

PARTICIPATORY EVALUATION AS A TOOL FOR ENHANCING THE ROLE OF
SELF-HELP GROUPS IN HEALTH PLANNING

by

DEBORAH LEE CAMPBELL

B.A., Simon Fraser University, 1980
M.B.A., City University, 1990

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS TO THE DEGREE OF

DOCTORATE OF PHILOSOPHY

in

THE FACULTY OF GRADUATE STUDIES

School of Community and Regional Planning

We accept this thesis as conforming
to the required standards

THE UNIVERSITY OF BRITISH COLUMBIA

January 19, 2000

© Deborah Lee Campbell, 2000

In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of School of Community + Regional Planning
The University of British Columbia
Vancouver, Canada

Date February 14, 2000

ABSTRACT

This dissertation explores the potential of participatory evaluation as a tool for involving self-help groups in health promotion. To explore this potential, I engaged twenty-one women representing seventeen women's self-help groups in Vancouver in an exercise to consider how well the Vancouver/Richmond Health Board: (1) included groups such as theirs in a recent community participation process and (2) supported self-help groups as complementary health services. The Health Board was invited but did not become involved.

On the whole, participants perceived that the Health Board adopted a top-down approach to community health promotion and did not include or support their groups adequately or equitably. They believed that the Health Board had failed to develop a sense of trust and camaraderie between the Board and self-help groups and that the Board's efforts to reach out to these groups did not involve planning approaches that fostered such relations.

This dissertation reveals that it is not necessary to have to choose between a consensus and conflict approach to participatory evaluation. Evaluation can be placed on a

continuum ranging from one extreme to the other and can adopt elements of both forms of evaluation. The grass-roots, flexible nature of our exercise enabled participants to conduct the evaluation using either or both of these stances. Our exercise was more consensus-oriented but also involved elements of the conflict approach.

The nonattendance of the Health Board gave participants the opportunity and confidence to organize, to take control, to become empowered, and to act. This absence, however, made it difficult for self-helpers to work collaboratively with the Health Board during the evaluation and to share understandings and reach a consensus with them about our findings and how they can be used to make transformations in health promotion. On the other hand, our exercise enabled participants to find alternative ways to work with the Health Board in the future. In other words, we adopted an incremental rather than revolutionary strategy and, therefore, may have only temporarily compromised educative authenticity to achieve catalytic and tactical authenticity.

TABLE OF CONTENTS

Abstract	ii
Table of Contents	iv
List of Tables	ix
List of Figures	x
Acknowledgements	xi
Dedication	xii
Chapter 1: Introduction and Overview	1
Introduction	1
A Brief Chapter Overview	4
Background to the Study	5
Community Health Promotion	5
The Role of Self-Help Groups in Community Health Promotion	8
The Community in Health Promotion	8
Community Participation in Health Promotion	10
Self-Help Groups and Community Participation	11
Levels of Participation	13
Non Participation	13
Token Participation	13
The Highest Rungs	14
The V/RHB and Its Community Participation	15
Initiative	15
Formalizing Community Participation	16
The V/RHB and Bottom-Up Versus Top-Down Avenues of Participation	18
Methodological Approach, Objectives, and Methods	21
A Brief Look at Participatory Evaluation	22
Study Objectives	23
The History and Rationale Behind the Study	24
Self-Help Groups	26
Women and Women's Self-Help Groups	28
Vancouver	36
The Vancouver/Richmond Health Board	36
Participants Involved	37
Gathering Information	37
Literature Review	38
Duration of Study	38
Researcher's Views and Biases	39
Role of Researcher	40
Expected Challenges and Constraints	41

Dissertation Structure	43
End Notes	45
Chapter 2: Research Methodology, Methods, and Procedures	47
Introduction	47
Ensuring Methodological Integrity	48
Ensuring Methodological Integrity: Through the Eyes of Lincoln and Guba	49
From Positivism to Constructivism	49
Ontology, Epistemology, and Methodology	50
Criteria of Trustworthiness	53
Ensuring Methodological Integrity: Through the Eyes of Sandelowski	54
Auditability	55
Credibility and Fittingness	56
Defining Terms	57
Lincoln and Guba's Criteria of Authenticity	59
Honouring Subjective, Experiential, and Lay Knowledge	61
Exploring Alternative Knowledge	61
Discussion	67
PAR as an Appropriate Methodology	68
Participatory Action Research and Community Health Promotion	68
Participatory Action Research and Self-Help Groups	72
Androcentrism in Participatory Action Research	81
Implication and Redress	83
Discussion	86
Participatory Evaluation: Conflict Versus Consensus Approaches	87
A General Description	87
Critical Evaluation	88
Consensus Evaluation	91
Conclusion	96
End Notes	98
Chapter 3: Methods and Methodological Findings	100
Introduction	100
The Participatory Evaluation Exercise	101
Designing the Evaluation Process	101
Participant Recruitment	102
Participant Involvement and Contribution	107
Determining/Meeting Needs	114
Generating Information	115
Recording, Categorizing, Presenting, and Analyzing Information	117
Distributing Information	121
Making Recommendations	123
Assessing The Exercise	124
Discussion	125

The Questionnaire Process	126
Process Versus Outcome	128
Direct Participation, Social Participation and Equity	129
Dynamic Indicators of Participation and Support ..	131
Our Questionnaire	132
The Spider Web	136
Our Webs	138
The Value of This Model	139
Limitations	140
Discussion	142
Challenges, Constraints, Limitations, and Opportunities	143
Participant Recruitment and Involvement	143
Attempts to Recruit Health Board Members	155
Applying to the Vancouver/Richmond Health Board for Funding	160
Focus of the Exercise	162
Confidentiality	164
Language	166
Added Opportunities	167
Conclusion	169
End Notes	171
 Chapter 4: Substantive Outcomes	173
Introduction	173
A Brief Overview	173
Presentation of Information	174
The Role of the Health Board in Involving and Supporting Self-Help Groups in Health Promotion	176
Discussions During Meetings	176
Evaluation Ratings on Questionnaires	178
Respondents' Discussions: Health Board Contact Prior to 1998	196
Post 1997 Contact: Discussions From Questionnaires	202
Post 1997 Contact: Conversations During Meetings	203
Bottom-Up Efforts to Contact the Health Board	204
Discussion	206
Maintaining Integrity, Autonomy, Control, and Sustainability	208
Desire for Independence	209
Preserving Integrity, Control, and Sustainability	210
Exploring the Potential of Self-Help Group Umbrellas	212
Internal Versus External Control	216
Bureaucracy	216
Politics and Political Control	217
Attitudes of Professionals	219

Democracy and Equity	220
Discussion	222
The Position of Self-Help Groups in Health Promotion ..	228
Value of Self-Help Groups	228
Definition	231
Stepping Outside	232
The Special Structure of Self-Help Groups	234
V/RHB Attitudes Towards Self-Help Groups	235
V/RHB Attitudes Towards Self-Helpers' Expertise ..	236
Usages of Health Board Resources	237
Discussion	243
The Position of Women in Self-Help Groups and the Health System	244
Discussion	244
Participants' Understandings of the V/RHB and the Health System	245
The Health Board	245
The Health System	250
Discussion	251
Contacted Stakeholders	251
Where to From Here?	252
End Notes	254
 Chapter 5: Discussing Methodological Integrity and Participants' Assessment of the Exercise	255
Introduction	255
Maintaining Methodological Integrity	255
A Relativistic Ontology and Monistic, Subjectivist Epistemology	256
Hermeneutic Methodology	257
Criteria of Trustworthiness	260
Credibility	260
Transferability	261
Dependability	261
Confirmability	262
Discussion	262
Criteria of Authenticity	263
Fairness	263
Ontological and Educative Authenticity ..	264
Catalytic and Tactical Authenticity	266
Discussion	267
Participants' Assessment of the Exercise	280
Evaluative Comments Provided During Meetings ..	281
Discussion	283
Problems Encountered	285
Assessment of the Questionnaire	286
Discussion	288
Conclusion	289
End Notes	290
 Chapter 6: Implications	291

Introduction	291
Implications for Future Participatory Evaluations	291
Future Participatory Evaluation Initiatives	292
Adopting Rifkin Et Al.'s Model	295
Implications for Health Boards/Regions	297
Expanding the Role of Self-Help Groups in Community Care	297
The Importance of Participatory Evaluation and Self-Help Groups	302
Employing Participatory Evaluation	303
Supporting Self-Help Groups in Health Promotion	305
Implications for Self-Help Groups	306
Implications for Planners	308
End Notes	314
 Appendix 1: Vancouver/Richmond Health Board Annual Review ..	315
Appendix 2: Participatory Evaluation Questionnaire	324
Appendix 3: A General Aide Memoire	343
Appendix 4: Revised Letter of Participant Recruitment	346
Appendix 5: Revised Letter of Information and Informed Consent Form	350
Appendix 6: Exercise Objectives and Tasks	354
Appendix 7: Draft Exercise Assessment Form for Core Participants	357
Bibliography	365

LIST OF TABLES

Table 1:	The Values and Principles of Self-Help Groups	81
Table 2:	Raw Data for Needs Assessment	181
Table 3:	Raw Data for Resource Mobilization	183
Table 4:	Raw Data for Participatory Approach	185
Table 5:	Raw Data for Leadership Styles	187
Table 6:	Raw Data for Horizontal Linkages	189
Table 7:	Raw Data for Vertical Linkages	191
Table 8:	Frequencies for Questionnaire Sub Indicators	192
Table 9:	Frequencies for Questionnaire Indicators (Overall Ratings)	192

LIST OF FIGURES

Figure 1: Epp/Health and Welfare's Framework for Health Promotion	20
Figure 2: A Conception of Groups and Organizations to Which the Women's Health Advisory Committee Should Be Accountable	21
Figure 3: An Example of a Spider Web Configuration for Baseline Measurements of Indicators	137
Figure 4: An Example of a Spider Web Configuration at Time 1 and Time 2 for all Indicators	138
Figure 5: Web Configuration for Indicators of Participation and Support	193
Figure 6: Web Configurations for Sub Indicators of Participation and Support	194
Figure 7: Bar Chart for Indicators of Participation and Support	196
Figure 8: Community Care: Our Three Spheres of Action	298

ACKNOWLEDGEMENTS

I would like to thank:

The participants in our participatory evaluation exercise for giving generously of their time, knowledge, and resources and making this dissertation possible;

Members of self-help groups/organizations who provided us with letters of support for acquiring funding and who otherwise supported this dissertation;

Dr. Judith Ulan and Helen Turbett for their assistance with my dissertation;

Doan, Thai Thong (Tom) for designing the graphics I used throughout my dissertation and Lin Yuh-Ren (Jack) for designing the graphics I utilized for my dissertation defense;

My mother, father, and brother, Marjorie June, Harold, and Daniel Campbell, respectively, for their years of unending patience and support; and

My friends Helen Turbett; Dr. Judith Ulan; Lin Yuh-Ren (Jack); Duong, Lam Tan (Joanna); Doan, Thai Thong (Tom); Doan, Quay Nguyen (Kevin); Ho, Hue (Helen); and Christian Barthol for always being there when I needed them.

DEDICATION

In addition to thanking my father (Harold Campbell), mother (Marjorie June Campbell) and brother (Daniel Campbell) for their support, I would like to dedicate this dissertation to them. They have been there for me all of my life and have made my education possible.

CHAPTER 1: INTRODUCTION AND OVERVIEW

INTRODUCTION

Over the years in Canada, there have been many initiatives in the area of community health promotion and the devolution of health care. Health promotion can be defined as fostering "the combination of educational and environmental supports for action and conditions of living conducive to health" (Green and Kreuter, 1991, p. 4) and includes "investment in an empowered, active citizenry, who in partnership, can deal with health concerns formerly the exclusive purview of health professionals" (Harris, 1992, p. S62). Academics and practitioners alike have agreed that devolving the responsibility of health promotion to the community level can potentially foster healthier individuals and communities.

The community health promotion movement has developed many of its own avenues for participation. Having recently become part of this trend, for example, the Vancouver/Richmond Health Board (V/RHB) has¹ created Community Health Committees, Neighbourhood Health Groups, and Population Health Advisory Committees.

These committees and groups are made up of local residents and have an important part to play in community consultation. An abundant body of literature suggests, however, that, as top-down and imposed avenues, these types of avenues for health promotion might have a limited role in fostering long-term

commitment and a sense of ownership over the process (Berger and Neuhaus, 1977, 1984; Romeder, 1982). This literature indicates that planning from above, even if the planning mission is to bring about greater levels of participation, has often failed to develop a local interest in community planning (Berger and Neuhaus, 1977, 1984; Romeder, 1982). Planning from above has also limited the ability to tap the informal or popular expertise potentially available to a community and to the planning process².

To realize sustainable community involvement, the literature suggests it is essential to identify and respect local "ways of doing", i.e., indigenous, grass-roots means or avenues of participation, and to work with them. (See Anyanwu, 1981, 1988; Berger and Neuhaus, 1977, 1984; Chesler, 1991; Kraemer Tebes and Tebes Kraemer, 1991; Romeder, 1982.) This study focuses on one bottom-up avenue of participation in health promotion, i.e., self-help groups (see page 11). Health promotion can benefit from the identification and engagement of appropriate research and planning methods to work with these groups.

There is a dearth of material analyzing the potential of participatory evaluation³ as a tool for enabling health system beneficiaries and stakeholders such as self-help groups to provide input into health promotion.

This dissertation assesses that potential through the development of a participatory evaluation exercise involving self-helpers⁴ in one health jurisdiction, the Vancouver/Richmond Health Board (V/RHB), in evaluating that

Board's efforts to include and support them in health promotion.

It is important to emphasize here that the exercise involved only one set of invited stakeholders, self-help groups. For reasons discussed later, members of the V/RHB (i.e., paid staff and volunteers including board directors) elected not to be involved. This limited the potential of this exercise to provide a complete evaluation of the V/RHB's efforts to support the role of self-help groups in community health promotion initiatives.

The purpose of the exercise, however, was not to provide a formal evaluation of the Health Board. Rather, it was to explore the dynamic nature of participatory evaluation and its ability to adapt to various challenges, including one as significant as the nonattendance of the service delivery stakeholders (i.e., here, the V/RHB). Participatory evaluations of this kind do not seem to have been previously documented in the participatory evaluation literature.

The exercise had two goals: (1) to benefit the specific participants and the wider communities of interest they represent and serve and (2) to contribute to methodological knowledge about participatory evaluation that can be useful to the Health Board and health planners⁵ in general.

The dissertation explores the potential of participatory evaluation by: (1) documenting the quality of relationships developed and participants' involvement in the exercise as a result of the approach undertaken, (2) assessing the effectiveness of the exercise in giving a voice to a population

whose subjective, experiential, and lay knowledge has been largely untapped; (3) analyzing the personal benefits of such involvement for participants; (4) presenting the types of information participants were able to generate as a result of the approach taken; (5) reviewing alternative strategies and methods participants developed and proposed to equitably involve the Health Board in subsequent, ongoing evaluation efforts, and (6) drawing general lessons for using participatory evaluation in health promotion work.

A BRIEF CHAPTER OVERVIEW

The remainder of this chapter is organized into four major parts. First, the chapter provides background information on the general community health promotion movement and how self-help groups do or can fit into this movement. This includes a brief overview of possible levels of participation they can choose. It then looks at the community participation initiative adopted by the Vancouver/Richmond Health Board, a product of its community health promotion efforts and the subject of this participatory evaluation exercise, and the roles self-help groups (bottom-up avenues) were envisioned to play in this initiative.

From here, this chapter examines the methodological approach, objectives, and methods involved in this study and its exercise. It provides us (the readers)⁶ with introductory "how", "who", "what", "where", "when", and "why" information

related to the exercise, information which is presented in greater detail in Chapter 3.

This chapter concludes with an outline of the structure of the dissertation.

BACKGROUND TO THE STUDY

COMMUNITY HEALTH PROMOTION

Davey and Dwyer (1984) argue that, to have a truly participatory health care system, it is essential for community members to be involved in decision-making as well as task performance. Community members are already involved on different levels and to different extents with providing health care. Residents look after their own health, the health of their families, and often the health of their communities. It is largely professionals, however, who are acknowledged for caregiving roles. It is also largely professionals who are given decision-making powers over others and over community programs.

Community members have considerable knowledge about what their health needs are and have their own popular (experiential and lay) expertise regarding how to meet these needs. As Osteria (1991) shows, residents can work quite effectively with health professionals at all levels of planning, and community health programs can become more reflective of local needs as well as become more self-reliant and self-sustaining. Further, with a growing awareness of the potential to mobilize resources

for local initiatives and self-help, she continues, communities can reap even more benefits from such mobilization.

In addition, the process of health promotion, itself, can foster considerable health benefits. Through community involvement, people can become empowered and gain control over their lives (Arnstein, 1969; Boyce, 1993; Brown, 1991; Corega, 1992; Epp/Health and Welfare Canada, 1986; Green and Kreuter, 1991; Harris, 1992; MacFarlane, 1996.)

With declining resources and new community health care/promotion programs, local residents are becoming more and more responsible for their health and the health of their community. This is especially so for women. Given this reality, health professionals need to assess the methods they use for working with the community.

Osteria (1991) and Davey and Dwyer (1984) challenge the top-down development framework. They question the assumption that professionals have the sole ability to plan for a community and consider what local residents have to offer the process. They point out that there is an interrelationship between people and their social environments; both have an impact on, and are products of, each other. Finally, they conclude that, given the above, professionals should respect and foster bottom-up planning.

Canada's health care system is becoming increasingly attacked by planners, the public, and academics alike. It has been criticized not just for being top-down but also for focusing on disease care rather than health care (BC Women's

Hospital and Health Centre Society, 1995; Checkoway, Chesler, and Blum, 1990), for putting greater emphasis on curative medicine rather than education, prevention, and promotion (Checkoway, Chesler, and Blum, 1990), and for relying largely on Western health practice and practitioners at the expense of their "alternative" counterparts. The Canadian health care system is seen as reductionistic for it has traditionally looked at health as the absence of physical disease and has failed to adequately acknowledge that health is the result of a complex interdependence between all aspects of life (social, spiritual, emotional, mental, physical, and economic) (BC Women's Hospital and Health Centre Society, 1995).

On the other side many health professionals are now seeking new definitions and understandings of health. They are beginning to look at health promotion as well as health care and to see health as much more than absence of disease. The World Health Organization (1986) sees health promotion as an enabling process whereby people are more responsible for controlling and enhancing their health (cited in Romeder, 1990) and the Government of Canada (1988) defines mental health as the capacity of individuals, groups, and the environment to effectively interact together. The Vancouver Health Board (n.d.), for example, explains:

Our views of health are changing. We now understand that health is more than "not being sick". Health does not simply mean health care. Health is not guaranteed by access to medical services. Rather, health is a "resource for everyday life". This way of understanding health recognizes that adequate income, a

clean environment, secure housing, employment opportunities and local social support all affect people's health. (p. 1).

In addition, more health professionals are acknowledging that the public needs to be involved in the decision-making process and are recognizing local avenues of participation in health care, promotion, and planning in general. Much, however, remains to be done in operationalizing the concept of participation. Participatory evaluation of health systems by intended beneficiaries, generally, and by one particular constituency - self-help groups - provides one potential approach to such operationalization.

THE ROLE OF SELF-HELP GROUPS IN COMMUNITY HEALTH PROMOTION

The next few pages help us to better comprehend the importance of self-help groups in community health promotion by demonstrating that they are communities and vehicles for community participation as well as stakeholders and constituencies. It is first, however, necessary to examine the concepts of community and participation, especially as they apply to health promotion. This will be done with the assistance of Green and Kreuter (1991) and Rifkin et al. (1988).

The Community in Health Promotion

According to Green and Kreuter (1991), the community is the most appropriate "centre of gravity" for health promotion. At one end of a continuum, the provincial/state and federal

governments can play a role in health promotion through policy development and the provision of leadership, funding, and information. At the other end, individuals can contribute through controlling their own behaviours and the determinants of their own health.⁷ It is at the community level, however, where people can collectively determine the most effective initiatives for bringing about social changes affecting more complex lifestyle issues.

Bringing health promotion to the community enhances the relevancy of initiatives for stakeholders and promotes more active involvement of stakeholders in health planning. The more extensively citizens are involved in health planning and in health promotion initiatives, the greater the potential for them to meet their own needs and the greater their commitment to making and perpetuating such changes. (See Boyce, 1993; Corcega, 1992; Green and Kreuter, 1991; Harris, 1992; MacFarlane, 1996.)

For Green and Kreuter, community is defined both structurally (e.g., an area defined by geographical or political boundaries) and functionally (a place defined by shared feelings). These authors adopt the functional definition provided by Isreal (1985, p. 72). i.e., a community is a location where "members have a sense of identity and belonging, shared values, norms, and communication, and helping patterns". Further, they explain that the structural component of this definition serves to narrow the focus to the local level.

This two-component definition closely resembles the

definition of Rifkin et al. (1988) discussed below. Rifkin et al., however, employ a somewhat more complex composite definition of community which they use to define community participation and their two functional communities are not defined by a shared geographical place.

Community Participation in Health Promotion

Rifkin et al. look at three meanings of community used in community health promotion, especially in primary health care (PHC). In the first meaning, "Community is a group of people living in the same defined area sharing the same basic values and organization" (p. 933). In the second, "community is a group of people sharing the same basic interest" (p. 933). In the third, community is a target population or a group at risk. These authors see this last definition as:

rooted in the epidemiological view of community. In PHC, in terms of equity, effectiveness, and efficiency, groups of people need to be identified so that resources can be allocated to the greatest effect. (p. 933).

Next, these authors turn their discussion to three common meanings of participation. The first insists that participation (or involvement as it is referred to by the World Health Organization) must be active. The second is to have choice which means that people implicitly or explicitly have the right to have control over decisions affecting them. Finally, choice must have the potential of being effective, i.e., appropriate

mechanisms must be available for enabling choices to be implemented.

Taking the above into consideration, Rifkin et al. developed their own definition of community participation. For them, it embodies all the meanings of both community and participation.

Community participation is a social process whereby specific groups with shared needs living in a defined geographical area actively pursue identification of their needs, take decisions and establish mechanisms to meet these needs. In the context of PHC, this process is one which focuses on the ability of these groups to improve their health and health care and by exercising effective decisions to force the shift in resources with a view to achieving equity. (p. 933).

Self-Help Groups and Community Participation

Self-help groups are vital communities which constitute forms and avenues of participation. To explain, self-help groups are, themselves, a form of action; they also enable their members to take further action, have choice over decision-making, and provide the essential mechanisms to put choice into action. Members can use self-help groups not only as tools to heal themselves, i.e., forms of health services, but also as avenues to participate in health planning by state agencies (Berger and Neuhaus, 1977, 1984; Romeder, 1982).

Local, bottom-up avenues of participation in health promotion include self-help/mutual-aid, other voluntary organizations, and daily support networks based on family, social, and geographical ties (Berger and Neuhaus, 1977, 1984; Checkoway, Chesler, and Blum, 1990; Romeder, 1982, 1990).

Berger and Neuhaus (1977, 1984) refer to these as mediating structures for they bridge the gap between individuals and professionals or institutions. Epp/Health and Welfare Canada (1986) consider these essential mechanisms for health promotion.⁸

Self-help groups fit well with the second and third meanings of community given by Rifkin et al. above. If we look at how the Self-Help Resource Association (1995) defines self-help, this will become more evident. For this association:

"self-help" refers to groups of people suffering life crisis or afflictions/disabilities who get together for mutual support in relieving the suffering that might otherwise occur. Such groups function in a non-profit/charitable capacity and are focused on a particular health or social problem. (p. 7).

Furthermore, despite the fact that self-help groups are organized on an interest basis and transcend any artificial or imposed geographical boundaries, we can say that these groups typically draw their membership from a limited geographical area. There is a limit, for example, on how far individuals will travel to belong to a specific self-help group or organization. The members of any one self-help group, therefore, typically share the same geographical context, or community, and its sociopolitical environment. As communities of interest inside a geographical community, or region, self-helpers can be seen as a constituency.

LEVELS OF PARTICIPATION

Having considered participation in health promotion, it becomes essential to look at the possible levels of such involvement. Arnstein (1969) provides one of the most widely known discourses related to the meaning of participation. For her, there are eight levels of participation corresponding to the degree to which stakeholders have power in relation to determining the end product. These levels, or rungs on a ladder, range from non participation to full stakeholder control.

Non Participation

The first and second rungs are Manipulation and Therapy and do not really involve participation. On the lowest rung, Manipulation, people are "given" the opportunity to sit on advisory committees or boards but are invited primarily for the purpose of being educated by the powerholders or for providing them with support. On the second, Therapy, powerholders see powerlessness as a sign of mental illness. With this in mind, emphasis is placed on providing remedies for stakeholders' "pathologies" rather than on addressing root causes of the problems or the "ills" of society and the social structure.

Token Participation

The third, fourth, and fifth rungs are Informing, Consultation, and Placation which are token in nature and largely serve to perpetuate the status quo. Informing involves

the one-way flow of information from the top down with no opportunity for feedback, negotiation, or influence from below.

On the Consultation rung, stakeholders are consulted, through such avenues as attitude surveys and public forums, but their voices are seldom taken into account by powerholders.

Placation, a higher level of tokenism, allows for a few select stakeholders to have token seats on advisory and action committees. These stakeholders have only superficial authority and no policy making influence.

The Highest Rungs

The last three rungs are Partnership, Delegated Power, and Citizen Control. Partnership enables stakeholders to share power with traditional powerholders through joint planning and decision-making (via boards, committees, and structures for problem solving), through negotiation, and through making trade-offs. Once in place, groundrules cannot be changed by powerholders without stakeholder consent. On the other hand, to be truly effective, involved communities must be backed by solid power and resource bases along with an accountable leadership ready to fight with the community to take this control.

With Delegated Power it is possible for stakeholders, through negotiation, to acquire the majority of decision-making seats and authority over a planning initiative. By having this majority position, stakeholders can ensure that specific planning initiatives are accountable to them. At this level, powerholders must take a proactive, as opposed to reactive, role

when it comes to problem solving. Further, stakeholders themselves frequently take on subcontracts for planning initiatives.

On the top rung, Citizen Control, stakeholders can take on full control over the policy making and managerial functions of a program or institution, in all stages, over all components, and at all levels. This form of participation often involves a neighbourhood corporation having direct access to and control over funding.

THE V/RHB AND ITS COMMUNITY PARTICIPATION INITIATIVE

According to the V/RHB's 1997 Inaugural Health Plan Summary, British Columbia's health reform process was sparked by the 1991 Royal Commission on Health Care and Costs (the Seaton Commission). Both the Vancouver Health Board and the Richmond Health Board were born out of this reform process. The Vancouver/Richmond Health Board, as we know it today, came into being when these two Boards amalgamated in 1996.

As indicated in this Summary, the V/RHB was "intended to be an 'umbrella' organization coordinating all aspects of health service delivery in the region - from hospitals, to continuing care services, to mental health agencies and more..." (V/RHB, 1997, p. 1). The V/RHB comprises a volunteer board of directors (the governing body), various public and professional board committees, and health board staff. According to the V/RHB (1998), the board of directors holds monthly meetings and has

eighteen members. At least three of these members are from Richmond, two are from outside the region, and the remainder are from Vancouver proper. Each of these individuals is appointed by the British Columbia Ministry of Health. (See Appendix 1 for more information.)

The Board's mandate, mission, and vision are as follows:

- Mandate: "to develop and implement a regional health plan".
- Mission: "To promote and provide for the physical, mental and social well-being of people who live in the Vancouver/Richmond region and all those who receive health services within the region".
- Vision: "People working together to build healthy communities and foster better care for all".
(V/RHB, 1997, p. 1).

FORMALIZING COMMUNITY PARTICIPATION

In their 1997-1998 Annual Report, the V/RHB declares that "a strong health care system depends on public involvement. Your Board is committed to public participation" (The V/RHB, 1998, p. 25). The Vancouver/Richmond Health Board (1997) explains that Vancouver's formal initiative for acquiring community participation in health planning came with the introduction of the New Directions plan. This plan was formally announced by the Government of British Columbia in early 1993 and was officially called New Directions for a Healthy British Columbia (Vancouver Health Board, n.d., p. 2). Even though this is a plan for regionalization, it also focuses on "bringing health care closer to home". Translated, this means devolving responsibility for health care back into the community. It is

explained that this "means changing on two fronts: more local input into decision-making and a greater emphasis on community based services" (New Directions in Health, 1993, p. 1).

For Vancouver (and Richmond), this New Directions plan has translated into a permanent and formal community consultation or participation initiative which, at present, has no formal title. This initiative fits into the Inaugural Health Plan's fundamental guiding principles: (1) Guaranteeing access to a public system", (2) "Breaking down barriers between the health system and the people it serves", (3) "Bringing health services 'closer to home', and (4) "Ensuring accountability" (the V/RHB, 1997, p. 2). This plan also has these major goals:

- Goal 1: Promote and advocate improvements in the broader determinants of health.
- Goal 2: Improve the performance of the health system.
- Goal 3: Develop integral and well-coordinated health services.
- Goal 4: Develop health promotion and disease, disability and injury prevention programs.
- Goal 5: Ensure greater public participation and responsibility in the health system.
- Goal 6: Promote greater choice and control by individuals using the health care system.
- Goal 7: Respect, recognize, and support health service providers as a vital force in contribution improvements in the health system. (The V/RHB, 1997, pp. 4-7).

To promote this participation in decision-making, the V/RHB has formed Community Health Committees, Neighbourhood Health Groups, and Population Health Advisory Committees. Community

Health Committees work with residents to identify their health needs and priorities, develop community health plans, and coordinate local health services. Neighbourhood Health Groups are voluntary groups comprising local residents, local health service providers, and neighbourhood organizations. They function as intermediaries to help residents and service providers to give input into community health planning. Each of these groups is represented on the Community Health Committee that encompasses it. Finally, Population Health Advisory Committees represent people from each of the following marginalized populations: people with mental illness; people with disabilities; women; First Nations people; children and youth; seniors; people who are gay, lesbian, bisexual, and/or transgendered; and members of ethnic and cultural minority groups. Their major function is to advise the Regional Health Board and Community Health Committees (Vancouver Health Board, n.d., p. 4). The Vancouver/Richmond Health Board (1998) underlines that the existence of these avenues of involvement is proof of the Board's strong commitment to public participation. According to the Board, there are roughly 150 volunteers sitting on committees who have been providing 15,000 hours of services per year.

THE V/RHB AND BOTTOM-UP VERSUS TOP-DOWN AVENUES OF PARTICIPATION

Since the community participation process became formalized in Vancouver, a great deal of effort has been put into developing the new avenues for public involvement noted above

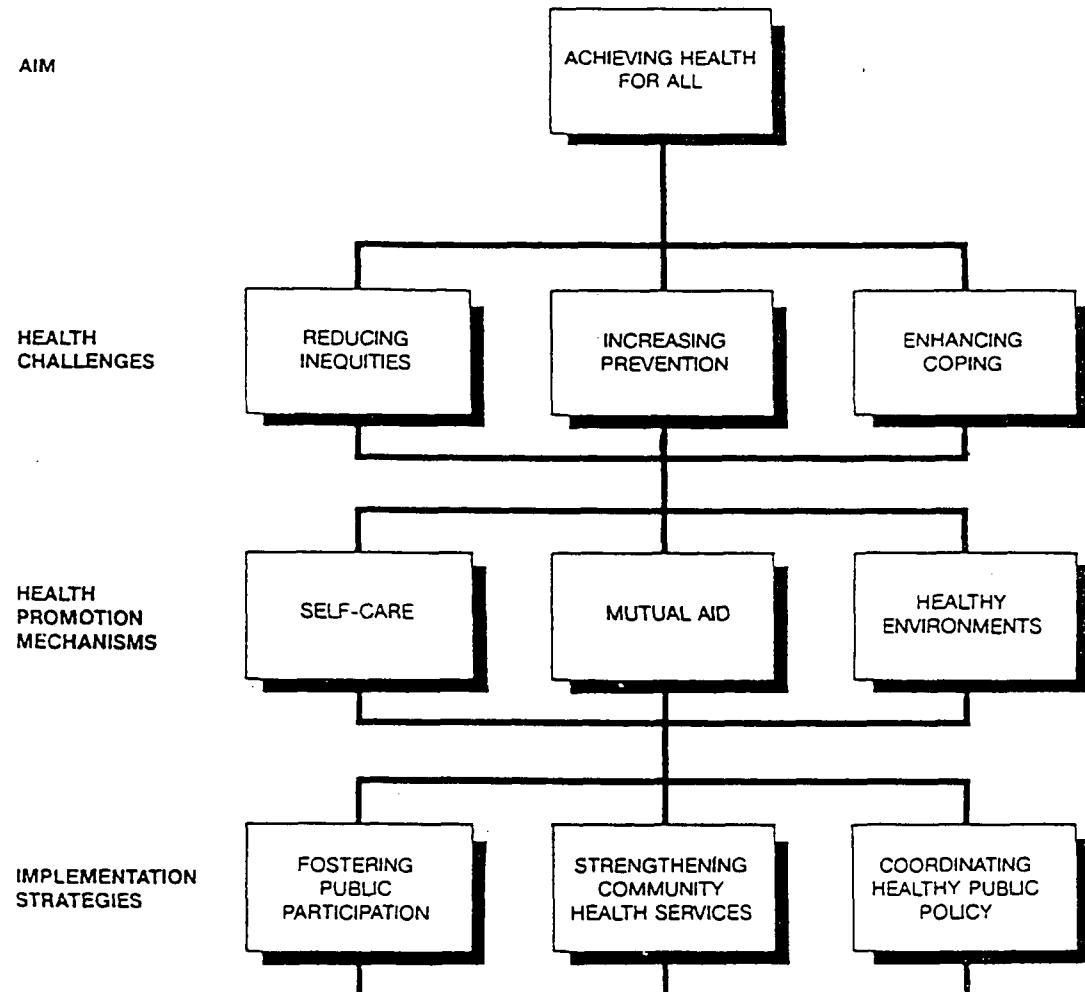
(i.e., committees and groups). One characteristic these committees or groups share is that they are not naturally occurring, nor locally generated. In fact, they have been designed by the Health Board from above and have required considerable professional and volunteer support to establish and maintain. Additionally, each has been formed on a geographical basis, with imposed boundaries dividing the various provincial health regions.

Even though these committees and groups were designed to acquire local input from indigenous avenues for participation, there have been several problems involved in actually doing so. First, I have not found a clear framework to assist staff and volunteers to work with these local avenues. Further, I have heard a great deal of scepticism expressed by some local residents regarding the extent and form of resources that will accompany the devolution of health care/promotion responsibilities. In fact, there is considerable confusion regarding the degree to which these responsibilities will actually be devolved and what form this devolution will take. It is also unclear how this new, broader or holistic health care approach will involve other sectors of our society (e.g., social services). On top of this, the fostering of health committees and groups has had growing pains.

The V/RHB has acknowledged the role of self-help in health promotion, in theory. For example, the Board relies on the work of Epp/Health and Welfare Canada (1986) which not only expresses the value of self-help in health promotion but demonstrates how

it fits into the Board's framework for health promotion. In fact, members of the Health Board hand out copies of this framework to the public (see Figure 1).

Figure 1: Epp/Health and Welfare's Framework for Health Promotion



Epp/Health and Welfare Canada (1986, p. 8).

On another level, one Health Board member responsible for overseeing the development of the original Women's Health

Advisory Committee developed the following matrix (Figure 2) which acknowledges the importance of being responsive to self-help groups.

Figure 2: A Conception of Groups and Organizations to Which the Women's Health Advisory Committee Should be Accountable

ACCOUNTABILITY					
SELF-HELP GROUPS (including women's and alternative groups)	PROFESSIONAL ASSOCIATIONS	COMMUNITY ORGANIZATIONS (including advocacy groups)	COMMUNITY HEALTH COUNCILS (geography)	NON-PROFIT AGENCIES	
					ETHNO-CULTURAL DEMOGRAPHICS (Chinese, Vietnamese, South Asians, Latinas, et. al.)
					MENTAL HEALTH
					FIRST NATIONS
					WOMEN LIVING WITH DISABILITIES
					POVERTY GROUPS
					YOUTH
					SENIORS

COMMUNITIES OF INTEREST

METHODOLOGICAL APPROACH, OBJECTIVES, AND METHODS

This section introduces the methodological approach used in conducting the research for this dissertation, the study's objectives, and the history and rationale behind this study. It discusses the participatory evaluation exercise and the inclusion of the specific stakeholders and their geographical context. Next, it provides a brief overview of the duration of the exercise, the participations involved, the methods and

procedures used to gather information, and the literature search conducted. It then presents the views and biases I, as a researcher, held when I entered the field, examines my role as a researcher, and looks at the possible challenges and constraints I felt the exercise may encounter. Chapter 3 provides detail about the methodology, methods, and procedures involved in the exercise as it progressed.

A BRIEF LOOK AT PARTICIPATORY EVALUATION

Research for this dissertation centred on a participatory evaluation exercise which participants and I initiated and conducted. The exercise followed the same principles and values of participatory action research defined by Green et al. (1995, p. 4) as "systematic inquiry, with the collaboration of those being affected by the issue being studied, for the purpose of education and taking action or affecting social change". Participatory evaluation is one form of PAR inquiry. It systematically involves stakeholders in generating information for the purpose of evaluating and enhancing a specific initiative. Participatory evaluation can be an integral step in a larger PAR initiative or an independent PAR project such as ours.

Chapter 2 gives a broader understanding of PAR, participatory evaluation, and their interconnection. It discusses principles such as consciousness raising, equity, and empowerment as well as education and taking action or affecting social change.

The exercise relied primarily on the subjective, experiential, and lay knowledge of participants and other contacted stakeholders and on appropriate methods for generating or capturing this knowledge. Chapter 2 looks at the role of these alternative forms of knowledge in health promotion, self-help groups, and participatory evaluation. The specific methods and procedures used in participatory evaluation to generate knowledge is discussed later in this chapter (i.e., Chapter 1) and in Chapter 3.

STUDY OBJECTIVES

My objectives in conducting and assessing this participatory evaluation exercise were:

- to work with Vancouver-based women's self-help groups to design and implement a participatory evaluation tool for analyzing past and future efforts to include self-help groups in community health planning and to support them as health services and for guiding future efforts of this nature.
- to learn from this work about the potential of conducting participatory evaluation without immediate representation from the implementing stakeholder group (the V/RHB).
- to fulfill, in both the exercise and the study of the exercise, all of the criteria of authenticity as outlined by Guba and Lincoln (1989) and Lincoln (1992) which relate to providing an environment for participants (self-helpers) which promotes equity in representation, mutual learning and respect, empowerment, and action (see Chapter 2).
- to explore alternative ways to achieve equity in representation, mutual learning and respect, and consensus between self-helpers and the Health Board despite the absence of this latter set of stakeholders.

THE HISTORY AND RATIONALE BEHIND THE STUDY

This study came about as a result of a fortuitous needs assessment I made when working on another study, or project, for my dissertation. The original project included the development of a PAR training program for marginalized women. During the time I was organizing this study and looking for funding, I met with a number of women's groups in the region and attended a variety of forums, seminars, and workshops on women's health, on the Health Board's Closer to Home and community participation initiatives, and on women in the health system. Further, in 1995 I worked on a volunteer basis with the (then) Vancouver Health Board to help establish the original Women's Health Advisory Committee.

As time went by, I realized that I would not get sufficient funding to conduct my study and about that time, the knowledge I had gained about the Health Board and the health system, women in health, and self-help groups sparked my current interest. By listening carefully to various stakeholders, I discovered that these people felt a need to have the Health Board and general health system respect the role of self-help groups in health promotion. In this way, even though stakeholders did not initiate this study and then invite me to work with them, this study grew spontaneously out of the identification of the needs of those around me (i.e., members of women's self-help groups). (These needs are described in detail in Chapters 3 and 4.) I came into the field, therefore, expecting and promoting a dynamic, participant-driven, and participants-oriented exercise.

During this needs assessment period, with the help of others, I decided my new research should involve stakeholders in a participatory evaluation exercise to analyze relations between Vancouver-based women's self-help groups and the V/RHB. Developing such an exercise took on special significance for me when I discovered during my literature review that there was a dearth of information specifically linking participatory evaluations with self-help groups and health promotion. As a result, the focus of this study became the exercise itself - its development, documentation, and implications for health promotion.

I realized that a dissertation such as this could make a contribution to knowledge in the field of health planning by linking together: (1) PAR in the form of participatory evaluation; (2) self-help groups, particularly women's groups; and (3) community health promotion as both a top-down and bottom-up process. None of the studies I have reviewed, however, make this linkage. In particular, I discovered there is a need for research that develops and assesses applications for participatory evaluation whereby self-help groups continue to conduct a participatory evaluation despite the absence of the key service delivery stakeholder group.

Beyond my own interest in the potential of participatory evaluation, I wanted to assist self-help groups, particularly women's groups, in acquiring a voice about their concerns and to assist health promoters in enriching their tool kits for fostering community participation. All three components, PAR,

self-help groups, and health promotion, have been critiqued from a feminist perspective because of their gendered assumptions, research process, and conclusions. Further, all highlight the potential for conflict and power inequities to exist between women self Helpers and members of the V/RHB. With this in mind, it is essential to use participatory evaluation carefully to ensure women have the opportunity to express themselves and participate in health promotion and its evaluation. This issue will become clearer throughout this dissertation, especially later in this chapter and in Chapter 2.

Self-Help Groups

During the informal needs assessment that led to this study, it became clear that the stakeholders I talked to, especially women self helpers, and a growing number of authors believe that community health planning must be as holistic (inclusive and comprehensive) as possible and that this means not only looking at all influences on a person's health but also exploring all practical avenues for involving residents in community health promotion (BC Women's Hospital and Health Centre Society, 1995; Checkoway, Chesler, and Blum, 1990; Epp/Health and Welfare Canada, 1986; Romeder, 1982, 1990). Self-help groups are seen as vital avenues for both health care and health planning (Berger and Neuhaus, 1977, 1984; Romeder, 1982, 1990).

In my initial project development, several self-helpers indicated a need for support in evaluating the health system. Literature on self-help groups confirmed this need (see Chapter

2). These women wanted to have their voices heard and to have some input into, and impact on, the health system and its health promotion initiatives. The literature indicates that many self-helpers want their groups to be recognized, respected, and supported by professional or formal health care/planning organizations. This need is especially important because: (1) self-helpers are people who have been experiencing life crises, afflictions, or disabilities who feel they would benefit from membership in a self-help group and (2) many of these people have been especially marginalized and feel more comfortable seeking help from grass-roots, informal, and member-controlled health services.

The growing number of self-help groups in Vancouver and the existence of an active Self-Help Resource Association, alone suggest that this form of health service is in demand. Further, we have seen above that both provincial and federal health ministries in Canada and the V/RHB have acknowledged the value of this form of complementary health care, its value in health planning, and the need to reach out to, and work, with these groups.⁹

Research in the health field (see Berkman and Syme, 1979; Romeder, 1982, 1990) has indicated that social networks and support groups are vital components of health maintenance and healing. People have a tremendous ability to learn from others and to heal themselves.

For Green and Kreuter (1991), health promotion actions and behaviours can be those of groups and communities as well as

individuals and others who control or impact on the determinants of health. This supports the idea that self-help groups are avenues, or agents, of health promotion. Green and Kreuter also directly acknowledge the role self-help groups play in encouraging healthy living conditions and resources to help people take greater control over the factors impacting on their health.

Women and Women's Self-Help Groups

Women's self-help groups were chosen for the exercise for a variety of reasons. First, women, especially women from immigrant, refugee, First Nations, and visible minority groups and those experiencing physical disabilities and mental health concerns have been particularly marginalized in and by Canada's health care system and in society in general (BC Women's Hospital and Health Centre Society, 1995).¹⁰

In addition, women use British Columbia's health care system 25 per cent more often than men (BC Ministry of Health and Ministry Responsible for Seniors, 1995), they are responsible for providing the bulk of health care activities, especially those functions which are poorly paid and volunteer (including self-help groups), and are largely responsible for overseeing the health of their families (BC Women's Hospital and Health Centre Society, 1995; Davey and Dwyer, 1984; DuBois, 1988; New Directions Development Division, 1995; Osteria, 1991). In spite of this, they are inadequately recognized or compensated for their role. Further, until this role is shared equally between

women and men, increasing community responsibility for health care will translate largely into increasing women's work without knowing, as of yet, the extent of compensation they will receive in return. As a result, women, as stakeholders, will likely be more significantly impacted by the devolution of health care responsibility than will men.

With the help of Fee (1983), Staudt (1997), and Armstrong (1996), we can gain an understanding of why women have been so marginalized. Fee (1983), for example, explores three forms of social criticism which have been used to explain why women have been oppressed in the medical system. Liberal feminists, she explains, "see the social subordination of women reflected in the sexual structure of the organization of medicine" (p. 19). In other words, males comprise the bulk of the higher positions in the medical profession. She stresses, in fact, that this skew is more prominent in the medical profession than in other areas of employment. Women in and out of health professions typically are poorly paid, have little power, and are not heard. Women's symptoms of illness are often treated as psychosomatic and, as a result, given less attention. For liberal feminists, she continues, this form of oppression can be overcome within the existing medical system by correcting the imbalance between men and women in the upper echelons.

On the contrary, according to Fee, radical feminists see the need to change entire social systems. To overcome their oppression in the medical system, women must not only push their way into top career positions but they must also fight from the

bottom as patients. Women must overthrow the patriarchal family which serves as the foundation of the medical system. The medical profession reflects this inequity by having (male) doctors (accredited with technical and scientific knowledge) take the role of fathers, by having (female) nurses (limited to nurturing duties) assigned the roles of wife and mother, and the patients given the role of children. "In addition to their demystification of paternalist ideology, women have created special social organizational structures to combat specific symptoms of their oppression. Among these are the consciousness-raising group, the women's center, the rape crisis center, the women's commune, and the self-help groups" (p. 23).

Lastly, Fee informs us, Marxist feminists believe that gender inequities in the health system stem from the system's preoccupation with profit versus serving people's needs. In this system, women have less economic and political power and occupy the lower rungs in the division of labour. The medical system is fragmented into specializations and women perform less skilled duties. They typically find themselves excluded from the (male controlled) realms of science and technology and from decision-making functions. Social causes of diseases are ignored. Diseases unexplained by biological causes are confined to the category of psychosomatic illnesses. Moreover, natural functions such as pregnancies and childbirth are classified as forms of illnesses and treated as such. According to Fee, Marxist feminists claim that the only way to overcome these gender inequities in the health system is to overthrow the

capitalist mode of production for a democratic socialist one.

I argue that each of these explanations summarized by Fee is founded on women's experiences and can be combined to give us a comprehensive understanding of why women are marginalized in the health system.

Staudt (1997) looks at the relationship between bureaucracy and women which can further enhance our understanding of the position of women in the health system and the general social system. She explains that women principally make up the lower socioeconomic ranks generated by the market economy which has given women few resources to even fuel their self-help efforts. She adds, however, that women have not fared much better with the existence of government bureaucracies.

In the eyes of many, major state investments in economic and social development are necessary: to ensure political stability; to provide access to food, health, and education; and to sustain the kind of economic growth that supplies people with the means to assure their livelihood. Yet such investments are made in ways that allocate neither opportunities nor resources in an even manner. (p. 5).

From here, Staudt cautions us about the dangers of depending on internal bureaucratic politics and the limited number of women who infiltrate these realms. For her, by doing so, "we invest dangerous faith in hierarchical institutions staffed with experts" (p. 17). It is essential for internal bureaucracies to be made accountable to outside agents or risk "goal displacement" where bureaucracies pursue their own agenda which often entails maintaining and enhancing their own authority,

resources, and staff.

People-oriented development theorists, she says, recommend that bureaucracies employ a "learning process", which benefits from local knowledge, resources, and direction, as opposed to a top-down approach which excludes such inputs. She insists that, despite the potential of this participatory approach to empower grass-roots stakeholders, men typically swell the ranks of those included from the "bottom". Finally, she declares, if women are not included in bureaucracies they often form their own groups outside these organizations.

This analysis can, therefore, help us understand not only why women are marginalized in the health system but also why they turn to alternative forms of organizing and health care¹¹.

According to Armstrong (1996), deinstitutionalization can, ideally, lead to greater personal growth, skills development, and independence for people with health problems. In reality, however, accompanying cut backs have served to both increase women's work and limit the choices for care givers and receivers.

