaucrats, sponsors & participants in the project?
How did these groups view participation?
Who defined the health issue in the project and how to address it?

- * Determine interest group's agenda, influence and their impression of role of other groups.

Were there any unforeseen problems because of the way participation occurred?
Did this affect your group?

- * Determine unintended consequences.

HEALTH & WELFARE OFFICIALS, NON-GOVERNMENT EXPERTS

What factors have affected the development or functioning of health promotion projects?
How has community participation in health promotion changed over the years?
Has the government influenced the type of participation occurring in projects?
Does the government view participation as important in health promotion?
Is there a negative side to participation?

- * Determine purpose of participation in health promotion.

Do business or labour have a position on community participation in health programs?
Have international factors affected the call for participation in health promotion?

- * Determine the effect of economic and global influences on community participation program.

Is there government effort towards increasing participation in communities? How and why is this happening?
Is there a move toward formalizing community participation in decision making in Canada?

- * Determine the factors which may have an effect on the future of community participation as a strategy.

<u>OTHER INFORMATION (ALL)</u>

Do you know of any other information or documents that I may find useful?
Do you know of any other people that I should talk with about the project or HPCP?

APPENDIX B

PROJECT DESCRIPTIONS

The following are brief summaries of the population of sixteen HPCP projects in this study. The descriptions have been organized by target group. Consumer organizations are indicated by √. Case studies are indicated by *.

PERSONS WITH DISABILITIES

√ Drug and Alcohol Abuse and Persons with Disabilities
* This project addressed the problem of substance abuse for persons with disabilities. Activities involved raising awareness of individuals, professionals and health service providers regarding the specific circumstances of disability which affect identification, treatment and support of substance abuse problems. Educational material, focus groups, conferences and a speakers' bureau were organized to initiate community discussion of the issue.

Awakening
√ This project addressed the problem of low levels of awareness of the community and persons with disabilities about disability health issues. Activities were aimed to increase participation of disabled persons in community activities and planning. A needs assessment, public meetings and educational events were held to improve community awareness of disability issues.

Information Brochure
This project addressed the problem of a lack of information about head injuries for injured persons, family members and professionals. Activities involved developing an information brochure about the problem for educational purposes. Information was gathered from service providers and community members in assembling the brochure. Arrangements were made for dissemination of the brochure across the province.

Educational Workshops Project
This project addressed the problem of a lack of active participation of chronic psychiatrically disabled persons in educational and skill development programs. Activities focused on the development of planning and problem solving skills in the organization of educational meetings. A series of meetings were organized with the assistance of the target group to educate persons with psychiatric disabilities about self-help skills.

* Independent Living Centre
√ This project addressed the need for community services for persons with disabilities. Activities focussed on advocacy assistance, peer interaction, information provision, skill development and increasing community awareness of the needs of persons with disabilities. Programs were established to provide services in these areas.

The Family and Disability - Talking It Out
This project addressed the problem of acquired disability in parents of young children. Activities were aimed at improving communication skills and problem-solving between the spouse, children and the person with a new disability. Discussion groups were organized to identify issues for inclusion in a video about the problem.

Citizen Advocacy
This project addressed the problem of social isolation of persons with developmental disabilities. Activities focussed on public education and strengthening the target groups' self-care and social skills. A one-to-one volunteer program was expanded to include cross-disabled persons. Community education events were organized to increase public awareness of the needs of persons with developmental disabilities.

WOMEN

Psychotropic Drug Booklets
√ This project addressed the need for information about use of mood-altering drugs for low literacy women. Activities were aimed at prevention and early intervention for women with this problem. A series of information pamphlets were developed, tested and distributed across the province.

Birthing Booklet
√ This project addressed the problem of a lack of information for pregnant women and their families about out-of-town deliveries. Activities were aimed at alleviating stress by providing basic medical and non-medical information about out-of-town deliveries. Input was obtained from a series of workshops and from professionals in the development and distribution of an educational booklet.

Public Education, Advocacy and Communications Project
√ This project addressed the health needs of immigrant and visible minority women. Activities were aimed at increasing the mutual understanding of these women and the health care system about the barriers to accessing health services. A series of workshops and public meetings were held to bring together women, service providers and policy makers.

* Health and Disabled Women Network
√ This project addressed the health needs of women with disabilities. Activities focused on identifying needs, developing skills and information and joint planning for improving access to health services. A series of workshops and training sessions were conducted to identify needs and improve personal skills. Information packages were developed and disseminated. A symposium with health professionals and policy-makers was held.

Project COPE

This project addressed the problem of substance abuse among women criminal offenders. Activities were aimed at self-help and peer support in the control of addictions. Women in the target group were trained as peer supporters and conducted a needs assessment. Self-help support groups were established. Community education was implemented through public presentations.

ADOLESCENTS

* Ethnic Youth Mental Health Project

This project addressed the problems of familial stress and cultural conflicts in ethnic youth. Activities focussed on developing self-expression and coping strategies in youth.
A training package and video were developed and used in a series of workshops with ethnic youth and families.

* Prevention of Sexually Transmitted Diseases among Street Youth

This project addressed the need for appropriate information about STD's for urban street youth. Activities were aimed at developing and distributing information and facilitating discussion among street youth about the problem. A needs assessment was conducted among youth and street workers. A variety of educational materials and videos were developed, tested and distributed.

Teen Suicide Prevention Video Package

This project addressed the problem of teenage suicide. Activities focussed on increasing awareness among youth about how they could discourage a friend's potential suicide. A video and educational manual were developed, tested and distributed.

NATIVES

Beyond the Abuse

√ This project addressed the problems of sexual and substance abuse among native people. Activities were aimed at changing these behaviours through public education media. A needs assessment was conducted with individuals and professionals. A series of advertisements were developed for different media and transmitted across the region.

APPENDIX C

HPCP PROJECT CHARACTERISTICS

	NAME	LOCATION	TARGET GROUP	MODE
*	Drug and Alcohol Abuse and Persons with Disabilities✓	Ontario	Disability	Board
	Public Education, and Communications✓	Toronto	Women	Board
*	Health and Dis-Abled Women Network✓	Ontario	Women	Advisory
*	Prevention of STD's Among Street Youth	Toronto	Adolescents	Employee
	Project C.O.P.E.	Hamilton	Women	Employee
	Teen Suicide Prevention	Bancroft	Adolescents	Employee
	The Family and Disability-Talking It Out	Sudbury	Disability	Volunteer
*	Independent Living Centre ✓	Thunder Bay	Disability	Volunteer
	Northwestern Ontario Birthing Booklet ✓	Thunder Bay	Women	Volunteer
	Psychotropic Drugs and Older Women ✓	Kingston	Women	Volunteer
	Educational Workshops	Cambridge	Disability	Volunteer
	Beyond the Abuse ✓	Sioux Lookout	Natives	Volunteer
	Awakening ✓	Kapuskasing	Disability	Client
	Brockville Citizen Advocacy	Brockville	Disability	Client
	Head Injury Project	St.Catharine's	Disability	Client
*	Intercultural Health Share	London	Adolescents	Client

(* CASE STUDY, ✓= CONSUMER ORGANIZATION)

APPENDIX D

ANALYSIS OF PARTICIPATION IN COMMUNITY HEALTH PROMOTION PROGRAMS

INTERVIEW CONSENT FORM

Will Boyce has explained to me his study on the analysis of participation in Health Promotion Contribution Program projects. This study is being conducted for his doctoral dissertation under the supervision of Dr. M. Kelner in the Department of Community Health at the University of Toronto. I consent to be interviewed as part of this study. I understand that I may withdraw from the interview at any time. I consent to the data obtained from this interview being used in the preparation of his dissertation and subsequent derivative materials, such as scholarly papers, intended for publication. I understand that I will receive a copy of this consent form.