Considering a large percentage of women are in the full-time workforce, Armstrong explains, women have become increasingly time stressed. Due to the lack of alternative forms of health care, this has led to a growing number of women being forced to decrease their hours of paid work. She emphasizes, too, that women are also in the majority when it comes to receiving health care and that they often reject having to be dependent on, and

vulnerable to, a close female relative. Further, these caregivers don't necessarily have the ability, desire, or resources to look after a family member. This is compounded by patients having less time to see and confer with members of the medical profession. As a result, more women have been experiencing a decline in their power and in the quality of their health.

In addition, for Armstrong, "the rhetoric of community involvement in designing and implementing this movement back to the community has not been realized in practice either" (p. 140). Public consultation about health reform has primarily taken the form of data collection rather than democracy. "This is not what the women's health movement meant about choice and empowerment!" (p. 140).

Armstrong underlines that women in Canada began decades ago to express their dissatisfaction with the health care system and its assumptions about health care delivery. The women's movement has focused on their right to control their own bodies, especially in regards to their reproductive role. She points out that the Vancouver Women's Health Collective was born out of this movement. Here, "Self-help, social and emotional support, and prevention were stressed as critical care" (p. 131). In fact, according to Armstrong, the Vancouver Women's Health Collective began as a small women's self-help group.

They were concerned that health care as practised in Canada in the postwar period had become increasingly doctor- and hospital-centred. In this system, it was assumed that doctors are experts who objectively

diagnose and treat on the basis of scientifically established procedures applied to individual women in order to cure them. (p. 130).

The women's health movement, she continues, questioned the "authority, expertise, and practice of doctors" (p. 130). It helped prepare women to become part of the decision making process by providing health education.

We also have to look at the special nature of women self-helpers and the role they can play in community health promotion. As people turning to self-help groups, women self-helpers are experiencing at least one life crisis, affliction, and/or disability which they are addressing and which is (are) often specific to women. In addition to having shared needs, as members of self-help groups these women share roughly the same basic concerns and goals and hold certain beliefs and values - i.e., those associated with self-help groups and their reaction to the way women are treated in the Western health care system. (Also see discussion in Chapter 2 on PAR and Self-Help Groups.) Further, they work together as women to identify and effectively address their needs. With this in mind, these groups can be said to form specific communities of interest and can also be identified as target and at risk populations.

Additionally, women's self-help groups, like self-help groups in general, share a limited geographical boundary and context. They can, therefore, be classified as constituencies, given that they are communities of interest (i.e., self-helpers

and women) inside a larger geographical region. Participants, in the exercise studied here, for example, were:

1. Communities of women involved with women's self-help groups which are based in the city of Vancouver (i.e., having contact names and addresses inside Vancouver proper) and living within the larger geographical area of the Vancouver Lower Mainland; and
2. Both communities of interest, sharing basic values and organization, and target/at risk communities, by virtue of the fact that members are turning towards self-help groups to deal collaboratively with critical issues affecting themselves and their families. (See the section titled Community Participation in Health Promotion presented earlier in this chapter.)

Given their multiple qualifications as communities, constituencies, and avenues for participation in health promotion, women's self-help group members are important sources of knowledge for health promotion. By listening to the voices of women self-helpers, health planners of all kinds can acquire insight into: (1) how these stakeholders view the health system and how they feel it can be improved; (2) the value of self-help groups as health services and as potential participants in health planning; and (3) how (women's) self-help groups want to be included in health planning and supported as health services.

Another explanation for the centrality of women in this exercise is that the original needs assessment conducted for this study primarily involved women and women's communities. It was through conversations with women in Vancouver during the needs assessment that I first became interested in pursuing this research.

Vancouver

I chose Vancouver as the geographical area for this exercise for a number of reasons. First, I am most familiar with this region, its self-help groups, and its Health Board. In fact, I have been involved in many personal and community development efforts in the Lower Mainland, including doing volunteer work for the Health Board. Much of this work has focused on women from various minority or marginalized groups and relates to issues of health using the wider definition. Second, individuals I conversed with during my fortuitous needs assessment indicated a need to look into how well the V/RHB has included local self-help groups in community health promotion. Third, I began my field work in this region before the Vancouver Health Board merged with the Richmond Health Board to form the V/RHB, which accounts for the exclusion of Richmond in this exercise. Fourth, it is much more manageable to choose a more focused geographical area. To sum, I conducted preliminary research here as it relates to my study, found a need for this study, and developed strong connections in relevant communities.

The Vancouver/Richmond Health Board

I felt the V/RHB would be an ideal case for testing the effectiveness of a participatory evaluation as a method for involving self-help groups in health promotion because: (1) the women self-helpers I met in Vancouver felt there was a need to do such a study and (2) I was familiar with this organization and developed relevant contacts in the Health Board who

initially indicated they would participate in this exercise.

PARTICIPANTS INVOLVED

In total, 21 self-helpers (individuals) participated in this study, representing 17 groups. Sixteen participants were involved in meetings (representing 13 groups) and 11 of these also filled in questionnaires (representing 10 groups). Sixteen participants filled in questionnaires (representing 13 groups), 5 of which did not engage in meetings (representing 5 groups, one of which was represented by another participant in meetings). All of these participants are women who are members of Vancouver-based women's self-help groups/organizations.

GATHERING INFORMATION

This study and its participatory evaluation exercise involved triangulation in relation to sources of information and methods of information collection. Prior to and during formal field work (the participatory evaluation exercise), I gathered background material from a variety of different forums focused on the Health Board, women in health, and self-help groups and worked in and with women's groups and organizations, self-help groups, and the Health Board. The results of one workshop I attended on women and health are presented in The British Columbia's Women's Hospital and Health Centre Society (1995). I also collected information from Health Board members through informal discussions. Further, participating self-helpers were involved in the study's exercise through focus groups, phone and

in-person discussions, and questionnaires. I also used participant observation to help me assess the methodological integrity of the exercise and the benefits to participants.

LITERATURE REVIEW

I conducted an extensive literature search during which I found that there is a great deal written relevant to the various components of this study. This material looks at the role PAR, self-help groups, and participatory evaluation can play in community health promotion. It explores both the conflict and consensus approach to participatory evaluation and the implications this may have on participation and findings.

It also focuses on how women are involved in self-help groups, community health care, and the health system. Additionally, it demonstrates the value of doing qualitative research when conducting studies in the area of community health promotion which is especially important, given the extensiveness of the study's/exercise's reliance on this form of research. This chapter and the remainder of this dissertation, especially Chapter 2, draws on this material.

DURATION OF STUDY

This study began gradually in 1995 and was completed in early 2000. The participatory evaluation exercise commenced in July of 1997, when its first meeting was held, and terminated in July of 1998 when the last questionnaire was collected. This does not mean that participants' involvement ended there. Two

participants assisted me with this dissertation until I completed it. Both participants helped me analyze results obtained and one provided invaluable feedback on my presentation of these findings. A number also indicated they will continue to work alone and with other participants, including myself, on an ongoing basis to foster better relations with the Health Board and the health system.

RESEARCHER'S VIEWS/BIASES

I came into the informal needs assessment initially without any particular feelings about the Health Board. In fact, I had little knowledge of it at all. I did not enter the field with any preconceived notions about how well self-help groups were included in health planning or supported by the Health Board as health services.

It was only after I entered the field that I began to acquire hunches about these matters. These hunches, based on comments made by self-helpers, were: (1) the Health Board has not been committed to participatory initiatives and (2) the Board has not supported or included self-help groups.

I did come into this study, nevertheless, with certain biases. Through first- and second- hand experience and a literature review, I had come to believe that the health system typically treats women, especially those who are marginalized, with less respect than they treat their male counterparts. Another bias (or belief) I hold is based on my understanding that women as health care workers have traditionally been

underpaid or unpaid and not given the same status as men. I, therefore, anticipated that targeted self Helpers would talk about the status the health system gives to both self Helpers and women as health care providers and consumers.

I am also concerned about bureaucratization and professionalization of health and social services. I think people should have more control of their communities and community resources.

Finally, I initially felt that, despite conflicting views and real or perceived power differences between our two stakeholder groups, both self Helpers and Health Board members would become active participants and work together to develop common understandings and strategies for participatory health promotion.

As we can see later in this dissertation, participatory evaluation allows for researchers' biases and provides practical ways to ensure they do not undermine methodological integrity (see Chapters 2 and 5). The most important first step is to openly acknowledge these biases as I have done here.

ROLE OF RESEARCHER

In this exercise, I was not some detached researcher conducting an experiment but an active participant free to express my views. As a researcher conducting a participatory evaluation, it is not only accepted but also expected that I was passionate about the subject of investigation and that I held my own biases so long as I was honest about having them and was

open to divergent opinions. Sometimes in my writings, however, I appear dominant in this exercise because some participants asked me to take a strong facilitative role and because participants chose not to be involved in the entire exercise and not to make as many decisions as I did as a researcher. Participants had the opportunity to give my work their final approval. In other words, this balance of labour was not imposed from above but assigned from below.

EXPECTED CHALLENGES AND CONSTRAINTS

On a similar note, I entered the field anticipating participants and I might encounter certain potential barriers and challenges. Due to participatory evaluation's focus on meeting criteria of authenticity (see Chapters 2 and 5), I also believed that these challenges and constraints would be more easily overcome by engaging participatory evaluation rather than traditional, Western forms of evaluation which are typically more top-down and results-oriented and involve little stakeholder participation.

As this study involved people, largely women, from a variety of cultures and linguistic groups, I felt language and culture might create barriers to communication. Further, through research and experience, I have learned that many women, especially women from immigrant and refugee groups, have many problems becoming involved in activities outside the home or family. For example, I expected that women may have found it challenging to find time to participate in the study, given

their many responsibilities inside and outside the home. Even women with husbands at home often have to find child care or child minders to look after their children because their husbands won't or can't take responsibility for minding them. Being frequently in lower income brackets, many of these individuals find paying for such care difficult. Also I have learned through my work in social services that many husbands and fathers often try to keep their wives and daughters at home to tend their families. Further, some men feel threatened by "their women" leaving the home to learn from others and become more independent. It is interesting that these are the same sorts of problems many women have in accessing the health care system and being heard as consumers and healers.

An additional problem inherent in health research is the mistrust and lack of communication between professionals and residents, especially those who are marginalized. During preliminary field work, many individuals expressed that they were tired of being asked to provide input into this or that project or study, including those related to the Health Board, only to see nothing come from their efforts.

Having already established relationships with key groups and organizations and having decided to engage a participatory form of evaluation, I perceived that stakeholders would see me as student and lay person working with them rather than as a professional working for the health system. With this in mind, I felt it would be relatively easy to establish trust.

DISSERTATION STRUCTURE

Chapter 2 gives a more in-depth and theoretical overview of the methodology used during this study and its participatory evaluation exercise and of the important role played by alternative forms of knowledge in health promotion. It also demonstrates the relationship between PAR and community health promotion, self-help groups, women, and consensus and conflict approaches to participatory evaluation. It discusses methodological perspectives and procedures considered essential for maintaining methodological integrity and the potential challenges involved in achieving specific criteria of authenticity, given the nature of our evaluation exercise.

Chapter 3 systematically presents the methodological findings generated along the way. Chapter 4 documents substantive outcomes concerning participants' perceptions of how well the V/RHB includes and supports self-help groups in community health promotion and related issues. It also looks at how women perceive their involvement in self-help groups, community health care, and the health system. Chapter 5 assesses how well methodological integrity was maintained with special attention being paid to issues related to achieving criteria of authenticity with or without Health Board involvement. It includes information participants provided to assess this exercise.

The concluding chapter examines the implications this research has for participatory evaluators, self-helpers, health

planners, and planners, in general.

END NOTE

1. I realize that the Health Board can be referred to in both plural terms, because it is a collection of members (paid and volunteer staff), and singular terms, because it is an entity in itself. For the sake of consistency, however, I talk about the V/RHB in singular terms throughout this dissertation. The exceptions to this rule are participants' quotes and the participatory evaluation questionnaire which was completed before this dissertation was written. In this chapter, I refer to both the Vancouver Health Board (i.e., the Board before it amalgamated with the V/RHB) and the Vancouver/Richmond Health Board and to the material each has written.
2. See Chapter 2 for discussion regarding the value of subjective, experiential, and lay knowledge for planning.
3. I use the term participatory evaluations to describe a whole range of evaluations working within the constructivist paradigm. Examples of other terms used to describe participatory evaluations are: participatory, action, stakeholder, fourth generation, constructivist, hermeneutic, interpretive, qualitative, and naturalistic evaluations. Some authors make a sharp distinction between terms (e.g., stakeholder versus participatory evaluations), while others are, or appear to be (judging by their works), less concerned about making such distinctions. In fact, a number of authors use one or more of these terms interchangeably.
4. Though I understand that the term self-helper can also be applied to people in the larger self-help mutual/aid movement, for the purpose of this paper, I restrict this term to refer to members of self-help groups.
5. By this term I am not solely referring to formal planners. I often refer to local people as local, popular, lay, or informal planners or experts because people all plan their environments to some extent and we all know a great deal about ourselves, our families, and our communities. This is true, for example, in the case of health care. Community members can be placed somewhere along a continuum of professionalization. They can be family members nurturing their and their family's health or fully professionalized health planners or anywhere in between. They can also satisfy a number of health care roles simultaneously (e.g., one individual can care for an elderly parent at home and also be a licensed medical doctor).
6. To confer participant ownership of this study and work done, I frequently use the inclusive plural terms we, us, and our. As done here, I also use such plurals when referring to planners and readers because I wear many hats. I'm a participant, and a planner, and a reader. When I am specifically referring to participants apart from myself, I use the terms they and them.

Further, like a growing number of academics, I write in the first person to personalize my writing. This writing style also reflects the principles of PAR and participatory evaluation, i.e., inclusiveness, informality, and identification. Finally, I use three tenses throughout this dissertation because some processes are in the past, some are currently in progress, and some will continue in the future.

7. For discussion on the levels of health care from self-care to self-help/mutual aid to community care, see Checkoway, Chesler, and Blum (1990); Epp/Health and Welfare Canada (1986); Katz (1981); Levin (1990); and Romeder (1990).

8. As alluded to above, self-help and community participation are integrally related. The Ministry of Health, Republic of Indonesia (MHRI) (1988) explain that, in their country, self-help (or mutual-help) and community participation even share the same name - Gotong Royong. In fact, according to the Ministry, these two concepts are one and the same. This is an important revelation for many in the West, despite the fact that self-help was once a far more important and respected component of our daily lives too. It has also fostered an environment conducive to community health promotion within the country of Indonesia.

9. For more details describing self-help groups, especially in relation to PAR and their role in community health promotion, see Chapter 2 and the following writings: Anyanwu (1981, 1988); Berger and Neuhaus (1977, 1984); Berkman and Syme (1979); Borkman (1990); Brown (1985); Checkoway, Chesler, and Blum (1990); Chesler (1991); Davey and Dwyer (1984); Dumont (1974); Epp/Health and Welfare Canada (1986); Fals Borda (1984); Gartner (1985); Gaventa (1993); Government of Canada (1988); Green and Kreuter (1991); Guay (1984); Katz (1981); Killilea (1976); Ministry of Health, Republic of Indonesia (1988); Osteria (1991); Reissman (1985); Romeder (1982, 1990); Self-Help Resource Association (1995); Sheilds (1967); Vittano (1972); World Health Organization (1986).

10. It should be noted too that these groups include women from each of the Health Board's Population Health Advisory Committees (see page 17). These committees were established by the V/RHB because it became aware of the marginalized position of these populations within the health system.

11. Staudt warns us, on the other hand, that experience shows us that in these groups, there is always the potential for women to form their own, mini bureaucracies which may or may not be beneficial depending on their degree of accountability and effectiveness.

CHAPTER 2: RESEARCH METHODOLOGY, METHODS, AND PROCEDURES

INTRODUCTION

To demonstrate the effectiveness of employing participatory evaluation to involve self-help groups in health promotion and to give a voice to an otherwise seldom heard group of stakeholders, this dissertation engages in (i.e., develops, implements, and tests) a specific evaluation exercise (or potential model) focused on a specific health promotion effort - the Vancouver/Richmond Health Board's community participation initiative. The dissertation demonstrates the types of information participatory evaluation can generate and assesses the specific methodology, methods, and procedures used during this evaluation exercise.

This chapter commences with an overview of the various criteria and processes participants and I chose to adopt during this, essentially qualitative, study to maintain methodological integrity¹. Next, because the study relies a great deal on subjective, experiential, and lay knowledge, this chapter provides a brief discussion explaining the value of these "alternative" forms of knowledge for health research and planning. It also looks at the role of PAR in health promotion, the role of PAR in working with self-help groups, and the relationship between PAR and women. This leads into an overview of conflict and consensus approaches to participatory evaluation and to the conclusion which recapitulates the theoretical and

methodological questions this chapter raises for this study, the meta-evaluation of the evaluation exercise, to address.

ENSURING METHODOLOGICAL INTEGRITY

The research for this dissertation adopted the methodological perspectives and procedures recommended by Guba and Lincoln (1989), Lincoln (1992), and Sandelowski (1986) which are summarized in the next section. I originally chose to rely on these authors' works for the following reasons. Combined, their perspectives and procedures constitute a comprehensive and relevant catalogue of alternative methodological underpinnings appropriate for engaging a participatory evaluation. First, they provided a framework or set of guidelines to keep the evaluation exercise on track, or in other words, to make sure this was truly a participatory evaluation.² Second, Lincoln and Guba's³ perspectives were used at the end of the exercise to help assess how successfully it achieved methodological integrity and generated useful knowledge.

Originally, Lincoln and Guba's perspectives were to be used to guide and assess the exercise. Later, however, it became clear that it was essential to examine certain premises underlying these perspectives. This is done at the end of this chapter. Issues raised here will re-emerge in Chapter 5 when I analyze them in relation to our methodological and substantive results.

ENSURING METHODOLOGICAL INTEGRITY: THROUGH THE EYES OF LINCOLN AND GUBA

Guba and Lincoln (1989) and Lincoln (1992) explain that fourth generation evaluation, (a form of participatory evaluation) adopts a constructivist, as opposed to a positivist, paradigm. As a result, this form of evaluation has: (1) a relativistic ontology, (2) a monistic, subjectivist epistemology, and (3) a hermeneutic methodology and uses its own unique quality criteria for ensuring: (1) authenticity and (2) trustworthiness.

From Positivism to Constructivism

According to Guba and Lincoln (1989), the constructivist paradigm and evaluation came about due to dissatisfaction with their conventional counterparts who embrace contrasting methodological perspectives (see below). In their own words:

the use of the conventional paradigm is inappropriate to fourth generation evaluation, because conventional methodology does not and cannot contemplate direct work with stakeholders and their constructions (that much of the methodology is simply missing); because the conventional paradigm is tied to the verification mode and cannot deal with discovery processes; because the conventional paradigm strips contextual factors rather than taking them into account; because conventional methodology is aimed at generalizations and not specifications; and because the value-free posture assumed within the conventional paradigm is logically disjunctive with evaluation's goal of making value judgements. (pp. 62-63).

They then summarize three, even more serious, philosophical issues that make conventional views unsuitable for

participatory, or fourth generation, evaluations:

- (1) The theory-ladenness of facts, and the factual underdetermination of theory. (p. 63).
- (2) The value-ladenness of facts. (p. 64).
- (3) The interactive nature of the known-knower dyad. (p. 66).

Throughout this chapter, we can see just how much participatory and conventional evaluations differ.

Ontology, Epistemology, and Methodology

Lincoln and Guba compare positivist and constructivist ontology, epistemology, and methodology. The views of the positivists are presented below first to reflect the evolution of views from the former to the latter. Despite this evolution of thought, however, these two distinct sets of beliefs can still be seen as parallels.

Ontology. Guba and Lincoln (1989) report that conventional or positivist evaluation employs a realist ontology which maintains that there is only one reality. This reality exists regardless of the observer's interest in it and functions according to immutable natural laws which often take the form of cause and effect (or if-then) relationships. "Truth is defined as that set of statements that is isomorphic to reality" (p. 84).

Participatory evaluation, on the other hand, uses a relativistic ontology. Guba and Lincoln (1989, p. S7) and

Lincoln (1992, p. 84) assert that in their ontology there exists "multiple, socially-constructed 'realities'", which are not governed by immutable natural laws of any kind, be they linearly caused or not. Here truth is defined as the construction arrived at by consensus which is: (1) the best informed in relation to the quality and quantity of information and (2) the most sophisticated in regards to the power with which the information is understood and put to use. Further, this holds true regardless of how many other constructions also satisfy that criterion.

Epistemology. According to Guba and Lincoln, positivists use a dualist, objectivist epistemology which is consistent with a realist ontology. Here, it is both feasible and imperative for observers to "exteriorize" the phenomenon they explore. Observers must maintain a state of "subject-object dualism", or in other words, they must remain distant, detached, and unbiased.

On the contrary, Lincoln and Guba underline, participatory evaluators follow a monistic, subjectivist epistemology which "asserts that an inquirer and the inquired-into (a human being) are interlocked in such a way that the findings of any given investigation or inquiry are the literal creation of the inquiry process" (Lincoln, 1992, p. S7). This position disputes the dualistic perspective which separates ontology and epistemology and simultaneously makes it impossible and undesirable to attain objectivity. Added to this is the premise that knowing is an

interactive process whereby the respondents and researchers become both learners and teachers and, together expand their knowledge and abilities.

Methodology. Guba and Lincoln (1989) state that conventional evaluators engage an interventionist methodology which reflects their ontological and epistemological beliefs. This methodology "strips context of its contaminating (confounding) influences (variables) so that the inquiry can converge on truth and explain nature as it really is and really works, leading to the capability to predict and to control" (p. 84).

Participatory evaluations, according to Lincoln and Guba, however, abide by a hermeneutic methodology, a methodology which "includes context as a part of the nature of the thing to be known; physical, psychological, political, economic, geographical, cultural, and familial terrain" (Lincoln, 1992, p. S7). Lincoln underlines that the term naturalistic is used simply to express that this research is to be conducted in a natural, rather than laboratory, environment. It is hermeneutic, she continues, because it includes an ongoing dialectical process of, for example, "iteration, analysis, critique, reiteration, reanalysis" (p. S7). This process culminates in a common, negotiated agreement between all participants with their emic (insider) and etic (outsider) perspectives.

CRITERIA OF TRUSTWORTHINESS

For Guba and Lincoln (1989) and Lincoln (1992), constructivists adopt their own criteria for judging rigor which they call quality criteria for trustworthiness. Providing parallels to positivism, the constructivist approach substitutes credibility for internal validity, transferability for external validity, dependability for reliability, and confirmability for objectivity.

Despite the fact that they are positivist parallels, these constructivist criteria play an important role in maintaining methodological integrity. Here, each positivist perspective (i.e., internal validity, external validity, reliability, and objectivity) is summarized, followed by its' constructivist counterpart (i.e., credibility, transferability, dependability, and confirmability).

According to Guba and Lincoln (1989), internal validity refers to the degree to which a dependent variable or outcome can be explained by controlled variation (change) in an independent variable. Credibility refers to the degree of congruence between the researcher's representation of participants' constructions and their actual constructions.

External validity deals with the assessment of how well we can apply the findings of one research initiative to other contexts and participants. Only complete randomization would ensure complete generalizability. Transferability deals with the assessment of similarity between the sending and receiving context. Sufficient information about the study and its

processes must be provided to enable the receiver to determine if this study can be applied to alternative situations.

Reliability focuses on the consistency of a specific study or instrument and whether it can produce similar measurements on subsequent repetitions. To ensure reliability, researchers must, for example, adhere to a consistent methodology, hypothesis, and set of constructs. Dependability focuses on ensuring stability of information or data over time but only applies to specific changes in a researcher's own mental or physical state (e.g., boredom and fatigue). Dependability is not compromised when changes can be attributed to the evolution of a researcher's methodology or constructions. In fact, this evolution is expected.

Objectivity centres on ensuring neutrality, that bias, values, and prejudice, do not influence a research process or results. Researchers can avoid such influences by abiding by strict (standardized) methods. Confirmability centres on assuring that information/data, understandings, and results, are grounded in the context and the participants providing the material, as opposed to being the fruits of the researcher's own imagination.

ENSURING METHODOLOGICAL INTEGRITY: THROUGH THE EYES OF SANDELOWSKI

Sandelowski (1986) provides us with a variety of alternative (non positivist) procedures for ensuring methodological integrity. These procedures augment, and overlap with, the

methodological perspectives presented by Lincoln and Guba. They were followed throughout the exercise and the development of this dissertation. (See Chapters 1 and 3, in particular.)

Auditability

Borrowing from Guba and Lincoln (1981), Sandelowski explains that auditability is the criteria of merit or rigor associated with qualitative findings. Auditability is achieved when the researcher leaves a clear decision trail concerning the study from its beginning to its end. It also means that others can follow the progression of events in the study and understand their logic.

According to Sandelowski, auditability is demonstrated primarily in the research report and is specifically achieved by a description, explanation, or justification of:

1. how the researcher became interested in the subject matter of study,
2. how the researcher views the thing studied
3. the specific purpose(s) of the study,
4. how subjects or pieces of evidence came to be included in the study and how they were approached,
5. the impact the subjects or evidence and the researcher(s) had on each other,
6. how the data were collected,
7. how long data collection lasted,
8. the nature of the setting(s) in which data were collected,
9. how the data were reduced or transformed for analysis, interpretation, and presentation,

10. how various elements of the data were weighted,
11. the inclusiveness and exclusiveness of the categories developed to contain the data, and
12. the specific techniques used to determine the truth value and applicability of the data (see page 57). (pp. 34-35).

Qualitative research should also have available: memos, data display charts indicating coding instructions and the actual placement of data into categories, and the way different elements of the data were linked to each other.

Credibility and Fittingness

For Sandelowski, prolonged contact with subjects and independent analysis of data by another researcher can serve to validate findings. To achieve credibility and fittingness (defined on pages 57 and 58), we need strategies to manage problems such as the holistic fallacy, elite bias, and going native that can emerge in qualitative research. These are:

1. checking for the representativeness of the data as a whole and of coding categories and examples used to reduce and present the data;
2. triangulating across data sources and data collection procedures to determine the congruence of findings among them;
3. checking that descriptions, explanations, or theories about the data contain the typical and atypical elements of the data;
4. deliberately trying to discount or disprove a conclusion drawn about the data;
5. obtaining validation from the subjects themselves.

Defining Terms

In the above discussion, Sandelowski introduces a number of potentially unfamiliar terms. I now clarify these terms by extracting definitions from her work.

Truth Value. In qualitative research, truth value rests in the discovery of human phenomenon or experiences as they are lived and perceived by the participant. Therefore, truth is subject-oriented. Threats to internal validity are rare in qualitative research because this research seldom involves the testing of subjects. Further, researchers can compensate for such effects as subject history and maturation by being sensitive to the fact that participants have their own experiences that take place within a historical context. Subject mortality (loss of participants during the evaluation) can be compensated by forging close relations between participants and researcher.

Applicability. To acquire applicability, qualitative researchers focus on the study of phenomena in their natural environments which have few controlling conditions. This serves to reduce risk to external validity. Sample populations are chosen for the relevant qualitative material they can attribute and for the extent and intimacy of their involvement.

Credibility. Sandelowski (1986, p. 30) claims that:

A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own. A study is also credible when other people (other researchers or readers) can recognize the experience when confronted with it after having only read about it in a study.

Fittingness. She also explains that:

A study meets the criterion of fittingness when it can "fit" into context outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences. In addition, the findings of the study, whether in the form of description, explanation, or theory, "fit" the data from which they are derived. These findings are well grounded in the life experiences studied and reflect their typical and atypical elements.
(Sandelowski, 1986, p. 32).

Holistic Fallacy. Making information appear more patterned, regular, or congruent than it actually is which occurs when a researcher makes conclusions claiming to represent all the information when it is, in fact, not fully included.

Elite Bias. Failure of a researcher to establish typicality or atypicality of the information given by participants in relation to their reality.

Going Native. Becoming so involved with participants that a researcher can no longer distinguish their experiences from their participants'.

Lincoln and Guba's Criteria of Authenticity

Lincoln and Guba do not provide positivist parallels for criteria of authenticity. According to Guba and Lincoln (1989), this is so because it is essential to go beyond merely developing methodological perspectives which parallel their positivist cousins. Criteria of authenticity break the bonds of positivism, or stated differently, give us the freedom to stop playing "'in the friendly confines' of the opposition's home court" (p. 245).

These parallel criteria, they continue, are also primarily methodological criteria. "That is, they speak to methods that can ensure one has carried out the process correctly" (p. 245). While positivists place primary emphasis on method to ensure trustworthiness of result, they underline, fourth generation evaluators also place equal weight on outcome, product, and negotiation criteria.

Relying solely on criteria that speak to methods, as do parallel criteria, leaves an inquiry vulnerable to questions regarding whether stakeholders rights were in fact honored. To put the point more bluntly, prolonged engagement and persistent observation (or any other methods one might choose) do not ensure that stakeholder constructions have been collected and faithfully represented. (p. 245).

Furthermore, these authors claim that, even though quality control is inherently built into the hermeneutic process, and that this is well grounded in the principles of constructivism, this approach may still prove problematic for some. This is so because, being so implicit, this means of quality control may be

insufficient to convince those who require more explicit evidence.

Guba and Lincoln then explain that criteria of authenticity were developed to overcome this potential concern. These criteria emerged directly from the constructivist assumption that anyone could have invented them even if they knew nothing about positivism or its assertions regarding its rigor. "These criteria can be explicitly confirmed and would be addressed in any case study emerging from a constructivist evaluation" (p. 245).

Lincoln (1992) adds that:

In the instance of authenticity, criteria have been created for fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. These criteria are intrinsic to the constructivist paradigm itself and deal with problems of imbalances of power and representation, false experiencing (including false consciousness), misunderstanding, impracticality, and disempowerment. (pp. S7-8).

Finally, Guba and Lincoln (1989) elaborate on these criteria. To start, fairness addresses how well various constructions and their corresponding value structures have been sought and respected during the evaluation. Ontological authenticity concerns how well stakeholders' own emic constructions and their use have been cultivated. Educative authenticity refers to how well the evaluation has improved each stakeholder's comprehension of and respect for the constructions of the stakeholders not within their group. Catalytic

authenticity refers to how well the evaluation has generated and facilitated action. Finally, tactical authenticity looks at how well stakeholders have been "empowered to act" (p. 250).⁴

HONOURING SUBJECTIVE, EXPERIENTIAL, AND LAY KNOWLEDGE

An essential principle of participatory evaluation is that the evaluation process should respect, listen to, and act upon the indigenous knowledge of the stakeholders involved. In participatory evaluation, it is as least as important to generate subjective knowledge about perceptions of an initiative as it is to know about professionally and scientifically gathered quantitative data. In the participatory evaluation exercise, which is the focus of this dissertation, participants were asked to draw on their own experiences and understandings in evaluating the V/RHB's efforts to include and support the role of self-help groups in health promotion.

Given this emphasis, it is imperative to understand what is meant by subjective, experiential, and lay knowledge. Assisted by a variety of authors in the field, the ensuing few pages are dedicated to explaining these concepts.

EXPLORING ALTERNATIVE KNOWLEDGE

Taylor (1982) looks at inequality in access to decision-making and exercise of power and relates power to subjective understandings. He emphasizes that communities require more than economic equality. They also need a rough

equality of participation in collective decision-making and in the employment of power.

An extensive inequality of participation is inconsistent with the condition that relations between people are direct and many-sided, for in the matters in which there is not full participation by everyone there is effectively mediation between people: problems and disputes are solved not by the parties involved dealing directly with each other but by those who participate. (Taylor, 1982, pp. 102-103).

Borrowing from Buber (1958), Taylor adds that the quantity and quality of communal life is adversely affected when human groups allow others to control their common affairs. Blatant inequalities in the employment of power, he continues, also negatively impact on community, undermining the potential for building reciprocity and maintaining direct and many-sided relations. For him, anything which is valued is a possible base for the employment of power, adding that two such bases are economic or material resources and control of force. He also adds, however, that it takes more than the equal distribution of each of these bases to ensure an equal distribution of power. This is so because there are other things of value such as information and an individual's good opinion which are not equally distributed and because whether a person has power over another hinges on her preferences in addition to her resources.

I would argue that the equal distribution of both information and good opinions is also essential for obtaining equality in access to decision-making opportunities. Appropriate/fair decision-making is dependent on the

accessibility of relevant information (including good opinions) and parties with less access to this resource are likely to be at a disadvantage in the community building process.

Additionally, good opinions can be as vital a component in the decision-making process as "scientific" or "objective" facts especially, if these opinions include local knowledge and ways of knowing.

Furthermore, equalities in the decision-making process and in power distribution are strongly interrelated and feed back on each other. Involvement in the decision-making process can be empowering in itself. In turn, empowered people are more likely and able to contribute to the decision-making process. (See, for example, Green and Kreuter (1991), Guba and Lincoln (1989), Lincoln (1992)).

According to Dalton (1986), in planning education and practice, planners still largely rely on the rational comprehensive model. In these circles, "when applied to problem solving and decision-making, rationality depends upon technical analysis and the assumption that knowledge can help humans gain control over their environment" (p. 147). Further, she notes that this view is perpetuated both in educational institutions and in the workforce and serves to maintain the status quo.

She then underlines that within these environments, strong emphasis on objective analysis encourages planners and potential planners to study aspects of a community which can be most easily measured. These people try to model complex environmental systems in order to explain conditions and

ultimately to predict impending events and their outcomes. She then remarks that, while trying to decrease uncertainty, they either slight individual and social behaviour or reduce it to probabilistic analysis. For her, this, unfortunately, overlooks the human capacities to "think, learn, and read emotionally" which significantly limit the usefulness of future projections based on prior events (p. 151).

Of utmost importance, for Dalton, is that, while promoting communication, mediation, and similar planning skills, planners must accept the validity of others' perceptions and experience. She then concludes that:

If academics truly want to see planning practice change, they cannot be satisfied with debating the meaning of rationality and lamenting its dominance, but must be able to demonstrate how other forms of knowledge and processes for plan making can work in practice. . . . As the function of cities and regions changes with post-industrial society, what is the role of planning? Is it not better to take the risk of exploring new possibilities now, as the field did in the 1960s, than to flounder because the profession is unable to respond to changing community conditions? (p. 150).

Over the years, however, there have been a large number of planners who have been advocating and practicing more participant-centred approaches emphasizing subjective experience. For example, while critiquing Friedmann (1987), Sandercock and Forsyth (1990) suggest that although Friedmann largely ignores feminist critiques of positivist epistemology or new feminist perspectives, his attention has shifted away from technical planning towards espousing subjective knowledge as the

basis of radical planning.

In fact, like Dalton, Friedmann (1988) makes an essential distinction between cognitive and existential rationality, the latter being particularly dominant in community development struggles within disadvantaged communities.

Sandercock and Forsyth then point out some of the "ways of knowing" feminists add to those more traditionally validated. These include talking, listening, tacit or intuitive knowledge, creating symbolic forms, and acting. These are often referred to as subjective, feminine, or local ways of knowing and doing.

To begin, they stress the importance of talking, especially the oral traditions and gossip. They note that Belenky et al. (1986) define gossip as "conversations among intimates, talk about feelings, about the personal, the particular, the 'petty', but not necessarily the trivial" (Sandercock and Forsyth, p. 20).

Borrowing from Belenky et al. (1986) and Spacks (1985), Sandercock and Forsyth continue to say that gossip penetrates right to the truth of things in a manner similar to poetry or fiction. Through this means of communication, which moves between the large and the small, the specific and the general, people swap small shared truths.

Secondly, they underline the necessity of listening to people and summarize Forester (1989) who describes listening as being "the social policy of everyday life" and a vital component of planning. They also add that Friedmann (1973) includes the role of listening in mutual learning.

Thirdly, Sandercock and Forsyth explain that theorists and researchers such as McLintock, Polanyi, and Einstein, discredit sole reliance on scientific, observable ways of knowing and advance the utility of adding tacit or intuitive knowledge to enrich our understanding of the complexity of life.

Fourthly, according to Sandercock and Forsyth, creating symbolic forms such as painting, music, and poetry, are vital ways of knowing but may be more important than planners are willing to consider even today.

Lastly, these authors state, "By acting and reflecting on the meaning of action we come to know the world in a way that is not available to us through books full of scientific and technical knowledge" (p. 21).

They conclude this discussion by emphasizing that:

All of these ways of knowing are subject-related (it is we who do the talking, listening, acting, . . .), which reminds us of the essentially autobiographical, and thus gendered, nature of knowledge. More than this, though, knowledge is a social construct. Different knowledges must be shared, through communication, to construct meaning. The construction of knowledge involves communication, politics, passion. It is unfinished business. (p. 21).

Fals-Borda (1980) also emphasizes the utility of approaching popular bases to knowledge:

Were we to accept the premise that common people's science or folklore - that is to say practical, vital, empirical knowledge which has allowed them to survive, to interpret, to create, to produce and to work over the centuries with direct natural means - has its own rationality and causality structure, it would be convenient to begin by trying to understand such

rationality and such structure within the scope of what they have of themselves or of specific. (p. 19).

For Borkman (1991), "Professional knowledge is university based, analytical, grounded in theory or scientific principles, and abstract. In contrast, experiential knowledge is grounded in lived experience, concrete, pragmatic, and holistic" (p. 5). Experiential knowledge involves emotional involvement, subjectivity, and caring. Further, within our society today, professional, scientific knowledge is the dominant "legitimized and institutionalized way of knowing" (p. 5) while experiential knowledge is barely recognized and respected by persons other than the knowers, themselves. Borkman also extends this classification system to include lay knowledge, which is based on folk information or common sense acquired through daily life, information handed down intergenerationally, and information taken by individuals from the mass media and professionals, including scientists.

Taking a concept developed by Cronbach (1975), Kraemer Tebes and Tebes Kraemer (1991) suggest we focus more on understanding local events accurately and developing explanatory concepts for human and social phenomena rather than on coherent theory rooted in general laws and broad empirical generalizations which "will be hopelessly mired in the search for higher order interactions which are, ultimately, unknowable (p. 754).

DISCUSSION

Alternative types of knowledge, ways of knowing, and ways of

doing, can play an important role in planning, and health planning is no exception. Given this, it is exciting to realize that there is a growing number of people now recognizing this value and recommending its inclusion in various types of research.

PAR AS AN APPROPRIATE METHODOLOGY

In the next few pages, we can see that PAR and participatory evaluation are ideal tools for capturing these forms of knowledge. We can also see that self-help groups largely rely on such alternative forms of knowledge which makes these alternative methodological tools especially relevant for this study. More generally, these pages review the relationship between PAR and community health promotion, self-help groups, women, and participatory evaluation. These relationships are being discussed, here, to demonstrate the potential of participatory evaluation for working with women and self-help groups and for advancing community health promotion initiatives.

PARTICIPATORY ACTION RESEARCH AND COMMUNITY HEALTH PROMOTION

Despite the fact that more and more planners are studying participatory planning and are putting this into practice, such radicalism is still yet to be fully embraced by the majority of planners, especially in Western industrialized countries (Dalton, 1986). Most are conservative regarding the degree of public involvement they solicit.

PAR, a relatively new paradigm, is being used by a small, but growing, number of planners today. It comes out of the radical tradition and advocates empowering and mobilizing people, especially those most disadvantaged, to gain more control over their lives and to become more self-reliant. More specifically, it promotes full participation of all concerned citizens in all stages of research and planning, from the initial identification of need, to implementation of projects or programs, to analysis of results and evaluating the study, to deciding issues regarding control and dissemination of results.

According to Brown (1985), PAR is a people-centred learning process which helps bring about greater levels of social awareness, participation, and equity and which fosters self-reliant methods of addressing local needs. Anyanwu (1988) concurs and adds that one of PAR's major strengths is that both the process and results of this type of research are of direct and immediate benefit to the community. The biggest key is that research is done by and with the people, not on or for.

Lindsey and McGuiness (1996) point out that PAR can be used as a tool to counter intellectual elitism and professional privilege and to make sure that the research conducted is relevant. It is essential to point out that, for research to be relevant, it must focus on issues the community has identified as important.

Green et al. (1995, p. 4), define PAR rather succinctly. For them, participatory research (i.e., PAR) is a "systematic inquiry, with the collaboration of those being affected by the

issue being studied, for the purpose of education and taking action or effecting social change". Looking at the relationship between PAR and community health promotion, they explain that:

Participatory research and health promotion both seek to encourage community participation, respond to issues important to the community, empower individuals to take action and find solutions to those issues, encourage capacity-building within the community, and take social or political action to address the determinants of health.

In fact, PAR and community health promotion are quite compatible. To start, Osteria (1991) informs us that PAR became involved in health development in response to the following three major considerations: First, traditional quantitative research has largely failed to address the intricate nature of many social and development issues. Second, it is necessary to have a concise understanding of the antecedents of health issues that will foster a pragmatic approach to health planning that is trainable. Finally, there is a need to recognize that people have to be active participants in the development of health programs. To continue, in reference to PAR, Osteria states that:

Within the health sphere, the approach is novel since it is posed as a viable alternative to previous efforts by programme planners to effect changes drawn from community felt needs and participation. Participatory research in health is essentially community action drawn from the enlightened participation in decision making and health analysis. In this approach, the community is primarily involved in the determination of its own health problems and the formulation as well as evaluation of the solutions. (p. 5).

For Dhillon and Philip (1994), "Health promotion is the social action of health development" (p. 9). It has formulated three strategies for creating healthy lifestyle and good health. These are advocacy for health, social support, and empowerment of the people.

Corcega (1992) explains that "the essence of the participatory health research lies in the fundamental principle of drawing in the actual physical and intellectual resources of the community upon which the research is to be based and for whom eventual action is envisaged" (p. 186). It is grass-roots in nature and focuses on shared learning experiences.

Corcega stresses that classical research emphasizes research designs that separate research and participants. The agenda of funders accentuates this practice and, as a result, researchers turn their attention to producing quantifiable results and outcomes and neglect process. Opposing this preoccupation with statistics, she explains that:

The development of educated, self-reliant citizens capable of making decisions regarding their own future does not lend itself to quantification. Successes and failures of helping people gain pride and confidence in their abilities to make things happen, believing they can and will change their lives for the better, cannot all be explained by statistics. (p. 186).

Wuest and Merritt-Gray (1997) explain that PAR has the following characteristics: (1) problems or issues to address come from within the community; (2) research is designed to bring about social and political change; (3) the various

elements of research, action, reflection, and evaluation interact with each other in an iterative fashion; and (4) change and action occur throughout the research process as well as upon its completion. They also stress that community researchers control all stages of the research and work in partnership with external or professional researchers. I add to this that we can include participants, themselves, as community researchers.

In short, PAR and health promotion as described above, are people-centred and people-controlled, they are bottom-up and participatory. With this in mind, PAR makes an ideal tool for use in participatory health planning.

PARTICIPATORY ACTION RESEARCH AND SELF-HELP GROUPS

For Anyanwu (1988), community development is a participatory process involving all community members who mobilize for social action. Anyanwu states that one of the goals of community development as a process is to "educate and motivate people for self-help" (p. 11). He also reminds us that democracy itself is founded on the principle of "by the people" which, to him, is actually just saying "self-help".

A common theme running throughout the literature is that democracy involves self-reliance or self-help (Anyanwu, 1981, 1988; Brown, 1985; Fals Borda, 1984; Sheilds, 1967). It is said that people must stop relying on elite scientists to plan our lives and communities for us. We need to control our own lives and our own resources in changing and uncertain times to obtain an equitable position at any geopolitical level. The

methodology we choose as planners should reflect these needs.

Self-help groups are a vital component of bottom-up community planning, including health promotion, and the PAR paradigm. Even though PAR can be applied to other organizations, both large and small, and can be used to enhance community participation and action on a larger scale without having to take root in any one organization, their particular form and function make self-help groups ideal niches for PAR. In order to address this issue more fully, it is first necessary to describe the form and function of self-help groups.

Gartner (1985) defines self-help groups quite concisely:⁵

Self-help groups are by and large consumer-initiated, peer-oriented, problem-centered groups in which the participant is both the helper and the one to be helped. They provide a way for individuals in a collective setting with others who face similar situations to assume responsibility for their own bodies, psyches, and behavior, and help others to do the same. (p. 25).

Riessman (1985) explains that self-help groups comprise individuals with the same problem or need and whose members handle their problems together. "The group always involves face-to-face interactions; personal participation is critical and bureaucratization is anathema to self-help organization" (p. 2). He notes that it is a form of bottom-up, as opposed to top-down participation and the base of self-help action is the small group. He adds that, even when a self-help organization expands considerably, as has AA, the form of connection is not at all the same as it is for the classic bureaucratic model.

"The self-help ethos includes a resistance to things being done for the self-help group (or to them) by outside experts, professionals, or leaders, and a strong desire for self-governance and independence" (p. 2). This does not mean, he insists, that they reject government or professional assistance. Rather, these groups promote independence and rely on participants' indigenous knowledge. "It strongly emphasizes giving help (and being helped by doing so), receiving help (and knowing how to receive help), and helping oneself (the narrower but still relevant sense of self-help)" (p. 2).

The self-help understanding of the nature of help, he contests, is very different from the professional theory of practice. Professional practice is based on systematic knowledge and scientific methodology and dominant in every phase of this practice is the fundamental fact that the assistance rendered is a commodity to be bought, sold, promoted, and marketed.

However, in self-help groups, he declares, in all but rare cases such as Weight Watchers, assistance is given freely. Further, these groups also typically rely less on systematic knowledge and conscious use of methodology and more on individual experience, codified experience, and wisdom. Help, he continues, is rooted in the experiences of the participants with the problem who have found their own methods for helping each other.

For him, free from the shackles of the market, self-help groups can start to develop "helping combinations and patterns

in novel, fresh ways, unencumbered by professional assumptions" (p. 2). Further, constraints of time, location, and format are also removed.

According to Riessman, in self-help groups, people are transformed into resources. He informs us that not only is the quality of help changed and viewed differently as a result of being freed from the market and professional assumptions, but its quantity is increased tremendously.

Finally, according to this author, self-help groups empower participants and their communities rather than make them dependent, emphasize prevention of dysfunction, engage in advocacy, and create political awareness and action.

Chesler (1991, p. 758) asks: "Why is so much of the research produced by a friendly scientific community marginal or not useful to people active in self-help processes and groups?". For him, one answer is that the traditional research paradigm and the methods it typically uses seldom suit the nature of self-help groups along with their goals for information or action. Self-help groups, he notes, are a unique social phenomenon. These groups are the antithesis of rationalized bureaucracies in that they are voluntary and grass-roots in nature and are more like nascent social movements. They form their own understandings of the problems to address and how to resolve them based on their own experiences.

For Chesler, the processes occurring in self-help groups strongly resemble private interactions in a family or intimate

relationship rather than secondary social relationships. With this in mind, he claims, it may be necessary for researchers to have a more intimate knowledge of the research group and issues and preferably to have the same or related experience.

Considering the importance of personal and collective empowerment for self-help groups, Chesler underlines the value of inquiry methods and actions for change that encourage the empowerment of individuals.

For him, both the structure and process of self-help organizations suggest that we cannot know or predict their reality *a priori*. "Standardized or highly controlled research designs simply may not be feasible; or, in order to be feasible, may overlook or inappropriately squeeze group realities into oversimplified models" (p. 764).

On a similar note, Katz (1981, p. 142) explains that "Changes in goals and in the nature of membership, sometimes unaccompanied by structural changes, seem to occur frequently in self-help groups and to result in organizational difficulties". Through example, he illustrates that goals and programs sometimes change to accommodate differences in participants' character and expectations. He also demonstrates how an organization can begin by addressing small, specific, and immediate issues and can expand its concerns with time. He concludes that this implies one essential dimension of self-help groups: "the dimension running from those that deal with transitory to those dealing with long-term problems" (p. 143).

He notes, too, that there is an overall tendency for the

structure of self-help groups to rely on membership solidarity and autonomy rather than professional elitism. Finally, he underlines, both the bureaucracy and professionalism commonly a part of mainstream social services are typically absent in self-help groups.

Killilea (1976) explains that self-help organizations are, among many things, an expression of the democratic ideal by which people determine how they view themselves and through which they demand the kinds of services they feel are appropriate to meet their needs (p. 46). She adds that within this movement there is a hearty trend towards "debureaucratization" and "deprofessionalization" of social services.

According to Vittano (1972, p. 7):

A new emphasis on broad democratic participation is motivating clients and other nonprofessional groups to become involved in policy-making and service delivery in many social institutions. . . . Some interpret these phenomena as manifestations of a growing anarchy; others view them as signs of an evolving, more democratic society. . . . The challenge is particularly evident in the emergence of self-help groups - groups that emphasize power of their members to assist one another rather than depend on the help of professionals. (Cited in Killilea, 1976, p. 47).