I agree to the following procedure concerning the confidentiality of my interview data:

This interview will be tape recorded (audio only) and then transcribed. I agree that only Will Boyce and a transcriber will hear the tape and that it will be subsequently erased. I agree that transcripts will only be viewed by Will Boyce and his research committee, will be kept in locked storage and will be destroyed upon completion of this work unless I give permission for them to be archived as indicated below. I understand that an identification number will accompany my transcripts, the list of code numbers and identities stored separately. I understand that data will never be directly attributed to me but that a general description of my background may be given as explanation.

Name of Respondent: ....

______________________________ ______________

Signature Date

I agree that the transcript of this interview may be archived as a source of information on participation in community health programs. Access may be given to it from January 1, 1994. I understand that the transcript will be anonymous but that a general description of my background may be given as explanation.

______________________________ ______________

Signature Date

APPENDIX E

OPERATIONAL DEFINITIONS OF CATEGORIES

CONTEXT - describes the general environment in which participatory projects operate

TASK ENVIRONMENT - describes the societal factors which may affect participation and the potential of the sponsor group to encourage participation

Societal Factors
- general social and cultural acceptance of participatory projects (tradition in the target group or community, attitudes towards gender, age, race, class and disability, usual role of local leaders and family systems, isolation, reliance on public vs. locally organized programs)
- political support (priority and funding support for HPCP, coordination of programs between federal-provincial-municipal levels, commitment to health promotion as a strategy, views on the place of participation in publicly resourced programs, allocation of resources to facilitate participation, institutionalization of participatory mechanisms)
- economic influences (perceived competition from business or labour, interest in economic integration of target group, job training opportunities)

Sponsor Factors
- the composition of the sponsor group (directed and staffed by professionals or by members of a target group/local community)
- sponsor's history of work in the community and acceptance of sponsor by other community groups
- perceptions about sponsor by other interests, especially sponsor's ability to promote participation
- new social movement characteristics (degree of independence and self-direction, publicly identified values, reputation)
- resource mobilization (sources of financial and human resources, time spent in securing funds, strategies used to solicit funds, adaptations to project plan to fit funders' criteria)

PROGRAM FACTORS - describes the bureaucratic elements which may have direct or indirect influences on participation

Personnel Factors
- background of program officers and managers (community development, technical, health professional)
- roles in solicitation and development of projects
- ongoing assistance and direction to projects
- commitment to participatory strategies

Organizational Factors

- regulations regarding forms and strategies of participation (advisory committees, boards of directors, payment of volunteers, payment for meeting expenses)
- the practice of public consultation and its role in government decision-making
- emphasis on forming partnerships and coalitions in communities

Funding Factors

- levels of funding for community projects vs. national projects and program infrastructure
- priorities given to particular target groups
- methods of establishing target group legitimacy and eligibility for funding

Evaluation Factors

- role of evaluation in the program
- utilization of evaluation findings (political and practical)

DETERMINANTS - describe factors which may have more direct influence on participation in projects

<u>PURPOSES</u> - describes the intended and unintended purposes of participation in projects

Purposes of Participation

- publicly stated and privately expressed purposes and rationales for participation (bureaucrats, sponsor staff, community members and professionals)

Paradigm of Health

- expressed views on underlying causes of target group problems (biomedical, lifestyle, environmental, social-structural) and rationale for choice of health promotion approaches (health service planning, health education, mutual aid, self care, healthy public policy, community development)

Project Objectives

- health promotion approach (health service planning, health education, mutual aid, self care, healthy public policy, community development) and form of participatory strategies

PROJECT CHARACTERISTICS - describes the project's structural and organizational characteristics which may influence participation

Inclusion/Exclusion Biases - project factors which encourage or restrict participation based on the sponsor's definition of target group membership (e.g., persons with certain types of disabilities but not others), representation or selection of particular individuals to become involved based on skills (technical or educational qualifications), recruitment methods (personal contact, mail, public notices and presentations, media, referral from agencies, non-voluntary), and barriers to participation (transportation, economic affordability, physical access, language, child care)

Benefit Factors - factors concerning benefits of participation which make involvement of community members more or less likely such as tangibility (benefits which are seen to be of practical use, e.g., a job rather than a skill improvement workshop), probability (benefits which are highly likely to be received and in which there is little risk of losing existing benefits), immediacy (benefits which will appear soon rather than in the long term), and divisibility (benefits which can be received in amounts which fit the participant' needs rather than in standard amounts)

Design Factors - factors which affect participation due to the way in which projects are designed or planned such as:
- program linkages and allies - linking project objectives so that multiple needs of community members are met, use of other community agencies to provide services or resources which the sponsor cannot provide
- program flexibility - allowing flexible arrangements for roles of community members depending on their interests and availability
- resource availability/usage - availability and use of resources to facilitate participation (for publicization of opportunities, payment of volunteers, child care, travel costs)
- administrative characteristics - accessibility of project staff to community members, staff initiatives to promote involvement
- staff:participant ratio - optimal number of staff to encourage and facilitate participation yet not take too much responsibility

DIMENSIONS - describes the process of participation in community projects

WHAT KIND? - describes different stages or aspects of projects in which participation may occur

Decision-Making - the generation of ideas (defining issues), formulation, assessment and making choices about options (initial decisions), formulation of plans for putting selected options into place (ongoing decisions), and deciding organizational matters such as membership composition, leadership selection and meeting procedures (operational decisions)

Implementation - contribution of financial, labour, information, equipment and supply resources
- administration and coordination of project activities (as board members, advisory committee members, employees, volunteers)
- enlistment in project activities (as clients) but not necessarily in benefits

Benefits to Individuals - material benefits (eg employment, clothing, food), social benefits (services or publicly available goods such as health clinics), personal benefits (self-esteem, sense of efficacy, social support, political power)

Evaluation - includes evaluative activities such as local project evaluation, advocating for policy changes (direct lobbying), and influencing public opinion through media (indirect influence)

WHO? - describes the entire set of participants involved in community projects and some of their distinguishing features and interests

Community Members - includes target group members, families and other individuals who are interested, or in conflict, with the project activities

Sponsor Staff - includes board members, managers and support staff who have roles and interests in the project

Government Personnel - includes elected officials, senior bureaucrats and program staff

Professionals - includes health, education and social welfare professionals who by virtue of training and experience have a role in the project

Others - includes local businesses, labour, and those community members who are not directly involved in the project

Characteristics - background characteristics which may affect the participant's actions and interests (age, gender, family status, education, social-ethnic-cultural-religious-language divisions, occupation and income, length of residence)
- target group characteristics - physical, social, emotional factors which facilitate or impede participation
- leadership patterns and roles

HOW? - describes the particular sources, patterns, and dynamics of participation in the project

Basis of Participation - source of the initiative for participation - from the grassroots or from the national centre
- the incentive for involvement which may vary from payment for participation through voluntary involvement to coercion

Form of Participation - organizational features which affect participation, i.e., leadership roles, rules or conditions for participant involvement, complexity of the organization
- direct participation of target group members or indirect involvement through representatives

Extent of Participation - numbers of participants
- frequency, duration and periodicity of involvement
- range of activities in which individuals participate

Constraints on Participation - individual and organizational features which impede participation (motivation, skills, availability of information, remuneration, employment criteria, work shortage, lack of sponsor resources, scheduling)

Participant Consensus - convergence and divergence of participant views
- methods of obtaining agreement
- consequences of disagreement

Effects of Group Participation - group empowerment or development of capacity of persons to obtain their goals
- interactions with participants in other groups
- limitations and consequences (wasted time, adverse reputations, disadvantage to another group)

Control and Power - positions and actions of powerful groups, influence of project participants on decisions and activities, conflict between groups

APPENDIX F

SUMMARY OF STRUCTURAL FACTORS' EFFECTS ON TYPES OF PARTICIPANTS

STRUCTURAL FACTORS	ICYP	PUSH	ICHC	HAGI	DAWN
COMMUNITY MEMBERS					
Target Group Status	? Number - Range + Number + Range	- Range	-/+ Nos. + Range	- Range	- Range
Target Group Experiences	- Number - Range			- Number	- /+ Nos
History & Target Group Mandate		- Range + Number	- Group Range + Number	- Range + Number	
STAFF					
Organization Structure		- Number		- Number	
Leadership			+ Number		+ Number
PROFESSIONAL					
Project Objectives		+ Profs	+ Profs		+/- Profs
Strategy Mandate			+ Profs	- Health + Other Profs	
BUREAUCRATS					
HPD Staff				+/- Burs	+ Number + Burs