In her work, Killilea (1976) supports Dumont's (1974) assertions that: (1) self-help groups are based on equity, power redistribution, and the decentralization of authority, (2) the redistribution of political and economic power is insignificant without redistributing power given to

professionals, and (3) advocacy and consumer control have surfaced as oppositional forces to professionalism and have culminated in the self-help movement.

Chesler (1991) argues that PAR, as an alternative paradigm, fits in very well with the "highly participatory and experiential culture and goals" of the self-help movement (p. 758). He also notes that PAR uses technologies of data collection and analysis that are congruent with the reliance on local wisdom and popular leadership reflected within the self-help movement. For Chesler, the ways in which PAR typically employs research findings is more consistent with the organizational structures and action needs of self-help groups as well as their empowerment potentialities.

Chesler (p. 765) asserts that:

Respect for the personal struggle, experiential wisdom, and emergent social dynamics embodied in the self-help process requires researchers to cast a skeptical eye on professional expertise and power (including their own).

Borkman (1990) speaks about her threefold classification of knowledge as it applies to self-help groups. She contrasts "the experiential information of self-helpers with the lay-folk information of their families and friends and with professionals' knowledge of the relevant area in question . . . (p. 5). She stresses that, even though experiential knowledge is not exclusively the domain of self-help groups, their nature - one of sharing experienced problems and collectively resolving

them - makes this the ideal arena for such knowledge.

This is backed by Kraemer Tebes and Tebes Kraemer (1991) who highlight the fact that a distinguishing characteristic of support groups (including self-help groups) is their reliance on experiential knowledge. Further, researchers working with these groups have traditionally respected qualitative knowing and engaged qualitative methodology. This is so, for them, because support groups "have inherent complexities that limit rigorous quantitative study" (p. 753).

The work of both Borkman (1991) and Kraemer Tebes and Tebes Kraemer (1991) provides further evidence of the special relationship between self-help groups and PAR, given their congruent values and principles. When these authors talk about experiential, lay, and professional knowledge, they are largely referring to knowledge pertaining to the specific personal issues bringing self Helpers to a specific group (e.g., a disability or the loss of a child) and the related understandings held by co-members, friends, family members, and professionals.

I am a firm believer that sharing first-hand or "insider" knowledge of a specific personal issue can play an invaluable role in the healing process. I have seen this therapeutic effect at work in self-help groups. Furthermore, based on my experiences with self Helpers over the years, I understand that issues of concern to self Helpers, frequently extend beyond these specific personal matters and can include the way the health system relates to self Helpers, their groups,

complementary health care, and the communities they serve (e.g., women or consumers in the psychiatric system). It is important to note that self-help groups have experiential and lay knowledge of these issues and, at times, professional knowledge. Such concerns and knowledge are often responsible for members of the public selecting self-help groups over more mainstream health services.

Examining the relationships between self-help groups and PAR, Chesler (1991) explains that, along with the distinct opportunities and constraints involved in research with self-help groups, comes the need to use different methods of social inquiry and action. PAR's fundamental principles, he emphasizes, are quite congruent with the desired goals of self-help groups which are:

- member/informant participation in the design and operation activities;
- local and grass-roots orientation;
- freedom from professional control;
- opportunities to learn new skills;
- participation in new social processes; and
- attaining outcomes of consciousness raising and empowerment. (p. 765).

Moreover, Chesler suggests that we should engage PAR while conducting studies with self-help groups because this methodology gives self-helpers vital control over initiatives that involve them and can foster safe and trusting environments.

Since many self-help groups develop explicitly to fill gaps or create change in the service delivery system, they are not likely to trust establishment-based researchers, even applied or action researchers, and especially not researchers embedded in the professional bureaucracy delivering services people feel are inadequate. . . . Groups and individuals struggling for legitimacy and influence, or simply wishing to preserve their privacy, may require some degree of control over the researcher's freedom to investigate, to interpret and publish their results, and some evidence of researcher's commitment to their partisan cause. (p. 765).

To sum, we can say that self-help groups are founded on, and promote, the principles and characteristics listed in Figure 1. These reflect the principles and characteristics of PAR:

Table 1: The Values and Principles of Self-Help Groups

indigenous/experiential knowledge	consumer control
membership control	autonomy
face-to-face interaction	individual rights
education	empowerment
consciousness raising	political awareness
advocacy	community action
absence of bureaucracy	volunteerism
free exchange of help	democracy
flexibility	intimacy
limited involvement of professionals	

ANDROCENTRISM IN PARTICIPATORY ACTION RESEARCH

Lee and Weeks (1991), emphasize that "Community organizing theory, implicit in the writings of 'social action' authors such as Alinsky (1972), Freire (1972), and Piven and Cloward (1977) is based on assumptions about class, poverty, and unity, as well as the nature of politics and community" (p. 220). They

continue to say that these assumptions are both vital to and challenged by the experience of women's movement organizing. Further, gender and the structure of women's lives are essential factors to include in social analysis.

According to Lee and Weeks, however, none of these four social action authors indicate that their theoretical framework might be differentially applied to groups of people having attributes additional to that of poverty, such as race or sex, which might further specify the disadvantage. They also suggest that this does not mean these community organization (PAR) theorists overlook the importance of understanding the culture of the people researched. What is missing, they say, is the notion that social analysis can benefit from looking at the unique experience of factions of the population such as women, rather than assuming, as community organization theorists have, that theoretical frameworks can be universally applied to all groups and life situations.

She concludes that what becomes clear from such analysis is that "women and gender as a focus for analysis have been ignored, minimized, or marginalized in the growing literature of participatory research practice and theory" (p. 63). This pattern of marginalization and invisibility, for her, denotes that women have been denied the full empowerment and transformation potential of PAR.

For Maguire (1987), women and gender have not yet had a central position in PAR theory or practice.

When participatory research claims to empower a community or group, are the women in the community equally as empowered as the men? When participatory research declares its intention to attack oppressive social structures, is patriarchy one of them? There is little evidence that this is the case. (p. 60).

In other words, she exclaims, patriarchy has been one of the last systems of domination to be challenged.

The sense of unity for women today is often very intense, especially for disadvantaged women. Evidence for this is the strength of women's formal and informal networks (economic, social, and political) and women's active role in struggles to improve quality of life at all geopolitical levels (from the individual, to community, to international). (See Moser, 1987, 1989; Reinharz, 1984; Surarith, 1987; and Thorbek, 1987, 1988.)

According to Maguire, for instance, Tandon (1981) holds that PAR has clearly aligned itself with efforts to transfer power from haves to have-nots. She contends, however, that the efforts to shift power to female have-nots has been less clearly made. For her, Tandon fails to note that male power structures, whether haves, have-nots, or in between, have a less than stellar record of voluntarily sharing power with women.

IMPLICATIONS AND REDRESS

The above critique further drives home the importance of broadening the PAR paradigm to include women, especially those most marginalized/disadvantaged. PAR researchers must always be careful not to perpetuate androcentrism so typical in the scientific paradigm. For Maguire, "Participatory research

appears to be colluding, however unwittingly, with the predominant male bias of the social sciences" (pp. 60-61). Despite that fact that PAR has worked to overcome the positivist monopoly on knowledge creation, she warns, males may take over this female paradigm.

For Lee and Weeks, the assumptions held by community organization/PAR theorists such as Alinsky, Freire, Piven, and Cloward are too limited in view of the experience of women's movement organizing. From there, they note the implications of the above analysis for future theory development and women's community organizing.

Firstly, to be directly helpful to women's organizing, PAR must learn from the women's movement that gender and the structure of women's lives are essential components of social analysis and social action.

Second, greater attention must be paid to looking at women as a functional community in addition to or instead of a geographic one. "The task of organizing demands new tools and strategies in view of the barriers to community which arises from the structure of women's lives" (p. 225).

Maguire adds to and supports these suggestions. She insists that feminist PAR would include or consider the following:

1. Feminist participatory research would be built on a critique of both the positivist and androcentric underpinning of dominant social science research as well as on the exposure of the androcentric aspects of participatory research to date.
2. As a comprehensive research approach, feminist participatory research would give discussion of gender a central place on

its issues of agenda.

3. Feminist participatory research would give an inclusive feminism, which recognizes and celebrates diversity, a central place in the theoretical debates within the participatory research community. . . . It would not simply try to integrate feminist concerns into male-centred theories.
4. Feminist participatory research would give explicit and equitable attention to gender issues in each of the five phases of participatory research projects⁶.
5. Feminist participatory research would give explicit attention to how men and women, as a group, benefit from the participatory research project, including benefits from participation in the process as well as benefits from the final product or action.
6. Feminist participatory research would pay attention to gender language use.
7. Feminist participatory research would pay attention to composition and issues of the research team, equally including gender, class, race, and culture.
8. Feminist participatory research would include gender as a factor to consider in overall project evaluation.
9. The feminist participatory research community and networks, would purposefully review and track all participatory research projects with gender in mind. (pp. 129-132).

Finally, Maguire concludes by noting that these suggested considerations, applying to various stages of the planning research process, are not at all an exhaustive nor complete list. "Instead they are a beginning for dialogue and experimentation in a participatory research community committed to strengthening the creation of knowledge as a force for radical social and personal transformation which equally includes and benefits women and men, as well as naming patriarchy as a system to dismantle" (p. 133).

Despite the fact that more recent works such as Maguire

(1996) still discuss the need to see a more intentionally feminist PAR, it is vital to emphasize that there is a large and growing number of authors who do see women and women's issues being of central importance in PAR. PAR not only strongly reflects women's ways of knowing, thinking, and doing, but feminist PAR is almost synonymous with feminist research.⁷ (See the section referring to Honouring Subjective, Experiential, and Lay Knowledge presented earlier in this chapter.)

DISCUSSION

In this section, we have seen the potential of PAR to play an invaluable role in health promotion. We have also seen the value of employing a PAR approach when engaging in research or other initiatives involving subjective, experiential, and lay knowledge; women; and self-help groups.

Given that participatory evaluation is a child of PAR, it seems a logical conclusion to suggest that participatory evaluation is an ideal tool for working with self-help groups to explore their role in community health promotion. We do not know, however, what role participatory evaluation can play in bringing about an effective and equitable evaluation of health promotion initiatives for both sets of stakeholders, i.e., self-helpers (the recipients) and members of the Vancouver/Richmond Health Board (the implementers), when only the former, are engaged in the evaluation. This dissertation provides answers to this unknown.

PARTICIPATORY EVALUATION: CONFLICT VERSUS CONSENSUS APPROACHES

Participatory evaluation can be divided into consensus versus conflict approaches. Knowing the principles and values held by evaluators in both camps is essential to the development of this dissertation and to comprehending the methodological findings and substantive outcomes that are generated. This next section clarifies some of these differences. Later, I relate this discussion to the information already provided in this chapter to give a general understanding of the theoretical discourse this dissertation helps resolve.

A GENERAL DESCRIPTION

Participatory evaluation, whether in the consensus or conflict camp, is an essential part of any true PAR study. Participatory evaluation can be conducted, however, as a study in itself. Either way, it is participant-centred and participant-controlled and encourages full and active involvement of all participants in all stages from beginning to end. Furthermore, like PAR, it is a valuable tool for community health planning (see Fawcett et al., 1996; Muller, 1980; Rifkin et al., 1988; and Thompson, 1992) and for working with women and self-help groups.

Vargas Vargas (1991) stresses that "we must consider evaluation: (i) as a participatory process (ii) with an education sense" (p. 268). For her, evaluation is an integral component of a participatory educational process. Beneficiaries

and promoters alike plan, initiate, and control the project and they do so as equals and as subjects as opposed to objects. In addition, the two motivational factors behind educational evaluations are empowerment and experiential learning.

In a participatory process, people involved in the project develop a methodology for reviewing their own experience. They use workshops, meetings, and other collective methods. They apply different kinds of techniques at different moments of the process. Either with some external help or without it, they programme the steps in relation to the specific objectives to be achieved: they gather the necessary information, analyze it, and derive their conclusions in order to improve their plans for their future. (p. 269).

CRITICAL EVALUATION

Paulston (1979) summarizes common understandings of the major differences between the consensus (or equilibrium) and conflict approaches to evaluation. First, these approaches are equated with the liberal and critical paradigms respectively. Liberals emphasize consensus, individualism, and utilitarian values and view reform as incremental stages leading to greater efficiencies within existing systems. Evaluation is, therefore, used as a tool for generating information to bring about such improvements. Conflict evaluators, on the other hand, believe that liberal reform maintains the status quo. For them, evaluation is a vehicle for social critique and for exposing inequities and how they are born, perpetuated, and justified.

For Sirotnik and Oakes (1990), critical theory maintains that the purpose of evaluation or social inquiry is to spawn social justice. To achieve this goal, it is essential to have

freedom of speech.

The naturalistic-hermeneutic sciences have a practical interest - that of understanding human behaviour in a situational context, promoting some form of consensus among the participants, and perhaps even reaching some level of acceptance of what is. But a critical social science has at its core an emancipatory interest; it is not content with what is but rather with what can and should be. (p. 45).

These authors stress that many evaluators over the years including, for example, Bryk (1983); Guba and Lincoln (1981); Patton (1978, 1980); Thompson (1980), and Williams (1986) "advocate no value position - that is no moral imperative, no ethical commitment, no normative stance serves to make explicit what 'good' is at the heart of an inquiry" (p. 37). They explain that most of these evaluators either do not consider values because they are seen as metaphysical issues outside the domain of scientific, objective study, or adopt a subjectivist, relativistic position which views values as pertinent "only as they are interpreted or negotiated, or both, within specific contexts of human understanding and social interaction" (p. 38).

Boyce (1993) underscores that we have to understand that inequality between various interest groups exists and we have to ensure our evaluations address, rather than perpetuate, this imbalance. For him, evaluation should be an integral part of the empowerment paradigm where social justice and equality reign over efficiency. He explains that we can trace the theoretical origins of this approach back to neo-Marxism and critical theory. Critical theory, he continues, sees conflict as a

natural part of social change and it insists that power imbalances between participants impact on the outcomes of social programs. Further, in addition to addressing issues of power inequalities and social justice, critical inquiry must employ a methodology that involves new methods and analytical tools which serve to empower participants.

House (1993) states that there are inequalities between stakeholders in regards to the potential to influence, utilize, or be protected from evaluation. To maintain social justice, he asserts, it is essential to ensure the equal representation of multiple and often conflicting interests. He is unsure, however, about how this is to be accomplished. For him, it is simply not adequate to describe these various interests in a neutral manner. "The critical political question to ask is: Whose interests does the evaluation serve?" (p. 10).

House (1990) also looks at evaluation studies as tools for bringing about social justice. "Public evaluation should be an institution for democratizing public decision making, for making decisions, programs, and policies more open to public scrutiny and deliberation" (p. 23). House punctuates that, despite lack of consensus on their meaning, concerns such as justice, impartiality, and equity, are not arbitrary nor relative.

To summarize, these critical theorists emphasize that consensus theorists/practitioners: (1) do not take a moral or ethical stance on issues such as equity; (2) ignore or downplay the existence of conflict and power inequities and the role they play in empowerment; (3) take a collaborative, incrementalist

approach to evaluation involving multiple steps/studies; (4) work within the system; and (5) serve to maintain the status quo.

CONSENSUS EVALUATION

There may be cases where the above conception of the consensus approach may apply in full. As we can see below, however, it is not appropriate to make sweeping generalizations. Consensus evaluators often do take an ethical stance and use evaluation to enhance equity between stakeholder and to transform existing systems within society. They also frequently acknowledge the existence of conflict and power inequities and their potential to impact on the evaluation's ability to generate equity and transformation.

We should also remember that as a form or stage of PAR, participatory evaluation, both within and outside the critical paradigm, recognizes the need to fight for equity, justice, and empowerment because people have been oppressed and marginalized. Further, like critical evaluation, PAR grew out of critical and neo-marxist theory. (See, for example, Brown, 1986; Brown and Tandon, 1983; de Koning and Martin, 1996; Green et al., 1995; Lee and Weeks, 1991; Manzo, 1991; and Wuest and Merrit-Gray, 1995.)

Feuerstein (1988), for instance, underlines that participatory experience in adult education and community development has influenced participatory evaluation. For her, in this approach "people are involved in defining their own

evaluation needs, building on existing intellectual and leadership capabilities and practical skills, and refining group work methods" (p. 16). She notes that these evaluations can help participants develop their ability to systematically analyze their own reality and to enhance their self-reliance and self-determination.

This authors insists that increasing participant control, self-reliance, and self-determination strikes considerable controversy, however, because few people in control of development activities are truly willing to share power as easily as responsibility. Similarly, some development systems seem to have problems accepting transference of power to the periphery. "Such shifts involve changes in patterns and responsibilities for decision-making and resource allocation. They also reveal differences in conceptual frameworks between those at the 'top' and those at the 'bottom'" (pp. 16-17).

Brunner and Guzman (1989) reinforce this assumption in the passage below. According to them, participatory evaluation is the product of project teams involved in popular education and PAR initiatives in developing nations (what I prefer to call low consumption countries).

It shares their theoretical foundations, ideological convictions, and methodological principles. It can be characterized as a methodological component of educational development projects that aim to empower the dominated groups in a society so that they will be able to join the struggle for a just and egalitarian society. (p. 10).

Next, in her summary of the evaluation-as-politics paradigm (originally defined by Smith and Glass, 1987), Thompson (1992) recognizes that competition exists between stakeholder groups. "The evaluation-as-politics paradigm sees each program as having stakeholders and active partisans competing with each other for a greater share of authority over resources and social affairs" (p. S69). Evaluations and politics are so highly intermingled, she continues, that it is essential to be prepared for such rivalry from the first to final stages.

Mark and Shotland (1985) recognize that evaluation involves value judgements throughout, including those pertaining to the identification and inclusion of qualifying stakeholder groups. They are concerned about the existence of conflict, power inequities, and the need to empower participants during the evaluation process. These authors clarify that stakeholder evaluations represent a movement towards addressing considerations beyond utilization and accurate representation in decision making. The most prominent other considerations, they explain, are justice in evaluation and participant empowerment. For these authors, evaluations should aim for real, as opposed to pseudo empowerment and ensure that the most marginalized voices are most heard.

They assert that we should take great care to ensure that more powerful voices are not given preference over others due to manipulating the process in their favour. In addition, we should understand that many stakeholders may want more than just having their voices listened to in the evaluation. They may

want to have real input into the program and its future. In other words, evaluations should foster real control over these processes as opposed to just merely the appearance of control which serves to appease those most marginalized and, hence, to buffer real change and maintain the status quo.

Weiss (1986a) explains that the stakeholder approach recognizes that programs represent many, diverse interests and that evaluation is "a conveyer of information, not a deliverer of truth; an aid, not a judge" (p. 154). Moreover, Weiss (1986b) warns us that even though stakeholder evaluation is an attempt to rectify inequities in power and resource distribution, these evaluations can be used to divert participants' attention away from the larger and more important issue of participating in program reform.

The arguments provided here closely resemble those advocating for critical evaluation. We can now examine how consensus evaluators differ from conflict evaluators and fit the description set by them. We can say that consensus evaluators work collaboratively with, but not necessarily within, the existing system and they tend to engage an iterative or incremental approach sometimes using multiple studies. They also set consensus as a goal.

For instance, Feuerstein (1988) stresses that "The task of the researcher is not to produce knowledge but to facilitate the construction of knowledge by the community itself" (p.23). Evaluation should establish trust and confidence and involve mutual learning, the sharing of experiences, and negotiation.

Brunner and Guzman (1989) see participatory evaluation as a collaborative process. For them, "Participatory evaluation is an educational process through which social groups produce action-oriented knowledge about their reality, clarify and articulate their norms and values, and reach a consensus about further action (p. 11).

In the evaluation-as-politics paradigm, or what she refers to as the fourth paradigm, Thompson (1992), advocates that we use as wide a range of stakeholders as possible in each evaluation, employ multiple methods and perspectives, stick to small designs to maximize adaptability to changing circumstances and stakeholder needs, and make the results relevant and accessible to each stakeholder group. "A series of related studies gives greater flexibility, and lends itself readily to the fourth paradigm and to evaluation of health promotion action" (p. S69). In addition, Thompson stresses that participatory evaluators can successfully mediate between diverse and competing, factions.

Mark and Shotland (1985) do not address whether it is essential, or possible, to arrive at a consensus through evaluation. On the other hand, despite recognizing that mutual education is not an easy thing to accomplish, they assert that this is an essential component for establishing meaningful participation.

Weiss (1986a) stresses that stakeholder evaluation can serve to shift control from one, dominant group to stakeholders in general. She also asserts that the stakeholder approach takes

into account that large-scale programming is evolutionary in nature. Furthermore, Weiss (1986b) notes that there is no reason why evaluation can't involve a number of smaller studies rather than just one "blockbuster". Lastly, Weiss (1998, p. 29) explains that "it is through the ongoing process of discussion over time that meanings can be negotiated and common interpretations reached".

CONCLUSION

This chapter commenced with an overview of the methodological perspectives and procedures recommended by Guba and Lincoln (1989), Lincoln (1992), and Sandelowski (1986).

According to Thompson (1992), Guba and Lincoln (1981) and their naturalistic evaluation clearly fall within the evaluation-as-politics paradigm. Earlier discussion in this chapter on Lincoln and Guba's methodological perspectives reveals that these authors adopt a consensus approach. Their criteria of authenticity represent the ideals we should follow if we want to work within this approach. We can question, however, if these ideals are possible to achieve.

We have to take into account how women, self-help groups, and alternative knowledge and ways of knowing are marginalized in the health system and that members of the V/RHB were absent from our exercise. With these factors in mind, this dissertation was undertaken to demonstrate whether it is possible to use participatory evaluation to: (1) attain the

equitable representation of both sets of stakeholders; (2) overcome conflict between these stakeholders; (3) develop collaborative relations; (4) reach a consensus; (5) empower participants; and (6) make appropriate transformations in the health initiative we are evaluating. In other words, could we simultaneously satisfy Lincoln and Guba's criteria of educative, catalytic, and tactical authenticity and adopt a truly hermeneutic methodology, a relativistic ontology, and a monistic, subjectivist epistemology? The process of answering these questions also allowed me to illustrate whether it is necessary for evaluations to adopt one approach or the other, i.e., the consensus versus conflict approach, rather than elements of both.

The next two chapters provide the essential methodological and substantive information we used to answer these questions in Chapter 5.

END NOTES

1. The evaluation questionnaire included a simple task whereby respondents were asked to quantify their perceptions of Health Board inclusion of and support for self-help groups. This was the only quantitative information acquired during this exercise.
2. For references to Lincoln and Guba's varied works in this area, see Carey (1997); Firestone (1993); Greene (1987); Harris (1992); Johnson (1997); Mark and Shotland (1985); Morse (1997); Swanson, Durham, and Albright (1997); Thompson (1992); and Thorne (1997); Wilson and Ambler Hutchinson (1997); Wuest and Merrit-Gray. For reference to Sandelowski, see Bottorff (1997); Carey (1997); Johnson (1997); Lipson (1997); Morse (1997); Norris (1997); Sandelowski (1997); Swanson, Durham, and Albright (1997); and Thorne (1997); Wilson and Ambler Hutchinson (1997); Wuest and Merrit-Gray (1997).
3. When referring to Lincoln and Guba in this section, I am relating that both Guba and Lincoln (1989) and Lincoln (1992) share this same view. In fact, their works are very similar, the latter being a more condensed and slighted updated version of the former. I only refer to either of these works separately when directly quoting or discussing something not mentioned in the other.
4. Several other authors embrace most or all of these methodological perspectives in their works, for example, Brunner and Guzman (1989), Cousins and Earl (1992), Greene (1987), Feuerstein (1988), Uphoff (1991), Vargas Vargas (1991). Further, between them, Cousins and Earl (1992) and Mark and Shotland (1985) cite fifteen additional works which espouse at least one of these perspectives. In Cousins and Earl, see Bryk (1983); Greene (1988a, 1988b); Huberman (1980, 1987); Kennedy (1983); King and Pechman (1982, 1984); Weiss (1983, 1986b); Weiss and Bucuvalas (1980). In Mark and Shotland, see Cook (1985); Cronbach et al. (1980); Guba and Lincoln (1981); Hirschman (1970); Patton (1980); Weiss (1983, 1986b).
5. As a basis for recruitment, I use the definition of self-help groups as outlined by the Self-Help Resource Association (1995).
6. Maguire is referring to the following five stages of research:
 - Phase 1: Organization of the Project and Knowledge of the Working Area.
 - Phase 2: Definition and Generation of Problem.
 - Phase 3: Objectivization and Problemization.
 - Phase 4: Researching Social Reality and Analyzing Collected Information.
 - Phase 5: Definition of Action Project.
7. For more on feminist research and feminist PAR, read

Barnsley and Ellis (1987, 1992); Bruce Christmas (1988); Clarke (1992); Crowley and Himmelweit (1992); Driscoll and McFarland (1989); Du Bois (1983); Dumont (1989); Fonow and Cook (1991a, 1991b); Friedman (1992); Grant, Ward, and Rong (1987); Gunew (1991); Hanen (1989); Huizer (1986); Kirby and McKenna (1989); Lips (1987); Maguire (1987, 1993, 1996); Marshall (1988); McGrath, Kelly and Rhodes (1993), Mies (1983, 1991); Moore (1988); Reinhartz (1981, 1983, 1984, 1992); Smith (n.d., 1988); Stanley and Wise (1983a, 1983b, 1990a, 1990b); Tomm (1989); White and Stewart (1988).

CHAPTER 3: METHODS AND METHODOLOGICAL FINDINGS

INTRODUCTION

This chapter provides an overview of the methodological path our participatory evaluation exercise took. It demonstrates the benefits of employing a participatory evaluation approach for health planning, for recipient stakeholders, and for participants. It documents the various methods and procedures engaged to design, implement, analyze, and assess the evaluation exercise and its questionnaire (shown in Appendix 2). It also demonstrates the problems and opportunities experienced during this process and how participants and I worked to overcome our challenges and constraints.

During these processes, the twenty-one participants involved in this evaluation exercise (i.e., a sample of Vancouver-based women self-helpers) gave a huge amount of diverse information. In fact, there was far too much information gathered from them about how they wanted to conduct the evaluation exercise to include directly here in its raw state. Despite not seeing this raw information in this chapter, it is essential to note that participants played a major role in determining the direction and shape of this exercise and we can see this influence. Their comments have been incorporated into the structure and processes of this exercise as well as the design of the evaluation questionnaire.

In this chapter, we can see some overlapping and

repetition. This is essential because the various issues, actions, and lessons involved in this exercise can be discussed in different ways for different purposes.

THE PARTICIPATORY EVALUATION EXERCISE

DESIGNING THE EVALUATION PROCESS

Participants had the opportunity to engage in all of the following iterative elements of this participatory evaluation:

1. Needs Assessment: Identifying the initial need for the exercise and the specific needs the exercise, itself, could satisfy;
2. Formulation of the Evaluation Design: Determining what the exercise should accomplish (goals and objectives) and how (choosing appropriate methods and processes including designing the evaluation questionnaire);
3. Choice of Target Audiences and Means of Dissemination: Determining who the exercise was meant to influence and help and how to effectively and equitably distribute the findings to these audiences;
4. Implementation of the Evaluation: Conducting the ongoing exercise process (meetings) and implementing the evaluation questionnaire;
5. Analysis: Analyzing the methodological findings and substantive outcomes generated;
6. Making Recommendations: Making recommendations for planners, self-helpers, and other stakeholders; and
7. Exercise Assessment: Assessing the success or failure of the exercise and evaluation questionnaire in accomplishing what they set out to do.

Due to the iterative and overlapping nature of these elements, they were not necessarily used as section headings in

this chapter.

Participants and I made use of an aide memoire (a list of general steps and questions to consider during meetings) which was rather general and was used largely to give an overview of the exercise and show participants how they could belong (See Appendix 3). The specific steps involved in designing the evaluation questionnaire are outlined later in this chapter.

PARTICIPANT RECRUITMENT

This exercise invited individuals from two groups of stakeholders: (1) V/RHB paid and volunteer staff, especially those who have been working with/for women in the community health promotion process and (2) women in women's self-help groups in Vancouver.

This represents a narrowing in focus from my initial proposals for this dissertation. I originally was going to do an exercise comparing community participation initiatives in the North Shore and Vancouver Health Regions but limited this exercise to the latter Region for the following reasons. First, my major contact in the North Shore Region retired from her position. Second, I realized the scope was far too wide for me to take on, given the time and resource constraints under which I was working.

I also widened my focus somewhat from a preceding proposal. Initially, this exercise was intended to include only Vancouver-based women's self-help groups which had actively been trying to involve themselves in the V/RHB's health planning

initiatives. I felt this would help to recruit stakeholders who were open to this process. About the same time I realized I should be opening this exercise up to all Vancouver-based women's self-help groups, very early in this exercise, two or three participants made the same point. The reason they gave for this change was that the onus should be put on the V/RHB, rather than on self-helpers, to involve self-help groups in community health planning. We intended to measure how successful participants felt the Health Board had been in including self-help groups, not how enthusiastic and diligent these groups had been in trying to involving themselves. When I took this new idea to other participants involved at this early stage they agreed with this decision. This change meant that I had to recontact a number of stakeholders to inform them of this new condition for qualification.

Even though I originally indicated that only women's self-help groups would be qualified for participation, we soon decided to accept groups including men, but only if they focused chiefly on issues important to women. For example, two groups had some male membership, however, the health issues these groups addressed primarily affected women and the groups were largely or totally female-controlled and female-oriented.

To recruit participants, we used the Self-Help Resource Association's (SHRA) definition of self-help groups and their terms for qualification. For the SHRA:

In this context, "self-help" refers to groups of people suffering life crisis or afflictions/

disabilities who get together for mutual support in relieving the suffering that might otherwise occur. Such groups function in a non-profit/charitable capacity and are focused on a particular health or social problem. (SHRA, 1995, p. 7).

From here, they outline that qualifying groups are:

Mutual aid peer-support and/or non-profit societies which meet the above definition and are run by and for their members to whatever extent possible. These groups shall charge no fees other than nominal membership dues. (SHRA, 1995, p. 7).

Lastly, those excluded are:

Groups whose purpose is primarily political advocacy and/or lobbying for their specific cause. Groups led by professionals who charge a fee or which are considered groups therapy. Groups providing self-help for personal profit or gain. (SHRA, 1995, p. 7).

The process of identifying and including stakeholders evolved along the way and was determined by participants and the time available. In total, at minimum of 61 self-help groups were identified and invited to participate. The reason why I can't be certain about the exact number over 61 is because I contacted some organizations which had more than one self-help group associated with them. I, therefore, refer to both self-help groups and organizations, the latter being associated with at least one self-help group. Further, some groups invited to participate did not classify themselves as self-help groups and disqualified themselves as a result. I was not able to determine whether they were, indeed, self-help groups or not.

It is possible too that there were some self-help groups inadvertently left out because they were not discovered. With this in mind, it is difficult to establish the exact population of women's self-help groups/organizations that could have been included.

Despite the fact that a number of Health Board members indicated their interest in the evaluation and, in some cases a strong interest, they chose not to participate in this exercise. They indicated that too many projects competed for their attention and that they had many other priorities. Later in this chapter, I include information by contacted stakeholders explaining more fully why they made this decision.

I chose to recruit self-help groups which had contact addresses within Vancouver proper for reasons discussed in Chapter 1. Recruitment continued throughout the exercise, new stakeholders were contacted when discovered and known ones were reinvited as the exercise progressed and took new directions.

Self-helpers were invited to participate through letters of recruitment (See Appendix 4). Qualified women's self-help groups and organizations were identified through community directories and through referrals (i.e., the snowball technique). To ensure they were still in operation and to acquire accurate addresses, I first phoned a number of self-help groups and organizations. Despite the fact that I explained clearly that I was not recruiting them over the phone, some individuals talked at varying lengths about the issues addressed in the exercise and whether they were interested or not and

how. I sent out letters and, after digesting the information and often going through their boards, interested groups contacted me. Further, three groups asked me to come in and give an overview of the exercise either before or after their board met.

One issue participants brought up at different times was whether they had to include all the members of their group in the exercise or if it would be sufficient for them to serve as representatives of their groups. My reply was that they were free to involve their groups in any manner they felt would most effectively use their time and meet their needs and wishes. These participants were in close contact with members of their groups and knew their issues well. One participant stressed that, in addition to knowing these issues through such contact, she had access to participants' evaluations of their programs to assist her. We can say that there were times when participants represented their groups because the information they gave reflected common knowledge (e.g., number of Health Board visits or shared constructions such as the desire for their group to be relatively autonomous) and times when participants gave their own opinions based on their own understandings (e.g., their experiences with the Health Board or health system).

Further, participants took responsibility for recruiting members of their groups. In fact, they helped to recruit participants from other groups as well.

I also invited Health Board staff (volunteer and paid) to participate through letters of recruitment. I initially made

contact with some of these stakeholders via the telephone to identify the most appropriate "targets" according to the Health Board and to get proper addresses for mailing out letters. Some were contacted directly and a number of them, front-line community developers (see page 153), were asked to help recruit members from the various Community Health Advisory Committees and Population Health Advisory Committees.

PARTICIPANT INVOLVEMENT AND CONTRIBUTION

As planned, members of self-help groups and the V/RHB were invited to contribute to, and have control over, the entire evaluation exercise. Health Board members chose not to get involved, even though some expressed a keen interest in this exercise and some talked to varying degrees with me on an informal basis. This was quite unexpected because it was this keen interest, especially by one key contact, that served to confirm that I had, indeed, picked an appropriate research topic. The V/RHB also chose not to fund my project when I applied to it for funding. Reasons given for lack of support were that the Health Board felt other projects better met needs they identified as important. I took down notes from these contacts and include all relevant information I acquired from them later in this chapter when I talk about the problems participants and I encountered during this exercise. To simplify the presentation of this material, I did not assign these stakeholders any codes. I included their comments for the sake of providing as complete a picture of my meetings

(telephone and in-person discussions and focus groups) with stakeholders as possible.

Self-helpers did respond, on the other hand. In total, 21 self-helpers participated in this exercise, representing 17 self-help groups and organizations¹. Sixteen participants took part in meetings (representing 13 groups/organizations) and 11 of these also filled in questionnaires (representing 10 groups/organizations). In total, 16 participants filled in questionnaires (representing 13 groups/organizations). Even though five of these participants did not participate in meetings, one had a co-member involved in meetings instead of her. All of these participants are women who are members of Vancouver-based women's self-help groups or organizations.

Participating self-helpers came from diverse backgrounds and brought with them rich and diverse "packages" filled with experiences, expertise (professional, lay, and experiential), and understandings. As self-helpers, these individuals are experts about their own specific health issue(s) that led them to become involved with a self-help group. They turned to self-help groups as alternatives to or complements of the formal health system. They are all knowledgeable about the self-help group(s) they belong to and some also have a more generalized knowledge of self-help groups and their role as health service providers. Many participants have been involved with the Health Board in different capacities, from applying for funding to doing volunteer work for it. A number are experienced in fighting for self-helpers, women, and marginalized people and

their issues and all have first- and second- hand knowledge of the health system. All participants had completed secondary school and most have had some post secondary education ranging from college diplomas and Bachelor degrees to Ph.D.s and Post Doctorates. Some had acquired at least part of their education from alternative health care training institutions and most had attended local forums, workshops, and courses related to self-help groups, women, and the health system.

All but three participants were of European origin and most were born in Canada. Of the remaining participants, one is of Vietnamese origin, one is of Indian origin, and one is an Aboriginal Canadian. All participants had at least a good working knowledge of English even though some spoke English as a second language. Most individuals ranged from being on some sort of government assistance to being in the low or mid income bracket. Only three participants fell into a higher income bracket. Some participants had risen to the mid income level after experiencing financial hardship. Participants were between the ages of 25 and 55. There were both single and married women and women with and without children.

One potential participant helped me with the structure of the questionnaire but did not classify herself as a self-helper. I did not use information she gave during meetings because she did not send revisions to me. On the other hand, I did take heed of the technical information she provided regarding designing the evaluation questionnaire.

The contacted individuals associated with the remaining 44

plus self-help groups/organizations turned down this exercise for a variety of reasons including lack of: (1) time; (2) staff; (3) resources; (4) trust in researchers, professionals, and the Health Board; and (5) belief in the potential of such studies to make changes. Further, a few contacts felt their participants were too vulnerable to partake in this exercise because, before they could step outside their groups, they first needed to heal and become sufficiently empowered.

Some non participating self-helpers gave additional information. I took down notes from conversations with these individuals, again without assigning codes, and include them in Chapter 4. One of these self-helpers felt another woman in her group would have been a more appropriate member to work with and passed me on to her. This referred contact became an active participant. Another planned to meet with me on two occasions, but failed to do so both times and I never heard from her again. The last contact provided some interesting information over the phone but had no time to become involved. Interestingly, all three of these contacts gave at least as much information as one woman I classified as a participant. This latter woman was so classified because she indicated a desire to be a participant even though she talked little during meetings.

Those who participated did so on many levels. Closer to one end of the continuum there were participants who included themselves to some extent in every stage of the evaluation. Closer to the other, there were those who only filled in the evaluation questionnaire. There were participants who came in

during part of the exercise and left before the end while there were others who came in later and remained till the exercise was completed. As stated above, we had 9 core participants from 7 groups/organizations. With the advice of two participants, we organized an advisory committee. In total, five of the core participants joined me in this process.

Participating self-helpers had considerable control over the methods they used to involve themselves; the details of confidentiality; who they wanted to work with; where, when, and how they wanted to meet; and so on. Participants were given an overview of the stages involved and were reminded they had the freedom to choose: (1) the stages they worked on, (2) the time and energy they wanted to expend on each, and (3) to end their involvement at any time. In other words, participants were given the freedom to choose the extent to which they wanted to become involved not just whether they wanted to take part. They took this freedom. In fact, one option noted and, upon occasion taken, was to just fill in an evaluation form.

Up to five of us met at one time to develop the evaluation (including the exercise and questionnaire). We intended to (and may) organize larger groups in the future (after the completion of the exercise), but did not assemble all participants in the same meetings during the exercise itself. Some participants felt more comfortable meeting me alone or in smaller groups and some wanted to remain anonymous (in regards to other groups) and, therefore, chose to meet only within their own groups.

For lack of time, all participants, except for two, ended

their involvement before I began to write up (present) the results in the dissertation. All participants were given the opportunity, however, to review the information they gave me to ensure I recorded and presented it correctly. More specifically, I typed up the notes I had written during meetings and gave them to participants for their revision and acceptance. They were also invited to read all parts of my dissertation before and after it was completed. Further, input gathered regarding distribution of results will guide the distribution process. Finally, two participants gave me valuable feedback on how I analyzed information and one of these was involved more extensively in this process and gave me feedback on how I presented information and wrote up implications.

Participants were involved in the exercise through phone discussions, in-person discussions, focus groups, and the evaluation questionnaire. I define a focus group as a process whereby two or more participants are guided by a facilitator to explore common issues. Discussions involve participants in an unfacilitated dialogue which also explores common issues.

In total, there were 40 telephone discussions (lasting roughly 20 to 90 minutes), 19 face-to-face discussions (taking approximately 20 to 180 minutes), and 9 focus groups (spanning about 90 to 180 minutes). All phone discussions and all but one in-person discussion involved only one participant and myself. There were three of us engaged in the remaining in-person discussion and anywhere from three to five of us engaged in focus groups. Finally, participants spent 20 to 90 minutes

filling in questionnaires.

When permitted by participants, I relayed information verbally from meeting to meeting and from participant to participant to unite individuals and groups. Finding time in participants' busy schedules was challenging but we managed to find adequate time to meet. Both relaying messages back and forth and having participants prepare for meetings, whenever possible, served to maintain a sense of continuity and collaboration.

Furthermore, a number of self-helpers gave me considerable support when I applied to the Health Board for funding and some indicated they will do presentations to the Health Board and perhaps even do follow-up focus groups with its members.

Participants in this exercise provided their full consent prior to being involved in the exercise. (See Appendix 5 for the consent form.) Research was conducted with utmost respect for security and confidentiality. Further, I asked participants for permission to quote or closely paraphrase what they said.

All participants were assured they would be given complete access to all information that does not violate issues of confidentiality. They also had the opportunity to read the material and give it their final approval for publishing and distribution.

Due to the informal nature of meetings, the sum total of hours met and the number of hours contributed per participant are difficult to calculate.

DETERMINING/MEETING NEEDS

Participants were given the chance to make this exercise meet their own needs and those of their groups and were told they could have parallel goals and objectives to meet these needs. I explained that our only restrictions were that I had to work within the structure outlined by the University of British Columbia Behavioural Research Ethics Board and my dissertation committee and that I had to produce my dissertation. This meant that they could "kill many birds with one stone" through this exercise. I also told participants I would compensate them for their time by serving as a resource person.

Core participants indicated that having multiple components to this project was a good strategy. The reasons they gave for this opinion were that this would add to the value of the exercise and benefit self-help groups. In particular, this diversification served to: (1) prepare for the possible lack of Health Board response, (2) help self-help groups meet needs more specific to their own members, (3) add to the literature, and (4) help women's self-help groups organize and share resources.

Participants had a wide variety of feasible suggestions to work on during the exercise. Some of these were highly integrated with the initial exercise objectives and structure and some served to broaden them. For instance, as just alluded to, we talked seriously about communicating the results of the exercise to each health region in British Columbia, including the V/RHB, through oral presentations. One participant

suggested that we also conduct follow-up focus groups with board members after we make our presentations. This was offered as a means of organizing women's self-help groups to make important recommendations to the V/RHB and other health regions and to continue relationships already established. We did not arrive at a suitable date to commence such initiatives, but felt it was best to wait till after this exercise was completed and participants had a break to attend to their other responsibilities.

Secondly, we decided that, as a resource person, I could: (1) help write grant proposals, (2) volunteer for odd jobs and special events, (3) help groups network and work collaboratively, and (4) hold small seminars and write articles on issues such as self-help and health promotion, PAR, and participatory evaluation. I have already been involved in tasks one to three and will continue to offer my services when requested.

GENERATING INFORMATION

During the exercise, as noted earlier, information was gathered from meetings (informal in-person and phone discussions and focus groups) and the evaluation questionnaire.

Participants and I met in offices, board rooms, participants' homes, a restaurant, and even one community centre. Further, conversations often began prior to scheduled meeting times and continued after with conversations occurring while we were still in the room, retiring to other areas, walking down the street,

and in my car.

Each meeting was democratically facilitated even though each group and individual took a different level of responsibility for facilitating the meeting. Some worked well with very little structure, while others expressed that they wanted more. They were free to make this decision. They told me how best they work together and gave me directions regarding how to facilitate their involvement so as to make them comfortable.

Participants had a number of suggestions to help gather information. Following one individual's suggestion, we assigned tasks to participants that they could do on their own and to prepare for subsequent meetings. In addition, participants in one discussion group explained that they felt the exercise was a little unclear and that I should explain it in simpler terms to help them understand it and be able to explain it clearly to others in their self-help groups. I was told that I should break it down in smaller, more practical, and manageable sections which can be expounded on if requested. I responded by giving participants and other stakeholders new outlines detailing the exercise's various tasks and showing them how they may get involved (see Appendix 6). One of these participants suggested I use an open flow chart that would be continuously modified/revised with subsequent learning as another tool to facilitate the understanding of the exercise. With limited computer skills, hardware, and software, this was more challenging and I was not able to design such a diagram in time for the exercise.

To assess the exercise, I relied on participant observation (i.e., attending to conversations and the ways participants interacted with each other), my notes, and comments made on the questionnaire. I initially intended to get core participants to fill in a questionnaire assessing the evaluation exercise but, due to their time constraints, participants decided to let me conduct this assessment on my own. This is discussed in more detail later in this chapter. If we do engage in presentations to the Health Board in the future, this may be a more appropriate time to reintroduce an assessment of the exercise.

RECORDING, CATEGORIZING, PRESENTING, AND ANALYZING INFORMATION

During each discussion with participants, I wrote down every bit of information given. I tried to record this information using participants' own wording but often had to reword material slightly to keep up with the conversation and to ensure I could later understand what was said². I chose not to tape interviews because I feel that it is invasive and intimidating and that it violates the relaxed grass-roots nature of participatory evaluations. This was the general consensus among participants.

I frequently had time while still in the meetings to get feedback on whether I had recorded things appropriately. After I typed up written notes, each participants was given at least one (more) opportunity to see their notes and ensure I "got it right". They gave their final approval.

It is important to point out here that due to the

participatory and iterative nature of this exercise, participants were continuously analyzing information throughout their meetings through feedback and revision of ideas. In other words, recording of material and analysis (and looking at implications) went on simultaneously and involved participants as well as myself. These processes are hard to separate.

Further the process of categorizing, itself, is analysis. Originally, I intended to do considerably more summarizing of information so as to shorten its presentation. After spending considerable time doing so, it occurred to me that a great deal of rich detail was being missed in this process. Readers would not be able to see participants' own ways of thinking and expressing themselves. Finding material documenting the various stages of qualitative research of this nature was difficult and, as a result, I had little understanding of the most effective ways of presenting outcomes. After reading another dissertation, lent to be me by a member of my dissertation committee, I discovered that, within the world of qualitative research, presenting full, raw information in the text itself, despite its volume, is totally acceptable. Armed with this understanding, I changed tactics and included as much detail as possible without violating confidentiality.

Even though I was an active part of each meeting and had an active role in helping participants to develop and articulate ideas, I chose not to present my comments. Further, sometimes I chose to paraphrase passages that represent a collective thought between two or more participants. In one case, we agreed not to

differentiate comments made by individuals when they met together.

To present this information, I first divided it into two categories: (1) methodological findings and (2) substantive outcomes that the process generated. However, there were some overlaps. Refer to Chapter 4 for discussion related to categorizing substantive outcomes.

The categories used to present methodological findings under the wider heading "Participatory Evaluation Exercise" represent integral stages or components of participatory evaluation. I ordered these specific headings in a manner which would facilitate the flow of the chapter. Other researchers may have chosen another pattern. The more specific processes involved in designing the questionnaire were discussed separately because the questionnaire was a focal point of the exercise. Headings in this discussion came from Rifkin et al. (1988) and from the activities involved in designing the questionnaire. Finally, challenges, constraints, limitations, and opportunities were presented apart from the other findings to enable the reader to understand the advantages associated with adopting a flexible and iterative model (e.g., making it possible to attract and maintain participant involvement, to generate practical findings, and to benefit participants). Categories in this section represent participatory evaluation stages/components and the general issues and activities involved.

By including information in its raw state, I not only preserved the richness of detail, but also allowed the reader to

see my own biases that may have crept into the process of summarizing. Further, this will enable readers to have a better understanding of why I presented and analyzed the information the way I did and how I came to my conclusions. It also enables them to make their own categories and conclusions and, thereby, adds to the relevance and value of the exercise.

As indicated before, only two participants were able to provide input into the presentation and analysis of this material. Nevertheless, both were very involved with this exercise, were in contact with other participants, especially members of the core groups, and were well acquainted with their ideas and understandings. As a result, their help was invaluable. Having more participants involved in these latter stages would have been even more effective in this regard. Ideally, participants should be involved to a much greater extent in the presentation and analyzing stages but, being a participatory evaluation, this exercise encouraged participants to give only the time and resources they could expend.

When I suspected that information may have compromised participants' confidentiality by revealing the identity of their groups, I asked them for feedback regarding what they wanted me to rephrase or eliminate. This problem did not come up for material gathered during meetings because participants made it clear during meetings what information they were willing to reveal. Luckily, I successfully traced questionnaires to those with potential breeches of confidentiality and got their permission concerning what material I could use. It was also

fortunate that these respondents were not among those who sent their questionnaires in anonymously and insisted they remained so.

The desire of some participants to have their questionnaires remain anonymous prevented me from being able to ascertain more detailed information as to why they gave specific ratings to indicators and sub indicators. Another reason for not acquiring this follow-up information was the lack of time participants had during this stage. In the majority of cases, participants gave ratings I could predict, given the conversations we had during meetings and I had no need to get subsequent information from them. Only one of the participants who gave different (somewhat higher) scores than expected explained her reasoning for doing so. The two participants who subsequently had time to help me with the latter stages of this exercise had given expected ratings based on past discussions.

For details on how this exercise achieved methodological integrity, please refer to Chapter 5.

DISTRIBUTING INFORMATION

One of the most obvious outcomes of this research is my Ph.D. dissertation which is designed to make an impact on the academic world. However, this is only one means of distribution and one audience. This is a PAR exercise and, as such, is a grass-roots, bottom-up process controlled by and for the stakeholders (i.e., women self-helpers). Its primary concern was to benefit stakeholders and the public in general. With

this in mind, this research went well beyond an academic exercise.

Given this, I asked participants to choose their target audiences and means of dissemination. Participants mentioned that they would like to have professionals and students in law, medicine, and psychology have access to this material in order to educate them about self-help groups and their role in health.

Furthermore, participants and I discussed, at length, that we should ensure material is written in a way that all people, even, and especially, those most marginalized, can appreciate and understand. We also agreed to make sure we locate these people and distribute this information to them in appropriate ways. This is especially important because self-help groups serve to unite, educate, and empower those most vulnerable and most in need, those in crisis or have afflictions and disabilities. With this in mind, I will find more "people-friendly" ways to make this material understandable. I will also seek out the most appropriate methods of distribution to make this material even more accessible. Furthermore, as indicated, participants would like to target health boards as audiences to inform them about how they would like their self-help groups to be supported and included in health promotion.

For distribution purposes, participants chose various forms of media (newsletters and newspapers, for example), informal discussions within self-help groups, presentations, and focus groups.

I will make this material available to any interested party including members of the general public, social and health planners, members of the Health Board, self-help groups and organizations, health practitioners (lay and professional), and academics. I will use those channels chosen by participants and find others that are appropriate.

As noted above, this project was designed to improve equity between stakeholders, to empower, to educate, and to mobilize and take action. I also hope that the knowledge acquired here will help: (1) to make community health planning more inclusive and equitable and, hence, demarginalize the marginalized, especially in regards to self-help groups, and (2) to encourage the V/RHB to provide needed and desired resources to help self-help groups thrive and better serve the needs of their members and communities. Other spin-offs may include improving the relationship between professional and popular planners and increasing the general understanding of the V/RHB's community consultation process by "everyone" involved.

MAKING RECOMMENDATIONS

Room for questionnaire respondents to make recommendations to the Health Board was made both on an ongoing basis and at the end of the evaluation questionnaire. In addition, because this evaluation exercise can serve as a guideline for future efforts to involve and support self-help groups, each indicator and sub indicator acts as a recommendation. To explain, the questions asked on the questionnaire were included because participants

felt they were important to consider. Participants were, in effect, making recommendations to the Health Board that these are the indicators and sub indicators the Board should be following and the questions they should reflect upon when they reach out to self-help groups to include/support them. Further, presentations and focus groups will provide a forum for self-helpers to make recommendations to the Health Board(s) face-to-face.

ASSESSING THE EXERCISE

To acquire feedback on the success of this exercise, i.e., whether we met our goals and objectives and those inherent in PAR/participatory evaluations, I intended to give core participants a questionnaire assessing the evaluation. These specific candidates were selected for this task over others because they had the necessary experience with the exercise to provide this input. Participants agreed to do the assessment and gave it their approval, but due to time constraints, it was cancelled.³

Other (non core) participants were given a chance to assess the questionnaire on the form, itself. However, core participants were not given this chance because: (1) they had the opportunity to make such comments during meetings and (2) the exercise assessment form I was originally going to give them included a question asking for such feedback. In view of the fact that these participants did not receive this auxiliary exercise assessment, I should have asked for such information on

their questionnaires too. Assessment outcomes are presented in Chapter 5.

In addition, to assess how well this exercise maintained its methodological integrity, I used the methodological perspectives by Lincoln (1992) and Guba and Lincoln (1989) as a checklist (see Chapter 5.) As explained in the section on Generating Information, I based my assessment of the exercise on participants' comments, behaviours I witnessed during the exercise, and the comments participants wrote on the questionnaires.

For example, due to the fact that the Health Board was not involved to round out the conversations that took place in this exercise, I was watchful about the potential for participants to perpetuate or intensify inaccurate information or perceptions about the Health Board. I discuss the results of this observation in Chapter 5 under the heading Ontological and Educative Authenticity.

DISCUSSION

This section shows us the participatory nature of this exercise and the contribution made by participants. Being a PAR exercise, it is essential to document the methodological steps taken to generate the results obtained. By documenting these steps we helped to ensure methodological integrity and provided valuable methodological lessons. By following guidelines for maintaining this integrity, we helped to maximize the quality and utility of our results. (Refer to Chapter 5.)

The process of developing the evaluation questionnaire, alone, generated an abundance of valuable methodological findings. This next section focuses on these findings and how they unfolded.

THE QUESTIONNAIRE PROCESS

Coming from the critical (or empowerment) paradigm, Boyce (1993) questions the practice of focusing on process rather than on the impact of participation. He explains that "Missing in these analyses have been the crucial evaluations of outcome and impact" (p. 92). More specifically, he looks at gains made in the areas of community participation, participant control, and participants' health and equity status. As will become evident below, this focus is in direct opposition to Rifkin et al. (1988) who stress the difficulty of measuring impact and emphasize the value of assessing process.

To recap what has been discussed so far, participants and I entered this evaluation exercise interested in exploring participants' perceptions about input and process factors related to their involvement in the Health Board's community participation initiative as opposed to the impact participation had on participants. Further, given the early state of Health Board inclusion of self-help groups, we could not very easily measure the impact of involvement on participants, even though we did get some information on the effects of participants' (perceived) lack of inclusion and support (see Chapter 4). We

could, and did, however, discover the impact the evaluation exercise, itself, had on participants (see Chapter 5) and demonstrate the quantity and quality of substantive outcomes stemming from the use of this participatory approach (see Chapter 4). Further, as this chapter testifies, we also drew general lessons from our exercise regarding how to involve participants in health promotion processes.

In this section, I provide a brief overview of Rifkin et al.'s (1988) evaluation model for assessing participation in health programs. Here I explain the value of: (1) using process, as opposed to outcome, indicators; (2) understanding and addressing issues related to both direct and social participation; (3) employing a dynamic evaluation model to elicit self-helpers' perceptions regarding how well the V/RHB included self-help groups in community health planning and supported these groups as health services; and (4) using Rifkin et al.'s web configuration to present ratings data.

This section also demonstrates how participants and I adopted and adapted this model to meet the specific needs and context we encountered in this exercise. Even though I chose this model myself, core participants agreed to its utility and worked with me on its content and general design. They assigned most of the actual wording and presentation to me, however, for lack of time. Some participants, nevertheless, gave me feedback on various drafts.

Further, I was solely responsible for distributing copies of the questionnaires to the various self-help groups and

organizations, even though participants helped me identify potential groups/organizations for recruitment.

PROCESS VERSUS OUTCOME

Rifkin et al. underline the need to look at process when we evaluate health programs. They explain that, in the past, the health system has looked at cause and effect relationships and this is true of evaluations which have tried to identify specific outcomes and general impacts (e.g., health status) related to inputs. This means a reliance on quantitative and static measurements as opposed to qualitative and dynamic⁴.

For these authors, "The weaknesses of assessing economic development and health improvements in terms of linear causal relationships and/or through tightly controlled studies are magnified when trying to assess community participation" (p. 932, original source, Rifkin and Walt, 1986). For them, two factors make these effort even more difficult, their context (i.e., social, political, economic, cultural, and historical climates) and lack of clarity in defining terminology. "As a result parameters of such assessments, in an attempt to become globally applicable, become merely vague or basically descriptive" (p. 932).

Rifkin et al., continue this theme by noting that:

The World Health Organization, for example, in its publication concerning indicators for progress towards 'Health for All by the year 2000' states that community involvement (the term it prefers to community participation because it implies active rather than passive engagement in health activities) can be

assessed by the level of involvement in and degree of decentralization in decision making as well as the development of effective mechanisms for expression of peoples needs and demands. (Rifkin et al., 1988, p. 932, taken from WHO, 1981).

They explain, however, that when Palmer and Anderson (1986) tried to employ this framework, they found that existing ways of measuring participation were not precise enough because they were both new and rarely used.

DIRECT PARTICIPATION, SOCIAL PARTICIPATION, AND EQUITY

From here, Rifkin et al. add that Muller (1980) provides a strong conceptual and evaluative structure by developing a "basic needs" framework. Muller argues that society must be analyzed in terms of inequalities, particularly in relation to having access to society's benefits, including health services, and having a voice in national decision making. This framework includes two major forms of participation - social participation and direct participation. The former, social participation, is achieved when people who are marginalized in society gain access to services and a voice in national decision making. Direct participation, on the other hand, refers to a more limited, or targeted, form of participation, i.e., involvement in health care programs.

These authors include some indicators Muller has developed to measure social participation. These are: "awareness of the interpretation of health problems and their causes, awareness building, and the existence of organization(s) to change the

unacceptable situation" (p. 935). Despite recognizing the importance of making a link between direct and social participation, Rifkin et al., however, stress that their indicators do not do so.

In addition, these authors point out that the indicators they developed (see below) were designed to measure degree of participation without making a judgement that greater participation is a good or bad thing and without trying to correlate community participation with better health status. Each indicator, therefore, only measures increases or decreases in direct participation.

Whether or not this means increasing social participation depends on the nature of existing inequalities in a given society which may be along the lines of economic classes, tribes, gender, etc. In other words, this question focuses on the question of equity. (p. 935).

During the exercise, participants and I held the view that participation is a positive thing and a right. We discussed various types of participation we could scatter on a continuum from direct to social participation or from those involving a more limited form of transformation to a wider form. Using Muller's examples, for instance, our exercise encouraged expanding the awareness and understanding of health problems, their interpretations, and their causes, as well as identifying, organizing, and strengthening bodies to change existing situations, starting with self-help groups.

This concern for exploring both direct and social

participation was reflected in our questionnaire. Even though this questionnaire focused on (sub) indicators closer to representing direct participation, it did go beyond just looking at this, more limited, form of participation. This is most evident in regards to (sub) indicators on horizontal and vertical linkages. Furthermore, even though we have been working on a small scale, this questionnaire, and the exercise in general, may well be a catalyst for future efforts or studies concerned with increasing and assessing participation from one end of the scale to the other.

DYNAMIC INDICATORS OF PARTICIPATION AND SUPPORT

Rifkin et al. have used a dynamic evaluation model with five indicators: (1) needs assessment, (2) leadership, (3) organization, (4) resource mobilization, and (5) management. Each of these indicators has a continuum from one to five, high public participation on the right and low on the left or as these authors put it "with wide participation (community people plan, implement and evaluate the programme using professionals as resources) at one end and narrow participation (professionals take all decisions, no lay participation) at the other" (p. 933).

They originally had a sixth indicator - focus on the poor - which I feel should include other marginalized people. They eliminated this factor, however, for these authors feel it is difficult to convert to an indicator. They explain that an indicator of participation is necessarily an indicator of

equity. They also point out that it is not easy to single out the people who are most marginalized in our communities nor the activities which mark a more permanent reallocation of resources to raise their quality of life (i.e., demarginalize).

This exercise, however, began this process by involving one specific subset of marginalized people, i.e., women who are part of women's self-help groups. This subset overlaps with other marginalized groups such as people with mental and physical disabilities/illnesses, people suffering life crises or afflictions, people of colour, lesbians, bisexuals, transgenders, First Nations people, the economically disadvantaged, and so on. Additionally, this exercise can be adapted as a model to involve other marginalized populations in community health promotion processes and their evaluation.

OUR QUESTIONNAIRE

While designing this questionnaire, on my advice, we first considered using the same five indicator headings for participation developed by Rifkin et al. After various discussions between participants working on the design of the questionnaire and myself and after I carefully reviewed the relevant literature (i.e., the values, goals, and characteristics of PAR, feminist research, participatory evaluation, self-help groups, and health promotion), these were soon altered to make them more appropriate to our exercise at hand. Finally, with the help of my dissertation advisor and the approval of core participants, these were pared down to four.

The four indicators of inclusion we chose are the degree to which the V/RHB: (1) included self-help group in needs assessment; (2) mobilized resources to include self-help groups; (3) employed an inclusive participation approach; and (4) used interactive leadership styles.

The flexible nature of this model made such changes possible. We were free to adapt existing indicators to suit the specific nature of our evaluation and the needs of participants. We could modify, delete, and add indicators and sets of indicators as we engaged in the design process.

As the model "permitted", very early in this exercise we decided to add another set of indicators to those measuring the degree of involvement of self-help groups in health promotion. Participants felt it helpful to acquire support from the V/RHB (and the health system in general). With this in mind, two indicators of support were added. These are the extent to which the V/RHB: (1) supported the development of horizontal linkages between self-help groups and community members, groups, and organizations and (2) developed vertical linkages with self-help groups to enhance their role as health services. These indicators also reflect the values, goals, and characteristics of PAR, feminist research, participatory evaluation, self-help groups, and health promotion.

We then added to each question examples, or sub questions, to help participants make their ratings. Soon these examples became sub indicators and were assigned their own rating scales. Rating scales for indicators and sub indicators

represent continuums ranging from lowest to highest (no to full) participation or support.

It is important to note that, because we intended to have Health Board involvement, the questionnaire was also to be adapted into a self-evaluation for Health Board members to complete. This would have permitted us to compare perceptions and discern similarities and discrepancies and would have given us a basis to enhance communication.

Rifkin et al. start their rating scales for each indicator at number one, for they believed that all planning environments have some degree of participation. Our model started out with this same assumption but soon participants expressed that they would like to give lower ratings or have the opportunity to do so and, therefore, wanted to start our web at zero. Due to interpretation difficulties this potentially could create, I suggested we follow the usual methods for a Likert scale and make "one" represent no inclusion or support. Participants agreed to do so because they realized I also had to use these results for my dissertation which made it necessary to employ methods accepted in my field.

On each questionnaire, I provided participants with a brief introduction and instructions and asked them to give ratings regarding their perceptions concerning involvement and support by the Health Board prior to the end of 1997. I decided to concentrate on this period of time because I felt that the Health Board had relatively little knowledge of this evaluation exercise until I began contacting it for information on funding

in late 1997. I was aware that any contact the Health Board made with self-help groups after that time (e.g., funding for projects and invitations to forums) may have been partially due to the exercise's intervention. By asking for information on pre 1998 inclusion and support, I felt we could get a more accurate baseline measurement. Participants agreed with this decision.

At the end of the overall rating for each indicator, participants were asked to briefly describe the key experiences they used to come up with their ratings. Participants were also asked to make recommendations regarding ways the Health Board can involve and support self-help groups more effectively. This question was followed by a question asking participants whether they felt the Health Board had involved or supported their groups after the end of 1997. This was done because participants and I wanted to see whether the Health Board was seen as being more or less inclusive and supportive of self-help groups in this latter period. Finally, due to the fact that we wanted to get an idea of the types of bottom-up efforts self-help groups have made to contact the Health Board, we included a question to this effect.

Next, non core participants were asked to assess the evaluation. This section was added because I felt it was necessary to acquire this information to enhance future evaluations of this kind and to help assess the exercise. Reasons for not asking all participants to do this assessment are provided earlier in this chapter.

I asked participants to put an asterisk beside any information they wanted directly quoted because I was not sure of the extent to which I would be summarizing this information. This gave participants the chance to have their own words seen as they wrote them. Participants, however, were told when I contacted them about filling in the questionnaire that I may present their words in full in my dissertation unless doing so would breach the rules of confidentiality.

Through a series of revisions aided by participants, professionals, and professors on and outside my dissertation committee, we finally arrived at our finished questionnaire. All questions asked in this questionnaire, including indicators and sub indicators, were reviewed and accepted by participants helping me design the questionnaire. (See Appendix 2 for a complete copy of the evaluation questionnaire.) I then faxed, mailed, or hand delivered this questionnaire to participants or used it as an interview guide, depending on participants' desires and needs.

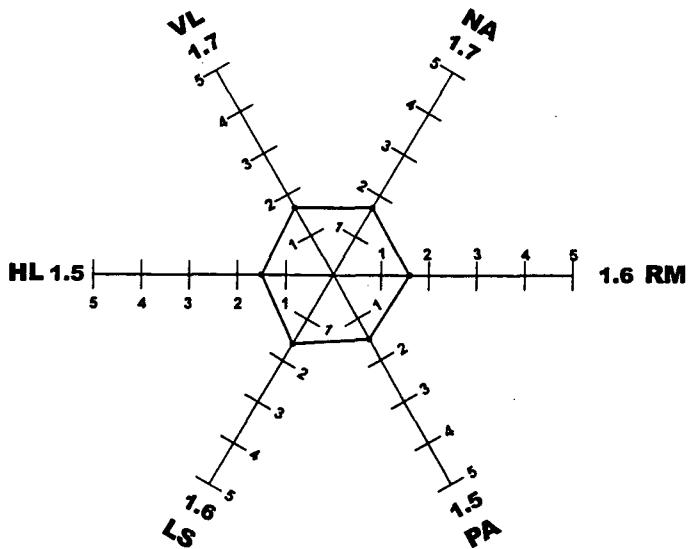
THE SPIDER WEB

After the last questionnaire was returned, I summarized, recorded, and analyzed ratings. This is where the spider web of Rifkin et al. played a vital role.

Rifkin et al. have designed a web shaped configuration whereby the continuum lines for each of the indicators are arranged like spokes on a wheel, meeting at the base and radiating outward. As can be seen in Figure 3, each radiating

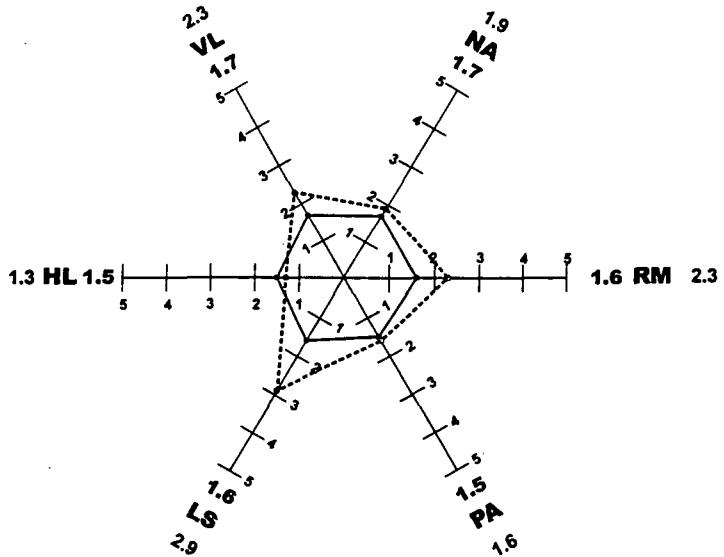
spoke has five points, ranging from one to five. For illustration purposes, I have applied the summarized data given for overall ratings of each indicator of Health Board inclusion or support on one of Rikin et al.'s web configurations.

Figure 3: An Example of a Spider Web Configuration for Baseline Measurement of Indicators



As each measurement is made, the point (bar) placed on each spoke (in our case, the specific degree to which self-help groups were perceived to have been involved or supported) can be connected with those placed on the other spokes so as to make a spider web design. All subsequent evaluations can use this, then, as a baseline to compare future efforts to bring self-help groups into health promotion and to support them (see Figure 4).

Figure 4: An Example of a Spider Web Configuration at Time 1 and Time 2 for all Indicators



OUR WEBS

In our web for overall ratings, indicators measuring both inclusion and support were included together. Unlike the web designed by Rifkin et al., our rating of "one" starts at the hub and the first bar represents a rating of "two". We also developed a web for each sub indicator. There are, therefore, seven webs in total, as can be seen in Chapter 4. Chapter 4 also provides a bar chart demonstrating the overall rating for each indicator.

Ideally this baseline measurement should have been made (i.e., an exercise should have been conducted) prior to the V/RHB's initial community health planning process, but a first measurement can be treated as a baseline at any time.

THE VALUE OF THIS MODEL

Indicators and the ratings given along each of their continuums can be used to compare differences in level of participation/support "(1) at a different time in the same programme, (2) by different assessors of the same programme, (3) by different participants in the same programme" (Rifkin et al., 1988, p. 934). In our case, we can refer to sets of stakeholders instead of assessors (e.g., self-helpers versus V/RHB members). This exercise only engaged in the third application even though participants and I may do at least one follow-up evaluation exercise to compare with the first. Follow-up evaluations may or may not involve the V/RHB.

One of the beauties of this model is that it is dynamic. Plotting ratings on each (sub) indicator continuum and comparing these to ratings of subsequent evaluations can "allow us to assess health programmes in a varied relationship accounting for progressive or retrogressive periods and analyzing relative change" (p. 934). As Rifkin et al. say, this separates this evaluation model from those which rate participation in "a linear relationship or in terms of a standard" (p. 934). I add here that this model also simplifies the evaluation by providing a quick visual reference which can help participants gain a better understanding of the process and results. Further, the ratings process has the potential to spark more qualitative discussion and analysis which can help us discover why such ratings were given and what can be done to improve them. In addition, ratings given for one evaluation can quickly and

easily be visually compared to those given at an earlier time which can also generate "why" questions and answers. Presenting results in web configurations should enhance this feature even further. Finally, as a dynamic model, it has the potential to maintain relationships and lines of communication between groups of participants by involving them in an ongoing, more permanent process.

LIMITATIONS

We must realize that this model uses Likert-like scales which are ordinal, as opposed to interval, scales. This limits the type of mathematical computations one can make. Moreover, I decided to use scales that are open in the middle (i.e., there were no guidelines given for ratings two through four). I chose to do so to limit the complexity of the questionnaire to make it easier for participants to follow and answer. Participants gave me the freedom to make this decision. Considering there are thirty-five different continuums, this also made this questionnaire easier to develop. On the other hand, each continuum is open to interpretation making results less standardized.

Sometime after these questionnaires were returned, it occurred to me that ratings done during potential future evaluations may be attributable to having a different mix of participants as opposed to changes actually occurring regarding the Health Board including and supporting self-help groups. I have not yet talked to participants about this issue because we

have not regrouped to continue this participatory evaluation initiative. Most of the participants in this exercise, however, indicated a willingness to continue their efforts to work with the Health Board. It also occurred to me that a change in sample in the future may also be attributable to a change in the incentive of self-helpers to get involved in initiatives involving the Health Board if the Health Boards start to show a greater interest in self-help groups. In other words, the sample size may increase as the ratings do.

Additionally, on subsequent evaluation questionnaires, participants can identify whether they have filled in a prior questionnaire or not. "Old" participants can be asked if they made any changes regarding their responses and to explain why they did or did not do so. "New" participants can be asked if they were contacted before and, if so, why they changed their minds about their current involvement.

It is also essential to point out that rating scales were included largely as a heuristic tool to give quick visual references regarding base, and possibly future, measurements. As of yet, only one participant has seen the recording and analysis of these ratings and their placement into webs. On the other hand, participants involved in designing this questionnaire indicated that this method of presenting results seems effective. A number of participants, especially those in the core group, also suggested that they would like to review this work after they have taken a break to attend other responsibilities. If, at that time, we organize meetings with

the V/RHB and other health boards, we will present this work to their members.

Due to the fact that I did not do follow-up investigations with each questionnaire respondent, I was not able to ascertain whether the rating scales were helpful in stimulating discussion on the questionnaire, itself.

This lack of follow-up was a limitation. To explain, because questionnaires in our exercise were kept anonymous, when participants did not provide an explanation on the questionnaire as to why they gave their ratings, some valuable information was missed. This was especially true when ratings varied from those expected, given participants' comments during meetings, or when participants were either not involved in meetings or gave us little information we can use to elucidate their ratings. (Also see Challenges, Constraints, Limitation, and Opportunities below.)

Lastly, as in the exercise as a whole, the failure of the second stakeholder group, the Health Board, to partake in this questionnaire, limited the amount and type of information gathered and made validation of substantive outcomes more difficult.

DISCUSSION

This discussion gives an overview of the instrument the design group and I developed to evaluate how well self-helpers believe the V/RHB involved and supported self-help groups. By adopting a participant-driven dynamic model which accounts for

variations in contexts, using process indicators, addressing issues of inclusion and support for stakeholders, and being aware of the need to measure (and stimulate) social as well as direct participation, we helped to ensure our exercise met as many of the values and principles of participatory evaluation as possible (see Chapter 2).

CHALLENGES, CONSTRAINTS, LIMITATIONS, AND OPPORTUNITIES

During research, we experienced some of the challenges and constraints I expected to find (see Chapter 1) and others we did not. The problems we did experience were broken down into six major categories: (1) participant recruitment and involvement; (2) recruitment of Health Board members, specifically; (3) focus of the exercise; (4) role of researcher; (5) confidentiality; and (6) language. This section discusses these problems and describes the creative ways we overcame them and how they often translated into benefits and opportunities. Lastly, this section takes a quick look at some additional opportunities we came across.

PARTICIPANT RECRUITMENT AND INVOLVEMENT

Most of the potential barriers I expected to see in regards to recruitment and involvement did not turn up. We did not meet even one self-helper who had domestic responsibilities or a spouse's attitudes stand in her way of being involved. Only one woman had child care concerns and we worked our way around these

by meeting during her work hours and by having me pick her up after she dropped her children off at child care or school and drop her off in time to pick up her children later in the day.

There were other constraints we had to consider in this area, however, from those which are inherent and inevitable to those which are circumstantial and alterable. Some problems were due to the nature of self-help groups and the context in which they operate. Some were less specific.

Identifying and locating qualified self-help groups took time and energy. As mentioned above, fitting self-help groups, which are largely communities of interest and target/at risk groups, into a geographical boundary, created a methodological challenge. Self-help groups often transcend sharp geographical boundaries and contact numbers and addresses for each group often shift back and forth between regions. Some move out and some move in. Further, groups are continuously starting up and folding, making it difficult to track down. We experienced each of these challenges.

As suggested, we also faced challenges when making a decision about which groups were eligible for our exercise (i.e., qualify as Vancouver women's self-help groups). For starters, when we went into the field there was no information available regarding whether the Health Board implemented a deliberate strategy for including self-help groups in community health promotion or not. We can add to this the birth and mortality rates of self-help groups and migrating contact bases.

These issues were addressed by, and helped justify, the use

of participatory evaluation/PAR methodology and methods. We could not with any accuracy measure the percentage of self-help groups included in the Vancouver community health promotion process over the years, for example, but were able to find groups qualified for this exercise, by stipulating that their current contact addresses be within Vancouver proper, and were able to explore the degree to which the Health Board has tried to involve the groups which responded to our exercise.

We also gave stakeholders an opportunity to develop a participatory evaluation model to: (1) measure and analyze perceptions of past Health Board performance regarding including and supporting self-help groups and (2) provide useful information to guide and enhance future health promotion efforts by the Health Board and to evaluate these efforts. By working together to develop this evaluation, all parties had the chance to acquire a better understanding of the community health promotion process and to have control over how it was evaluated.

In addition, we showed how well Rifkin et al.'s (1988) participatory evaluation model can be used to evaluate a new health initiative involving new participants in a new environment to meet new needs. In fact, Rifkin et al. have encouraged their readers to borrow their model for our own research purposes and inform them of its use and value.

Another barrier participants and I discovered was that self-help groups and their members must first have their needs met before they would be able to, or could justify, being involved in an exercise of this nature. These are constraints

placed on them because self-help groups typically have to operate with limited resources.

To overcome these constraints, I came up with a number of practical ideas. First, I built in a process whereby participants could identify these barriers and work with me to come up with solutions together. Some of these are short term solutions, for example, the volunteering of my time to help compensate them for their work. Some of these have the potential to meet longer term needs, for example, working together on funding proposals and on getting funding sources to recognize their need for support.

Another way I helped to justify participants' efforts was to make sure the exercise addressed their needs (i.e., identified them correctly and led to action to satisfy them). To effectively accomplish this, I ensured that we did a continuous (informal) needs assessments throughout the exercise and adjusted the exercise to meet these needs.

I also built in a process which enabled participants to use this exercise to help them meet additional needs they felt were important to them. This not only served to justify their involvement in this exercise but has the potential to solve resource restriction on a longer term basis.

Also, by giving stakeholders a choice regarding how they could become involved, those who felt this exercise too daunting for them and their limited resources were able to choose to participate on a limited basis (e.g., giving feedback on work completed or solely filling in an evaluation) rather than to

decline.

A helpful suggestion made by participants was to break down the various elements involved in this exercise. For instance, we could give stakeholders examples of ways they could use this exercise to meet their needs. This would have helped overcome language barriers, if we had them, and did help participants make more informed decisions about the level of involvement they wanted to have and the specific needs they could meet through this involvement (i.e., from simple to more complex).

Finally, with participants' permission, I applied to the Health Board for funding to help develop and implement this exercise. I felt that money received could help compensate participants for their involvement and provide me with a wage and resources to cover costs. Despite considerable support from many groups and individuals (outside the Health Board), we were not successful in getting this funding.

However effective these strategies were, they did use considerable time and energy which can, alone, be a constraint. I learned from this exercise that one of the best ways for researchers to reduce this problem is to know at the outset of the research what time and energy we are able and willing to expend to compensate participants for their efforts and to be as honest with participants as possible about our abilities and what we intend to accomplish. This worked very well for us and served to build camaraderie and trust.

Insufficient time and resources primarily led to challenges and constraints we were able to overcome relatively

successfully. Sometimes, however, these factors became limitations we could not bypass. For instance, participants and I finished designing the evaluation questionnaire towards the end of the exercise and they were returned about the time participants indicated they wanted to take a break from this exercise to catch up on other work. Consequently, I was not able to go back to participants for clarification regarding their ratings and comments on the survey. This constraint was compounded by the need to respect anonymity. In other words, participants were not asked to become involved in a follow-up review of the questionnaire. These concerns are important because the lower the level of participant involvement, the more challenging it was to maintain methodological integrity (see Chapter 5).

Without sufficient staffing and other resources to free up time, self-helpers will have to limit their involvement in projects like mine (see Chapter 4). Being process-oriented, participatory evaluations and other forms of PAR, are especially time consuming and, therefore, potentially inhibiting to self-helpers and their groups. This is, especially unfortunate, given the potential of participatory evaluation to meet the specific needs of self-helpers and their groups when they can free themselves to participate.

One of the most hindering factor for recruitment was the University of British Columbia Behaviour Research Ethics Board guidelines. A participatory evaluation is informal, democratic, and cyclical in nature. It gathers its participants through the

"snowball technique" and other informal methods and is open to bringing new participants into the process throughout the entire exercise. As the process is refined and new understandings are generated, it reaches back into the various stakeholder communities and, with these new understandings and approaches, makes subsequent sweeps. The standard recruitment form accepted by the Behaviour Research Ethics Board is an inflexible, one time, component of a linear process. As such, it is not relevant for participatory evaluation/PAR.

Realizing that I could not proceed with this exercise without engaging in an iterative recruitment process, I decided to break away from standard procedure, but still work within the general ethical guidelines. For example, I found unintrusive ways of giving stakeholders multiple chances for, and ways of, getting involved. This included sending out revised/new information to stakeholders on what we were doing, how the exercise might meet their needs, and how they could become involved in new ways.

Some stakeholders did not respond to my exercise for reasons other than the above constraints or disinterest in the exercise itself. Some did not receive recruitment letters mailed or faxed because this material did not arrive at their address. Some material simply got lost between members. For example, at times, material was not passed on to the appropriate people in the first place or when these people resigned they failed to turn it over to their replacements.

High turnover rates, often the product of burnout and the

very nature of self-help groups (i.e., people become healed and move on), did, upon occasion, lead to a lack of continuity, a subsequent decrease in momentum, and even the failure to participate.

Formal procedures within some groups caused similar problems in continuity and lack of momentum. For instance, most groups had to clear their involvement with their boards which was time consuming. In some cases, such delays led to subsequent disinterest. This was compounded by the fact that self-help groups are often studied to death and even more so by the fact that studies take valuable time and resources and frequently do little or nothing to benefit their participants and their groups.

These experiences have left self Helpers wary of many "outsiders" such as researchers, professionals, and the Health Board and added to existing levels of distrust. Researchers, as a result, have to vie for attention and overcome distrust and resistance. When participants were unsure of my motives and whose interests I had in mind, theirs or the Health Board's, for instance, they were especially hesitant to work with me. The aforementioned strategies, however, proved instrumental in overcoming these problems, too, by showing participants that I was committed to meeting their needs to the best of my ability.

The constraint of having to recruit solely through fixed letters of recruitment to satisfy the Behaviour Research Ethics Board simply failed to consider these issues. Several recruitment sweeps were essential to ensure all stakeholders had

sufficient information to consider and as many chances to participate as possible. In addition, a quick, one time, letter of recruitment was not only insufficient to recruit effectively but also violated the informal, grass-roots, democratic, and ongoing dialectical nature of participatory evaluation. Recruitment should be a very casual, interactive, process.

Maintaining momentum, at times, was also difficult because each participant had to fit this exercise into her time schedule and because there were times when some groups were on hold waiting for others to contribute. Also we had the problem of waiting for various groups to take recruitment or updated information to their board meetings which they held infrequently.

To address this problem, I tried to keep participants updated as well as possible on what was going on between meetings and we found work we could prepare for the next time we were to meet. Further, having participants do tasks on their own time, as one participant pointed out, meant that it was not always necessary to meet with me to contribute to the exercise. This also served to fill in gaps created between meetings.

Another opportunity came when one participant suggested we could organize an advisory committee for this exercise. Seizing this opportunity, we found that this committee helped us a great deal by giving the exercise greater structure, giving it credibility, marketing it, and providing synergy and momentum. It was explained by one participant that it often takes a few people or groups to organize something and get it off the ground

before others become attracted to it. If established groups are among these initiators, the greater is the chance that the exercise will be respected. The only risk would be if participants or potential participants have a unfavourable opinion of the core groups involved. This turned out to be far from the case for us because each group seemed to be held in high regard by the relevant parties (e.g., participants and members of other self-help groups and women's organizations).

Next, even though we would like to have had Health Board members work with us, their absence made communicating our real feelings and opinions that much easier. We no longer had to worry about possible critical feedback inhibiting Health Board recruitment and subsequent involvement in the exercise. Further, by changing the Board's role from participant to target audience, we had more control over the process.

On the negative side, we lost valuable input and a more rounded set of information which made validating substantive outcomes more difficult. If we give presentations and provide Health Board members with the opportunity for feedback, however, we will have avoided excluding them altogether. We could have just delayed their input, diminished their depth and breadth of involvement, and made them somewhat more passive participants. If we do organize focus groups with Health Board staff after presentations, we can engage them more actively. In effect, we will be giving them a second chance to participate.

Before we realized the Health Board was not going to participate, we had the challenge of recruiting its members. In

addition to being unsuccessful in recruiting paid and volunteer members who worked directly for the Health Board, we arrived at an impasse in regards to recruiting members of the various Community Health Committees and Population Health Advisory Committees. To reach these individuals, we had to go through the Health Board's community developers who we can define as front-line paid workers who coordinate relations between committee volunteers and their communities based on geography or interest. These individuals essentially served as gatekeepers which meant that gaining direct access to committees was difficult. One participant was willing to give me a list of members of one or more of these committees so I could contact members directly, but there was insufficient time to do so and I felt this might seem threatening or disrespectful to the community developer(s) involved. In other words, after these community developer had decided not to involve their committee members, I did not want to "go behind their backs".

Participants did not feel that lack of Health Board response was a barrier because they found practical ways to use this exercise to organize women's self-help groups to have their voices heard by the health system (e.g., through the series of presentations they considered giving to the health boards). The V/RHB may, therefore, now become a strong target for dissemination of information. Further, without the Health Board, we were, indeed, quite assertive about expressing ourselves.

The failure of many self-help groups to become involved and

the limited involvement of some participating groups also gave instructive input. Our exercise demonstrated how few resources self-help groups receive, the limited staff they have, the long hours members work, and so on.

The lack of trust in working with researchers, professionals, and other "outsiders" compounded these constraints. Participants indicated that when they felt insecure about how they could be involved or about the level of control they could have, they were less active in the exercise, or less confident that they were contributing effectively, or both. Each has a different learning style and needs and some wanted very little structure, while others wanted more. Some also felt somewhat vulnerable, especially at first. To address these concerns, I ensured that participants were in control of their involvement. They made their own decisions regarding where we met, how, and when; who they included in each meeting; and how much facilitation they wanted me to do for them. (Refer to the section above entitled The Participatory Evaluation Exercise.) Furthermore, having a choice over where we held our meetings gave participants the opportunity to meet on their own turf where they felt comfortable and had geographic and structural accessibility. This was, therefore, both a practical and potentially empowering process.

During the exercise, I discovered that the definition of self-help groups created a small problem for recruitment. Even though these groups were identified by formal self-help directories and fit the definition I used, a number of groups

were not clear on whether they were actually self-help groups. One felt her group worked more as a collective because it had a somewhat wider scope and others felt they were support groups rather than self-help groups because they had a paid facilitator. This was a relatively easy challenge to overcome and simply required informing stakeholders that, despite their variation, they fit the SHRA definition.

Additionally, high turnover in membership in their self-help groups made it difficult for some self-helpers to provide certain details about Health Board involvement and support. Participants worked around this the best they could by asking other, longer term, members about these issues and by doing other research. Moreover, the fact that some participants had this problem meant we had already gained valuable information about the extensiveness or sustainability of Health Board involvement and support of their self-help groups.

We faced two other constraints regarding involvement which are discussed more completely in the section entitled Our Questionnaire. As previously explained, questionnaires came back around the time all but two participants decided to opt out of the exercise and some participants insisted on filling in their questionnaires anonymously. This made acquiring follow-up feedback on questionnaire responses difficult.

ATTEMPTS TO RECRUIT HEALTH BOARD MEMBERS

The following documentation of conversations I had with Health Board staff provides useful information about the work

done to recruit this set of stakeholders and about their responses. As explained earlier in this chapter, no codes were assigned to these participants. I add, here, that this material overlaps with substantive outcomes related to perceptions of Health Board inclusion and support of self-help groups.

I made my first attempt to recruit a Health Board member roughly one year before I successfully recruited my first participant (i.e., a self-helper). This contact and I had worked together to some extent when I was conducting research for a contract position I held in her jurisdiction and we had developed a good relationship at that time. This contact indicated that it was important to do this exercise and to include self-help groups. She told me that she would love to be a part of this exercise and would help me with all stages, even data collection. Unfortunately, she never returned my calls and when I found her in her office one day (about a year and a half after I first contacted her) she explained that she passed on the letter of recruitment and related information to those she worked with and that she would have to first ask for Health Board approval. I never heard from her again.

The second Health Board member contacted said that members of the Women's Health Advisory Committee were not ready to participate, they couldn't find the time to get involved, and they were not interested. I talked to her months later and she said she'd give me a call but never did.

Contact number three noted that the Health Board had done little outreach and that the Women's Health Advisory Committee

was not active in the community. She also said that the V/RHB was not active regarding involving service providing organizations but was about to embark on such initiatives. She said, however, that it was not supportive of our exercise (project).

Another contact underlined that this exercise was a great idea, she was interested, and that it would be very useful. She explained that the Health Board wanted to get into advocacy and to do more evaluations. When I asked her for a letter of support for the project, nevertheless, she told me it would be a conflict of interest to do so. This was the last conversation I had with her.

The next contact said he liked this exercise and that it would be helpful. He also emphasized, however, that he would only become involved if it was not funded by the Health Board because it would be a conflict of interest for his organization to become actively involved in a project it funded. On the other hand, he made no offer to get involved after the project was determined to be an unsuccessful candidate for funding.

He also suggested that the Health Board had done little in regards to outreach to social and health service providers and to provider empowerment. Further, he felt the Health Board had employed a poor model for involving the public and had done little implementation. According to this contact, if the Health Board was to participate, the exercise should actively include their committees in the evaluation framework.

He explained that he wanted to have a better understanding

of the relationship between self-help groups and the Health Board. However, for him, this project was too narrow in focus. He professed to have a lack of knowledge about self-help groups and self-help group activity, did not know how to define them, and wanted more generalizable information.

He also saw problems with sampling procedures because he felt anecdotal material may be biased. Further, he suggested, it may be difficult to validate the assumptions of Health Board members regarding their impressions versus recorded data or his understandings versus real issues. For this reason, he felt it would be difficult to collect information. Finally, he anticipated there might be problems working with self-help groups. He asked, for example, what would be the Health Board's level of involvement and what could/should be done?

Another contact talked about the value of, and need for, such an exercise and the necessity of channelling funding appropriately and being accountable. I did not hear from her again.

The seventh contact said she would consider only filling in the evaluation questionnaire, but showed very little interest in being involved in the project. In the end, she did not volunteer for any part of the exercise.

Another, contact simply stated that the Health Board recognized the value of informal caregiving and of building on what self-help groups do, and do well. For her, the Health Board has not tried to do what self-help groups do, but has supported them in their efforts.

The ninth contact insisted that the Health Board's work is very participatory and that the Health Board feels that self-help groups are important. She emphasized, nonetheless, that these groups are not at all a priority.

She insisted that I would not get far with this dissertation, that I would never finish on time, and that, if I stood any chance at all of getting the Health Board involved it would be at the management level, not at the policy level. Later, however, she said I should approach the community health nurses. The Health Board and committees, according to her, probably had not yet involved self-help groups and were not ready to do so.

The original Women's Health Advisory Committee (i.e., the Committee I helped establish as a volunteer for the Health Board), she informs me, was disbanded, the new one was just starting up, and members weren't ready to do this type of work for it takes time. In her view, the committee has other problems. She claims that the former WHAC members had their own agenda that was not appropriate. She also noted that most "community developers" employed by the Board are not real community developers but, rather, public health nurses.

According to her, of the roughly fifty people she had interviewed about Health Board issues in one of her research projects, not one mentioned self-help groups. She explains that the problem is taking action from theory, i.e., going into the community and getting community participation. For her, issues of process, structure, and content are in the way. She

questioned why the community has not been involved in any decision making. She subsequently answered this question, herself, by claiming that people aren't used to being involved. She pointed out that the Health Board has tried hard to work with communities, but public expectations are too high. She added that there has been a gradual move from the biomedical model to the community participation model. Consumers and community members have only recently been included in the picture. She said that Health Regions were set up for many reasons, e.g., bringing the health budget into the global budget, but not for doing community development. She concluded that if we do complete our framework, the Health Board can choose to use it or not to use it.

APPLYING TO THE VANCOUVER/RICHMOND HEALTH BOARD FOR FUNDING

During this project the V/RHB offered a Community Initiative Grant for health related projects in Vancouver proper. When I decided to apply for this funding to facilitate my research, this set in motion processes which both helped and hindered the development of this exercise.

To begin, I felt that this grant would provide us with resources to help compensate participants for their involvement and provide me with a wage and resources to cover costs. Despite considerable support from many groups and individuals (outside the Health Board), however, we were not successful in getting this funding.

This exercise (or "project", for funding purposes) was

expected to come from participating stakeholders (i.e., Vancouver women's self-help groups and their communities) and to meet their needs. As a result, it had to include letters of support from these communities. Originally, we had to acquire support from Health Board staff as well as self-help groups. As two of the above contacted stakeholders verified, however, the Health Board decided later that having candidates contact V/RHB staff members would lead to a conflict of interest because many of these employees would, or could, be on the project evaluation and selection committee. I was informed that I could involve Health Board staff only after the final decision was made. This, of course, was problematic in that having the Health Board involved would have added considerably to the value and relevance of the exercise. This concern became even more important when the Board informed me that the final selection for projects would come at least one month after the original deadline it gave me. It is important, however, to re-emphasize that the Health Board, on the whole, showed little intention of working with this exercise before this time.

On the other hand, the process of acquiring support letters and a sponsor added to the value of the exercise. I found a self-help group willing to sponsor the project and received ten letters of support from various individuals (self-helpers, professionals, and professors). Further, other self-help groups indicated interest in being involved. I also found a great deal of cooperation among participating and contacted self-help groups and organizations. Despite being in direct competition

for the same funding, the majority of these groups/organizations wrote me letters of support, assisted me in other ways, or both. Applying for this funding provided a more immediate goal for self-help groups and brought them together.

I hoped that self-helpers would see that I was trying to get funding to help compensate participants (e.g., for child care, transportation, and refreshments), and that this would indicate my concern for making this exercise a participant-focused and participant-driven venture. I looked at this funding as an enabling grant. I also hoped that it could help foster better collaboration from the Health Board.

Despite the lack of funding, participants respected my efforts and this exercise continued on, making use of the resources we had available. By not acquiring such funding and not gaining Health Board involvement in this exercise, participants felt even freer to speak their minds.

FOCUS OF THE EXERCISE

As noted earlier, this exercise began with an initial focus on determining how successfully the V/RHB had included women's self-help groups in health planning. After listening to participants, however, it soon became clear that they also wanted to explore how successfully the V/RHB was in supporting their groups as health services. To meet participants' needs, therefore, their desire to examine the nature and extent of Health Board support for self-help groups was subsequently incorporated into the evaluation process and questionnaire.

The fact that one whole set of stakeholders (the V/RHB) did not participate in this exercise meant we had to maximize the potential of our work despite their absence. What could have become a major failure in a more rigid, positivist, evaluation was turned into a challenge and an opportunity to use the exercise to respond to this problem in a productive way.

Based on their own experiences, participants involved very early in this exercise believed that the Health Board had done little to include and support their groups and felt that it may be more appropriate to use this evaluation process to acquire baseline measurements, to develop a proactive guideline or framework for the V/RHB to follow, and to educate, empower, and organize women self Helpers to have their voices heard and integrated into health promotion.

I also add that, originally, this exercise was going to place equal emphasis on methodological findings and substantive outcomes generated from the evaluation process. Having realized that this evaluation is incomplete, in that it presents a picture based almost wholly on participants' perceptions, a one-sided story, it became clear that participants and I should focus on documenting methodological processes and lessons learned and qualify substantive outcomes as possible types of information a participatory evaluation can acquire from people often slighted in planning processes.

The exercise became a forum for self-Helpers to express themselves, to grow from the evaluation process, and to share what they have learned. Given this change in focus, the title

of this dissertation had to be modified which explains the discrepancy between the real title and that heading letters of recruitment, consent forms, and questionnaires. The title Analyzing the Inclusiveness of Self-Help Groups in Community Health Planning became Participatory Evaluation as a Tool for Enhancing the Role of Self-Help Groups in Health Promotion. The presentation of the material had to change somewhat, too. The "silver lining", here, of course, is that, in addition to giving participating self-helpers a voice, this substantive material is now documented for the Health Board to see and respond to as it sees fit. Moreover, this material is available to self-helpers and other interested parties to see.

CONFIDENTIALITY

Some groups expressed considerable concern about having their involvement and the information they volunteered kept confidential. This was especially so among communities that have been disempowered by the formal health system and among self-help groups/organizations that were less engaged in lobbying and advocacy.

This problem of confidentiality proved problematic for some because they wanted their voices to be heard but were afraid of ramifications for themselves and their groups. It also reveals their distrust of professionals and the health system. The fact that some participants insisted that their questionnaires were not only to be kept confidential but that they were also to be kept anonymous, i.e., that even I could not identify who sent

them, implies their lack of trust in researchers as well as professionals and the health system.

To earn their trust, all participants were assured that their involvement and the information they would provide would be protected by strict regulations concerning confidentiality and that they would have complete input into what information would be made available to the public and what information would be associated with themselves and their groups. Their input was, in fact kept confidential and they had the opportunity to check over all information they made available to me and to ensure it was recorded properly. Participants were also given control over, and had input into, how this information was to be analyzed. This is an inherent part of the ongoing dialectical nature of this approach to evaluation. Additionally, they had complete freedom over who they shared information with during meetings. Finally, we discussed, on a limited basis, how more vocal groups, accustomed to lobbying for their rights and needs, can express the voices of those intimidated by this process in future initiatives of this kind.

Another potential problem came to the fore, however, when we applied for Health Board funding. To make this application, we had to acquire letters of support from various individuals. A number of self-helpers gave me letters and indicated to the Health Board that they would give support of some sort or another. This means that Health Board members may feel that they know the identity of groups that were actually involved in the exercise. To rectify this concern I note, here, that those

who were actually involved in this exercise were not necessarily those who gave their support. With time delays, we both gained and lost participants and their groups. Further, those who indicated they would give their support did not necessarily mean that they would be active participants.

LANGUAGE

Language was discussed as a potential problem in regards to recruitment, the active or full involvement of participants, and dissemination of information. While everyone felt that we should be as participatory as possible, there was disagreement over timing. Some participants felt we should first concentrate on getting participating groups organized and on disseminating information to the Health Board and community groups/organizations with the largest voices. Others suggested we try to involve those more marginalized (including those with an inadequate grasp of English) as early as possible which means simplifying the language used. In other words, we disagreed over the balance between outcome and process.

Interestingly, this issue resolved itself as we went along. To begin, we cast as wide a net as possible to get all women's self-help groups on board. Further, we decided to make the results as accessible as possible to as many as possible as soon as possible. Moreover, we did not encounter any self-help groups where language was considered a problem for recruitment or involvement. On the other hand, we are aware that if results are to be more widely distributed, language may create a barrier

or challenge in the future. Due to time and resource constraints, however, we were forced to leave such considerations for future efforts.