APPENDIX F - CONTINUED

SUMMARY OF STRUCTURAL FACTORS' EFFECTS ON SPONSOR STRATEGIES

STRUCTURAL FACTORS	**ICYP**	**PUSH**	**ICHC**	**HAGI**	**DAWN**
Target Group Experience	- Number			- Number + Posns	
Resource Mobilization	+ Posns - Number - Number - Group Number	- Number + Posns	+ Posns	- Number - Number	- Number
Program Linkages		- Group Number	+ Number - Group Posns	+ Group Number	+ Number - Range

APPENDIX F - CONTINUED

SUMMARY OF STRUCTURAL FACTORS' EFFECTS ON PARTICIPANT ROLES AND ACTIVITIES

STRUCTURAL FACTORS	ICYP	PUSH	ICHC	HAGI	DAWN
Strategy Mandate	+ Number + Posns	+Posns	- Posns - Range - Number	-Number -Activ.	
Organization	+ Number - Range - Posns +/- Posns	+ Posns + Number	+ Number - Posns	+ Posns - Infl. - Range	- Posns + Posns
Project Activities	+ Activ. + Posns - Number	+ Activ. - Number	+/- Posns - Number	- Group Posns - Group Infl.	-+ Nos + Number + Range
Leadership				+ Posns - Infl.	+ Posns
Target Group Experiences	+ Posns			+/- Nos.	

APPENDIX F - CONTINUED

SUMMARY OF STRUCTURAL FACTORS' EFFECTS ON INFLUENCE AND POWER DYNAMICS

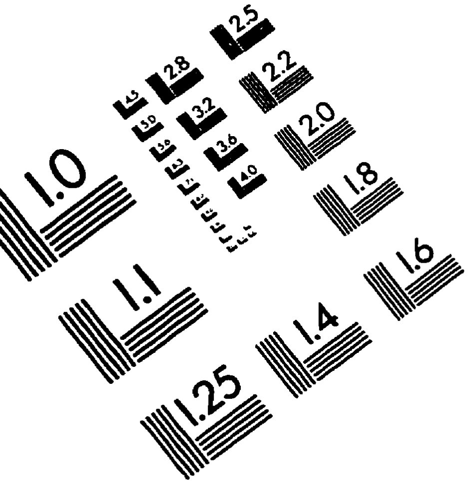
STRUCTURAL FACTORS	ICYP	PUSH	ICHC	HAGI	DAWN
Strategy Mandate	- Infl.	+ Infl.	- Infl. + Prof Infl.		
Target Group Experiences	+/- Infl + Infl				+ Local Infl.
Target Group Status		+/- Infl.	- Infl.	- Infl.	
Organization Structure	- Infl			- Infl.	