ADDED OPPORTUNITIES

This exercise ran into many other opportunities. To begin, this is the first exercise of its kind in Vancouver and it came along at an appropriate time. Many self-help groups indicated a need to be included in planning and a need for support.

Similarly, despite a lack of their involvement, a number of Health Board members noted that they will eventually have to do work of this nature (i.e., conduct participatory evaluations and reach out to self-help groups). This exercise can then be seen as proactive research.

We also recruited very productive, committed, flexible, and assertive self-helpers who effectively contributed to the evaluation exercise. In fact, we established a core group of nine participants. Further, five of these formed an advisory committee with me and may, along with other participants, continue the work we have done beyond this exercise (e.g., giving presentations to provincial health boards and generating sufficient funding to do so). This suggests that the exercise met participants' needs, including the need to become empowered, and that it found effective ways participants could work on this exercise.

Participants were very skilled in co-facilitating focus groups and interviews. This is partially due to luck and

partially due to the fact that they were given the freedom to choose the appropriate styles of learning and participation to match their needs and abilities.

The exercise also gave us the opportunity to build quality relationships. By the time the exercise was completed, participants and I had known each other for several months and, in some case, years. In addition, I worked with a number of participants in other capacities (e.g., fundraising for their groups and organizations, attending related events, doing volunteer work together, and so on). This, plus the participatory approach we engaged, helped build trust along with an understanding and appreciation of each other, of our knowledge, and of our input (see Chapter 5).

We did not get an external researcher to look at our findings, which according to Sandelowski (1986) can be helpful for validating findings. This was because there were no other researchers doing work of this kind that I knew of in Vancouver and we had insufficient resources to bring in a second researcher for such assistance. On the other hand, there were enough independent minds working on this exercise as participants that their triangulating feedback was useful for validating findings from the exercise and questionnaire.

Additionally, this exercise was extremely cost effective. In fact, it required very few external resources. Participants donated their time, their facilities, and sometimes even snacks. Two groups also donated use of their photocopiers. This is, to a large extent, due to having common goals,

objectives, values, and needs and to working together to address these.

These opportunities were found and fostered by ensuring that participants were in control of the planning process from the initial needs assessment onwards and by adjusting the exercise to meet the shifting needs and conditions of the communities and participants. On top of this, to successfully recruit and maintain participation, we utilized and developed local initiative and abilities.

CONCLUSION

By abiding by PAR and participatory evaluation values, principles, and methods, participants and I were able to adapt to, and even overcome, the majority of our many challenges and constraints. In fact, most often we made them work in our favour.

Participants and I learned a great deal from this exercise and I have documented the methods and procedures we engaged to maximize the number of stakeholders recruited, to enhance involvement and its benefits, to custom design the exercise to meet participant needs and their environment, even as they changed, to guarantee confidentiality and build trust, and to ensure people weren't excluded due to language barriers.

In addition to having an opportunity to discuss their understandings, share information among themselves, and to document methodological findings, it is also essential for

participants to have their voices put on record, listened to by others, and addressed. Chapter 4 now documents and discusses our other results, the substantive outcomes we generated through the evaluation exercise. These outcomes are very informative and represent participants' perceptions regarding how well they believe the Health Board had included and supported their self-help groups as participants in health promotion.

END NOTES

1. This made calculation of actual numbers of groups very difficult and imprecise. For example, the largest number of self-helpers to come from one group was four. One of these members also represented another participating group within her organization and the members of her organization as a whole. Only one participant actually represented two separate self-help organizations and their groups. For the sake of simplicity, at times, I refer to self-help groups and organizations solely as self-help groups or groups. I chose not to focus on how many groups each self-help organization involved and how they did so because their numbers were in a constant state of flux and participants did not bring such information up in conversation. This exclusion also served to reduce potentially identifying material.

2. Over the years, due to poor organizational ability in note taking, I became adept at recording lecture material almost verbatim. I would later take these notes home and organize them in my own time. This skill proved invaluable in this exercise.

3. Despite the elimination of this exercise assessment questionnaire, the processes involved in its development and lessons learned are interesting. I started this process by gathering a number of questions the assessment might have included and by asking core participants whether they were willing to do an assessment of this nature. I then asked for their input into the design. Only the core participants were to be given a questionnaire to assess this exercise and I explained to participants that this was so because only those more fully involved would have sufficient knowledge of the process and nature of this exercise to assess it at this depth.

I tried to make this assessment as simple, short, and relevant as possible. I started by including questions pertaining to Lincoln and Guba's methodological perspective (see Chapters 2 and 5). Initially, I was going to use all of their methodological perspectives, i.e., those relating to ontology, epistemology, methodology, criteria of trustworthiness, and criteria of authenticity. As I started to write out a draft of this questionnaire, however, it became clear that this would be very problematic. I realized that all of these perspectives, except criteria of authenticity, are quite complex and would require considerable time and energy for participants to understand well enough to use to assess the exercise. One participant also found this to be the case.

Criteria of authenticity are relatively easy to understand and to use to assess an exercise of this nature. When I took this issue to participants, they agreed. With this in mind, I designed an assessment which included questions reflecting these criteria.

I then added questions to get feedback on each stage of the exercise, from recruitment and identifying the need for the

exercise to this assessment. Participants felt these were appropriate questions.

4. I argue that it is possible, at times, to determine how empowering a specific health promotion initiative has been for participants through the use of qualitative methods and measures. We can use this exercise, which can be seen as a health promotion initiative in itself, to validate my claim (see Chapter 5). Whether this is possible to do during other, larger scale, health initiatives is difficult to say and beyond the scope of this study.

CHAPTER 4: SUBSTANTIVE OUTCOMES

INTRODUCTIONA BRIEF OVERVIEW

The process of developing and implementing this study, including the questionnaire, led to the generation of a rich variety of interesting information which I placed into categories and sub categories. Moreover, meetings amassed far more information than the questionnaires themselves.

This chapter is dedicated to presenting and analyzing participants' voices and demonstrating what types of substantive information can be generated from the specific participatory evaluation approach taken in this exercise. It is essential to note that this material represents the views of a faction of self-helpers (one of the two stakeholder groups invited), rather than all self-helpers or even all women self-helpers. The significance of this substantive information to participatory evaluation as a research and planning tool will be discussed in Chapters 5 and 6.

The first few sections of this chapter record and analyze participants' perceptions of how well the Health Board had involved their self-help groups in health planning and supported them as health services. This chapter then explores five additional categories, all of which overlap with each other to some extent. These involve issues related to: (1) maintenance of the integrity, autonomy, control, and stability of self-help

groups; (2) the position of self-help groups in health promotion; (3) the position of women in self-help groups and the health system; (4) participants' understandings of the Health Board; and (5) participants understandings of the general health system. It also includes information gained through informal conversations with contacted stakeholders who did not become participants.

In this chapter, we can see that some passages or partial passages resurface from time to time. There are occasions when overlap and repetition of information are essential to maintain the richness of details given and to show how they relate to key issues.

Prior to presenting this information, this chapter commences with a brief overview of how substantive information was coded, categorized, and then presented in this chapter.

PRESENTATION OF INFORMATION

We can see that, throughout this chapter, there are a number of passages which are either paraphrases or quotes. Quotes are denoted by the letter Q and paraphrases are denoted by the letter P. These letters will be followed by either the letter Q, signifying information given during questionnaires, and the specific number assigned to the participant providing this information, or the letter M, signifying information given during meetings, and a specific number. The following examples display the two combinations used in this study: Q/Q14 and P/M5.

After reading through the substantive information generated, I began to place this material into categories and sub categories for presentation. Some information fell into more than one category which explains why it is repeated. Participants were not involved in the coding of information, except for choosing code names originally used, and they were not involved in processing or presenting this information. One participant, however, took the opportunity to provide feedback on this chapter and the dissertation as a whole.

If this were a more formal evaluation where both the Health Board and self-help groups were involved and where we placed primary emphasis on the substantive outcomes, categorization would have involved a more complex process. In view of the fact that substantive outcomes in our exercise are treated as a sample of voices from a small group of stakeholders, general categories and sub categories were chosen simply as a means to present this information. By leaving the material in as raw a state as possible, readers can design their own categorization scheme(s). Some headings represent a priori categories based on time (e.g., pre and post 1997 contact with the Health Board) and on themes coming out of the literature (e.g., the need for self-help groups to maintain their integrity, autonomy, control, and sustainability). Other headings emerged from examining the results (e.g., discussion involving the pros and cons of establishing umbrella groups for self-help groups).

I did not paraphrase any information given on questionnaires but, rather quoted this material directly. Any potentially

identifying information was eliminated or modified, however. At times, comments made during meetings are attributed to more than one participant because they were formulated together. Upon occasion, quotes I took from participants during meetings are embedded in paraphrases. Please refer to chapter 3 for elaboration on how I recorded the information and collected data during the exercise.

As we can see by the number of passages, information is presented in raw or near raw form. Throughout this chapter, information is summarized and analyzed based on my understandings and interpretations. By being able to see this material largely as I heard it, readers can make their own interpretations and implications.

THE ROLE OF THE HEALTH BOARD IN INVOLVING AND SUPPORTING SELF-HELP GROUPS IN HEALTH PROMOTION

DISCUSSIONS DURING MEETINGS

During meetings, most participants (11 out of 16) noted that the Health Board made little to no effort to involve their groups in health planning. Most (again 11) also indicated that their groups were not at all, or not adequately, supported by the Board. There were no participants who stated that the Health Board had sufficiently included/supporting them.

The following passages refer to participants' perceptions that the Health Board had not involved or supported their groups or put theory into action, i.e., as one participant said, "walking their talk".

P/M1: Self-help groups aren't recognized by the Health Board and the Health Board knows it. . . . The Health Board talks about a framework for action and wanted to get feedback regarding political acceptability but did not seek feedback to help make the framework a dynamic process. Once the information was collected, the framework stayed the same. Health Board members feel they know their communities and don't question this belief. They don't know how to monitor change nor integrate public input. They may come up with a new framework but won't change it with input. On the other hand, I understand that this may be a practical move because the more dynamic a model becomes, the more resource intensive and time consuming it becomes.

P/M3, M5, and M7: Our organization was involved in some sort of Health Board forum but our group itself was not to our knowledge. There was a lack of depth/extensiveness regarding inclusion in health planning. . . . The Health Board may have involved larger organizations we are associated with but not our self-help group. In other words, the invitation to participate did not filter down.

P/M6: The Health Board made a promise to involve the public or consult them but it did not keep it. . . . The Health Board hasn't acted upon the information it has taken from communities (e.g., from self-help groups). . . . The Health Board did not address the issue of including self-help groups in health planning during a workshop in a conference on self-help, despite the fact that it had indicated its workshop was on this topic. This has been typical in other environments.¹

P/M6 and M9: The Health Board has many dedicated, well meaning, staff but they haven't been very effective regarding support and inclusion and the system is wrong. . . . There is a lack of connection between the public and the Health Board.

P/M9: There was some contact made by the Health Board in regards to our organization but, to my knowledge, not to my self-help group. The major point is that we are looking at how well the Health Board has actually tried to involve self-help groups themselves. If it did at all, it certainly did not create a long-term, solid relationship nor involve us deeply in health planning.

P/M9 and M12: If the Health Board truly believes in its adopted philosophy of including self-help groups in health planning, why has this not been a priority and been accomplished? The keys are accountability and putting theory into reality or "walking their talk". . .

. . . The key is lasting involvement.

P/M14: Self-help groups are not included in health planning. . . . Self-help groups are not supported by the Health Board. . . . Despite the importance of self-help groups for the Health Board and for PHACs and CHC's, no action was taken and I am surprised the Health Board did not respond to this project.

More briefly stated:

P/M5: There is no established link between the Health Board and self-help (including information).

P/M8: As of yet, we have not seen hide nor hair of the Health Board except for one time.

EVALUATION RATINGS ON QUESTIONNAIRES

Results from the evaluation questionnaire (ratings and subsequent discussion) provide more information on participants' perceptions of inclusion and support by the V/RHB. These questionnaires were distributed near the end of the exercise and results were not discussed by participants due to issues of confidential and anonymity and to time constraints. As a result, my analysis of participants' ratings and related comments is relatively limited.

The next few pages present the indicators and sub indicators included on the questionnaire along with the corresponding ratings given by participants. I display this information in four different ways. First, I provide two types of tables, the first tabulating raw ratings data for indicators and sub indicators and the second giving their frequencies. I also demonstrate how average (mean) ratings for indicators and sub

indicators can be built into web configurations. Finally, I use a bar chart to compare the average ratings for indicators.

A rating of 1 signifies no inclusion or support. The overall rating for each indicator was based on the ratings participants gave for each sub indicator and other factors they felt important to consider. In other words, an overall rating of 1.2 given by one participant for Resource Mobilization will not necessarily be the average of ratings for each sub indicator included in this indicator category. These average ratings vary little and, as a result, I chose to include this bar chart just to demonstrate another means of displaying data. The differences between average ratings for each sub indicator are also so small that I decided not to do bar charts for each sub indicator. The data are provided in full, however, so the readers can do so themselves.

These pages are followed by a discussion including the comments participants provided to explain their ratings. This material is taken from sections scattered throughout each questionnaire.

Indicators and Sub Indicators for Needs Assessment

To what degree did the V/RHB include your group in assessing the needs of your group and its members?

How well have the V/RHB:

1. Included your group in full and active discussion regarding its health needs?
2. Involved your group in various stages of the needs assessment from its design to implementation, analysis, and evaluation?
3. Elicited information from your group that is important and relevant to its members?
4. Used needs assessments as a first step towards involving your group more deeply in community health planning (i.e., in processes which respond to and meet your needs, for example, decision making and implementation)?

Table 2: Raw Data for Needs Assessment

<u>Participants</u>	<u>Questions</u>				O.R.*
	1	2	3	4	
1	2.7	2.7	2.0	1.0	2.0
2	2.0	1.0	3.0	2.0	2.0
3	2.0	1.0	1.0	1.0	2.0
4	3.0	4.0	3.0	2.0	3.0
5	1.0	1.0	1.2	1.0	1.2
6	2.0	1.0	1.0	1.0	2.0
7	1.0	1.0	1.0	1.0	1.0
8	1.7	1.7	1.4	1.5	1.3
9	2.0	2.0	3.0	2.0	1.5
10	1.0	1.0	1.0	1.0	1.0
11	1.0	1.0	1.0	1.0	1.0
12	2.0	1.0	2.0	1.0	1.5
13	1.0	1.0	1.0	1.0	1.0
14	4.0	4.0	4.0	4.0	4.0
15	2.0	2.0	2.0	1.0	1.0
16	3.0	2.0	3.0	1.0	2.0
Average **	2.0	1.7	1.9	1.4	1.7
Rank	1	4	2	7	4

* Each participant's overall rating for the specific indicator.

** Overall rank for each rating. These ratings ranged from 1.3 (a rank of 8 or the lowest average rating) to 2.0 (a rank of 1 or the highest average rating). For example, sub indicator Number 2 for Needs Assessment received a average rating of 1.7 which gives it a rank of 4.

Indicators and Sub Indicators for Resource Mobilization

To what level were V/RHB resources (e.g., funding, educational material, advertising material, staff assistance) used to involve your group in community health planning?

To what degree did the V/RHB use their resources:

1. To inform your group about their Community Participation Process and involve your group?
2. To acquire full participation in decision making and planning for change?
3. To benefit the members of your group?
4. To enable your group to participate and to compensate them for doing so?
5. In a flexible, open manner to reflect the needs/desires of your group members?
6. To foster a permanent participatory process?

Table 3: Raw Data for Resource Mobilization

<u>Participants</u>	<u>Questions</u>						<u>O.R.</u> [*]
	1	2	3	4	5	6	
1	2.0	2.0	2.0	1.0	1.0	1.0	1.3
2	2.0	2.0	2.0	1.0	2.0	2.0	2.0
3	1.0	1.0	1.0	1.0	1.0	1.0	1.0
4	3.0	2.0	3.0	3.0	4.0	3.0	3.0
5	1.0	1.0	1.0	1.0	1.4	1.0	1.0
6	1.0	1.0	1.0	1.0	1.0	2.0	1.0
7	1.0	1.0	1.0	1.0	1.0	1.3	1.0
8	1.0	1.0	1.5	1.4	1.5	1.0	1.2
9	2.0	1.5	1.0	1.0	2.0	1.0	1.5
10	1.0	1.0	1.0	1.0	1.0	1.0	1.0
11	2.0	1.0	2.0	1.0	1.0	1.0	2.0
12	2.0	1.0	1.0	1.0	2.0	1.0	1.0
13	1.0	1.0	1.0	1.0	1.0	1.0	1.0
14	4.5	4.5	4.0	4.0	4.5	4.0	4.5
15	2.0	1.0	2.0	1.0	1.0	1.0	1.0
16	1.0	1.0	2.0	1.0	1.0	2.0	2.0
Average Rank**	1.7 4	1.4 7	1.7 4	1.3 8	1.7 4	1.5 6	1.6 5

* Each participant's overall rating for the specific indicator.

** Overall rank for each rating.

Indicators and Sub Indicators for Participation Approach

How fully did the V/RHB involve your group in planning to meet the needs of your groups and its members?

How successful were the V/RHB in:

1. Maintaining a balance between nurturing new avenues of participation they developed (i.e., Community Health Committees and Population Health Advisory Committees) and your group (as a more bottom-up, pre-existing avenue)?
2. Actively seeking out your group for involvement (e.g., through recruitment material, forums, information sessions, focus groups, workshops)?
3. Demonstrating responsiveness and accountability to the members of your group?
4. Working towards developing effective collaborative relationships with your group for the purpose of health planning?
5. Applying new, more flexible, bottom-up approaches to involve your group?
6. Fostering full and active participation in all stages of planning and promoting shared learning, consciousness raising, empowerment, and social action in this process?

Table 4: Raw Data for Participation Approach

<u>Participants</u>	<u>Questions</u>						O.R. [*]
	1	2	3	4	5	6	
1	2.0	2.0	2.0	2.0	2.0	2.0	2.0
2	2.0	1.0	1.0	2.0	1.0	1.0	2.0
3	2.0	2.0	2.0	2.0	1.0	1.0	1.0
4	3.0	2.0	3.0	3.0	4.0	2.0	3.0
5	1.0	1.4	1.0	1.0	1.2	1.0	1.0
6	1.0	1.0	1.0	1.0	1.0	1.0	1.0
7	1.0	1.4	1.3	1.0	1.0	1.0	1.0
8	1.4	1.0	1.0	1.3	1.0	1.0	1.1
9	1.5	1.5	2.0	2.0	1.5	1.5	1.0
10	1.0	1.0	1.0	1.0	1.0	1.0	1.0
11	1.0	1.0	2.0	2.0	1.0	2.0	1.0
12	2.0	1.0	1.0	1.0	1.0	1.0	1.0
13	1.0	1.0	1.0	1.0	1.0	1.0	1.0
14	5.0	5.0	4.0	5.0	4.0	3.0	4.5
15	1.0	1.0	1.0	1.0	1.0	1.0	1.0
16	1.0	1.0	1.0	1.0	1.0	1.0	1.0
Average Rank**	1.7 4	1.5 6	1.6 5	1.7 4	1.5 6	1.3 8	1.5 6

* Each participant's overall rating for the specific indicator.

** Overall rank for each rating.

Indicators and Sub Indicators for Leadership Styles

How interactively did the V/RHB involve your group members in these meetings?

At what level did the V/RHB:

1. Use a facilitative leadership, i.e., one generating democratic and open discussion and valuing each participant's contribution?
2. Share leadership with members of your group?
3. Work with your group to find a style or styles of communication that reflect(s) your group's ways of doing things and thinking?
4. Actively listen and respond to all group members, especially those least heard, most dissenting, or most marginalized?

Table 5: Raw Data for Leadership Styles

<u>Participants</u>	<u>Questions</u>				O.R.*
	1	2	3	4	
1	3.0	1.0	1.0	2.0	2.0
2	1.0	1.0	1.0	1.0	1.0
3	1.0	2.0	1.0	1.0	1.0
4	3.0	3.0	3.0	3.9	3.0
5	---	---	---	---	---
6	2.0	1.0	1.0	2.0	2.0
7	1.0	1.0	1.0	1.0	1.0
8	1.0	1.0	1.0	1.0	1.0
9	2.0	2.0	2.0	2.0	2.0
10	1.0	1.0	1.0	1.0	1.0
11	1.0	1.0	1.0	1.0	1.0
12	2.0	1.0	1.0	1.0	---
13	1.0	1.0	1.0	1.0	1.0
14	5.0	4.0	4.0	4.5	4.5
15	1.0	1.0	1.0	1.0	1.0
16	2.0	1.0	1.0	1.0	1.0
Average		1.8	1.5	1.4	1.6
Rank**		3	6	7	5

* Each participant's overall rating for the specific indicator.

** Overall rank for each rating.

Indicators and Sub Indicators for Horizontal Linkages

To what extent have the V/RHB served to nurture respect and collaboration between your group and other self-help groups, professionals, and community members/organizations?

How well have the V/RHB:

1. Assisted your group in working together to share resources and organize to address common concerns?
2. Helped your group work with professionals and community organizations to share resources and organize to address common concerns?
3. Promoted networking and referrals between your group and other self-help groups, professionals, and community organizations?
4. Allocated resources to your group to help them develop these horizontal linkages?

Table 6: Raw Data for Horizontal Linkages

<u>Participants</u>	<u>Questions</u>				O.R.*
	1	2	3	4	
1	2.0	2.0	1.0	1.0	1.3
2	1.0	1.0	1.0	1.0	1.0
3	2.0	2.0	2.0	1.0	1.0
4	3.0	3.0	4.0	3.0	3.0
5	1.0	1.0	1.0	1.0	1.0
6	3.0	---	4.0	2.0	3.0
7	1.0	1.2	1.5	1.0	1.1
8	1.4	1.3	1.5	1.3	1.3
9	1.0	1.0	1.0	1.0	1.0
10	1.0	1.0	1.0	1.0	1.0
11	1.0	1.0	1.0	1.0	---
12	1.0	1.0	2.0	1.0	1.0
13	1.0	1.0	1.0	1.0	1.0
14	4.0	4.0	4.0	4.0	4.0
15	1.0	1.0	1.0	1.0	1.0
16	1.0	1.0	1.0	1.0	1.0
Average	1.6	1.5	1.8	1.4	1.5
Rank**	5	6	3	7	6

* Each participant's overall rating for the specific indicator.

** Overall rank for each rating.

Indicators and Sub Indicators for Vertical Linkages

How well have the V/RHB tried to work directly with your group to improve its potential and position as a health service? To what extent have the V/RHB:

1. Provided support to your group through public relations and marketing to help it become established, expand membership, and thrive?
2. Contributed resources towards advancing collaborative efforts between your group and the V/RHB (including staff, Population Health Advisory Committees and Community Health Committees) to meet the health needs of residents?
3. Allotted resources (e.g., resource material, facilitation training, funding) to help your group organize and evolve as effectively as possible?
4. Given your group support through recommending it to residents as an effective complementary health service?
5. Supported your group in a manner which honours and maintains your integrity as a grass-roots, bottom-up health service?

Table 7: Raw Data for Vertical Linkages

<u>Participants</u>	<u>Questions</u>					O.R.*
	1	2	3	4	5	
1	1.0	1.0	1.0	1.2	---	2.6
2	1.0	1.0	1.0	1.0	2.0	---
3	1.0	1.0	3.0	2.0	3.0	2.0
4	2.0	3.0	3.0	3.0	3.0	3.0
5	1.0	1.0	1.0	1.0	1.0	1.0
6	1.0	5.0	4.0	2.0	2.0	3.0
7	1.0	1.0	1.0	1.0	1.0	1.0
8	1.0	1.0	1.3	1.0	1.4	1.3
9	1.0	1.0	1.0	1.0	1.0	1.0
10	1.0	1.0	1.0	1.0	1.0	1.0
11	2.0	2.0	1.0	1.0	1.0	1.0
12	1.0	2.0	1.0	3.0	2.0	---
13	1.0	1.0	1.0	1.0	1.0	1.0
14	3.0	3.0	3.0	3.0	3.0	3.0
15	1.0	1.0	1.0	1.0	1.0	1.0
16	1.0	3.0	3.0	1.0	2.0	2.0
Average**	1.3	1.8	1.7	1.5	1.7	1.7
Rank	8	3	4	6	4	4

* Each participant's overall rating for the specific indicator.

** Overall rank for each rating.

Table 8: Frequencies Data For Questionnaire Sub Indicators

Rating	Frequency	Sub Indicators*							
2.0	1	NA1							
1.9	1	NA3							
1.8	3	LS1	HL3	VL3					
1.7	8	NA2	RM1	RM3	RM5	PA1	PA4	VL3	VL5
1.6	3	PA3	LS4	HL1					
1.5	6	RM6	PA2	PA4	LS2	HL2	VL4		
1.4	4	NA4	RM2	LS3	HL4				
1.3	3	RM4	PA6	VL1					

* Needs Assessment (NA); Resource Mobilization (RM); Participation Approach (PA); Leadership Style (LS); Horizontal Linkages (HL); Vertical Linkages (VL). To explain this coding system, NA1, for example, refers to Needs Assessment Sub Indicator Number 1 and RM4 refers to Resource Mobilization Sub Indicator Number 4. Further, for instance, only one sub indicator got an average rating of 2.0, eight sub indicators were given an average rating of 1.7, and three sub indicators received an average rating of 1.3.

Table 9: Frequencies Data For Questionnaire Indicators
(Overall Ratings)

Rating	Frequency	Indicators*	
1.7	2	NA	VL
1.6	2	RM	LS
1.5	2	PA	HL

* Needs Assessment (NA); Resource Mobilization (RM); Participation Approach (PA); Leadership Style (LS); Horizontal Linkages (HL); Vertical Linkages (VL). Two indicators (Needs Assessment and Vertical Linkages) acquired an average rating of 1.7, two (Resource Mobilization and Leadership Style) an average rating of 1.6, and two (Participation Approach and Horizontal Linkages) an average rating of 1.5.

The ratings for sub indicators range from 1.3 to 2.0 (i.e.,

a spread of .8) out of a possible range of 1.0 to 5.0. Average overall ratings, or ratings for indicators, range from 1.5 to 1.7 (or a spread of .3).²

Figure 5: Web Configuration for Indicators of Participation and Support

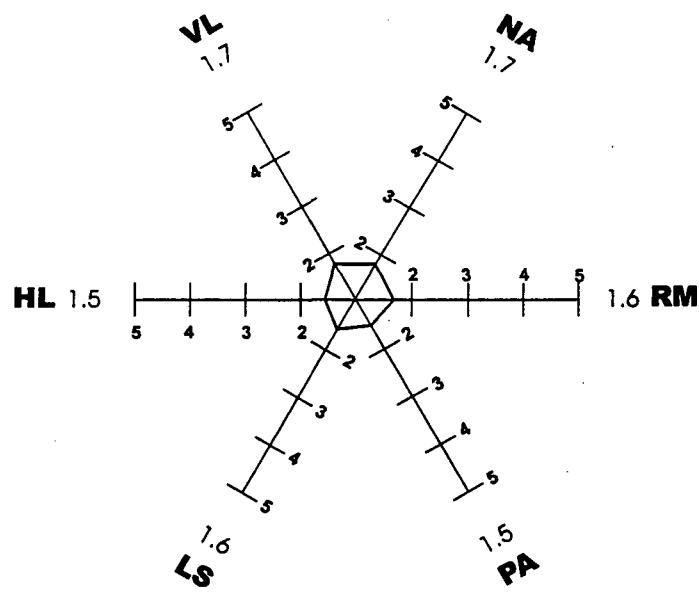
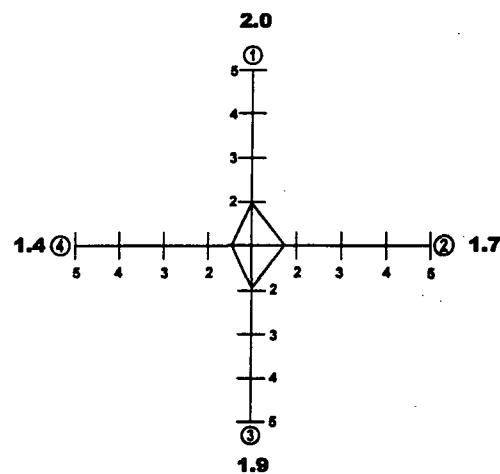


Figure 6: Web Configurations for Sub Indicators of Participation and Support

Needs Assessment



Resource Mobilization

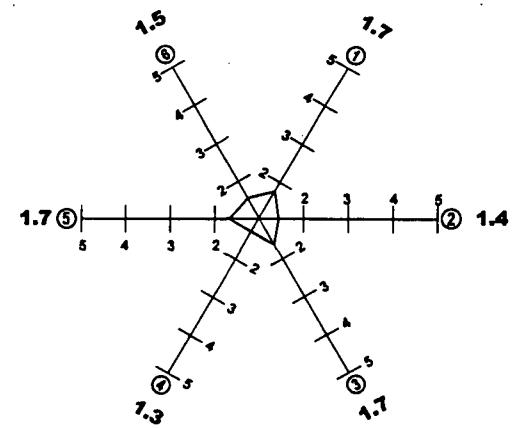
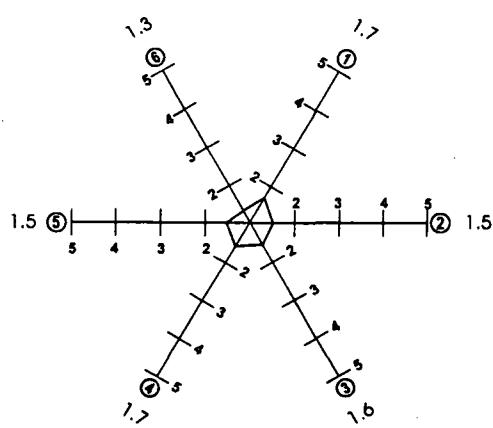
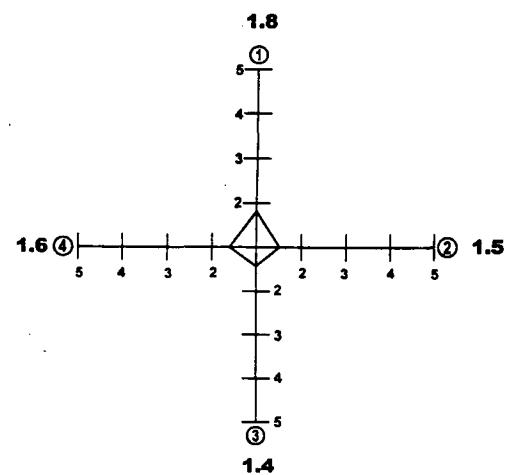


Figure 6: Web Configurations for Sub Indicators of Participation and Support (Continued)

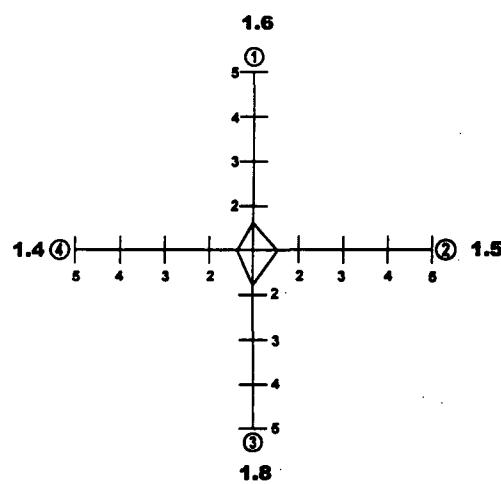
Participation Approach



Leadership Styles



Horizontal Linkages



Vertical Linkages

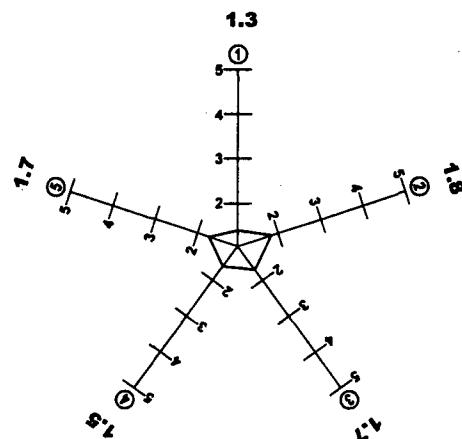
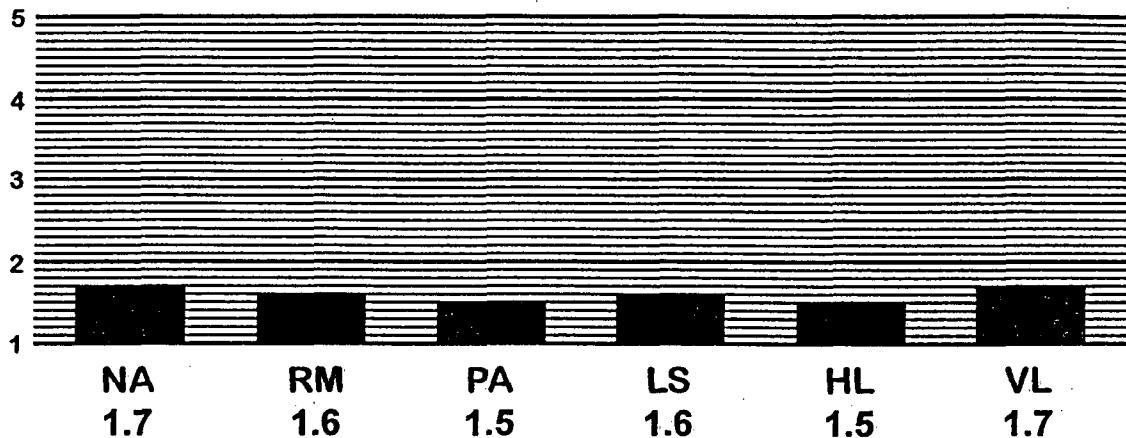


Figure 7: Bar Chart for Indicators of Participation and Support



RESPONDENTS' DISCUSSIONS: HEALTH BOARD CONTACT PRIOR TO 1998

Comments explaining ratings for inclusion and support for the period prior to the beginning of 1998 were varied and interesting. Such responses were found in different parts of each questionnaire, participants often answered more than one question with one response, and answers to one question were, at times, applicable to more than one question. With this in mind, I have included all responses to inclusion and support together in the following section. Ideally, these answers were to reflect relevant efforts by the Health Board prior to January 1, 1998. However, some of these were difficult to separate from responses to questions presented later in this chapter, i.e., those referring to recent efforts by the Health Board to include and support self-help groups and to the bottom-up efforts of

participating self-help groups to work with the Health Board.

(This concern is discussed in greater detail in Chapter 3.)

To start, four participants mentioned that the V/RHB had not included or supported them at all. According to one participant:

Q/Q7: Our organization has received no help of any kind from the V/RHB, not any information about discussions in which we might have been presumed to have information that might be useful to the Health Board or to the community as a whole. Any participation on our part has been because we found out about meetings and injected ourselves into them. . . . Sorry to be repetitious - V/RHB has never shown the slightest interest in our organization despite the numbers - we help an average of 500 women per month in each of our two centres. . . . We had a request from a woman who works for the V/RHB on a contract basis so she must have heard of us through hearsay - wanting a letter of support for her own organization which had to do with mental health and recidivism. We supplied her letter and that appears to be as close as our society had ever got to the V/RHB. . . . The evaluation itself is interesting but, based on our experience, won't change anything - we haven't seen any evidence that the Health Board does anything. . . . As before - no contact, no support.

Three other participants reported that they had no contact (involvement or support) with the Health Board. Two did not elaborate but one added:

Q/Q15: Well, now that I really look at it - what can I say? We have NEVER heard directly from the V/RHB about anything so far as I know.

Other participants indicated that the V/RHB involved and supported them but to a limited extent. These individuals made the following comments.

Q/Q1: Vague recollection of a rep. from the Regional Health Board coming and talking to group but do not believe there was ongoing information flow. Believe invitation to participate in an information forum. . . .

. . . The coordinator may have been contacted but information not passed on to groups if there were educational materials. . . . Cannot be definite about facts again operating on instinct but do not believe leadership shared or most marginalized people contacted but do want to say a woman did research on marginalized and homeless women that probably included members of our community. . . . Not sure how aware the V/RHB is of our group but do not believe any new members ever heard of us through the V/RHB.

Q/Q2: Have met with a couple of people employed at the Health Board - but don't feel they implement anything from our discussions. . . . There is an advisory committee for our groups/population - but not solely made up of us. Also the process of being appointed was difficult. . . . The Advisory Committee is somewhat removed and difficult to get in touch with. Very little information comes into the community from the Committee. . . . They [the V/RHB] don't approach us at all. . . . They've done nothing at all in these areas. . . . Have had a few meetings with some staff members - nothing has come of them so far but we keep hoping.
[Brackets mine.]

Q/Q3: Our agency was contacted by the V/RHB's Steering (Population Advisory) Committee for Aboriginal People. . . . Information was sparse. . . . Although recruitment was evident, there was strict limitations involved in becoming a member (interviews, resumes, 1st stage, 2nd stage, etc). . . . The facilitator took leadership roles at meetings, quite boring due to lack of participation of those attending. What's the point in attending? . . . V/RHB facilitators stated requirements for partnership and collaboration should be done among service agencies. . . . Received funding from them. Community Initiative Fund. . . . Overall communication with V/RHB has been through the Advisory Committees - Aboriginal. This evaluation shows the lack of Aboriginal input/participation with V/RHB's goals and objectives. V/RHB had good intentions on paper but due to lack of culturally appropriate services, the grass-roots people still continue to fall between the cracks.

In reference to the V/RHB's efforts to foster horizontal linkages, this last participant made simple notations such as:

Q/03: Only a statement made. . . . Requested the partnership with the project. . . . Verbal statement made.

Q/05: Their efforts to involve us have been very minimal - they sent us one notice of one meeting. I should add that we and other non profit groups are stretched well beyond our limits - we provide essential health prevention services needed with perhaps 2-10% of the resources needed. We don't have the resources or time to attend yet another meeting which may go nowhere but does take up our time which should go to precious services.

For her, questions of leadership styles were:

Q/05: Not relevant - we did not have the time and resources to attend [meetings].

In regards to the V/RHB fostering horizontal and vertical linkages she commented:

Q/05: They have done none of these things.

As noted elsewhere, one participant explained that her group had to initiate contact with the V/RHB, but that, once it had done so, its members were able to take part in meetings with the Board:

Q/06: Once we had contacted the Community Health Committee they were very helpful from that point on in letting us know of meetings and possible funding avenues.

On the other hand:

Q/06: There was never an offer of resource assistance. . . . The V/RHB has stressed partnerships but left it

up to groups themselves to decide what form they should take.

Q/Q8: I'm not personally aware of any actions taken by the V/RHB however I have heard of "network" gathering which have addressed needs. . . . There are some resource materials available but we are not well informed about them. There is some money allocated for activities and pays the individual who coordinates our meetings. . . . No personal involvement in activities of the V/RHB in supporting our group - just info that the V/RHB is our parent organization (?) and again being aware of the "network". . . . Because I am not an organizing member in my group, I have never had any interaction with the V/RHB. . . . Again, I personally am not aware of the actions of the V/RHB to support our group. This may be because the more senior members don't address these aspects at our meetings (although I doubt that) or that these kinds of actions are not happening. . . . Again, I have not experienced this kind of support.

Q/Q11: They [the V/RHB] suggested we use public health mail outs to family doctors to educate family doctors about [the issues we deal with] and about our services, which we did in May 1996. . . . We have written them about our programs and asked for a meeting, but they never replied. . . . We have never met or connected with V/RHB except the one time about the mailouts. They never wrote in answer to our request for a meeting. [Brackets mine.]

This participants also implied that at the time of the study there was limited involvement from the V/RHB, but says:

Q/Q11: I have to say that I would preface these responses with "as far as I know". Our organization has had a fair amount of turnover over the years and I do not know the full history of the Society to feel confident in saying there has always been limited involvement from the V/RHB.

According to others:

Q/Q12: There was some minimal discussion and interaction with us, but their main issue seemed to be governance. We were never sure where our consultation

and needs assessment went as the interactions were interested and respectful, but there was little to no follow-up. . . . We went to various levels of the V/RHB - They never came to us - but always acted interested. . . . Same [regarding leadership styles] (have improved in 1998 though). . . . If Anything at all happened I have given them a 2 rating but it is a minimal 2 - throughout - not just this section. . . . [We are] often recommended by staff at V/RHB. Given office supplies, etc. when came their way and they couldn't use. [Brackets mine.]

Q/Q16: One meeting arranged around funding and mostly from my initiative. There was no needs assessment. . . . Only one meeting - no follow-up, no ongoing interaction. . . . None [i.e., no support for developing horizontal linkages] forthcoming. . . . We received funding for one program; so at least they tried. [Brackets mine.]

One participant answered this evaluation a little more indirectly. She noted that the V/RHB gave her group relatively little support:

Q/Q9: Because the government didn't listen to disabled groups. They don't want groups involved, just individuals. They haven't bothered to recruit individuals from already established organizations representing their group's views. They have been re-inventing the wheel. The government haven't wanted to work with what was already established. . . . No matter what people said in the discussion group [Health Group/Committee], as a member of these groups, the government only used these groups to state grievances but not to resolve the issues at hand.

Lastly, two participants indicated a higher level of inclusion and support.

Q/Q4: [We were involved in the needs assessment] through the meetings with the V/RHB and the evaluation we had to fill out. . . . The V/RHB staff did assist in some of my groups workshops and First-Aid training. . . . My group is very independent. . . . We receive information (English/translated into Vietnamese) from

the V/RHB. [Brackets mine.]

Q/Q14: Our self-help group was contacted by a representative from V/RHB. . . . There was contact by the V/RHB with the volunteers in our office, however, our members were cool about the overtures from the V/RHB and reserved about future involvement with V/RHB resources. . . . The V/RHB actively fostered involvement of our group but there was a reluctance from our membership to fully involve their energies in a social process at the beginning. . . . Some members did participate in the Community Health Promotion process. . . . The V/RHB offered their services to our organization but our group preferred independent collaboration and consensus from among members before approaching other self-help groups. . . . Although the V/RHB is available as a resource, our group also pursues other agencies for information and services.

Interestingly, both these participants also noted that their groups were independent. (See discussion on the independence of self-help groups.)

POST 1997 CONTACT: DISCUSSIONS FROM QUESTIONNAIRES

On the questionnaire, participants were asked to comment on efforts made by the Health Board to include and support self-help groups after December 31, 1997. Some included this information while answering other questions.

Seven participants indicated that they were not recently included or supported by the Health Board, two gave no response, and one said "fill in the answers with information acquired during meetings", which could also be considered a non response because she did not give this information at any time. Those remaining talked briefly about their contact with the Health Board and give a range of responses.

Q/Q2: Did get a tiny development grant for a project - less than \$2,000 but for us it was a morale booster. Hope we can further develop the idea.

Q/Q4: The V/RHB did provide some facilitators for our health workshop and First-Aid training.

Q/Q6: We received some funding from the Health Board. The V/RHB lets us know of meetings re: health etc. in the community. So far, the V/RHB has been open to and listening to our thoughts/concerns re: health services in our area.

Q/Q12: Yes, some funding. Involvement with PHACs - perhaps joint projects.

Q/Q14: Involved our group in a meeting with other self-help groups on two occasions and wrote our recommendations on newsprint to be analyzed.

Q/Q16: They have not been involved/supportive at all except for funding. They are not interested in any interaction about ensuring voice.

POST 1997 CONTACT: CONVERSATIONS DURING MEETINGS

I also pulled out some relevant information generated during different meetings about post 1997 contact by the V/RHB. To begin, one participant in meetings talked about how much she appreciated a health forum she attended.. According to her:

P/M15: The Health Board forum I went to in January 1998 was important. . . . Some, those more marginalized such as recovering drug addicts, were given special priority regarding having their voices heard during the forum.

Another participants noted:

P/M12: I will be working closely with a health unit in Vancouver. This will give us security and direction.

Similarly, two participants expressed optimism about future

relations with the Health Board. Another acknowledged that new (project related) funding from the Health Board has increased self-helpers' interest in the Health Board:

P/M6: Over the years, most self-help groups have largely ignored the Health Board but this is changing with it giving funding. . . . New and innovative projects were funded by the Health Board [in 1998]. [Brackets mine.]

BOTTOM-UP EFFORTS TO CONTACT THE HEALTH BOARD

An important point came up during our meetings: two participants emphasized that they had to initiate contact with the Health Board to acquire support/input into planning. This impacted on the design of our evaluation questionnaire for it was the catalyst behind instructing participants to consider the initiatives of the Health Board to reach out to self-help groups to involve and include them, rather than the bottom-up initiatives of self-helpers to acquire this attention. One question was asked, however, near the end of the questionnaire to ascertain whether participants involved themselves in such bottom-up efforts.

Six participants said in one way or another that they did not initiate such contact. Five provided details.

Q/Q3: No [bottom-up efforts], other than participation with info session regarding the call for proposals. Nov./97. [Brackets mine.]

Q/Q5: No we haven't - we're struggling to provide even a small fraction of the services needed.

Q/Q10: The problem for my organization is that a lot of the medical information we are giving contradicts

the information the medical community gives out. In one sense this makes more work for the two "sides", each having to undo the "damage" done by the other side and each side believing they are right! Also, us volunteers are so busy helping the women we don't have time to "reach out" to the V/RHB. Our two approaches are so radically different I guess we leave one another alone.

Q/Q13: I have worked here only for a year, none during this time, unknown before.

Q/Q16: We have only interacted around funding proposals that they have given us. One attempt to get feedback through a long and complicated report needed. There has been no bottom-up efforts.

Two participants were not sure or aware of such contact, one told us to go to notes taken during earlier interviews but made no reference to this matter in her interviews, and one other gave no response.

Finally, six participants noted that they made some efforts to initiate contact.

Q/Q2: We have been in touch with staff of the Health Board since 1995, and seem to have cordial personal relations with them. Our initial contact was when we wrote a grant proposal for a project. They seem to think our ideas and concerns are valid, but nothing much else has happened.

Q/Q4: We still keep in contact with the Health Systems as well as with their committees.

Q/Q6: The Health Board did not include our group at all initially. It was only by persistent efforts on our part that we learned of the process/meetings and were able to take part. . . . All involvement we had came about through our own efforts. . . . During both time-periods [1997 and 1998], met with the Community Health Committee and they informed us of meetings etc. and were very helpful. [Brackets mine.]

Q/Q7: Not. . . . Any participation on our part has been because we found out about meetings and injected ourselves into them. As it is so unclear what the

Health Board does (beyond providing positions for NDP supporters), we have not tried to initiate a relationship.

Q/Q12: We went to various levels of the V/RHB - They never came to us - but always acted interested. . . . [In] both [time periods], looked for funding, credibility, etc. - see earlier comments. [Brackets mine.]

Q/Q14: Our self-help group has initiated contact with the V/RHB for speakers for our programs before 1997 and after. We are very satisfied with our relationship with the V/RHB and plan to maintain a relationship.

DISCUSSION

All average ratings for indicators and sub indicators measuring the degree to which the Health Board had included and supported self-help groups are low. Participants' comments in meetings and questionnaires give the same picture. In fact, I could not have predicted the higher ratings a few participants gave in their questionnaires from the information they had provided during meetings. Judging by these conversations, I expected to have scores of 1 or, at best, 2.

These higher ratings not only brought up the average scores, but also provide a challenge to understand, given their incongruence with information found in meetings and given the technical concerns regarding going back to their sources (i.e., lack of time and issues of anonymity).

Without going back into the field to review ratings, this analysis remains speculative. I do, nevertheless, have some insight into why these ratings were made. For example, when one respondent returned her questionnaire to me, she noted that she might have given higher scores because of more recent (post

1997) Health Board efforts to support them. (This was the only comment she made to explain her responses about her questionnaire.) In addition, two participants who gave higher ratings and indicated their general satisfaction with relations they had with the Health Board also had low expectations about the amount of support and inclusion they wanted from it.

Further, as noted in Chapter 3 and as can be seen throughout this chapter, despite providing largely a negative view of their relations with the Health Board, a number of participants also looked at the positive side and tended to give the Health Board the benefit of the doubt. This may have been implied by participant Q/Q12 when she commented on her questionnaire that "If Anything at all happened I have given them a 2 rating but it is a minimal 2 - throughout - not just this section" (see page 201).

Information provided on this questionnaire is food for further studies. Further, knowing that participants gave scant information about why they made their evaluations, despite being asked to do so, we can try to get more complete answers on future questionnaires by clarifying the importance of this material to the evaluation.

Other findings that have come out of both meetings and questionnaires are presented and discussed in the bulk of the remaining sections. This material provides greater insight into participants' relations with and understandings of the Health Board and health system and can help us understand the comments and ratings they made in regards to how well the Health Board

included and supported self-help groups in health promotion.

MAINTAINING INTEGRITY, AUTONOMY, CONTROL, AND SUSTAINABILITY

While in meetings, nine participants talked of the need for their groups to maintain their self-reliance and integrity which they felt should not be lost for any reason, be it having a greater voice in health planning or gaining greater Health Board support.

Before entering into this discussion, therefore, we must ask whether self-help groups actually need or want to be supported and included. This was a major concern of one participant who insisted that:

P/M6: Self-help groups don't make use of resources available to them now (e.g., SHRA facilitation courses). . . . Some groups are never satisfied with the amount of funding they get. . . . By opening up funding, we can create needs. . . . If self-help groups have the opportunity to become part of health planning, what type of commitment will they make to this process?

Judging from the participants' comments, the underlying belief is that self-help groups are effective because they are participant-controlled and participant-oriented and have the freedom and flexibility to meet their members' needs. These groups were seen as places where members have freedom to operate as they choose without any outside interference. For participants, once they become regulated, their groups may lose these strengths. Changing their focus or adding to it, they

felt, may bastardize the very nature of self-help groups and draw them into the mainstream health system. Even bringing these groups into the larger self-help movement and collective action may threaten their integrity.

In other words, for participants, such connections with the Health Board should have an enabling effect and should not interfere with the laissez-faire, self-help nature of self-help groups. The following comments reflect this concern, beginning with views about independence.

DESIRE FOR INDEPENDENCE

In the passages to come, participants let us know how independent their groups are.

P/M3, M5, and M7: Self-help groups are a form of protection and would exist independent of the Health Board and Health Board funding. . . . We are seeing that support groups work despite lack of external support.

P/M4 and M8: Our group doesn't want interference. We have free enterprise, flexibility, and are laissez-faire. We want control over our environment.

P/M8: Our group doesn't need much funding for we are self-sufficient and cheap. Money is not an issue for we run on a shoestring. This frees up health dollars. . . . We don't have to answer to too many people and have people with fancy degrees come in and control. . . . Budgeting is not necessary for stuff we can do on our own.

Further, one participant saw the diversity that exists between self-help groups in regards to the need for external support.

P/16: Some groups have a hard time organizing themselves, some have it easy in this regards. Some are self-sufficient, some need more help.

Two participants also told us in their questionnaires that their groups were fairly independent. One had this to say.

Q/Q14: There was contact by the V/RHB with the volunteers in our office, however, our members were cool about the overtures from the V/RHB and reserved about future involvement with V/RHB resources. . . . Although the V/RHB is available as a resource, our group also pursues other agencies for information and services.

PRESERVING INTEGRITY, CONTROL, AND SUSTAINABILITY

Each of the paraphrases below reveals the importance participants place on maintaining the values and principles of their self-help groups. They also imply a level of distrust regarding the Health Board taking control of their groups.

P/M3, M5, and M7: We must focus on how the Health Board can help us, not on how we could help the Health Board (e.g., by gathering data for it). What will we be trading for Health Board support? We do not want to lose our autonomy. . . . Most important for us is whether we could get Health Board support without losing our autonomy. Would we be monitored, for example?

P/M6: We should look at two points: (1) what funding needs are and (2) what to ask for to keep integrity/autonomy. . . . We should be careful about acquiring funding for self-help groups. Self-help groups must maintain their integrity and autonomy. They don't want regulation/control and the Health Board is a very regulation-oriented organization. . . . We must be cautious about making changes (i.e., regarding involvement and support) to self-help groups that may force them to re-invent self-help. Self-help groups may want to re-invent themselves but this should be their choice. For example, they may want to divert some resources to help them become involved in health

planning but this will change their focus or add to their focus. . . . Self-help groups are forces for personal development and, by opening their focus and becoming part of a larger mutual aid movement, they are no longer true self-help groups.

P/M6 and M9: We are not evaluating support for projects but for self-help groups as health services. We are looking at integrity and sustainability, not necessarily financial support. Further, we must maintain our integrity. We do not want intrusive, controlling involvement. . . . Self-help groups want to have funding to help them function as self-help groups, not to help the Health Board bring them into the mainstream health care system and regulatory control. With this in mind, self-help groups may be better off to ask for funding that meets their needs and ensures they maintain their independence.

Cautious about losing the integrity of self-help groups, one participant questioned how loyal self Helpers are to the principles of self-help groups if they reach out to the Health Board and extend their role.

P/M6: Groups that would like to open up and get support/involved in planning are primarily those that explore political topics or want to provide therapy. . . Many of the self-help groups involving themselves in health planning are those with a grudge and, therefore, aren't representative of self-help groups in general. This creates bias.

The fact that participants want to become more involved in health planning and to acquire support from the Health Board, but are not willing to change the inherent nature of self-help groups to do so, necessitates a closer look at the types of involvement and support these groups are willing to accept. Before we get to this stage, however, there are other related issues that should be discussed. For example, participants and I

inquired into the potential of developing an umbrella organization to channel resources to self-help groups. This proved to be quite a fruitful series of conversations.

EXPLORING THE POTENTIAL OF SELF-HELP GROUP UMBRELLAS

An interesting question participant explored is: how do we want Health Board funding to be distributed to self-help groups? One possible way, we identified, is to organize at least one self-help umbrella organization. Seven participants were involved in analyzing the practical implications, the pros and the cons, of developing such an organization and this discussion continued throughout various meetings. One individual wondered:

P/M6: What type of mechanisms should we look into regarding distributing resources from the Health Board to self-help groups. For example, would it be distributed directly from the Board or through existing organizations which can be used as umbrellas? We should use these organizations as umbrellas rather than creating new bureaucracies, if we go this route. . . . We need better organization between self-help groups, not just scattered groups. Central umbrellas can help self-help groups network which is important.

Three other participants noted that we should look into establishing an umbrella to serve as an intermediary between the Health Board and self-help groups. Further, very early on in this debate, two participants were even willing to see if their self-help groups would consider taking on this responsibility. On the other hand, doubts as to the viability of an umbrella began to emerge. For example, it was noted that:

P/M6: Organizations which can become umbrellas need more resources pumped into them to help them meet ongoing needs (staff, space, other resources). We need a stronger body to funnel funding to self-help groups.

Further, there is the issue of maintaining integrity and control. Participants expressed that an umbrella would have to be structured so it would not generate competition, lead to possible inequities between groups, and undermine the nature of self-help groups.

According to one participant:

P/M6: Do self-help groups want to remain autonomous or have an umbrella group and lose control? . . . We should guard against some self-help groups becoming competitive and vying for Health Board support. It is not a positive thing for self-help groups to become profit organizations and charge for courses and workshops, etc. If self-help groups have Health Board funding available, they may bypass self-help groups, their camaraderie, and working together and go directly to the Health Board for funding. This would serve to put self-help groups in competition with each other and push them out of the mutual aid movement. Some groups would become self-oriented bodies. . . . If funding goes directly to self-help groups, how do we prevent competitive territorialism and trendy groups organizing around trendy funding for trendy purposes? What about intentions/motivation and accountability and what will happen to those groups which have a history of serving their membership? Will these steady groups become slighted and weaken as a result and will trendy groups lose their integrity as self-help groups? Will Health Board funding, in general, destroy the integrity and stability of self-help groups for such groups are supposed to be controlled by participants, not by funding agent? The most vocal and least marginalized groups covered by an umbrella can end up getting more and more support at the expense of those more marginalized. . . . Funding in general tends to isolate.

Learning from past efforts to introduce an umbrella, this

participant also informed us that:

P/M6: Making groups into liaison organizations was tried and professionals took over and felt their role was to guide the self-help groups. It was professional versus grass-roots facilitators/members. . . . We don't want to end up doing what the Health Board is supposed to be doing.

Very simply put, for two participants:

P/M6 and M9: It would be tough to make groups like the SHRA into liaison organizations.

Additional words of caution came from two participants even more apprehensive about developing an umbrella. For them:

P/M1 and M12: The idea of having an umbrella organization is not so easy to implement. Ensuring equal distribution of resources would have problems. For example, organizing and maintaining such an umbrella would be very difficult. There would have to be some sort of regulations from the Health Board or by the umbrella group.

Participants conceded, however, that this would be less necessary if the funding was available to meet more generic needs that everyone can tap into equally (e.g., facilitator training and counselling to prevent "burnout") rather than specific needs which require more substantial assistance and regulation and may invite competition (e.g., specific project funding and child care). The former type of funding would serve to perpetuate the principles of self-help groups, while the latter could easily help bastardize them.

Doubts about the viability of an umbrella still lingered, nevertheless, especially when participants began to reflect further. For instance, two felt that an umbrella organization may:

P/M1 and M12: make it more necessary for women's self-help groups to become formal members and some mechanism would have to be developed to determine who qualifies. Also, ethnic groups and other non "mainstream" groups have different ways of doing things and may not be willing to compromise their values. Next, the Health Board is unlikely to fund such an umbrella anyway. . . . Establishing an umbrella would also just be shifting power from one body to another. There is considerable turnover in staff/volunteers in such organizations/groups and the original people may make it possible to just allow self-helpers to apply as they need generic funding, but as new staff bring in their personal agendas, guidelines would have to crop up. They would eventually start looking after their own needs over others' which is a phenomenon that can't be regulated. . . . An umbrella would also take the responsibility for this work away from the Health Board. In its place, we could just let self-help groups apply directly to the Health Board for funding.

Despite having her own reservations about the practicality of developing an umbrella, one of the other major members of this discussion countered this claim.

P/M6: Contrary to what other participants have said, establishing an umbrella group would not necessarily mean that self-help groups would have to apply for membership. Organizations, for example, like the SHRA, serve all groups and they don't have membership.

She did acknowledge, on the other hand, that:

P/M6: An umbrella organization would feel responsible and accountable to the self-help groups they work with and would need to have some rules and regulations.

This would be especially so for groups that acquire more substantial assistance. This would require a mini bureaucracy.

Finally, one participant emphasized in her questionnaire that there is a need for some sort of structure to be put in place for designating funding. She felt that the Health Board should:

Q/Q12: Help provide a structure for support, development, monitoring (if necessary), resources, and stats gathering.

This discussion brings us to participants' feelings and opinions about external control. Participants talked of top-down control and politics, domination by professionals, insufficient recognition of the expertise in their groups, and a lack of democracy and equity.

INTERNAL VERSUS EXTERNAL CONTROL

Bureaucracy

For one participant, bureaucracy is a barrier in the way of reforming community health planning:

P/M1: The community participation process is an educative process and has bureaucratic limitations. People in the Health Board want to do what is right but this is tough and people in the Health Board may have to get out to do what they feel is right. The Health Board just got co-opted by logistics, i.e., implementation is tough. The bureaucracy is so big and politics plays its role. For instance, the anonymous participants in this study are at a disadvantage if they can't see the Health Board eye-to-eye. The V/RHB is looking for statistics and anecdotes to ensure accountability. It is looking for BC Health Research

Foundation type projects which are academic. It wants quantification of qualitative data if it even uses qualitative data at all.

Despite her belief that the Health Board is steeped in bureaucracy, another participant had a slightly more positive view of the Health Board in this matter. According to her, the V/RHB was more responsive to her voice than are the staff in the organization to which she belongs.

P/M9: At least Health Board members listen. Having the Health Board gives us tangible support and is a better type of bureaucracy. The Health Board is not a monolith, i.e., it is made out of health committees and groups which we can approach more easily.

Politics and Political Control

In meetings, three participants reported that the Health Board was top-down. For example, according to the following participants:

P/M1: The Health Board is not addressing community issues and will continue to use top-down avenues to involve the public. The Health Board says it doesn't want pipes but people working together, but this is still only in theory.

P/M2: PHACs and CHCs are artificial constructions. . . Due to politics and other difficulties, the health Board has imposed committees. In other words, the process and structure are top-down. . . . The Health Board should not put a limit on growth. Despite the difficulties of getting public participation, it should have continued to let the process be participatory and bottom-up. The politics should not get in the way of representing people's needs, but it does.

P/M6: The Health Board initially intended to be bottom-up. The Health Board intended to have face-to-face focus groups. It may not have thought

about this exact sort of thing, i.e., our idea of doing presentations for the Health Board. The difference is that our focus groups will be initiated from the bottom-up. The Health Board kitchen table sessions, however, were just complaint sessions and fizzled out.

This concern was also evident in questionnaires.

Q/Q1: . . . do not believe leadership shared or most marginalized people contacted. . . .

Q/Q3: The facilitator took leadership roles at meetings, quite boring though due to lack of participation of those attending. What's the point of attending.

Q/Q12: There was some minimal discussion and interaction with us, but their main issue seemed to be governance.

On a similar note, while attending one of our meetings, one participant mentioned that:

P/M1: Politics has made it difficult to reach all people and the issue of equity has made it even tougher.

Another looked at politics and the dominance of professionals.

P/M10: The odd nurse has suggested to moms to go to her groups but most referrals are to professionals. This all boils down to politics. . . . Contradictory information leads to politics and conflict.

Another participant asserted during meetings that:

P/M2: The Health Board is not willing to listen to my self-help group. It is willing to do a conference but would not let groups like mine be in charge of the

process. Further, Health Board members are willing to listen to individuals but not to groups like mine. This is a political statement. "They did not want to get groups involved, just individuals. . . ." These groups are politically active (i.e., they fight for people's rights). . . . "They [Board members] are doing an injustice if they want to remain apolitical, they should include these groups." If Board members are interested, they should go to self-help groups. They don't want any coalitions controlling or facilitating forums because these coalitions are political. "In the long run, it would have been cheaper, if not, they would have gotten their monies worth." Rather than including self-help groups, they denied their involvement due to the political way they've handled things. [Brackets mine.]

She repeated this message in her questionnaire³:

Q/Q9 (M2): They don't want groups involved just individuals. They haven't bothered to recruit individuals from already existing organizations representing their groups' views. They have been re-inventing the wheel. The government haven't wanted to work with what was already established.

Another participant also expressed the belief that the Health Board felt insecure about self-help groups.

Q/Q3: I think that the V/RHB maybe feel threatened by self-help groups.

Attitudes of Professionals

Three participants expressed their disdain for having professionals control self-help groups. As we've seen before, one brought it to our attention that they had attempted to develop a self-help liaison organization once before but when they did:

P/M6: professionals took over and felt their role was to guide the self-help groups. It was professionals versus grass-roots facilitators/members.

Two participants talked about the way doctors and other professional relate to women and self-help groups. They gave examples where some professionals have shown respect for self-help groups and even recommended them to clients but, for them:

P/M9 and M12: these are rare instances. Some programs for women within the medical system impact negatively on women and they come out worse off. The whole medical model impacts negatively on women.

Additionally, having little faith in gaining cooperation from professionals, one participant underlined that:

P/M9: Even though I do not discount working with professionals altogether, most professionals will never work with us as health services so it is important to concentrate on involving the public.

Lastly, one participant just commented:

P/M8: Professionals can't be objective, they want to be paid.

Democracy and Equity

While in meetings, two participants brought up the issues of democracy and equity, the first in regards to involving the public in the community consultation process and the second in relation to the distribution of resources

and representing the needs and wishes of the community:

P/M1: The Health Board has had problems with the issue of democracy. Politics has made it difficult to reach all people and the issue of equity has made it even tougher.

P/M2: The Health Board wants to regionalize the health care system which is good in that it will localize health care but it will also knock down some existing systems to do so. This will make things more, rather than less, expensive. Hospitals are being closed down too, for instance, and if people had a say, this wouldn't happen. Therefore, there are inequalities regarding savings. This also applies to inequalities of wages and top heaviness in wages/resources. Why not cut back here?

A common point discussed by participants and contacted stakeholders, in general, is the fact that professionals involved in the province's health promotion initiatives are getting large salaries while so many residents in the province are expected to volunteer their services for free as health service providers and informal health planners. An example particularly noted by participants regarded news heard that Elizabeth Cull (former Minister, BC Ministry of Health and Ministry Responsible for Seniors) was called back by the Ministry (which may be a conflict of interest) at a salary of \$1,000 per day specifically to explore methods to get the public to do the same sort of work without any compensation. Even some of the most basic forms of compensation for volunteers such as child care, transportation, and refreshments were reported by participants to be neglected along with training and education.

The issue of equity came up elsewhere too, for example, in

regards to the need for self-help groups to share resources fairly, whether they are distributed directly or through an umbrella, and to participants' views on how the Health Board and health system relate to and support self-help groups, women, and people with mental illnesses.

DISCUSSION

The most dominant theme here is the desire for participating self-help groups to be in control over how their groups are structured and the processes they engage in within and outside their groups. I expected this concern. This was the general feeling I had when I conducted my informal needs assessment. Further, the literature I subsequently read on self-help groups is filled with references to this theme.

I did not expect that some participants strongly see a potential among self-help groups to be self-serving and competitive, especially when resources are scarce or perceived to be. In other words, participants maintained that ensuring self-help groups have control over Health Board support, does not necessarily ensure the equitable distribution of resources provided, just as ensuring self-help groups have better representation in health planning does not mean we won't find that some groups will benefit from this process at the expense of others.⁴ This made the types of support and involvement and who has control over these factors especially important for participants.

Control from above or outside self-help groups was seen as

unacceptable. Summarizing the words of one participant, regardless of the problems involved with ensuring democracy and equity amongst self-help groups, this regulation and control must be resolved by self-helpers themselves.

It is also essential to accentuate that only seven participants entered into discussion about an umbrella organization and only four revealed this level of distrust regarding other groups at that time. Two expressed this view later, when I asked them to validate my analysis, one who reaffirmed her previous conviction and one who volunteered this information for the first time (see Chapter 6). Further, there was only one participant not involved in this discussion who brought up the potential for self-help groups to vie for control. I did not get input from others regarding this concern.

On the other hand, participants admitted to having worked little with other groups and organizations and feared that doing so would dilute their limited resources and diminish their ability to act like self-help groups and serve their members. Furthermore, despite the fact that some had engaged in lobbying and advocacy, they expressed caution that this, too, should not interfere with their ability to serve their members. It is important to note, again, that over 61 women's self-help groups (out of an unknown population of women's self-help groups) were identified and approached for this study and only 17 groups responded (or 21 individuals). In addition, 4 groups were involved solely by filling in an evaluation. Finally, of the 13

groups which were involved in meetings, just 7 became core groups (incorporating 9 participants).

To summarize, most participants expressed a distrust in professionals, the Health Board, and the health system and noted that they would work with outside individuals, groups, and organizations only on their own terms.

There were some underlying issues influencing participants' comments on such issues as control and equity. One was their common understanding that the V/RHB's community participation initiative was relatively new and atypical, given the perceived top-down nature of the V/RHB and the general health system. During meetings, most participants in one way or another also indicated a concern about Vancouver's failing economy and some suggested this decline negatively impacted on how well the Health Board supported their self-help groups and included them in health promotion. This issue was most evident when we talked about establishing umbrellas and the need for self-help groups to fight for scarce and unequally distributed resources.

A dominant belief expressed by participants in meetings and questionnaires is that the Health Board does not have the right to make a top-down decision to "allow" bottom-up participation from self-help groups or the public in general. According to participants, the Health Board also does not have the right to determine the form this participation should take. Rather, these decisions should come from the bottom and the Health Board's position should be to provide as much support as possible to help these indigenous efforts. Participants

indicated that they have the right to be included in health planning and that this is not a gift given to them. Similarly, self-helpers in this study felt they had a right to Health Board support as well as to choose the types of support they get and how it should be allocated. In other words, for them, this should also be a process controlled from the bottom-up.

Throughout meetings and questionnaires, participants gave comments that back up their desire to maintain the innate nature of self-help groups. They did not want their groups to become dominated by bureaucracy. They did not want bureaucracy to infiltrate their groups, nor did they want their groups to be consumed by the bureaucracies outside their groups.

Participants opposed being victimized by external politics, and rejected political control, professional control, and professionalization. They called for democracy, equity, and the recognition of local, experiential expertise. For them, Health Board support and inclusion in health planning should strengthen, rather than diminish the autonomy, integrity, and sustainability of their groups.

Going back to the issue of developing relations with others beyond their groups, I underline that participants did not outright reject the idea of engaging in external relations and external activities. In fact, a large majority revealed considerably willingness to do so, or to do so more often, when: (1) their members' needs are first met; (2) they will not lose sight of what they believe self-help groups are formed to do; (3) they will not lose valuable resources; and (4) they are in

control of the process.

I did expect a certain amount of apprehension about the loss of integrity, autonomy, and sustainability that comes with developing relations with more powerful, external organizations like the Health Board. On the other hand, just as I did not expect to encounter a lack of trust about working with external bodies, I did not predict that there would be such a concern about how working with organizations in general or how lobbying and advocacy work could be perceived to alter the nature of self-help groups (i.e., primary emphasis being placed on members helping members to heal).

What this boils down to for participants is: What will self-helpers have to give up to gain and what will they gain? For example, they question how much control, integrity, and self-sufficiency may be lost by having a greater role in health planning and having support from the Health Board. Will this inclusion in health planning and support help or hinder the sustainability of self-help groups?

These findings can be related to Arnstein's (1969) work on levels of participation discussed in Chapter 1. Participants criticized obvious attempts by the Health Board to give self-help groups the appearance that they were participating (manipulation and therapy) or to involve them in token participation (informing, consultation, and placation). This is relatively clear. I am not as clear, however, about the exact levels of participation participants would like to engage in above placation.

My understanding, based on the information generated from this study, is that participants would like to have the highest level of participation (full citizen control) in regards to being in control of the resources given them to run their groups and their various projects. They expressed that they want no Health Board involvement in their affairs unless they invite it. They would also entertain the idea of having this level of control over self-help umbrellas, a wider scale of control, but only if necessary safeguards are established to avoid cooptation by members. This would be more difficult to control, but they did not rule it out completely.

When it comes to looking into the levels of control they would like to have in regards to their participation in community health planning, my understanding of their comments is that it would be impossible to have full citizen control, given the scope of this process, the priority self-help groups give to being health providers over informal health planners, and their limited resources. I do see, on the other hand, a desire on their behalf to be involved through partnerships and power delegation, but with the important condition that this is shared control. They appear to want a form of participation where all service providers (complementary and conventional) share power with other citizens and citizen groups and the Health Board. This form of participation would, ideally, come with appropriate forms of compensation and a commitment by the Health Board to giving them an equitable role in decision making. In the future, participants may want to explore what their exact

forms of participation would look like and develop their own definitions of participation.

THE POSITION OF SELF-HELP GROUPS IN HEALTH PROMOTION

VALUE OF SELF-HELP GROUPS

Throughout the meetings, all participants in one way or another expressed the value of self-help groups and the need for the Health Board to appreciate and support their position in health promotion. Some talked of the vital role played by these groups as a form of health care and support. One participant heralded the importance of self-help groups in her questionnaire. The following string of paraphrases and one quote give us an idea of what these praises look like.

The following participants made general comments about the value of self-help groups.

P/M1: Self-help groups are grass-roots service providers but the Health Board doesn't understand this.

P/M3, M5, and M7: It is important to have people to talk to and a group helps.

P/M5: Self-help groups meet social needs and using them is an innovative idea. Self-help groups address issues regarding helping to restore quality of life. . . I see self-help groups as a powerful concept.

P/M13: We need groups to take care of others.

Other participants talked about how self-help groups augment the support given by self-helpers' friends and family.

P/M4 and M8: Self-help groups give families a break from supporting friends/family of members.

P/M6 and M9: Self-help groups help families/friends who have burnt out while helping their family/friends cope. Women are accepted into self-help groups unconditionally.

P/M6 and M15: Self-help groups can give what families often can't. Families often fail to address issues and often even perpetuate them. It is frequently easier to get help from non family members and this can be essential to maintain confidentiality as well as to get needed help. . . .

P/M9: Self-help groups have taken over for the natural family and friends.

Two participants spoke of the benefits of self-help groups/organizations for reaching out to a specific target group.

P/M6: My group can serve to get seniors in touch with appropriate services/resources.

P/M6 and M15: An organization like the SHRA can have a role in helping seniors' isolation from resources, self-help groups, and other support.

One participant indicated that:

P/M8: Women's self-help groups are an extension of women getting together.

Four participants saw the value of self-help groups to the Health Board. For them:

P/M5: We need to show that, by supporting self-help groups, the Health Board will create jobs for themselves.

P/M9 and M12: Self-help groups are a tool for the Health Board.

P/M14: Self-help groups are important to the Health Board and its PHACs, and CHCs.

A number of participants praised self-help groups as alternatives to, or complements of, professional health services.

P/M3, M5, and M7: Self-help groups provide a good alternative to hospital care and changes are important.

P/M5: This is a new idea, i.e., self-help groups as a health care model. . . . Self-help groups have a healing power and we should be able to articulate self-help groups as a health care alternative. . . . Having a second opinion is important. Doctors typically have a limited perspective, just one, but self-helpers have many new ideas, opinions, intuitions, etc. . . . The Health Board/medical system has to realize that healing meetings (self-help groups) take pressure off the medical system.

P/M10: The counselling my group gives is important because people need to talk to someone who has gone through what they've gone through; they need dialoguing and healing. . . . My community knows from experience about the concerns of my group. . . . Without self-help groups, society would be far worse off. . . . Being involved in self-help groups has helped me. Self-help groups are tremendously important because doctors don't have time and can't be knowledgable enough. . . . New information is gathered by self-help groups that doctors don't and often can't get. . . . The medical system can be good when one needs something done but self-help groups can do the rest. . . .

Q/Q10: I believe that what we do and what other self-help groups do is to provide the support, empathy, the listening that no one else has time to do. I also believe people experience relief and even healing when they are heard. Self-help groups empower people to take control of their lives instead of being dependent on systems. If nothing else, the medical community should recognize how much money (tax dollars) is saved when volunteers support people in this way.

When four of us talked of the potential for self-help groups to be seen as branches of health care, one participant commented:

P/M15: I like the idea of self-help groups being a parallel branch of health care.

Countering this, two participants explained:

P/M6 and M9: We should introduce and maintain self-help groups as alternative health services, not branches.

After reflecting on this reply for awhile, I realized these two self-helpers were under the impression that I was talking about self-help groups as branches within the health system, to be under its wing so to speak. Knowing these two participants and their responses, I predict they would have no objections to being considered as equal and parallel branches of health care, i.e., respected complementary health services.

DEFINITION

We have seen in Chapter 3 that some self-helpers contacted had problems determining whether they were self-help groups or some other entity like a support group or a collective. Backing up the SHRA's definition of self-help groups, one participant underlines that:

P/M6: Self-help groups deal with crises and they need to focus on healing.

When asked about why self-help groups specifically address crises, while the self-help movement is more generic in definition, this participant answered:

P/M6: The fact that self-help groups are defined as people in crisis is largely the result of funding.

STEPPING OUTSIDE

During our various meetings, participants expressed that, providing it is on their own terms, they would like to extend their work with other groups and organizations in the community and to organize on a larger scale. These are some of the comments made.

P/M1: The Health Board feels that non profit groups are competitive and don't work well together, not realizing that competition has been forced upon them and that all such groups have variety within and between them.

P/M4 and M8: We are a support group and advocate and are stimulating. Our group has gone way beyond the Health Board. We are educational. This has not necessarily been our mission and individual goals but it has happened. . . . Over the years, the scene has changed for self-help groups. For example, there is the internet which is helpful.

P/M6 and M15: We think it is beneficial to have people clip newspaper articles for a common information bank.⁵ This could be done on a volunteer basis.

P/M6: We have missed a great deal of information by not reading these papers. . . . This study helped us get together but we have done some networking before. . . . There is a lot of turnover in self-help groups so many may not know about organizations like the SHRA but most should know the Health Board. This is due partially to lack of outreach work on behalf of the SHRA.

P/M6 and M9: Many groups are being marginalized and we have to work on making these groups less marginalized/ isolated.

In her questionnaire, one participant stressed that:

Q/Q14: Our volunteers feel that family ties come first and any time for themselves that they feel they can give to community responsibility comes next.

Given this priority, however, she underlines her group's commitment to being a part of the general community.

Q/Q14: Our group feels that it is a permanent participatory member in the community and is willing to hear new ideas. . . . Some of our volunteers are members in more than one self-help group at the same time.

Additionally, all participating groups had worked with professionals in at least one capacity but, again, on their own terms. These individuals typically had given lectures or facilitated discussions themselves whether outside or inside the groups. One participant summarized one of the most common patterns of involving a professional in groups meetings.

P/M8: We bring professional in who leave after their presentations so members can have a discussion.

The same participant noted the relationship women's self-help groups have to their social environment. According to her:

P/M8: Women's self-help groups are an extension of women getting together.

When I brought up the idea that we can look into developing a self-help group for self-help groups, two participants said simply:

P/M15: I like the idea of having a self-help group for self-help groups.

P/M16: A self-help group for self-help facilitators would be a good idea.

There are other comments showing participants' attitudes towards working with others outside their groups. For example, there are the discussions/answers regarding the bottom-up initiatives their groups had made to contact the V/RHB and the recommendations made in questionnaires/meetings. Equally importantly, participants were willing to get involved in this study, despite all the constraints they faced, and to consider giving presentations to the Health Board. In fact, participants wanted to use this study to help their groups organize and during this entire project participants were extremely cooperative and worked very well together. Finally, we also have to remember that participants were responsible for including questions about horizontal and vertical support in the questionnaire.

THE SPECIAL STRUCTURE OF SELF-HELP GROUPS

In one meeting, two participants talked of the flexible

nature of self-help groups, including their own, and the pros and cons of this characteristic.

P/M15: Our group is cyclical in nature and loose. There is a lack of membership continuity which has created problems with facilitation and continuity of structure.

P/M6: Turnover in leadership/facilitation is a good thing in that it leaves room for new blood, input from different people, and democracy. "One gets stuck in a role."

P/M15: I agree. . . . My group has smaller groups arranged in an informal way among participants. These groups have no formal structure or direction.

V/RHB ATTITUDES TOWARDS SELF-HELP GROUPS

On a related note, three participants commented that the Health Board does not understand the value/role of self-help groups.

P/M1: Self-help groups are grass-roots service providers but the Health Board doesn't understand this.

P/M5 and M12: Why doesn't the Health Board see prevention as an effective tool? . . . Does the Health Board care about self-help values?

P/M5: The Health Board/medical system has to realize that healing meetings (self-help groups) take pressure off the medical system.

Two participants stated or implied the same concern in their questionnaires.

Q/Q10: The problem for my organization is that a lot of the medical information we are giving contradicts the information the medical community gives out. In one sense this makes more work for the two "sides", each having to undo the "damage" done by the other side

and each side believing they are right! Our two approaches are so radically different I guess we leave one another alone. . . . It would have made a huge difference if we were supported, appreciated, and recognized by the medical community - let alone by society.

Q/Q12: Do nots - (1) not tokenize - also (2) not to use as a bin for all problems they don't know what else to do with. (3) Don't use us as a political entity. (4) Don't victimize members.

The fact, too, that most participants indicated their belief that the V/RHB had not adequately supported and involved their groups and that the Health Board may feel threatened by them may also imply that they felt that the V/RHB does not fully appreciate self-help groups. We can see similar feedback when participants commented on self-help groups as complementary health services.

V/RHB ATTITUDES TOWARDS SELF-HELPERS' EXPERTISE

On a connected note, one participant stated that the Health Board failed to see self Helpers as experts regarding their own health and health issues.

P/M3: The Health Board doesn't see members of self-help groups as experts about their lives even though it may recognize us as experts in our own work/study fields.

This concern also appeared in questionnaires. One participant made a recommendation to the V/RHB that it:

Q/Q2: Could recognize our expertise in our area and help us promote our group.

Another felt that the Health Board had failed to consider their expertise so far:

Q/Q7: Our organization has received no help of any kind from the V/RHB, not any information about discussions in which we might have been presumed to have information that might be useful to the Health Board or to the community as a whole.

USAGES OF HEALTH BOARD RESOURCES

The fact that so many participants felt that being more involved and supported by the Health Board could impact on them negatively does not imply that they do not see the possible beneficial effects, too. Most participants, whether in meetings or in questionnaires, indicated their desire to have such contact with the Health Board. No one stated or implied that they did not need such contact, even those most cautious about possible loss of integrity and control. Three, however, did not provide this information, one of them giving this explanation for not doing so.

Q/Q13: I'm unsure of what kind of support they can offer as I have no experience of it.

While in meetings, some participants gave general comments indicating their need and willingness to engage in such relations with the Health Board. For example, despite their concern about the potential for the Health Board to use support to control self-help groups, the following two participants still wanted to obtain its support.

P/M6 and M9: Self-help groups want to have funding to help them function as self-help groups, not to help the Health Board bring them into the mainstream health care system and regulatory control. With this in mind, self-help groups may be better off to ask for funding that meets their needs and ensures they maintain their independence.

In addition, even though one participant noted that some groups are independent, she also stated that some aren't.

P/M16: Some groups have a hard time organizing themselves, some have it easy in this regards. Some are self-sufficient, some need more help.

Three participants just felt that supporting self-help groups makes sense.

P/M3, M5, and M7: Getting money to groups would be productive. The money would be well spent.

P/M5: I now realize that self-help groups are entitled to support. Self-help groups meet social needs and using them is an innovative idea. Self-help groups are a good place to put money (funding). . . . This is a practical way to develop self-help group acceptance and use.

One participant stressed that self-help groups have a right to be involved in health planning.

P/M2: The Health Board should not put a limit on growth. Despite the difficulties of getting public participation, it should have continued to let the process be participatory and bottom-up. . . . Self-help groups have the right to control this participatory process, not just PHACs and CHCs, etc. . . . If the Board is interested in including self-help groups, it should go to self-help groups.

On top of this, the fact that a number of participants, both in meetings and in questionnaires, stated that they and their groups had initiated contact with the Health Board, is evidence that they want to be involved and supported.

Two participants suggested during meetings how they wanted to be involved in health planning:

P/M4 and M8: We don't need money just a voice and it would be good to have someone at the table at the Health Board to address issues.

Despite this downplaying of the need for financial support, we can see that there were, nevertheless, a number of participants who wanted such support and who gave examples of how Health Board funding should be applied.

Participants felt that, by being in control of how they could become involved in planning and what types of support they will accept, self-helpers can serve their participants and communities more effectively. In fact, the types of support preferred by participants, in general, reflected their desire to increase the quality and quantity of services they can provide to their participants and to maintain the sustainability, autonomy, and integrity of their groups.

In addition to wanting funding for various projects, the participants below would like the Health Board to:

1. provide funding for organizing self-help groups {M1} and offer guidelines for their organization {M3, M5, and M7};
2. provide/fund ongoing facilitator training {M1, M3, M4, M5, M6, M7, and M8} using a grass-roots, as opposed to acute

- care, format {M1} and to help develop a pool of facilitators and co-facilitators to help reduce burnout {M16};
3. provide or, preferably, give funding for, psychological counselling to members/facilitators to reduce burnout {M4};
 4. recruit new members for self-help groups {M3, M5, and M7}, market these groups {M3, M5, and M7}, and refer clients to them {M5};
 5. supply resources for the daily functioning of self-help groups, including child care, and for helping organizations like the Vancouver Women's Health Collective {M4 and M8};
 6. extend hours, increase staffing levels, and implement a 1-800 number {M12}.

This support can be given to self-help groups directly, through an umbrella, or both. If, indeed, self-helpers want to develop an umbrella:

P/M6: Organizations which can become umbrellas need more resources pumped into them to help meet needs (staff, space, and other resources).

Further, participants indicated that they would also apply Health Board resources towards:

1. helping to relieve isolation of members of the community by helping them access self-help groups {M6 and M9};
2. assisting participants in self-help groups to become more a part of the community {M9};
3. keeping self-help organizations/groups together {M6 and M9}.

These resources would also free them to do more than just provide direct services {M1} and to get more involved in community health planning {M12}.

In their questionnaires, most participants made

recommendations when asked to do so and some made related comments while answering other questions. These responses demonstrate their desire to have relations with the Health Board.

Some participants indicated the need for more support.

Q/Q3: Promote more funding resources to aboriginal agencies and community who work directly with Aboriginal community (grass-roots).

Q/Q5: If they really wanted self-help voluntary groups to participate, they should give us the resources to do so. Fund our services or at least pay for our time for attending. . . . Provide funding. We provide essential services. Give us at least some of the resources to do so. Without this, everything else is lip services.

Q/Q7: Our agency supports women in recovery from abuse - alcohol and drug, incest, etc. and refers many others to appropriate resources. It is possible that the V/RHB knows of our existence and that some of the many referrals we get from alcohol and drug agencies and others are through the Health Board, but we feel they could do much more to help women - if our alcoholism is affecting other people, there is a huge constituency out there! And we get no funding of any kind - a little help in that department would go a long way.

Q/Q8: Yearly or more often - meetings to report the services available to us and ask us what we would like to have. (I think we have wanted better distribution of our flyer so that women could find us.)

Q/Q11: (1) Encourage collaboration with Ministry For Children and Families. (2) Highlight self-help groups in publicity and media. (3) For us, to consider helping with training costs for our group facilitators and volunteers.

Q/Q12: Do nots - (1) not tokenize - also (2) not to use as a bin for all problems they don't know what else to do with. (3) Don't use us as a political entity. (4) Don't victimize members. Do's - (1) Respect groups for what they are. (2) Help provide a structure for support, development, monitoring (if needed), resources, stats gathering. (3) Refer. (4) Be as consistent as possible in an uncertain political

climate. (5) Aid collaborative process - with professionals and community.

One participant emphasized the need for more inclusion in health planning. For her, the Health Board should:

Q/Q16: -Listen to us. -Set up an interactive process that is population specific.

The remaining participants expressed their desire to be both included and supported by the Health Board.

Q/Q1: Believe a lot of your questions indicate how V/RHB can be supportive of self-help groups - including in leadership, in decision-making, talking or approaching most marginalized - have ongoing contact with self-help groups.

Q/Q2: Could recognize our expertise in our area and help us promote our group.

Q/Q4: To provide more guest speakers/staff to educate the group or to up-date them about Health and Health Systems.

Q/Q6: Let groups know of meetings/processes that are taking place so that they may be involved. Put self-help groups on mailing lists so they can receive information. Help with training needs. Funding. Take small groups' ideas/concerns as seriously as they do large agencies.

Q/Q10: I think that the V/RHB as a whole maybe feel threatened by self-help groups. Also probably, many self-help groups feel threatened by medical experts. The goal, I think, is to try and cooperate. We each offer different resources, also not everyone is comfortable with the informal, intimate self-help group setting. Like not everyone is comfortable with the medical setting. We need both. I realize I have not answered the question! Obviously, self-help groups should be included in meetings, should be consulted. Both sides should get together. . . . It would have made a huge difference if we were supported, appreciated, and recognized by the medical community - let alone by society.

O/Q14: -Distribution of a newsletter. -Sandwich/dessert meetings with/involving interested self-help groups. -Specific topics set up and invite groups to participate. . . . I believe the self-help groups would benefit by getting together to discuss community needs and set goals for implementing changes. . . . Assistance/support with fund raising issues for individual self-help groups. . . . Continue to enable groups to participate in community development programs, i.e., a self-help group has an information booth/table in a health fair show or mall.

DISCUSSION

Participants expressed their belief in self-help groups as viable complementary health services and as essential avenues for health planning and wanted the Health Board and health system to realize this value. However, as we have seen before, they also communicated a lack of trust in the Health Board's commitment to self-help groups and to including and supporting self-help groups. In fact, they felt they are not respected sufficiently by the health system, in general.

Participants had extended their duties outside their boundaries to varying degrees and invited the outside world within and, under the right circumstances, would like to increase these initiatives.

These communications reinforce our understanding of participants' loyalties to their groups and group members. They also tell us that participants recognized that the right forms of support and inclusion in health planning can serve the needs of their groups, their group members, and other interested parties.

THE POSITION OF WOMEN IN SELF-HELP GROUPS AND THE HEALTH SYSTEM

Issues specific to women in daily life and in the health system popped up in conversation on several occasions. These conversations involved a variety of issues.

P/M1, M6, and M9: Women run the majority of self-help groups and similar types of health services.

P/M2: Women with disabilities want their voices heard.

P/M9: Women make ourselves small for men and should no longer do so. Nelson Mandela's presidential address speech talks about how people should never make themselves small for others. . . . Women are in need of recognition by the health system.

P/M9 and M12: Women are the biggest users of the psychiatric system but there are few resources for them from community organizations. . . . Women with mental health problems are often given less respect than if they had other problems. . . . When women are not doing well, society blames us for our mental health problems, when we do well, they give the credit to doctors and their medicine. . . . Ignoring those marginalized leads to unexplored potential. . . . Women have to be treated better and fight for better treatment together in the health system.

P/M10: By embracing the whole thing [all aspects related to women and reproduction] we have a tremendous strength. [Brackets mine.]

P/M12: There is a lack of meeting women's needs in general.

Discussion

Throughout this exercise, participants frequently talked of how women were treated in the health system. We discussed numerous personal examples that were not recorded due to issues of confidentiality. Participants felt these anecdotes were too

personal to share and that, in some cases, they may reveal their identities. The findings of this exercise and the literature reviewed specify that women make up the bulk of self-helpers and other low or non paid health workers, they are respected less by the health system, especially if they have a disability, and they are marginalized. These responses are backed by the local studies I have seen (e.g., Gould, 1994a, 1994b) and become involved with (e.g., British Columbia's Women's Hospital and Health Centre Society, 1995) and the literature in the field (refer to Chapter 1).

PARTICIPANTS' UNDERSTANDINGS OF THE V/RHB AND THE HEALTH SYSTEM

We have seen a number of participants' communications about the Health Board and the health system throughout this chapter. These comments fell relatively easily into at least one category above. There were some comments, however, that were not so easy to place. To make sure they are included, I now list and, when necessary, summarize these remaining thoughts, starting with the Health Board.

THE HEALTH BOARD

Three participants indicated their dissatisfaction with the way Population Health Advisory Committees, Community Health Committees, and Neighbourhood Health Groups are structured and have evolved. One mentioned that she was not satisfied with the way her PHAC had treated her. Two talked of the faded

enthusiasm felt by members of these Committees and Groups as we can see.

P/M1: Many of the Health Board people involved in the initial needs assessment for this study have left and new ones have come on board. Those involved have lost their optimism and spunk due to the limitations they have been given.

P/M2: Neighbourhood Health Groups were not productive. My NHG was only effective in helping people to get to know their neighbours. This Group required far too much volunteer work. . . . I did some work with one NHGs and one PHAC but quit both. Radical members of my PHAC dropped out. . . . Support for Neighbourhood Health Groups has faded and so has their membership and activities. Members are now seldom meeting. With no support, the groups are giving up. They were also having to take on too much responsibility, especially given their lack of support. Enthusiasm has faded and they need new blood all the time.

Participants also made more general comments about the Health Board's committees and groups.

P/M1: Women on the WHAC are not yes women and just need to break out and have the freedom to act and get information, etc. . . . Some PHACs are into advocacy and are not acquiescent, while others are more conservative. I am disappointed in the progress of PHACs.

P/M2: The Health Board should give more money/resources (including larger stipends) to Committee members but if their voices aren't heard, all the money in the world won't help. Committees must include learning, i.e., participants should have the chance to acquire sellable skills, and money to help compensate them for their involvement. We just can't do this work for free. . . . There has been a problem filling my PHAC because a number of people have been boycotting it due to regionalization. This PHAC had problems. . . . Despite my NHG trying to get funding, it was unsuccessful. . . . I would like to have the freedom to move from PHAC to PHAC rather than to have to be stuck in only one. Committees may be working on

one passion I may be interested in and I would like the freedom to drop out and take a break. . . . People should go to the Committees we feel comfortable with and can go down to even smaller groups after (i.e., groups with even more differentiation). The Health Board should have hierarchies of groups, from larger to smaller or vice versa. In other words, there are subsets and overlaps regarding people's characteristics, needs, etc. (example: disabled person, disabled woman, woman). There is a continuum of narrowing of groups. We can also cross boundaries and understand similarities. We first need to feel comfortable with the smaller groups to which we belong and then branch out to work with others. . . . The people themselves need to recruit to represent larger group interests.

Participants also discussed other issues related to the Health Board. To begin, we saw earlier that two participants felt that the Health Board did not see self-help groups as tools for health promotion. They augment this by remarking:

P/M1 and M12: Why wouldn't the Health Board see prevention as an effective cost cutting tool?

From here, one of these participants adds:

P/M1: The Health Board didn't even give my idea about health prevention a place in its work. Acute care has a greater voice on the provincial level because it involves death and dying, etc., while issues such as prevention and support groups are not on the agenda.

Four participants felt it was confusing to talk about the Health Board for they really didn't know what it looked like.

P/M4 and M8: We are confused about the nature of the Health Board. For example, is it made up of volunteers?

P/M6 and M9: What does the V/RHB really means - its

boundaries, etc.? It is not just the Board of Directors but a huge set of people. This is confusing to people.

Four participants were concerned with more general issues of Health Board support, i.e., those extending beyond self-help groups.

P/M1, M6, and M9: Why do we have to keep re-applying to the Health Board for funding?

P/M2: The Health Board has resorted to generalizing to cut back on money but people are doing the work on a voluntary basis. . . . I can't understand why the Health Board refuses to supply individual attendants to people with disabilities. . . . A lot of small groups are losing their funding as they are amalgamating which violates the Closer to Home concept. "They are creating a monopoly when they are claiming they want to get out of it. They are just restructuring it differently."

P/M9: The Health Board has put my group's organization down; it has not funded it and has cut their Board.

Two participants talked about a problem with the Health Board's inclusiveness.

P/M15: The Health Board material and process did not meet personal needs so people did not develop interest and commitment. For example, at times, the people in my groups who handle incoming information would fail to pass it on because they felt it unimportant. Therefore, the information didn't filter through.

P/M6: I agree.

One participant discussed what she believed to be inherent problems of Health Board accountability.

P/M1: The Health Board has never defined its values. . . If it defined its values, it would have to be accountable to them. This factor has prevented it from doing so. To date, the Health Board has analyzed information its way.

Three participants ask:

P/M3, M5, and M7: How much information does the Health Board have for us and how relevant would it be for our more participant driven and centred approach towards health?

Another states:

P/M1: My ideas are too radical for the Health Board to support.

Further, in the Health Board's defense, one participants stresses:

P/M2: PHACs and health/social service organizations can't represent all people and there are factions which conflict in and between groups.

Finally, two underline that:

P/M1 and M12: The Health Board's intentions are there but . . .

In addition, a common reason why many self-helpers chose not to involve themselves and their groups in this study was that they felt that the Health Board would not listen to or act upon the results and that this study would, therefore, not justify their time and resources. (Refer to Chapter 3.) Further,

participants' responses reflected their general feelings towards the health system as a whole.

THE HEALTH SYSTEM

Participants had a great deal to say about the health system itself and all comments made, except for one, are rather critical.

P/M3: It is necessary for the health system to respect Mental Health consumers who are given labels and a stigma. It is necessary to break up the isolation of women in the psychiatric system.

P/M3, M5, and M7: We don't feel the psychiatric system is effective (e.g., re: re-hospitalization, etc.).

P/M9: Mental health issues are ignored/disregarded. . . The psychiatric system should look at the positive side and not the negative, i.e., it should de-stigmatize women in the psychiatric system.

P/M9 and M12: The psychiatric system must get away from the medical model and be more holistic, looking at women's total environment. Women have to be treated better and fight for better treatment together.

P/M10: The medical system preaches and is condescending.

P/M13: The medical system doesn't want alternative health practices. People changing the system are the most easily targeted.

This view that the health system deals inappropriately with mental health issues was considered especially relevant for self-help groups because:

M6 and M12: All self-help groups deal with some sort of mental health issue.

Last, but not least, we have our positive (hopeful) comment:

P/M5: Because people want it, more alternative health care is being included/covered by BC Medicare.

DISCUSSION

The responses made here show the same lack of trust and faith in the Health Board and the health system shown elsewhere in this paper. Moreover, they reflect a major point made frequently in the literature, i.e., that self-help groups and the mainstream health system still have differing attitudes about health, health care, and health planning.

CONTACTED STAKEHOLDERS

Contacted stakeholders were divided into two categories - self-helpers and V/RHB members. Information provided by the latter stakeholders is included in Chapter 3. Information given by self-helpers is presented below.

Three self-helpers contacted gave me some information that applies to this evaluation but did not become participants. This material is included, here, without any coding.