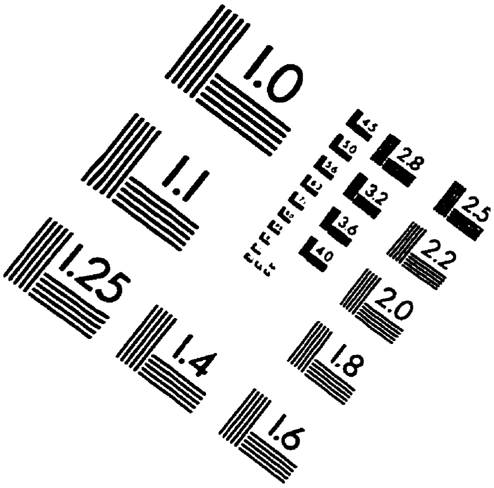
APPENDIX G

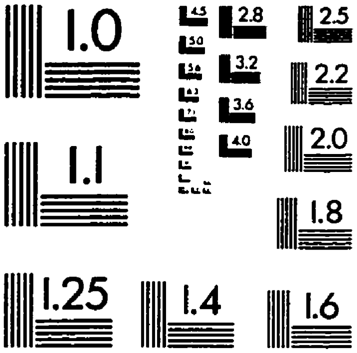
HEALTH PROMOTION CONTRIBUTION PROGRAM (HPCP) EFFECTS ON PARTICIPATION

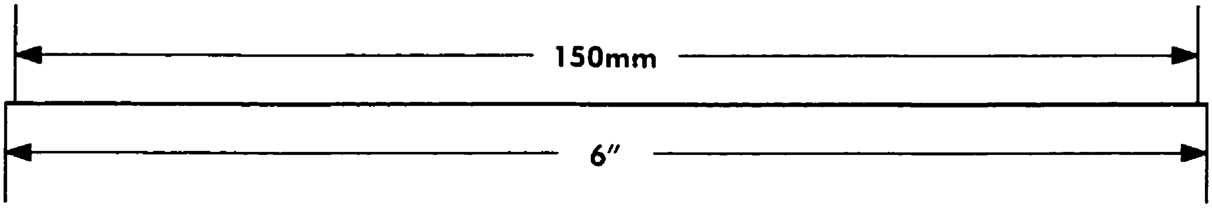
STRUCTURAL FACTORS	DESCRIPTIONS	HPD RESPONSE	EFFECT ON PARTICIPATION
PARTICIPANTS			
Target Group Policy	Focus on target group needs	No staff for low income groups	Groups with narrow focus
HPD Staff	Annual priorization, staff background & personal interests	Lobbying by HPD staff	Imbalance of projects for target groups
Resource Availability	Small scale, short-term funding	Selection of inexperienced organizations	Doubtful representation of community members
STRATEGIES			
HPD Staff	Large increase of projects, small increase of funding	Small staff increase, increased workload	Decreased, inconsistent support to projects
Program Administrations	Unclear expenditure guidelines, limits on volunteer payments	Inconsistent application of guidelines	Decreased practical supports and motivation of volunteers
ROLES AND ACTIVITIES			
Guidelines for Participation	Formalized models of participation	Insufficient resources, Inflexible requirements	Decreased attention to project goals, grassroots participation.
Program Administration	No evaluation of activities, participation	Changed reporting format	Little information or feedback to projects
HPD Policy Shift	Target group to target issue	Networks and partnerships	Increased participation of service providers, bureaucrats, professionals. Decreased community member influence. Co-optation to government agenda?

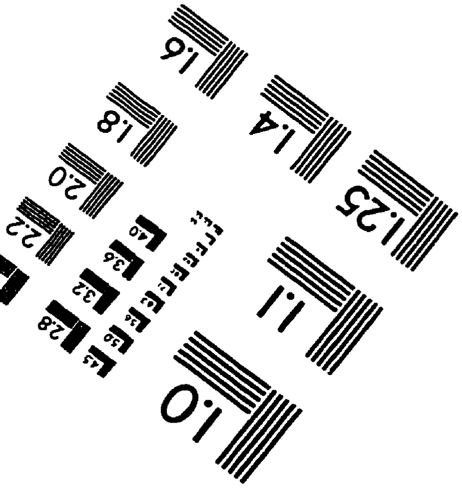
IMAGE EVALUATION TEST TARGET (QA-3)

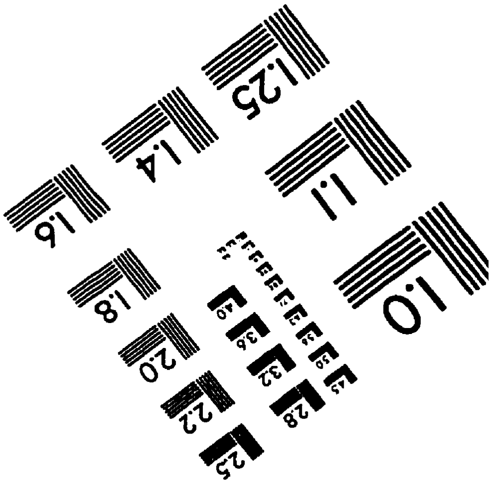












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