When I talked with the first contact, she asked me what I heard about the Health Board's receptivity to self-help groups. She then informed me that the gossip was that it was not participatory and does not listen. Interestingly, she underlined that there was one member of the V/RHB that was approachable. I told her that this woman no longer worked

there. To this, she replied: "If she got out, this is a good indicator to follow" regarding the quality of the environment at the Health Board. This woman said she was impressed with this Board member (a Board director) for, unlike the others, she did not put on airs and she spoke understandably from her own knowledge. This participant then explained that women with disabilities are ignored and that the V/RHB is not interested in listening.

The next contact stated that their group/organization received no real help from the Health Board. Like other stakeholders from self-help groups, she also asked whether this study would benefit the Health Board or her group. Finally, she noted that she was unaware that there was a Population Health Advisory Committee representing her group.

The last contact said two simple things: (1) women are marginalized and not taken seriously and (2) the problems we are facing are issues of control.

I have already noted the reasons commonly given for self-helpers' failure to partake in this study. To review, these are lack of trust in researchers, professionals, the Health Board, and the health system; lack of time and resources; and the vulnerability of their members and the need to help them heal before they are able to engage in other activities.

WHERE TO FROM HERE?

Chapter 5 looks at how well this exercise maintained

methodological integrity while generating methodological findings and substantive outcomes. The remainder of this dissertation continues to analyze this information and looks at the implications we can draw from it.

END NOTES

1. I went to this same conference and attended a V/RHB workshop on the relationship between the Health Board and self-help groups. The two Board members facilitating this workshop (I believe both were volunteers) replaced this theme with an opportunity to provide workshop participants with an overview of the Health Board's New Directions Initiative.

2. The average rating (rounded) for all indicators of participation and support combined is 1.6 on a scale from 1-5. Separately, each of these two categories of indicators also has the same rating of 1.6. The highest indicator averaged 2.0 and the lowest indicators averaged 1.3. None of the averages for overall ratings of each indicator had a rating of higher than 1.7. These ratings can be used as baseline measurements.

The ratings given by individual participants for individual indicators (overall ratings) and sub indicators range from 1.0-4.5 and 1.0-5.0, respectfully.

3. This was the only participants (i.e., Q9/M2) who gave me permission to associate her questionnaire responses with notes taken during meeting.

4 See Dahl (1982) for discussion regarding the dilemmas of pluralist democracy.

5. In most cases where passages are placed into blocks of passages, I have organized them numerically by code numbers, (e.g., passage P/M2 would be followed by passage P/M5). When there was more than one participant code, I used the first code number in a string (P/M2, M4 would be followed by P/M3). Further, P/M6 would occur before P/M6, M9. I did not use this system, however, when this would have interrupted the flow of ideas from one passage to another as it would have here.

CHAPTER 5: DISCUSSING METHODOLOGICAL INTEGRITY AND
PARTICIPANTS' ASSESSMENT OF THE EXERCISE

INTRODUCTION

This chapter summarizes and assesses the methodological and procedural steps taken during this participant designed exercise to achieve the standards of methodological integrity prescribed by Guba and Lincoln (1989) and Lincoln (1992) in Chapter 2. It also documents and analyzes comments made by participants which assess the success of this exercise, including the questionnaire, in regards to fulfilling: (1) the goals and objectives set by participants and me and (2) the principles inherent in participatory evaluation. (See Chapter 2.)

MAINTAINING METHODOLOGICAL INTEGRITY

This section examines each of Lincoln and Guba's methodological perspectives one-by-one and gives a brief summary of how they apply to this exercise. More precisely, it looks at the general environment and impact created by following these guidelines.

It is vital to point out here, however, that this section represents the analysis I completed on the evaluation exercise before I became familiar with current discourse concerning the conflict versus consensus approaches to evaluation. It is also important to repeat that the exercise went ahead without the presence of the Health Board. The significance of these facts

will become clear at the end of this section when I make them central components of my concluding analysis.

A RELATIVISTIC ONTOLOGY AND MONISTIC, SUBJECTIVIST EPISTEMOLOGY

We recognized that each participant brought her own constructions of reality into the exercise and that no one person has perfect, indisputable knowledge. Each participant had different experiences which shaped her understandings and had different abilities to express these. Participants, as can be seen in Chapters 3 and 4, held very similar views about the role played by the Health Board in including and supporting them, about the value of self-help groups, and about similar issues dealt with in the exercise. They were also open to learning from each other and were aware that, without the Health Board's input into the exercise, they acquired a somewhat incomplete and "biased" view. It is also true, though, that Board members' knowledge is not perfect. Neither is their ability to share it. A number of participants had tried to develop relations with the Health Board for months, and even years, and have, therefore, developed some insight into the ways Board members "know and do". Further, many had considerable knowledge of the Health Board in general (see the section on Ontological and Educative Authenticity).

As shown in Chapter 3, each participant's input influenced what others came to understand and what they said. Through direct and indirect communication (face-to-face and carefully relayed information), each participant acquired and gave new

understandings. Their final "truths" were sum products coming out of this interaction.

The knowledge they generated through this exercise is expected to be put to use to elicit feedback from the Health Board, to create new "truths" based on such interaction, and to promote changes based on these "truths".

By acknowledging, honouring, and sharing our information and understandings and recognizing how these shape the realities we see, or create, we have adopted a relativist ontology and monistic, subjectivist epistemology. By abiding by these alternative methodological perspectives, we were able to acquire subjective, experiential, lay, and, even, professional knowledge from participants and to generate new, more complex, and more complete understandings and constructions relevant to self Helpers, their communities, and the V/RHB. Participants' comments made during the evaluation exercise indicated that they benefited from each of the criteria of authenticity discussed below. (See participants' assessment of the exercise to follow.)

HERMENEUTIC METHODOLOGY

Carried out in various natural settings throughout Vancouver (e.g., offices, homes, public meeting places, and my car), this research embraced a naturalistic, hermeneutic methodology. By being in control of the places we met and how we interacted, participants played an active role in determining context. This exercise, however, took place in a larger context, a fact that

participants were aware of and discussed. During meetings, participants talked of both general and specific issues related to our context. Participants came into the exercise with the common understanding, for example, that the Health Board's community participation initiative was relatively new and that it had been overshadowed by a long, ongoing history of top-down health planning and health care.¹ We believed that women, especially those who are marginalized, have been treated relatively unfairly in the health system.² We were also aware of the general economic situation, the resulting decline in resources including human resources and funding, and the unequal distribution of these resources.³ Finally, we felt that these and similar factors had impacted on self-help groups and on how well the Health Board involved and supported them.⁴

We recognized that, as this exercise unfolded, participants' environments and experiences changed along with their understandings of their relations with the Health Board. These changes were partially the product of participants' involvement with the exercise itself and partly the result of their interaction with their external environment.⁵ Participants were encouraged to learn from, and during, this process and to share what they learned before and during their involvement. Throughout meetings, participants gave such information freely.

Participants had the freedom to come and go as they liked and their "mortality" (i.e., cessation of attendance), itself, provided valuable information. For instance, this exercise stopped meeting some participants' needs, some participants had

other, more pressing, responsibilities, and some participants ran out of time and resources.

Participants contributed to the generation of knowledge (e.g., their understandings of their relations with the V/RHB and how to conduct an effective participatory evaluation) in a variety of ways (e.g., through various types of meetings and through the questionnaires). Each dialogue during meetings was followed by subsequent feedback and revision. All information provided by participants that they did not deem confidential (see Chapter 3) was made available to every other participant to review, understand, question, and build upon until we arrived at some common final product.

By including the natural context as part of the exercise, rather than conducting the exercise in a laboratory, and by working together to develop common understandings, we generated knowledge that is relevant to participants and that can be used by them to take appropriate action (e.g., organize bottom-up efforts to help the Health Board more effectively support the role of self-help groups in health promotion), whether this knowledge is considered absolute truths or perceptions. Had we worked with the Health Board, we could have had more rounded and externally validated knowledge that could have led to even more appropriate action. Future initiatives stimulated by this exercise to involve the Health Board may give us this more complete and practical knowledge.

CRITERIA OF TRUSTWORTHINESS

This exercise was designed to meet Lincoln and Guba's criteria of trustworthiness which relate largely to maintaining methodological rigor. These methodological perspectives include the criteria of credibility, transferability, dependability, and confirmability.

Credibility

This exercise worked with participants to maintain credibility. Participants and I brought our own constructions (i.e., the ideas and understandings we developed in our lifetimes) into this exercise with us. Through interaction, we got to know each other's constructions and participants were given the opportunity to check the accuracy of my recording and analysis of these constructions. Despite the limited direct involvement of most participants in the final recording and analysis of information, participants were involved in ongoing analysis throughout meetings. They not only provided information, but continuously interpreted and reinterpreted information as it was generated. Further, their recommendations added significantly to my ability to analyze and explore implications. The whole process was both a learning experience and a system of checks and balances to ensure I, as the recorder and primary analyzer of the information collected during this exercise, did not misinterpret what participants had to say.

Transferability

Working hypotheses (i.e., dynamic assumptions regarding the relationship between self-help groups and the V/RHB) were developed by participants and left open to contradictions. This was done by supplying as much detail as possible to the reader (i.e., self-helpers; members of the Health Board; planners, especially in the field of health promotion; and others with an interest in this area) and to help them determine if they agree with these hypotheses and if they believe our exercise can be applied to other evaluations. This detail includes the working hypotheses, the general description of the participants and other stakeholders, where and how we met, and other processes and methods involved. The geographical location was described and the local context given. In this way, participants were able to see that the procedures used and issues generated in this exercise may be applicable to self-help groups (and other complementary avenues of health promotion), in general.

Dependability

In step with the methodological perspectives of participatory evaluation, this exercise emphasized consistency of data over time. As the primary agent responsible for recording and analyzing information generated, I was deeply concerned with ensuring the information was being accurately collected, recorded, and analyzed throughout the exercise and asked participants for feedback on whether this was being successfully accomplished. For this to happen, it was necessary

to maintain a flexible methodology and framework that adapted to changing circumstances, needs, and levels of understanding.

Confirmability

Participants were continuously given the opportunity to examine the information they gave me and to confirm whether I, as recorder and analyzer, "got it right". Each participant had the chance to check the data she presented to me, whether this information was accurate after being summarized and resummarized, whether I successfully represented the constructions created through interaction, and whether we agreed with the logic used to do so. Equally important, however, participants were given the chance to play an active role in collecting, recording, and analyzing information. As noted earlier, the limited direct involvement of participants in the presentation and analysis of information was partially compensated for by the opportunities they had to analyze the information throughout the exercise and to make recommendations necessary for analyzing and drawing implications.

Discussion

By meeting these four criteria of trustworthiness, we accurately captured our real voices as they were in our natural context and as they changed over the duration of the exercise to reflect changes in our context and circumstances. We provided a dynamic, hermeneutic participatory evaluation process which respected a relativistic ontology and a monistic, subjectivist

epistemology. In turn, we met criteria of trustworthiness parallel to those in the scientific paradigm and concurrently gave a voice to more marginalized people and groups who have valuable knowledge for the field of health promotion.

Furthermore, by recording full details of the exercise and its context, we enabled participating self-helpers and other readers to judge for themselves the potential of the substantive and methodological lessons we generated to be applicable to health promotion initiatives involving self-help groups in general or to other complementary avenues of health promotion. This, in turn, can serve to provide a broader and stronger base and position for self-help groups to request Health Board support for their role as avenues of health promotion as well as offer an effective participatory evaluation model for enhancing relations between self-help groups and the Health Board.

CRITERIA OF AUTHENTICITY

During this participatory evaluation exercise, I also worked with participants to maximize our potential to meet all of Lincoln and Guba's criteria of authenticity - fairness and ontological, educative, catalytic, and tactical authenticity. This was not as straightforward as meeting the criteria of trustworthiness.

Fairness

This participatory evaluation exercise was open to all members of Vancouver-based women's self-help groups and to all

staff at the Vancouver/Richmond Health Board. With the help of participants, I took considerable time to locate all qualifying self-help groups and letters of recruitment went out to each. Not all self-help groups were easy to locate, however, which means that, despite this effort, there may have been some groups inadvertently left out. I also made sure that all relevant Health Board members were invited.

As indicated in Chapter 3, all participants were given and took the opportunity to involve themselves as thoroughly and actively as they wanted to and to express their viewpoints. Multiple avenues of communication (i.e., various types of meetings and the questionnaire) were used to ensure they had this opportunity and they were comfortable using it.

All participating self-helpers were willing to work with Health Board members and share their understandings one way or another. Initially, contacted Health Board member expressed a similar sentiment about working and learning with self-helpers.

Ontological and Educative Authenticity

As a researcher and co-participant, I explained to participants that they should consider themselves as experts (through experiential, lay, and, sometimes, formal knowledge) regarding their own lives and the issues addressed by their self-help groups. They were encouraged to: (1) explore and analyze the issues they felt were important and to do so in their own way and (2) share their opinions and work together to understand each other's. This held true regardless of how

participants met, i.e., whether they met with me alone or with others within or outside their own exercise groups.

As a researcher, through general conversations, I relayed information generated, reviewed, and "released" by participants for general use from one individual or group to another. Feedback was obtained in successive rounds.

As mentioned in Chapter 1, I came into the field with some biases and developed some along the way. Following the principles of PAR, I acknowledged these to participants but made sure that these individuals were free, and comfortable enough, to express themselves and their biases, in turn. These self-helpers appeared confident with their own opinions and beliefs and we were all open to learning from each other.

The exercise achieved ontological authenticity by cultivating our own emic perspectives. It partially achieved educative authenticity by learning about and respecting the etic perspectives of participants in other self-help groups/organizations. The exercise was limited, however, in its ability to capture the etic perspectives of Health Board members, due to the absence of this group. As mentioned previously, participants had some knowledge of this stakeholder group and their health promotion efforts. They acquired this knowledge from first-hand experience, academic literature, and the media. Further, participants were willing to share this knowledge and their understandings with other participants. Moreover, I found that many participants were not only open and fair about their evaluation of the Health Board but those who

saw positive aspects of these other stakeholders and their initiatives helped to enlighten other participants about them. Positive comments can be seen throughout the substantive material presented in Chapter 4. As we can see in this previous chapter, there were times too when participants held themselves or their groups responsible for the lack of relationship development they saw between themselves and the Health Board.

Catalytic and Tactical Authenticity

Falling within the realm of PAR, this exercise was concerned with generating ongoing action throughout its history and subsequent action based on results. In fact, this entire evaluation exercise was action, in itself, which branched into many sub components.

The exercise was designed to empower participants and help them improve their sense of self worth by giving them and their groups a voice and by helping them to organize. Empowerment is not only an end but also a means to an end or, in other words, empowerment is not only a product of the exercise but also a catalyst to bring about changes (e.g., organizing bottom-up efforts to enhance relations between self-help groups and the V/RHB and enhance the position of self-help groups in health promotion). We can see this as a cyclical process. The more empowered a participant is, the more she is likely to take action and action, in turn, can bolster confidence (see Green et al., 1995; Green and Kreuter, 1991; and Lindsey and McGuiness, 1996).

Participants indicated that the exercise helped them become empowered and to organize, gave them knowledge, raised their consciousness about the value of self-help groups and their right to be more involved in health planning and supported by the Health Board. They also stressed that they intend to be more active about involving themselves in health planning and in acquiring support. (See participants' assessment of this exercise to follow.)

Lastly, the fact that, despite their limited time, resources, and staff, participants were willing to do this research and were willing to organize during this exercise and in the future to do presentations and follow-up focus groups with the V/RHB, gives an indication of the catalytic nature of this exercise.

Discussion

In Chapter 2, I summarize the discourse between advocates of conflict versus consensus approaches to participatory evaluation. In our evaluation exercise, this discussion is integrally linked to the Health Board as a stakeholder group and to our ability to fulfill Lincoln and Guba's criteria of authenticity.

Conflict and Control. Had the Health Board participated in our evaluation exercise, the potential inequities in power distribution could have created conflict between our two sets of stakeholders in regards to:

1. influence over the development of the evaluation;
2. freedom, or perceived freedom, to express opinions about Health Board inclusion and support for self-help groups;
3. perceptions about such inclusion and support and about the health system; and
4. the need to transform the health system.

Here, we could predict that self Helpers would be the disadvantaged stakeholders when confronting the Health Board. This would vary, of course, between self Helpers, given that some were more marginalized than others. It would be unlikely that a Health Board member would feel intimidated by the evaluation process, but a number of self Helpers were intimidated sufficiently to keep their involvement confidential. There were also the participants who wanted their questionnaires kept anonymous.

This exercise revealed that several participants, as women and self Helpers, felt intimidated by the Health Board and health system as a whole due to their past experiences. Additionally, some participants had engaged in direct confrontation with the Health Board prior to, and even during, the evaluation period and felt their voices weren't heard or respected. By expressing their opinions to the Health Board, or even about the Health Board, participants felt they may run the risk of not having their groups, or the organizations and networks they may belong to, supported or included in future health promotion initiatives. Some also worried about personal ramifications.

A number of participants would either not have met with the Health Board within this exercise or would not have expressed their true emotions if they did. Further, all participants were more willing to express their views without the presence of these other stakeholders.

The results of this evaluation suggest that participatory evaluation is an ideal tool for involving self-help groups. When we invite members of a health board/region into a participatory evaluation, however, we have to guard against professional control and understand the reactions self-helpers may have to this potentiality. We can reflect on the literature in Chapter 2 which informs us that: (1) people typically form and join self-help groups as a reaction against the professional health care system and (2) self-helper have a tendency to reject being regulated or dominated by professionals within and outside their groups.

Even though I was aware of these characteristics of self-help groups and the status of women in the health system, and I knew that there had been some previous tension between many self-helpers I met and the Health Board, I felt these two stakeholder groups could work together during the exercise. The Health Board had given its permission to conduct the evaluation, key Health Board members had indicated a strong desire to get involved and work with self-helpers, and self-helpers kept joining the exercise with an equal enthusiasm to involve the Health Board in some way. It was only after the exercise had started that I became aware of the nature and extent of this

tension and the impact this would have on the exercise. The nonattendance of Health Board members itself created contention.

Camaraderie and Consensus. We might question, therefore, whether Health Board members and self-helpers would have been able to reach a negotiated agreement on the structure and processes of the evaluation and on the quality and quantity of inclusion of and support for self-help groups in their community participation initiative?

Perhaps establishing trust and developing working relationships between self-helpers and the Health Board may take more than just one bottom-up evaluation process. We can look at Lincoln and Guba's criteria of educative authenticity as an ideal, an ideal we were unable to completely obtain in the exercise. On the other hand, whereas we may have lost some methodological integrity due to the absence of Health Board members and our inability to work directly with them to acquire and appreciate their perspectives, we were able to gain some information we may not have been able to had the Health Board been involved. We were uninhibited by the presence of the Health Board and we had the opportunity to build a sense of camaraderie and trust amongst ourselves. Moreover, it is essential to repeat that all participants were willing to involve Health Board members in the evaluation whether they were willing to meet them face-to-face or not.

Participants and I did not intend to engage in an evaluation without Health Board members or even start without them. We did

not try to exclude them to protect ourselves from potential intimidation regarding the expression of our perspectives or the development of the evaluation process or questionnaire. We were simply left part way through the evaluation without Health Board involvement.

In fact, even though participants to varying extents were relieved when the Health Board chose not to get involved, they were also quite disappointed that they did not have this input or the chance to share their understandings one way or another. Being so far into the evaluation and discovering that the Health Board was not going to become involved, what could participants and I do? We had to decide whether we were to terminate the exercise or continue with the understanding that it was a decidedly different type of evaluation due to this omission.

Going Forward. Participatory evaluation can involve a continuum of participant involvement and it may be difficult to determine where along this continuum an evaluation must fall before we can discount it as a participatory evaluation.

Giving the opportunity for involvement does not make it mandatory. This brings us to an important point. Given the level of participant involvement in the exercise, like Wuest and Merrit-Gray (1997, p. 296), we can ask: "How much and what form of participation is appropriate for the endeavor to be considered participatory?". Greenwood et al. (1993) stress that we cannot know *a priori* how participatory a PAR initiative will be.

Participation is a process that must be generated. It begins with participatory intent and continues by building participatory processes into the activity within the limits set by the participants and the conditions. To view participation as something that can be imposed is both naive and morally suspect.

Thus, we treat participatory action research as an emergent process in all cases, placing it on a continuum ranging from "expert research" to participatory action research. (p. 176).

Mark and Shotland (1985) point out that we do not know the "type or level of stakeholder involvement required for effective evaluation" (p. 605). Furthermore, it is commonly understood that evaluation can be placed on such a continuum (e.g., see Fawcett et al., 1996; Green et al., 1995; and Rifkin et al., 1988).

Greenwood et al.'s understanding can be applied to participatory evaluation. An underlying tenet of participatory evaluation is that participants have the right to choose for themselves how fully involved they become regardless of what mechanisms researchers have put in place to enable this participation. We can't force participants to involve themselves more than they are willing or able to and we cannot force stakeholders to become involved in the first place.

When an interest has been demonstrated by stakeholders or a set of stakeholders, however, we have to start with the general assumption that they will ultimately come on board. Given participatory evaluation's emergent nature, we have to bring participants into the process when they choose to do so. If we wait for every possible participant to get into the evaluation, which is in almost all cases an impossibility, we could never

start. The gamble here is that we may have so few participants, that it would limit the amount of shared learning possible or, worse yet, that an entire stakeholder group may opt out of the process altogether.

What happens when one of the two stakeholder groups chooses not to join in the evaluation? Does this silence the voices of the remaining stakeholder group or does it force this group to create alternative means to engage in evaluation and have its voice heard?

Further, traditionally, health planners have conducted evaluations without including recipient stakeholders and their methodological and substantive findings were seldom questioned. Similarly, if health promotion researchers were to invite participant involvement and, for whatever reason, this group did not participate, would the public question the decision of these planners to continue with the evaluation? Would it matter if participants weren't adequately informed, felt the process was not going to fairly represent them or be in their best interest, or just didn't want to put the time and energy into participating?

If we turn the scenario around and document an evaluation process which continued despite non participation by the implementing stakeholders, why would we be any more likely to question the findings or be justified in doing so?

This brings us to an important consideration: Should we measure how participatory an initiative has been based on its intentions and opportunities given to stakeholders to get

involved versus the actual outcome (representation of participants and the amount of time participants chose to contribute to the initiative)?

The potential existence of conflict and power inequities does not negate the value of participatory evaluation. This form of evaluation, in fact, places participant empowerment in a central position. It is just essential to find alternative ways of sharing knowledge and learning from each other that take these factors into considerations and ensure the evaluation adds to rather than detracts from participant empowerment. Critical evaluators themselves agree with this (Boyce, 1993; Paulston, 1983; Sirotnik and Oakes, 1990).

By going forward with or without the Health Board, we managed to accomplish three things:

1. Justify and honour, participants' investment in the exercise by continuing the evaluation;
2. Find alternative value in conducting an evaluation that only involves the recipient stakeholders (e.g., benefits for participants and their groups and contribution to knowledge in the area of health promotion theory and methodology); and
3. Explore alternative ways to involve the Health Board to ascertain and appreciate their perspectives and further add to health promotion theory and methodology.

Empowerment and Equity. Our exercise placed a great deal of emphasis on trying to maximize the benefits of being involved. It was intended to empower participants and bring about action (i.e., realize catalytic and tactical authenticity).

Participants indicated they felt empowered by:

1. being involved in, and gaining control over, the evaluation process;
2. organizing as women self-helpers;
3. having the opportunity for their voices to be heard, recorded, and presented; and
4. having the potential to create change in health promotion strategies and in the health system.

In retrospect, we can see this evaluation as one which would have partially offset the power inequities between self-helpers and the Health Board, even if the Health Board participated. This is so because, unlike the participatory evaluations I have seen in the literature (see Chapter 2), this evaluation was initiated from the bottom-up by the researcher in response to a needs assessment conducted in the self-help community, as opposed to from the top-down from a researcher within a planning body or hired by one.

Further, due to the fact that self-helpers became involved very early in this process, they had maintained control over the evaluation. Had Health Board members eventually become participants, they would have entered with this disadvantage.

Encouraged by the principles of participatory evaluation, participants maintained control over the decision to continue the exercise despite the nonattendance of the Health Board. They not only chose to continue, but they decided upon alternative ways of getting a dialogue going between their groups and the Health Board.

To sum, in effect, catalytic and tactical authenticity were more completely realized at the expense of achieving full

educative authenticity.

A New Evaluation Process. This exercise was intended to have two different stakeholder groups invest considerable time spread over the entire evaluation. In reality, we had one one set of stakeholders who, due to insufficient time and the desire for anonymity, had more limited input confined largely to the needs assessment, design, and implementation stages.

Without full participation, there may be times when analysis of results can be incomplete and, at best, speculative. In our study, for instance, how do we explain the few inconsistently high ratings some participants made on some (sub) indicators in the questionnaires when we were faced with barriers such as time and participants' requests to remain anonymous? Without all participants reviewing all my work, how do we know whether they will agree with the way I wrote the final draft of the questionnaire or processed, recorded, and analyzed information they provided (i.e., confirm my interpretations)? On the other hand, given that participants contributed as much as they were willing and able to, we have to accept this limitation so long as we acknowledge it. Similarly, we have to respect the decision of the Health Board not to participate and we have to accept that they had no opportunity to validate substantive findings generated without their collaboration.

We can also see that this evaluation exercise gradually came to address conflict and inequities related to control. We can note that, due to the absence of the Health Board during our

evaluation, participants had the opportunity to express their perspectives freely without feeling intimidated by these other stakeholders. Having had this opportunity, participants can agree to let those self-helpers unintimidated by the Health Board take essential information to them so as to be heard and understood. Further, some participants indicated they were less intimidated about working with the Health Board as a result of their involvement in this exercise (See the evaluation assessment to follow).

With this in mind, we can see this exercise as part of a pilot study acquiring baseline feelings and perceptions on Health Board inclusion and support and providing invaluable methodological/procedural lessons for health planners. Better still, we can consider this to be a first, and vital, stage of more participatory evaluation and general planning processes to come.

By involving participants in this first stage and providing an environment conducive to building trust and helping participants to become empowered, we may have helped to even out the power imbalances that exist, changed perceptions about these imbalances, or accomplished both. In turn, this may increase participant involvement in evaluation exercises and other health promotion initiatives in the future.

This exercise could be a prerequisite for breaking down barriers that may exist and for developing better relations between these stakeholders. Whether a consensus can be reached by both self-helpers and the Health Board is an impossible

question to answer at this time. We can ask, however, whether it is essential for these two sets of stakeholders to arrive at some common understanding or if it sufficient simply to ensure participants document and share their perceptions and understandings with the implementing stakeholders with the hopes of some day working closer together on health planning issues.

A New Understanding of the Evaluation. In summary, the exercise successfully achieved four of Lincoln and Guba's criteria of authenticity (i.e., fairness, and ontological, catalytic, and tactical authenticity) and three of their criteria of trustworthiness (i.e., credibility, transferability, and dependability). On the other hand, given the nature and extent of participant involvement and the absence of the Health Board, it only fully realized educative authenticity for the stakeholders that participated and only partially maintained confirmability. Finally, even though we set out to abide by Lincoln and Guba's methodological perspectives, this exercise adopted an ontology, epistemology, and methodology that reflected both consensus and conflict approaches.

Our evaluation exercise revealed an important finding: Rather than seeing a dichotomy between conflict/empowerment evaluators versus consensus evaluators, we can see a continuum. The major factors that will determine where an evaluation will fit along this continuum are: (1) the extent to which conflict and power imbalances are expected to impact negatively on the evaluation and the potential to bring about social justice; (2)

participants' intentions/motivations; and (3) who were in control over the evaluation. We can, however, also see elements of both approaches in one participatory evaluation, the desire to use the evaluation to critique and make a transformation and the desire to work collaboratively for the common good. Using the words of Weiss (1986a), we can both both judge and aid the health program.

Our evaluation had both elements, but participants' ultimate goal was to be collaborative, evidence for this being their desire to involve the Health Board during the evaluation and the decision to find alternative ways to engage the Health Board. We ended up deciding to, and being forced to, make incremental changes in a more collaborative fashion than to adopt a one-time revolutionary approach. Some evaluators even note that evaluation is not a panacea and that evaluations have to consider that programs are not perfect either. Both evolve.

The critical evaluators I note in this dissertation focus primarily on the impact of conflict and power imbalances on participants' ability to change the distribution of power and resources or to influence the program they are evaluating by using evaluation as an empowerment tool. Less attention was paid to the potential of conflict and power imbalances to inhibit participant empowerment within the evaluation and their ability to acquire an equal role in designing and implementing the evaluation. Participants felt we could use this evaluation to become empowered and to mobilize. For many participants, this is a necessary first step.

I relate this to social versus direct participation (see in Chapter 3, page 130) and suggest that our exercise fell somewhere in between. We could have adopted: (1) a conflict-rather than consensus-oriented methodological stance and (2) a transformative rather than a subjectivist, relativistic position, considering that the evaluation context involved conflict and inequities and that the goal of social justice is not arbitrary nor relative. Our reality, however, was a more peaceful and collaborative process, given that only one type of stakeholder participated; participants' desire to work collaboratively with the implementing stakeholders; and the bottom-up, flexible, and participant controlled nature of this exercise. Further, whereas participants felt strongly that they have experienced inequities in the health system and that the system has to be transformed, there was an overriding desire to first work with, but by no means within, the health system to share perceptions and to ascertain the actual "truths" they were to address. Armed with this stance, we may someday realize educative authenticity between self-helper and the Health Board.

PARTICIPANTS' ASSESSMENT OF THE EXERCISE

This section presents information provided by participants regarding the value of this exercise for them, their self-help groups, and their communities. It also looks at participants' assessment of the questionnaire they completed.

EVALUATIVE COMMENTS PROVIDED DURING MEETING

Seven out of the nine core participants engaged in this exercise gave a variety of comments during meetings about the value of this participatory evaluation, despite not being asked specifically to do so. In other words, this information was volunteered spontaneously during conversation. Some of these comments were directed towards me as a participatory action researcher and can be applied to anyone engaged in this form of research, some were aimed at the exercise (which they call a study), and some at the study itself. Please refer to Chapter 3 for information on how these passages were organized and presented.

P/M1: Due to the fact that the Health Board says it recognize the value of self-help groups, this project may point it in this direction. . . . The empowerment coming from this work is important, in itself.

P/M3: Power to you [the researcher] for listening to women's voices and showing what we need. I am grateful for the opportunity to have my voice heard and to challenge the Health Board. My group and community have a point to make. . . . This project may help decrease the number of people needing formal health care. Your writing info on what women have said will be a big help. I am happy about having a voice regarding what is relevant to us. [Brackets mine.]

P/M3, M5, and M7: This framework has considerable complexity and you [the researcher] have done a lot of work for the Health Board that will benefit it. . . . This is empowering. The participatory evaluation is empowering. . . . Value is also in the process' ability to generate new ideas and stimulate communication between self-help groups and the Health Board. . . . This project gives a method to ensure self-help groups are in existence. It allows self-helpers to say what they think. [Brackets mine.]

P/M5: I am impressed with your [researcher's] vision regarding participatory planning and the involvement

and support of self-help. . . . Your work reflects a wisdom. People will recognize that community development can be used as a community-oriented approach. . . . Your published dissertation will serve as a written record. It may do so even undocumented. Your work is innovative and ahead of its time. You're pointing the way and making a change in the world. If the Health Board ignores this project, at least something has been done. This work is "exciting, powerful, and threatening". This study is breaking ground and may never be recognized. This study represents self-help groups in action. This study helps document women's wisdom. It looks at inner self-knowledge and appreciation of self. I am worried that women's history is frequently erased. This work is in the same boat as other women's work about women's history. This project is articulating verbal tradition and a way of working together. It is defining this way of healing and how it can be measured against a drug. It is in touch with sources. Keep talking and get it on paper. [Brackets mine.]

P/M6: Through this study, we can help get the word out about the existence of self-help groups for women "in need" and who are isolated, and so on. We can make the Health Board more aware of what self-help groups exist. . . . We can help make people aware of the Health Board's existence.

P/M6 and M9: This evaluation will give us valuable information.

P/M9: One member has come out of her shell and this has opened up group dynamics, i.e., broken down barriers in the group. . . . You [the researcher] got good feedback in a short time. . . . Having participants come up with ideas and having them validated and appreciated is great. This respects unrecognized intelligence. Given our marginalized status, it is especially important for us to have our voices listened to and to be included. This helps us to realize our value and empowers us to talk to others. It raises expectations in our communities. . . . It is important to ask people to identify their needs because no one asks them. Providing a place on the questionnaire for participants to make comments will help the Health Board understand that this study is a valuable, empowering process. [Brackets mine.]

P/M12: Groups like mine seldom get asked to become involved in this type of study. . . . This study could become the beginning of involvement and recognition. . . . This study has helped my group's members to reflect on what their needs are and what they want to

do. This process has taught me a great deal and I have enjoyed the experience. This study has made me aware of our rights as self-help groups to acquire funding and be supported. Further, your [the researcher's] papers on self-help groups and health may prove helpful. [Brackets mine.]

DISCUSSION

Combined, these comments cover the range of criteria of authenticity. Participants talked of fairness and ontological, educative, catalytic, and tactical authenticity.

It is not surprising that those who were most involved had the most to say about the value of this exercise, especially as it relates to them and their groups. Being a participatory evaluation, a branch and stage of PAR, this finding is not at all unexpected. The process, alone, should produce these feelings, and the more a participant is involved, the greater the chance that all criteria of authenticity will come into play.

The fact that other participants did not volunteer this information does not suggest that they did not find this exercise of particular value to them and their groups. Their involvement, alone, reveals this message, because, as mentioned before, participants became involved and remained with the exercise because they believed it would meet, and was meeting, their needs and the needs of their groups and communities.

By being actively involved in this exercise, participants played a productive role in ensuring this exercise met their needs. In other words, they were indirectly praising their own efforts as well as built-in features of participatory

evaluation. Of course, the more involved they were, the greater was their chance of making this exercise meet these needs. The beauty of this evaluation exercise is that it was designed to meet participants' own needs. When they felt it was not doing so, or would no longer do so, they were "free" to opt out. With this in mind, they had little to lose from an exercise they considered to be a failure. By being actively involved, however, they played a role in its success. This means that the earlier stakeholders were brought in as participants, the earlier they had the opportunity to influence the direction the exercise took and the earlier they could make it meet their needs and contribute to its success. My work in this exercise was simply to facilitate this process, contribute as a co-participant, and support participants' efforts.

I add that, as Chapters 3 and 4 document, participants identified the types of needs they wanted this exercise to meet which demonstrates their belief in the potential of this exercise to benefit them.

The general feelings about the value of this exercise for participants and their groups were positive and participants worked very well together. Further, the fact that a number are seriously considering doing follow-up work with the study (i.e., future exercises) implies their belief in it. Finally, we developed a sense of camaraderie and trust and formed some long-term relationships that have extended beyond the exercise. This is not an unusual feature of participatory evaluation (or PAR in general) due to its informal, grass-roots, and intimate

nature. (Also see the section on Criteria of Authenticity.)

PROBLEMS ENCOUNTERED

This exercise also experienced problems from which planners can learn. For example, despite being generally successfully about acquiring and maintaining participants' trust, I fell short of this goal once, inadvertently. One participant became quite upset when she found out that I had written down the comments she gave me over the phone. I explained to her that I was under the assumption she knew I would be taking such notes and apologized for this transgression. This pointed out to me the value of having participants review notes taken and to be able to give continuous feedback on my actions. Learning from this mistake, I became even more cautious about maintaining confidentiality and earning trust. This same woman felt the exercise was too complex and eventually dropped out.

Another time, I had been so engaged in a conversation with one participant in a meeting that another told me she felt left out and redundant. This was revealed to me, again, when I read through notes taken because her voice was barely evident. Again, I apologized and avoided this mistake throughout the remainder of the exercise. This participant continued to be an active, core member of the exercise process.

In one meeting participants indicated that they wanted more structure and I, therefore, took a stronger facilitative role in subsequent meetings with these individuals. They wanted to keep a better balance between process and outcome, given time and

resource constraints. This increase in structure seemed to make these participants more comfortable working on the exercise and, as a result, they took a more central role. Stated more simply, it justified their time.

There were also awkward and disappointing moments when stakeholders failed to become involved when they initially indicated they would do so and when participants dropped out. There were times, too, when I was not sure whether we would have a sufficient number of participants to make this exercise worthwhile, especially to the participants themselves. Not only is there strength in numbers which ideally would give self-helpers a bigger voice, but there is a special dynamic that comes from a participatory, hermeneutic process which benefits from diverse input. This does not mean it was necessary to have a large number of participants but enough to allow for this diversity, for sharing of information, for learnings from one another, and for giving a sense of camaraderie and momentum.

Finally, there were the challenges, constraints, and limitations discussed earlier in this chapter and in Chapter 3 which we were often able to overcome and, at times, turn into opportunities primarily because we employed a flexible participatory evaluation model.

ASSESSMENT OF THE QUESTIONNAIRE

Six participants wrote comments on the questionnaire form which assessed the questionnaire. Core participants were not asked to provide these comments on this form because they were

originally going to do an assessment of the entire evaluation exercise, which included the questionnaire (see Chapter 3). One core participant gave some useful comments anyway. These are included here along with the other five. Two participants (Q/Q7 and Q/10) also add comments on the potential of the exercise, itself.

Q/Q3: It was confusing with the rating scale switching from 1-5 then 5-1.

Q/05: [In response to Resource Mobilization, Question Five: To what degree did the V/RHB use their resources in a flexible, open manner to reflect the needs/desires of your group members?] What does this question mean anyway? Good Questions. Awkwardly written.

Q/07: The evaluation itself is interesting but, based on our experience, won't change anything - we haven't seen any evidence that the Health Board does anything.

Q/Q8: [In reference to Participation Approach,
Question One: How successful were the V/RHB in
maintaining a balance between nurturing new avenues of
participation they developed (i.e., Community Health
Committees and Population Health Advisory Committees)
and your group (as a more bottom-up, pre-existing
avenue)?] Hard to understand.

Q/Q10: I found it very difficult trying to fit my experiences into categories. I found the categories confusing. I found this whole evaluation depressing. Probably because I am burnt out and retiring from the work I have been doing as a leader/counsellor in a women's self-help organization. It would have made a huge difference if we were supported, appreciated, and recognized by the medical community - let alone by society. I believe that what we do and what other self-help groups do is to provide the support, empathy, the listening that no one else has time to do. I also believe people experience relief and even healing when they are heard. Self-help groups empower people to take control of their lives instead of being

dependent on systems. If nothing else, the medical community should recognize how much money (tax dollars) is saved when volunteers support people in this way.

DISCUSSION

Rating scales were reversed from time to time because one participant suggested we should do so and because the other participants working on developing this questionnaire agreed to this structure. Ratings scales were reversed intermittently: (1) to avoid the potential biases that may be created by continuously presenting only the high or low end of the scale first and (2) to slow respondents down so they could read the questions carefully and give greater thought to their answers. For two participants, however, this proved confusing. There are, therefore, both pros and cons associated with maintaining a consistent order for rating scales and for making reversals.

In addition, comments were made about questions and categories being unclear. This may be at least partially explained by the fact that much less time was spent on designing the questionnaire than on other discussions during meetings. Had there been more participants and participation in this phase, we may have avoided this problem.

Finally, two participants indicated the potential futility of this questionnaire. This feedback underlines the necessity of justifying participants' time by fostering productive working environments and outcomes that meet their needs.

CONCLUSION

During this exercise, participants and I did our best to follow methods and procedures essential for achieving methodological integrity. We maximized the potential of our exercise to meet participants' needs, to document their understandings for the Health Board and other interested parties to see, and to find alternative ways to share our understandings with the Health Board and learn from them in the future. The assessment material provided in this chapter will help us hone these tools even further so they can be more effectively applied to future evaluations of the V/RHB and other health promotion initiatives.

END NOTES

1. This information came up in various ways during this exercise. For example, many of the comments made by participants in Chapter 4's "Maintaining Integrity, Autonomy, Control, and Sustainability" reflected participants' perceptions and concerns regarding the recency of the Health Boards' initiatives to involve the public in health promotion and to work with self-help groups (and the general public) as valid and equal entities. The fact that participants also predicted the potential lack of involvement of the Health Board in this exercise and their early preparation for this eventuality indicated their lack of trust in the Health Boards' interest in working with them through a bottom-up initiative. Also see P/M6 under "Walking Their Talk"; P/M6 and M9, and P/M2 in "Usages of Health Board Resources"; Q/Q2 in discussion under "Health Board Contact Prior to 1998", and Q/16 in "Post 1997 Contact: Discussion From Questionnaires".
2. Refer to "Women's Issues" and "Health System" in Chapter 4 for a discussion concerning participants experiential, subjective, and lay knowledge of how women are treated in the health system. Also refer to P/M2 and M9, and P/M12 in these sections and to the first and last contacted stakeholders included in Chapter 4.
3. See in discussion under "Maintaining Integrity, Autonomy, Control, and Sustainability" in Chapter 4. See also P/M2 under "Health Board Issues" and Q/Q9 under "Health Board Contact Prior to 1998".
4. Refer to discussion under "Maintaining Integrity, Autonomy, Control, and Sustainability" in Chapter 4. In addition, see Q/Q9 under "Health Board Contact Prior to 1998".
5. The questionnaire, for an example, asked participants to record any recent attempts of the Health Board to involve them and asked them to indicate when they had made bottom-up efforts to contact the Health Board, precisely because their relations with the Health Board may have changed while the exercise was in progress. Any increases in Health Board support and inclusion in health planning may have been due to four possibilities. Such changes may have been initiated from the top-down by the Health Board or from the bottom-up by participating self-help groups. They may have been direct results of our exercise or chance occurrences. Each of these combinations may have played a role here.

CHAPTER 6: IMPLICATIONS

INTRODUCTION

This dissertation demonstrates the role participatory evaluation can play in involving self-help groups in community health promotion. During our exercise, participants and I designed and tested a specific participatory evaluation model which not only fostered an appropriate environment to enable self-helpers to effectively contribute to this process and, hence, reinforced the tenet that participatory evaluation and self-help groups are ideally suited to one another, but also obtained substantive information about health promotion that further supports this view.

In this concluding chapter, I take lessons learned from this evaluation exercise and translate them into implications for health planning. These implications apply to our continuing participatory evaluation efforts and to future health planning initiatives involving the V/RHB, self-help groups, and health planners.¹

IMPLICATIONS FOR FUTURE PARTICIPATORY EVALUATIONS

This dissertation has taken a number of disparate entities and combined these into a specific participatory evaluation exercise. It adopted and adapted Rifkin et al.'s (1988) model for measuring participation in health promotion and employed

this new model to involve a specific set of stakeholders (i.e., women's self-help groups) in evaluating how well they were included and supported in health promotion efforts in a specific health region (i.e., the V/RHB).

FUTURE PARTICIPATORY EVALUATION INITIATIVES

The actual amount of resources necessary to continue our participatory evaluation exercise within our current context with our current stakeholders has been minimized as a result of our efforts. We have already organized a number of stakeholders which can serve as a base from which we can expand; we have designed, implemented, evaluated, and documented a cost-effective, flexible, and dynamic participatory evaluation exercise which can be opened up to new stakeholders, including Health Board members, and we have started a process which can be emulated and refined for use in other health regions. Due to its flexibility, we can apply this model to a wide range of stakeholders and contexts beyond Vancouver women's self-help groups and the V/RHB. Chapter 3 provides additional information on the potential value of this model for health planners and on its potential applications.

The participants in the exercise who want to continue their evaluation efforts can add to the effectiveness of our evaluation model by incorporating what we have learned and what participants had to say in assessment of the exercise. For example, we can clarify questions on our questionnaire and make the rating process easier to follow.

In considering the participants' views of the Health Board's relationship to them, I began to realize the extent to which they were concerned about barriers self-help groups face in developing relations with professionals, other groups, the V/RHB, and the general health system. Given this finding, we can add new questions to the survey we used. Examples of such questions are:

1. What types of self-help groups are concerned about issues of inclusion and support?
2. What do self-help groups see themselves as now? Would they like to change and, if so, what would they like to become?
3. What types of relationship would they like to develop with other groups and organizations?
4. When does a self-help group start taking on another identity and what does it become having done so?
5. How do self Helpers see their groups fitting into the broader community care environment (including the self-help movement and collective action) and how would they like to fit into this environment? (See page 297.)
6. Do self-helpers believe that Health Board support for their groups would serve to strengthen their involvement in the broader community care environment and, if so, how?
7. Do self-helpers believe that greater Health Board commitment to the community care model would serve to strengthen self-help groups, and, if so, how?

These questions can help us determine whether participants feel there is a need for funding and support. These questions can also help participants decide what forms of participation and support would best accommodate their groups' needs.

In addition to incorporating questions such as the above into subsequent questionnaires, participants can include them in

interviews, discussions, focus groups, and other research methods. In fact, they could be used in an aide memoire.

Participants and I engaged an ontology, epistemology, and methodology reflective of both the consensus and conflict approaches. Due to our desire to work with the system collaboratively and the absence of the Health Board, however, we employed methodological perspectives more representative of the consensus approach. The flexible, bottom-up nature of participatory evaluation "gave" us this option.

Ideally, members of self-help groups and the Health Board should have worked together on this one evaluation to come to common understandings. Ideally, the Health Board would have been active members, both stakeholder groups would have worked face-to-face to create an equitable and empowering evaluation environment, and all of Lincoln and Guba's criteria of authenticity would have been achieved without fear of compromise. Even though this did not transpire during this (stage of this) evaluation, the alternative strategies and research methods chosen by participants to involve the Health Board in subsequent rounds (i.e., incrementally) have the potential to ensure representation (participation in the exchange of constructions and a learning process), equity in regards to control over the evaluation and health programming, and empowerment.

By being involved in subsequent evaluation efforts, the Health Board could provide a more complete, two-sided, picture of the work it has been doing, explain its lack of or perceived

lack of inclusion and support of self-help groups, and begin a process of working effectively with self-helpers to address issues these groups deem important.

Not only can our future evaluation efforts give us the opportunity to include members of the Health Board and self-help groups, but they can give us subsequent chances to find strategies to maximize the number of stakeholders engaged within each stakeholder group and the depth and breadth of their involvement. It is essential to accept, however, that we cannot predict the extent or nature of participation beforehand, we cannot force participation, and we cannot wait until all possible stakeholders have become engaged.

Without consciously choosing one approach over the other during our evaluation exercise, despite the absence of the Health Board, participants and I gravitated towards the consensus approach. Only time will tell whether this stance will ultimately be effective.

ADOPTING RIFKIN ET AL.'S MODEL

A dynamic participatory evaluation questionnaire such as that based on the model we borrowed from Rifkin et al. provides planners and self-helpers with a tool for ongoing measurement of perceptions of Health Board inclusion and support (direct and indirect) for self-help groups, and for tracking changes in these perceptions over measurement intervals. Moreover, as a collaborative task for participants to accomplish, the process of designing the questionnaire can be used to unite

participants, preferably different stakeholder groups, and stimulate further discussion so as to elicit more qualitative data. Such collaboration has the potential to reveal stakeholders' constructions and their underlying value structures. Further, it can help build camaraderie, trust, respect, and common understandings. As another method of gathering information it can also be used to check the validity of substantive outcomes generated during meetings.

This model can also be employed to make comparisons between different health regions in regards to measurements of community participation efforts. In addition, we can use this model to compare different initiatives within an organization or system such as a health board. For example, we can compare perceptions regarding how much support is given to the regionalization process versus community health promotion (e.g., in the BC case, the community participation and "Closer to Home" initiatives) and how this balance changes. This can help us see priorities and shifts in priorities or the perceptions of such shifts. The model we adopted can also be used to compare perceptions held by different stakeholder groups about the nature and extent of Health Board support for a specific initiative. For instance, had Health Board members worked with self-helpers to create two versions of the same questionnaire, one for each stakeholder group, they could have determined whether their understandings were congruent. Lastly, our model can help members in each stakeholder group compare the extent to which their own perceptions of a health initiate have changed between

measurement intervals.

Our model is relatively simple in design and can be easily understood by the general public. Further, by being dynamic, it can provide a sense of momentum, of forward direction and responsibility to improve relations. Evaluations provide hardy incentives for making relevant changes in health initiatives by giving stakeholders the opportunity to: (1) choose indicators (sub indicators) they feel are appropriate; (2) rate an organizations or system on these variables; (3) make ratings at a future time to assess changes; and (4) make these ratings accessible to the general public.

IMPLICATIONS FOR HEALTH BOARDS/REGIONS

EXPANDING THE ROLE OF SELF-HELP GROUPS IN COMMUNITY CARE

Various health boards (or regions) may want to explore the substantive outcomes participants conveyed, i.e., their perceptions about the position of self-help groups in community care and the role of the health system in supporting this position.

After collecting this information, I developed a community care model which sees self-help groups as a subset of an immediate outer sphere, the larger self-help/mutual aid movement, and a subset of an extreme outer sphere, collective action, which is a more generalized movement (e.g., lobbying and advocacy work). We, therefore, have one circle inside another inside another as we can see in Figure 8.

In turn, these three spheres can be placed into the health movement called community care which brings health promotion down to the community level and ideally includes both formal and informal forms of health care.

Figure 8: Community Care: Our Three Spheres of Action



Substantive outcomes generated from this exercise indicates that whether or not self-helpers feel comfortable being a part of the self-help movement or collective action, will likely depend on the maintenance of an appropriate balance between the resources going back and forth between the two outer spheres and

their own and on the impact of such exchanges on their groups.

Health boards could invite self-help groups into the health planning process. They could also provide them with support targeted specifically at these groups, either through umbrellas or on a one-to-one basis. This can be called direct support. As substantive findings from our exercise suggest, it is essential, however, for these boards to do so on self-helpers' own terms and to back these commitments with indirect support, support allocated to developing a true community care model of health planning which endorses complementary as well as Western forms of health care. Without health boards showing a real commitment to the entire community participation/community care "package" ("walking their talk"), self-helpers may feel isolated, vulnerable, and anxious about stepping too far outside their groups or bringing in outsiders or outside influences. They may also feel the need to maintain their independence to protect themselves from being controlled by the health system.

This means, it may be necessary for self-helpers and the health system to work closer together in order to foster a more secure and collaborative environment before self-helpers will feel comfortable accepting external resources, assisting health boards with health planning, or otherwise working with outside professionals, groups, and organizations. As participants underscore, active membership in the second and third spheres need not and should not: (1) drain the valuable resources their groups use to serve their members; (2) diminish the integrity, autonomy, and sustainability of these groups; nor (3) create or

exacerbate the potential for competition between groups.

The two participants who provided feedback on my analysis of results both agreed with my conclusions. In the following paraphrase, one participant repeated her conviction that self-help groups should maintain their integrity and autonomy, but added, for the first time, her concern about competition. In this paraphrase, she asserts that:

P/M5: Self-help groups are more successful organisms if they are autonomous. My group enjoys being radical and does not want to be controlled. We are powerful just by meeting. Competition can come from the collective thing of having a top-down, hierarchical system that perpetuates the system within which we are interacting. This is imposed competition.

The other participant had something similar to say. For her:

P/M9: Professionals are taking over my organization and, if this keeps up, we will no longer be a self-help group. It is inevitable for competition between groups to develop and this is reinforced by the system. It is necessary to develop trust.

Participants expressed that they would like to have self-help groups recognized as valuable health services and central players in health planning. Information provided by participants here suggests that self-help groups don't want to reinvent their role, even though they may want to enlarge it, but rather, to secure their role within the community care environment. They want to go on serving their members, to maintain or increase their membership, and to meet the needs of

others in their interest groups and the self-help community. Under the right conditions, they would not likely say no to outside help to do so.

As some participants discussed, self-help groups could be parallel, yet equal branches in health care, branches that would work together with, but outside, the formal health care system. As such, they would be recognized, respected, and supported as valuable players in health promotion, but not coopted.

Results indicate that health boards need to understand that self-help groups feel they are largely unappreciated as vital players in community care. Boards also need to look to participatory evaluation approaches that match the nature of self-help groups, capture their unique understandings and contributions, and help these groups to meet their needs and goals.

Obtaining more information about self-help groups and about participants' perceptions regarding their role and status in the community care model and general health system is a good starting point. From here, health boards can work with self-help groups to determine the validity of perceptions and to make appropriate changes.

Further, knowing this information can help Health Board members anticipate and prepare for the possibility that their presence may cause conflict and intimidation. The best way to be proactive here is to develop good working relationships with self-help groups prior to and during evaluations and other planning initiatives. This point was validated both in the

methodological findings and substantive outcomes.

THE IMPORTANCE OF PARTICIPATORY EVALUATION AND SELF-HELP GROUPS

The voices of participants, along with their actions, underscore the need for health boards to go beyond talking academically about community participation and for them to go into the field armed with a commitment to participation and, as importantly, with the appropriate methodological tools to put theory into effect.

It may be difficult for the health system to spend as much time conducting a participatory evaluation as participants and I did in our exercise, but we can say that, given the valuable role of self-help groups in health promotion, we should expect to see an appropriate amount of resources used for this purpose and the most effective methodological tools being used to ensure these groups are appropriately included and supported.

There is considerable evidence to support the claim that the benefits to be gained from such initiatives outweigh the costs.² First, we can consider the richness of the substantive information generated regarding perceptions of Health Board inclusion of, and support for, self-help groups. We have also witnessed the potential of participatory evaluation to foster environments conducive to generating such information and to building relationships between self-helpers and health boards.

Employing Participatory Evaluation

As a tool for evaluating the Health Board's current community participation initiative and for guiding future Health Board efforts to do so, participatory evaluation exercises such as ours can serve to:

1. provide health boards/regions, and the general health system with invaluable information about how they and their actions are perceived by stakeholders and about how to enhance the role of self-help groups in health promotion;
2. increase the potential for self-help groups to be involved in health planning and to be supported more effectively and appropriately;
3. build lasting, more equitable partnerships between self-help groups and members of the health system which can promote a greater sense of trust between these groups;
4. create conditions which foster more open and active relations between self-help groups and others beyond their borders and strengthen their potential to play a role in the broader community care environment (including self-help/mutual aid and collective action);
5. improve the quality of self-helpers' lives by creating therapeutic environments that value their contribution and help them empower themselves to take control over decisions and initiatives affecting their and their communities' health, including the nature and extent to which the Health Board involves and supports their groups in health promotion; and
6. help facilitate appropriate action and mobilize essential resources more equitably and effectively.

Further, the process of using participatory evaluation to acquire feedback from self-help groups regarding the best ways to support and include these groups is itself a form of participation in health promotion.

There are some special issues we must consider, however,

when engaging in participatory evaluation. To start, it is essential to realize that restricted time, staff support, and other resources can limit the extent to which participants can, or will, contribute to a participatory evaluation or a planning initiative. Chapter 3 outlines some of the ways our evaluation exercise worked to overcome these problems, but it also demonstrates how difficult it was to acquire full participant involvement.

We have to consider that there may never be full participation in an evaluation or any PAR initiative regardless of our intentions or efforts. We have to prepare for consequent limitations such as lack of representation, incomplete findings, and challenges to achieving methodological integrity.

Planning and research environments may also restrict the degree to which a participatory evaluation can be participatory. Regulatory bodies may have to be challenged. Our exercise had to be creative to work within the research standards set by the UBC Behavioural Research Ethics Board as well as within the tenets of participatory evaluation. This was most evident in the case of recruitment where a linear, rigid, and one time recruitment process had to be replaced by one that was iterative, flexible, and dynamic. Again, Chapter 3 provides a more in-depth examination of challenges, constraints, and limitation our participatory evaluation exercise encountered and ways we overcame them.

Supporting Self-Help Groups in Health Promotion

Substantive information generated during the evaluation exercise suggests that there is a definite role for self-help groups to play in health promotion. When we consider the amount of resources pumped into Western health care and the formal health care system regardless of whether this is the most effective use of these resources, and the relatively small amount of resources expended on often ineffective community participation initiatives, it seems reasonable to allocate more resources to foster cost effective complementary health services such as self-help groups and to include these groups in health planning. During the process of her reviewing my analysis of methodological findings and substantive outcomes, one participant commented that:

P/M5: The time and attention necessary to get to know someone in need of health care can be prohibitive for professionals in the Western health care system. The role of self-helpers is to get to know individuals and it is easier and more effective to get this attention from co-self-helpers. These people have experienced the same health concerns and understand them and have the ability to give them a high level of care and attention, not medicine. Formal health care people make a living through their work, self-help is done on a volunteer basis. Those who make money in health care are threatened by competing resources, by self-help groups' voluntary nature. My friend tried to get information on self-help groups at a social service organization and couldn't find this information. Self-helpers don't have to deal with the sheer volume of people in need of help that doctors do and we give our time freely and on a one-to-one basis. This allows us to distribute the load. We need friends. Friendship offers true healing and we need a lot of it. "We need to build a culture which sees this as a way to be healthy and give health care." It is relevant and useful. Self-help groups are a powerful concept. Illness is often frightening and people don't

want to talk to people about their problems. Self-help groups have a huge impact here, they work and are real. The concept is "so old it's new". It is obvious, but a huge breakthrough. In this form, this evaluation is readable to a different audience and builds a "bridge between two cultures".

Self-help groups can, therefore, take over some of the most time and labour consuming health care functions and, thus, reduce health care costs. We should not solely look at the more intensive form of care self-help groups can provide, however, for as participants and the literature suggest, self-help groups provide a valuable complementary health care service overall, performing many of the same functions as the formal health care system and filling gaps (See Chapters 1 and 2). The fact that self-help groups are able to offer such services to the general public should alone signify the importance of engaging an evaluation approach such as participatory evaluation to ensure the voices of this population are included in health planning processes.

IMPLICATIONS FOR SELF-HELP GROUPS

One of the insights participants and I gained from this exercise is that self-helpers don't have to wait for the powers at "the top" to initiate contact with them. On the contrary, these stakeholders have the right to make themselves heard and to be involved in the decisions that affect their groups, their members, and their communities. They also have a valuable contribution to make to health planning and health care.

However, self Helpers may have to work hard to have their voices heard and, more importantly, respected and acted upon by the "powers that be". For example, according to one participant helping me with my analysis:

P/M9: Credibility is not given to self-helpers. We have to prove ourselves. Self-help groups are a continuous challenge to the powers that be. This is a good thing, especially in regards to the psychiatric system. We have to validate ourselves and our position, especially in psychiatry which is patronizing and dismissive. Of course, we are not recognized in the power structure! Self-help groups are a new threat to "them" (the health system). Behind me as a self-helper, I'll be challenged.³

Looking at the positive as well as the negative, she also commented that:

P/M9: Self-help groups haven't been funded as self-help groups. However, the Health Board is closer to us than what the old system had been.

It is not necessary for self-help groups to become more active members of the community care environment for them to serve a valuable role in health care. Substantive information produced in this exercise suggests that these groups can function without external support, without lobbying and advocating for their groups and communities, and without working with other professionals, groups, and organizations, including health boards/regions. By being more active in the self-help movement and collective action and by being in control of such initiatives, however, self-help groups can help gain a more

secure position as complementary health services.

To be involved in health planning and supported by health boards, and on their own terms, it may be essential for self-helpers to organize from the bottom-up. Participatory evaluation is an ideal tool for such an initiative: it can be adapted to meet the needs, circumstances, and abilities of self-helpers and it can help unite them and, thereby, serve as an important step towards expanding the role of their groups in community care. By working together through participatory evaluation, self-helpers can choose how to adopt a more diverse role in this community care environment and can do so without giving up their own identity, integrity, or sense of control.

This exercise also demonstrates that participants can take control over decisions that may not typically be associated with participatory evaluation. They made the decision about which approach they wanted to favour, i.e., whether oriented to consensus or conflict. For example, it was participants who decided to use a collaborative approach and to find alternative ways to involve the Health Board so they could share information and understandings with these other stakeholders. In effect, they served to redesign the evaluation process or set new boundaries.

IMPLICATIONS FOR PLANNERS

This exercise has helped me understand that democratizing health promotion may have to originate from the bottom. This

could be a challenging, yet powerful, niche for social/health planners interested in fostering healthy communities. As planners, we can serve as resources helping stakeholders organize from the bottom up, despite the limitations we may encounter, not the least of which involve acquiring resources (including funding) and cooperation from people "at the top". Even if we are professionals working within larger bureaucracies, for example in the health system, we need to promote, work with, and reward bottom-up efforts.

The two sets of information generated from this study, the methodological findings and the substantive outcomes, both lead to one major conclusion: To work effectively with self-help groups, planners (including researchers) need to conduct participatory evaluations, whether they are to stand alone or to be a stage or components of larger PAR initiatives. Planners also need to understand the sociopolitical context surrounding these initiatives, to acknowledge the existence of conflict and power inequities, and to prepare for these phenomena. Moreover, they should work with participants to determine the approach or approaches participants feel would best meet their needs, i.e., the consensus or conflict approach or both.

The issues involved in developing imposed avenues of participation, respecting local avenues, and finding appropriate ways of linking the two are very strongly related to the general tensions that exist between professional and local or popular experts and expertise during any research or planning task. (See Checkoway, Chesler, and Blum, 1990; Comstock and Mahamoud,

1990; Katz, 1981; Remine et al., 1984; Silverman, 1980; Wollert et al., 1984). Such tensions may always exist but they can be addressed and, with commitment, minimized within each planning environment.

As argued before, the benefits of using a participatory evaluation outweigh the costs. Further, time and resources do not have to be barriers. For example, participants in this exercise were concerned with the equitable distribution of Health Board resources to self-help groups and the equitable involvement of these groups in health planning more so than the absolute amount of resources and attention they receive from the Board⁴. It is, therefore, essential that planners be honest about the time and resources we have and what we can do with them. Together, participants and planners can come up with the most appropriate options for involving and supporting self-help groups, given time and resource constraints on both sides (self-helpers and planners). Even making an effort to work on these issues conveys a sense of respect on behalf of professionals. In other words, self-helpers are looking for a real commitment from the health system to work with their groups so as to enhance their role in health promotion and to take appropriate actions reflecting this commitment to participation - "walking their talk".

As planners, it is essential to adopt the most appropriate methodological criteria and procedures for the stakeholders and their communities. To do so, we must understand stakeholders, their needs, their abilities, and their resources as well as

their contexts. Moreover, we must work with stakeholders. What this boils down to is understanding the limitations of the technocratic planning approach and of each of the two participatory approaches (consensus and conflict).

Looking for an additional or alternative approach to planning in general or evaluation in particular, involves first understanding new methodological tools and their underpinnings and knowing when they can prove more effective than their conventional relatives. It secondly involves changing attitudes about planning.

Evaluation can be used as a tool to bring people together, to hear and understand different viewpoints, to educate, to empower, to develop capacities, to organize, and to take action. It can be used to make immediate transformations in health programming through a one time evaluation "blockbuster" or make more incremental changes through an incremental evaluation process.

We, as planners, must do our best to achieve methodological integrity, given our limitations, whether we are doing research in the positivist or constructivist camp. The fact that constructivist, or participatory, evaluation is not as well known in planning circles, means that extra care should be taken to both maintain and demonstrate methodological integrity when engaging in such research. In effect, participatory evaluators have to validate our choice of methodology as well as our substantive outcomes.

Considering the value of self-help groups to health

promotion, similar benefits can be obtained by planners familiarizing ourselves with these groups. It would be pragmatic for planners within health related fields to become knowledgeable about the nature of self-help groups and to explore what they have to offer health care and health planning, how to engage them in planning, and how to support them in appropriate ways.

We can say that there is a strong match between self-help groups and participatory evaluation. These two entities share the same values and philosophies. Both are, ideally, participant-oriented and participant-controlled and both believe in sharing knowledge (experiential, lay, and professional), face-to-face interaction, consciousness raising, democracy, individual rights, and striving for personal empowerment.

We should also ensure that those most marginalized in our communities have the opportunity to actively participate in planning. The results of the evaluation exercise in this study specifically emphasize the importance of adopting research and planning approaches that acknowledge, reflect, and capture women's ways of knowing and doing as well as those of men.

Finally, as planners look towards participatory approaches, and stakeholders demand them, we should consider applying participatory evaluation to a whole range of planning practices within health planning. Weiss (1998) states that "We cannot transfer (and use) evaluation findings mechanically from one place to another. But certainly we can gain important information about what happens in the sites studied, and we can

use that information as illustration and metaphor of what can happen under similar conditions elsewhere" (p. 29).

END NOTE

1. Also refer to the recommendations made by participants included in Chapter 4.
2. Upon reading this paragraph, the participant overseeing how I presented our results (i.e., participant M5) responded by underlining that "If a liaison position existed [within the V/RHB], such attention would be necessary". In other words, if the Health Board were to include self-help groups in health planning initiatives, for example by creating such a position, cost considerations would be an important variable.
3. By this statement this participant means that other individuals and groups may feel the need to question her influence as a self-helper.
4. During this exercise, for instance, participants were very willing to meet with me without having refreshments or getting some sort of financial compensation because they knew that I had their interests in mind: I tried to address their needs and help their cause, I tried to secure funding to provide such resources because I had few of my own, and I was willing to compensate them in other ways such as by doing volunteer work for their groups. As we have seen, a number of participants did not feel this sense of commitment from the Health Board nor did they see an attempt to compensate them, let alone equitably, for their contributions to health promotion. In addition, participants indicated that they want control over the decision making processes involved in: (1) research affecting and including them and their groups; (2) ongoing health planning initiatives; and (3) acquiring and using support from the Health Board and from all other external bodies. They expressed the importance of having this exercise justify their time and meet their needs. On the whole, stakeholders chose to refrain from this exercise or to terminate their involvement when they felt it would not meet the needs of their groups and they joined and remained with the exercise when they felt it would. I know, however, that there were participants who gave me more time than they felt they had simply because they knew how important this exercise and the study were to my degree. More significantly, they were more willing to take time out to help me when they realized I genuinely valued their work and their input and would work with them to ensure their needs were met.

APPENDIX 1: VANCOUVER/RICHMOND HEALTH BOARD ANNUAL REPORT
1997-1998

Providing Community Health Services



Community-based services — providing care, promoting better health, and preventing disease, disability, and injury — play a growing role in our health system. The Vancouver/Richmond Health Board

(V/RHB) directly delivers extensive community health services. In Richmond, these services are provided through Richmond Health Services, part of the V/RHB. Contracted agencies in both Vancouver and Richmond also offer comprehensive community-based services.

COMMUNITY HEALTH CENTRES

When the V/RHB developed its Inaugural Health Plan, the public called for health services that are closer to home and easier to access. The Health Board acted on those recommendations by approving the creation of community health centres, "one-stop" locations for health services and community development. In May, B.C. Health Minister Penny Priddy and V/RHB Chair David Levi announced the establishment of a community health centre at West Boulevard and



West 43rd Avenue. Two months later, together with Premier Glen Clark, they unveiled plans for another centre to open at Joyce Street and Crowley Drive. Over the next few years, the Health Board hopes to establish as many as 15 community health centres across the Vancouver/Richmond region.

Each community health centre will bring together different services in a common location with extended hours. The user-friendly centres will be more than just drop-in clinics — you will be able to see a doctor or nurse, have your child immunized, arrange home care for a family member, and access many other health and social services. Patients with chronic illness or complex health needs will receive coordinated support for managing their conditions. As well, individual centres will deliver unique programs that meet specific local needs.

Vancouver and Richmond residents will have an ongoing opportunity to help plan local services by joining or working with their community health committees, and linking directly with community health centre staff on projects. Community health centres will also support public involvement by providing meeting space to local groups that focus on health and other issues.

FROM ILLNESS TO WELLNESS

In addition to the core services outlined above, community health centres will emphasize programs that promote better health, along with those that prevent disease, disability and injury. This fits well with the Health Board's approach of expanding the focus from illness to include prevention and wellness. The V/RHB directly delivers many health promotion and prevention services including pre-natal classes; nutrition education; vision, speech, hearing, and dental screening and assessment; immunization and travel health clinics; seniors' wellness; youth clinics; and many others.



HIV/AIDS Action Plan

In October 1997, the V/RHB approved a comprehensive HIV/AIDS Action Plan for Vancouver's Downtown Eastside, and allocated \$4.6 million towards it. Since then, the Health Board has been steadily implementing the plan to combat the HIV epidemic among injection drug users in the area.

In October 1997, the V/RHB approved a

comprehensive HIV/AIDS Action Plan for Vancouver's Downtown Eastside, and allocated \$4.6 million towards it. Since then, the Health Board has been steadily implementing the plan to combat the HIV epidemic among injection drug users in the area.

Actions taken in the Downtown Eastside have included: hiring the full-time equivalent of eight nurses and extending street van and clinic hours; hiring 41 outreach workers and substance abuse counsellors; planning for a food bank; and planning a 24-hour resource centre for drug users.



HOME-BASED SERVICES

V/RHB home-based services enable people to stay in familiar surroundings while safely receiving care and support. These services maximize health care resources by freeing up hospital beds, and even more importantly support people to remain as independent as possible in the community.

Services such as the Antepartum Home Care Program — a joint initiative of British Columbia's Women's Hospital and Health Centre and the V/RHB — help fill the gaps between community and hospital based care. The program provides nursing support to eligible patients who remain at home with pre-term labour, hypertension in pregnancy, and other conditions.

Other programs, such as Vancouver-based Healthy Beginnings and the Richmond-based Healthy Babies and Families, directly deliver essential health information in a home setting. Visits by community health nurses to mothers and newborns after discharge from hospital, along with other services such as a "newborn hotline", help families with breastfeeding difficulties, infant sleeping patterns, and parental rest.

Vancouver and Richmond residents who live independently but need assistance benefit from home-based continuing care services. While the majority of continuing care clients are older adults (aged 65 and older), an increasing number of younger adults and children also receive these services. Teams of community health workers deliver in-home services such as basic nursing care, physiotherapy, occupational therapy, nutrition support, intravenous antibiotic therapy, and palliative care.



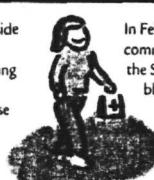
PARTNERS IN CARE

Aside from directly delivering services, the V/RHB has contracts or service agreements with more than 170 community-based agencies. These include organizations that offer residential care, home support, adult day centres, short stay assessment and treatment, and other services. In 1998, the Health Board began a collaborative process with the contracted agencies to establish long-term partnerships; improve consistency, coordination, efficiency, and effectiveness; streamline administration; and increase accountability.

CREATING A CONTINUUM OF CARE

Increasingly, community services work in close conjunction with hospital-based services. The V/RHB coordinates both aspects of this continuum of care to ensure access to a range of health services, when and where you need them.

In 1998, the Review of Acute and Rehabilitation Services — a major Health Board initiative studying the hospital sector of the health system — recommended ways to better coordinate and improve the balance between hospital and community-based services. Recommendations emerged to expand and enhance community-based services following thorough reviews of the research literature and discussions among V/RHB partners. One recommendation was that many of the patients receiving care in the community were doing as well or better in the community than in hospital. This recommendation led to the creation of the Street Nurses program.



In February 1998, the V/RHB announced a \$3 million commitment to the establishment of health services in the Sunrise and Washington hotels, both on the 100 block East Hastings Street. The Health Board was instrumental in bringing agencies together to fund the purchase and renovation of the single room occupancy hotels, resulting in more stable housing for the residents.

Vancouver/Richmond

Working Together

The following is a listing of many of the organizations and services under V/RHB (as of September 1998).

HOSPITAL SERVICES:

British Columbia Cancer Agency
Screen Mammography Program of British Columbia
Children's & Women's Health Centre of British Columbia
British Columbia's Children's Hospital
British Columbia's Women's Hospital and Health Centre
Sunny Hill Health Centre For Children
Providence Health Care
Holy Cross Hospital
Mount St. Joseph Hospital
St. Paul's Hospital
St. Vincents' Hospital; Arbutus, Broadmoor, Burnaby, Fraser, Langara, Youville Residence
Vancouver Hospital & Health Sciences Centre
C.F. Clarke Living Skills Centre
George Cope Centre
UBC Hospital
Vancouver General Hospital
Mayo Clinic - Vancouver
Richmond Health Services Acute Treatment Services
(The Richmond Hospital)

Louis Brier Home and Hospital
B.C. Drug & Poison Information Program
B.C. Reproductive Care Program
B.C. Transplant Society

COMMUNITY SERVICES:

B.C. Centre for Disease Control
Richmond Health Services Community Care
Richmond Health Services Population Health
V/RHB Community Health Services
V/RHB Centre for Disease Control
V/RHB Environmental Health

CONTRACTED AND FUNDED AGENCIES:

Adult Day Centres

ASK Friendship Centre
Association of Neighbourhood Houses (ANH) Cedar Centre
ANH - Mount Pleasant Adult Day Care
ANH - South Vancouver Adult Day Care
Chown Adult Day Care Centre
Cross Roads Project for Seniors
Dr. Peter AIDS Project
L'Chaim Centre for Adult Day Care
Lion's Den Adult Day Centre (Encourage)
Maple Ridge Senior Services, Maple Place
Day Care
Renfrew Collingwood Seniors' Society
Strathcona Adult Day Centre
Vancouver Order of Nurses Adult Day Care
West End Adult Day Centre (New Roots)
Rosewood Adult Day Centre
Kinsmen Home Support

Community Health

A-H Society
A Loving Spoonful
ANH - North Vancouver Neighbourhood House
Elizabeth Bagnshaw Society
Everywoman Health Centre
Japanese Community Services Association
Adult Diabetes Service, Community Hemodialysis Facility
Little Mountain Neighbourhood House, Congregate Meals
Multiple Sclerosis Society of Canada B.C. Division
Neurologics
REACH Community Health Centre
Richmond Connections
Sunset Towers Congregate Meals
Vancouver Second Mile Society
Victorian Order of Nurses: Vancouver/Richmond Branch
Western Institute for the Deaf & Hard of Hearing

HIV/AIDS Action Plan

Caregiver Centre
DIVAS Youth Health Outreach Programs
DTES Women's Centre
Greater Vancouver Food Bank Society
High Risk Project Society
Immunodeficiency Society of British Columbia
Kwassa Neighbourhood House Seniors Healthy Community
New Dawn Recovery Home for Women
The Rainbow Project Society
The Society to Support Family Bonding and Healing (DAAMS)
Vancouver Native Health Society
Watson Research Association
Wish Drop-in Centre Society

Home Support

ANH Home Support Services
Comcare
Emergency Home Support Services Association
Dove Medical Health Services
Greater Vancouver Community Services
• Kinsmen Home Support
• Lions Club Health Care Fund
• Citizen Health Support
• Para-Med Health Services
St. James Social Services Family Support
West Coast Health Care Services Ltd.

Housing

Canadian Partnership Against Homelessness
Creative Housing
Noble Housing
L&T Services
Low Income Housing Ltd.
Taylor Manor
Vancouver Resource Society

Keeping In Touch

Vancouver/Richmond Health Board
General Inquiries: 736-2033
Regional Office: 775-1866

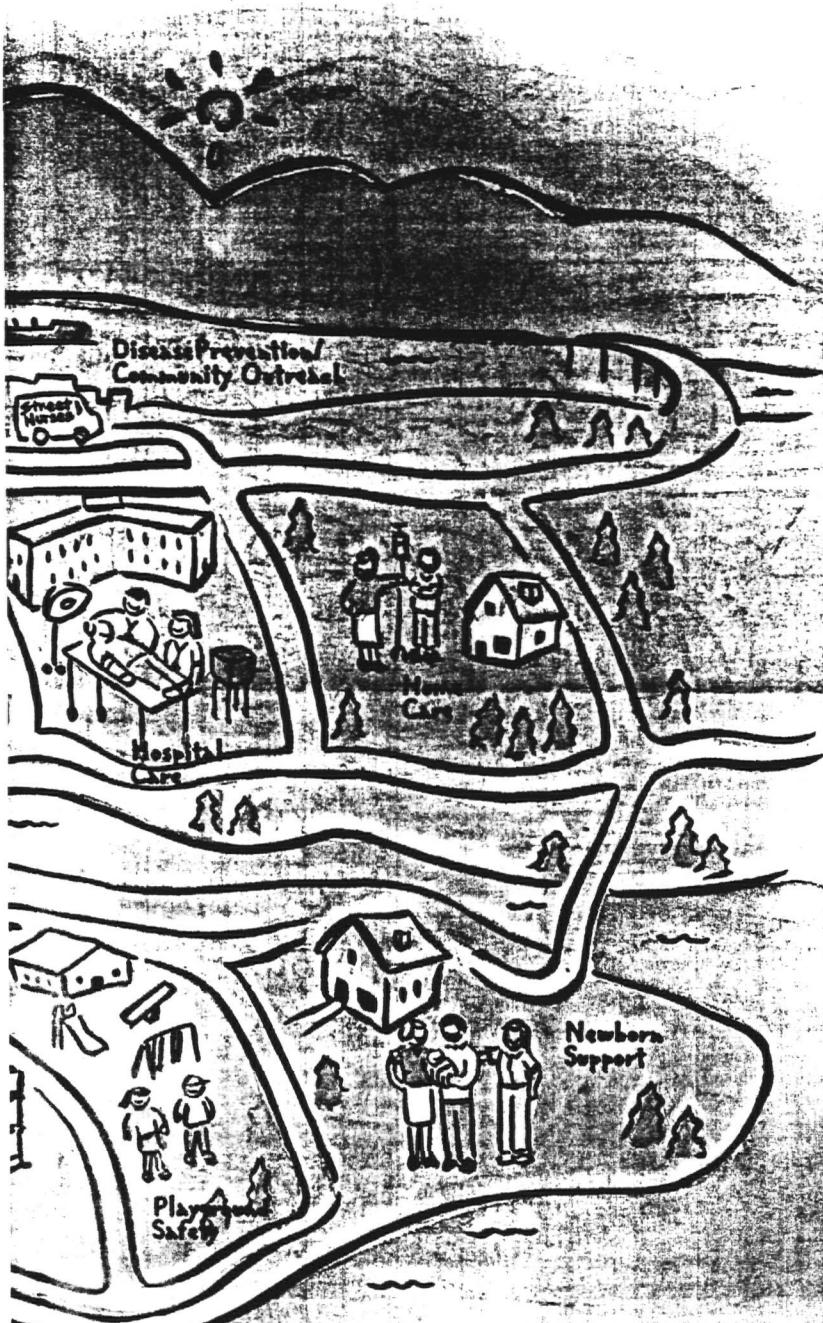
Health Units/Community Health Centres
Burnard/West End: 736-9844
East Unit: 872-2511
North Unit: 253-3575
South Unit: 321-6151
Community Health Centre on the West Side 261-6366

Environmental Health
General Inquiries: 736-2866

Clinics
Audiology Clinic: 659-1100
Bridge Clinic: 877-8550
Downtown Community Health Clinic: 255-3151
Downtown South Community Health Centre: 659-1144
Pine Clinic (Youth): 736-2391
Travel Clinic: 736-9244
Recorded travel health advice: 299-9000 (code 4636)
<http://travelclinic.vancouver.bc.ca>

Second Health Board

for Better Health



Hospitals

British Columbia Cancer Agency: 877-6000
 Children's & Women's Health Centre of British Columbia
 British Columbia's Children's Hospital: 875-2345
 British Columbia's Women's Hospital and Health Centre: 875-2424
 Sunny Hill Health Centre for Children: 434-1331
 Vancouver Hospital & Health Sciences Centre
 G.F. Strong Rehab Centre: 734-1331
 George Pearson Centre: 321-3231
 UBC Hospital: 822-7121
 Vancouver General Hospital: 875-4111
 Mary Pack Arthritis Centre: 879-7511

Providence Health Care

Holy Family Hospital: 321-2661
 Mount St. Joseph Hospital: 874-1141
 St. Paul's Hospital: 682-2344
 St. Vincent's Hospitals:
 Arbutus: 266-4166
 Brock Fahmi Pavilion: 876-7171
 Heather: 876-7171
 Langara: 325-4116
 Youville Residence: 261-9371

CONTRACTED AND FUNDED AGENCIES CONTINUED: Residential Care Facilities

Amherst Private Hospital
 Balfour Home
 Blackwood Lodge
 Braddan Private Hospital
 Britannia Lodge
 Broadway Pentecostal Lodge
 Calvary Christian Hospital
 Central City Lodge
 Columbus Residence
 Cooper Place
 Crosswicks
 Dogwood Lodge
 Fair Haven
 Fairview Court Residence
 Finney Home
 Fraserview Intermediate Care Lodge
 German Canadian Home
 Hotel Plus Care Society
 Hydrotel Guest Home
 Icelandic Care Home
 Karmelite Private Hospital
 Kopernik Lodge
 Lakewood House
 Little Mountain Place
 Louis Brier Home and Hospital
 May's Place
 Newmarket Hospital
 Pearl Villa Lodge
 Pinegrove Place
 Renfrew Care Centre
 Rossland Manor
 Royal Arch Masonic Home
 Royal Accor Care Centre
 St. Paul's Private Hospital
 St. Jude's American Home
 Taylor Manor
 Three Links Care Centre
 Trout Lake Manor
 Villa Care
 Villa Cathay
 Windermere
 Yatzenko House
 Youville Residence

Mental Health Services

Contracted/funded directly or through the Greater Vancouver Mental Health Service
 Arbutus Vocational Society
 B.C. Schizophrenic Society
 B.C. Society for the Survivors of Sexual Abuse
 Canadian Mental Health Association: Richmond Branch, Vancouver Burnaby Branch
 CHIMO Personal Distress Intervention Service
 Coast Foundation Society
 Delta Community Women's Centre Assoc.
 Galley Gachet Society
 Hollyhock Family Services
 Old Friends Society
 Lookout Emergency Aid Society
 Mental Health Action Research and Advocacy Assoc
 Pacific Health Consumer/Survivor Research Society
 Pacific Legal Education Association
 Portland Hotel Society
 People Help People Association of B.C.
 Vancouver Crisis Centre
 Vancouver Mental Patients Association
 Vancouver Mental Health Support Society
 Window of Opportunity Rehab Training Society

Mental Health Residential

Contracted/funded directly or through the Greater Vancouver Mental Health Service
 Aaron Place
 Alpine Lodge
 Aumar Ventures Ltd.: Southdale
 Birchwood Care Facility Ltd.
 Bridge House
 British Health Care Service Inc
 Campbell Family Care Home
 Canadian Mental Health Association: Richmond Branch, Vancouver Burnaby Branch
 Chezette House Care Facility Ltd.
 Coast Foundation Society
 Consigo Family Care Home
 Douglas Outside Residents Association
 Francis House
 Fraser House
 Hansen Family Care Home
 Grace House
 Jules Family Care Home
 Katherine Sanford Housing Society
 Kettle Friendship Society
 Langford House
 Labro Manor
 Lingbiason Family Care Home
 Lookout Emergency Aid Society
 Mani Management Corporation: Stirling House
 Mandor Residence
 Melody House Group Homes Ltd.
 Newmarket House
 Oliver Family Care Home
 P&H Naciones Corporation: Cape Lodge
 Paris Family Care Home
 Peninsula Care Home
 Rainier Resource Group Ltd.: Tilquin House
 Bayview House
 McRae Manor
 Rolling Woods Enterprises Inc.: Pender House
 Sciro Holdings Ltd.: Hampton Court
 Seaport Homes Ltd.
 St. Boniface Care Home
 St. Bernard House Ltd.
 St. James Social Services: Santiago
 St. Joseph's Lodge
 Trans-Enterprise Service & Care Society
 Vedder Family Care Home
 Valencia Family Care Home
 Victoria Care Society
 Waterfront Care Association
 Waterloo Rest Homes Limited
 Waverly Care Facility Ltd.: Emerald House
 Westminster House

Richmond Health Services

Acute Treatment Services (The Richmond Hospital): 278-9711
 Community Care: 278-3361
 Mental Health: 278-9711
 Population Health: 276-4047

Region-Wide Services

Newborn Hotline: 737-3737 (8:30 a.m. to 10:00 p.m.)
 Dial-a-Dietician: 732-9191
<http://dial-a-dietitian.ml.org>
 Home Hospice Care: 730-7688

Hospitals Evolve to Meet Future Needs



Hospitals play a significant role in the Vancouver/Richmond health system. On an annual basis, hospitals in the region care for approximately 100,000 inpatients; perform 66,000 surgical procedures (including 29,000 on a day care basis); attend to 235,000 emergency visits; and handle 500,000 outpatient clinic visits.

The Vancouver/Richmond Health Board is an umbrella organization responsible for coordinating all aspects of health service delivery in the region. Hospitals account for about 72% of the V/RHB's budget. They deliver services including: acute care (emergency, general medical, surgical, psychiatric, obstetric, and diagnostic services); rehabilitation; chronic care; ambulatory care (outpatient services not requiring an overnight stay); and one-of-a-kind services for all B.C. residents. In addition, Vancouver hospitals are principal centres for health sciences education and research.

The volume of most of these services has been relatively stable in recent years, but demand for specialty services has been increasing. In response to that demand, in 1997/98 the region's hospitals increased their capacity to treat conditions such as heart disease, cancer, kidney failure (with dialysis), HIV/AIDS, eating disorders, hearing loss, and head injuries.

Changes to technology and medical practice have resulted in less invasive procedures, shorter lengths of stay and recovery times, and more efficient service delivery. But there are opportunities to improve the use of hospital resources, which the Health Board identified in an unprecedented study — the Review of Acute and Rehabilitation Services.

KEY FINDINGS FROM THE REVIEW OF ACUTE AND REHABILITATION SERVICES

The V/RHB consulted the public about health issues in 1995 and 1996, and then began evaluations of three major areas within our region's health system: community, mental health, and hospital services. In July of this year, after 18 months of work, the V/RHB completed the evaluation of hospital services. The Review of Acute and Rehabilitation Services thoroughly examined the hospital sector of our health system. It documented the historical use and projected future need for hospitals, and made recommendations for enhancing both hospital and community services.

The review incorporated the best available data and input from more than 300 health service providers and about 200 members of the public. Highlights from the review's findings on hospitals include the following:

- Since 1991/92, outpatient procedures (not requiring an overnight stay) have increased 21%, while inpatient cases (requiring an overnight stay) have decreased 11%.
- The average length of stay in hospital decreased from eight days in 1991/92 to seven days in 1996/97.
- While the total number of cases in Vancouver/Richmond hospitals has remained constant over the past six years at about 179,000 cases per year, this number is expected to increase by 11% in the next five years.
- In the 11 Vancouver/Richmond hospital sites, the 2,390 acute and rehabilitation beds in use have an average occupancy rate of 81%.

- In 1996/97, 56% of cases in Vancouver/Richmond hospitals involved patients from within the region. The other patients were from the rest of the Lower Mainland (29%) and other areas in B.C. (15%).
- Population in Vancouver/Richmond is projected to grow from 672,154 in 1995/96 to 791,315 in 2007/08, putting more pressure on the health system.
- In the last fiscal year, more than 1,000 patients were in a hospital at a time when they would have received more appropriate care in a community setting such as a residential or transitional care facility, or at home with community health services support. (Transitional care refers to support for patients during the period between acute care hospitalization and a return home.)

Hospital Highlights



The following are some highlights from 1997/98:

- Planning proceeded for interior completion of 14 floors in the Vancouver Hospital & Health Sciences Centre (VHHSC) Laurel Tower.
- The B.C. Ministry of Health and Greater Vancouver Regional Hospital District approved \$38 million for construction of a state-of-the-art radiology department and trauma special care unit at the Vancouver General Hospital site of VHHSC.
- Providence Health Care launched the Comprehensive Health Enhancement Support System (CHESS), a computer program enabling patients at home to access disease-specific health care information.
- St. Vincent's Hospital (Heather), part of Providence Health Care, launched the Geriatric Falls and Fractures Prevention Program. The program is the first of its kind in Western Canada.
- The B.C. Research Institute for Children's & Women's Health opened two new laboratory wings: the Centre for Molecular Medicine and Therapeutics and Centre for Growth and Development. The Institute provides leadership and support for research at Children's & Women's Health Centre of British Columbia (C&W).
- The B.C. Ministry of Health announced funding of \$1.5 million for a residential facility treating children and adolescents with severe eating disorders. B.C.'s Children's Hospital, part of C&W, will operate the Vancouver facility.
- As part of a \$19.6 million development plan, the Richmond Hospital opened the Westminster Health Centre building, consolidating administration areas, expanding outpatient care services, and adding six inpatient psychiatry beds.
- The Richmond Hospital also began expansion of its Emergency and Diagnostic Imaging (radiology) departments, due to be completed in December 1998.
- The BC Cancer Agency and the Canadian Cancer Society, in cooperation with Health Canada, released Canada's first treatment guidelines for breast cancer. The guidelines will improve consistency of care.
- BC Cancer Agency was chosen as a test site for delivery of a new therapy for prostate cancer. Antisense therapy involves administering a drug that blocks the function of cancer-causing genes by using small segments of DNA to reduce or eliminate tumours. The therapy has fewer side effects than use of more traditional drugs.

Recommendations from the Review

In July, the Vancouver/Richmond Health Board unanimously passed recommendations from the Review of Acute and Rehabilitation Services. The wide-ranging recommendations include measures to enhance community based services and changes to improve use of hospital resources.

Some of the key recommendations:

- Establish a post-surgical unit focusing

- on orthopedic (bone) fractures, and a residential facility for elderly mental health consumers, both providing transitional care to patients in the period after leaving hospital and before returning to the community.
- Expand community mental health services.
- Expand home and telephone support for mothers and newborns.

- Expand general home care services.
- Keep the number of acute and rehabilitation hospital beds at the current level of 2,390.
- Complete several key capital projects, including the Vancouver Hospital & Health Sciences Centre tower.
- Use operating rooms more effectively.
- Develop new ambulatory care services following the completion of a study to determine regional priorities.
- Plan a moderate increase in funding for acute care services.
- Expect hospital group boards to develop plans for accommodating projected growth in case load, addressing service gaps, and achieving better efficiency.

Meet Your Health Board

A volunteer Board of Directors governs the Vancouver/Richmond Health Board. The 18-member Board includes members from Vancouver, at least three from Richmond, and two from outside the region. The V/RHB holds public meetings every fourth Thursday of the month at 7:00 p.m. Call 775-1866 for meeting locations.

David Levi (Chair) is President and CEO of the Working Opportunity Fund and a founding member of the Working Enterprises group of companies. He was chair of the VanCity Credit Union and is currently the honorary co-chair of the Pacific AIDS Resource Centre. He participates in the Leadership & Management Council of B.C.

David Esworthy has had a 40-year career in the foundry industry, complemented by a host of volunteer efforts. David was chair of Vancouver Hospital board and the Council of University Teaching Hospitals. He is a member of the Vancouver Board of Trade and the Canadian Equestrian Foundation.

John P. Kennedy is an accountant and the first Richmond representative appointed to the V/RHB. John was chair of the Richmond Health Board and is currently chair of Greater Vancouver Mental Health Service. He is also involved with the Richmond Lions Long Term Care Society.

Stephanie Killam is a municipal councillor for the District of Mackenzie who also works for Mackenzie Secondary School. She was chair of the New Directions steering committee for the Mackenzie & Area CHC, and is currently vice chair of the Northern Interior Regional Health Board.

Bert Massiah is a founding member of the original Vancouver Health Board, who has worked as an organizational consultant, university educator, therapist, and regional coordinator for the Ontario Ministry of Health. Bert has volunteered with many organizations including the John Howard Society.

Gentil Mateus is currently a consultant in Roseland, who worked for Cominco Ltd. in Trail for 19 years. Gentil was chair of Trail Regional Hospital, and is now a trustee on the Greater Trail Community Health Council and a member of the Health Employers Association of B.C. board representing East and West Kootenay.

Margaret McPhee is a retired consultant in gerontology and health services planning. She is a board member with Vancouver Hospital and Health Sciences Centre and an executive member of Yaletown House intermediate care facility. Margaret also serves on the Advisory Council for Seniors to the Minister of Health.

Bud Osborn is a published poet and Downtown Eastside community activist. He founded the Political Response Group which advocates for local housing. Bud has been a board member of groups including the Carnegie Community Centre and Downtown Eastside Youth Activities Society.

Silvia Wilson has been a health care worker at G.F. Strong Centre for ten years. She represents several health care unions on the Health Board, and has been involved in health care labour issues for a number of years.



Vancouver/Richmond Health Board Directors. Back (left to right): David Levi, Stephanie Killam, Dr. V.J. (Jim) Thorsteinson, Gentil Mateus, Sheila Rowswell, John P. Kennedy, Bud Osborn. Front (left to right): Silvia Wilson, Robyn Woodward, Margaret McPhee, Renee Taylor. Not pictured: David Esworthy, Bert Massiah, Jim Sinclair, Patricia Wilkinson.

Jim Sinclair is Second Vice-President of the United Fishermen and Allied Workers' Union and a member of the Executive Council of the BC Federation of Labour. He has written and spoken on free trade and economic issues.

Renee Taylor is a clinical law instructor at UBC. A member of the Nuu-chah-nulth at Alert Bay, she is a long-time First Nations advocate and a director for agencies providing services in the Downtown Eastside.

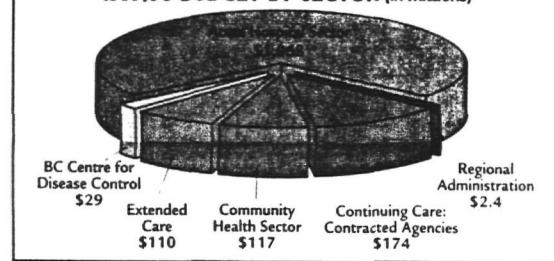
Dr. V.J. (Jim) Thorsteinson is chair of the Department of Family and Community Medicine at St. Paul's Hospital and Assistant Professor in the Dept. of Family Practice. He is involved in a number of health care initiatives for minority residents.

Patricia Wilkinson is Consumer Liaison to the Canadian Mental Health Association's BC division. She has been active in health reform for a number of years, serving on several committees associated with mental health issues.

Silvia Wilson is a health science instructional designer, College and a language teacher at G.F. Strong. She is a registered nurse who has worked in nursing and taught at the Immigrant Services Society. She has volunteered with the Positive Women's Network for positive women and their children.

Robyn Woodward is a maritime archaeologist and anthropologist who was a founding member of the original Vancouver Health Board. Her involvement in health reform has included an interest in the concerns of the multicultural community. Robyn has volunteered for organizations including MOSAIC and St. Vincent's Hospital Foundation.

VANCOUVER/RICHMOND HEALTH BOARD 1997/98 BUDGET BY SECTOR (in millions)



Financial Information

Vancouver/Richmond Health Board Consolidated Statement of Operations*

Year ended March 31, 1998

	Agency Funding
Revenue:	
Ministry of Health	147,192,122
Services fees	1,951,767
Patient Services	8,887,454
Other income	7,242,723
Amortization of deferred	
Capital contributions	4,083,075
	169,357,141
Expenses:	
Salaries and wages	95,061,786
Employee benefits	17,918,639
Homemaker contract services	1,450,513
Other contract services	8,278,677
Building costs	11,379,033
Professional costs	4,289,185
Administrative supplies and services	7,838,995
Medical, surgical and clinical supplies	16,474,741
Other health care supplies and services	3,813,560
Amortization	4,340,935
	170,846,064
Deficiency of revenue over expenses before the undemoted items	(1,488,923)
	Agency Payments
Cluster A (Providence Health Care)	249,571,675
Cluster B (Vancouver Hospital & Health Sciences Centre)	440,283,435
Cluster C (Children's & Women's Health Centre of British Columbia)	164,736,031
Cluster D (BC Cancer Agency)	106,180,656
Greater Vancouver Mental Health Society	41,657,287
Other agencies	7,783,585
Ministry of Health Services Bureaus	178,260,356
	1,188,473,025
Deficiency of revenue over expenses	(683,940)

*Excerpted from the full audited financial statements, which are available upon request. Revenue and expenses include Vancouver/Richmond Health Board direct services, Richmond Health Services Society, and B.C. Centre for Disease Control Society.

Executive Staff

Rick Roger, Chief Executive Officer

Jack Altman, Vice President
Community Health Services

John Blatherwick, Medical Health
Officer

Mark Chase, Vice President Planning
& Evaluation

Ron Climenhaga, Chief Operating
Officer Richmond Health Services

John Heath, Vice President
Corporate Services & Chief Financial
Officer

Sharon Martin, Director Community
& Public Involvement

Marleen Morris, Director
Communications & Health Education

Stu Noble, Chief Human Resources
Officer

Marleen Wong, Regional Director
Provincial Programs & Strategic
Initiatives

Ron Zapp, Chief Operating Officer
B.C. Centre for Disease Control
Society

APPENDIX 2: PARTICIPATORY EVALUATION QUESTIONNAIRE

B. INDICATORS OF INCLUSIVENESS

To follow are a number of rating scales for different indicators and sub indicators of public involvement. More precisely, these scales measure the extent to which you perceive the V/RHB have tried to involve and/or have welcomed your self-help group in their Community Health Promotion Process. Please note that this is the degree to which you were invited into the community health process by the V/RHB, not the degree to which your self-help group members have tried to involve themselves.

The overall rating scale provided at the end of each set of sub indicators is for you to rate the Health Board in regards to the entire indicator (e.g., Needs Assessment in general). The sub indicators are important sources of information in themselves but can also serve as aids to help you make your overall evaluation. Mark the rating for each indicator and sub indicator somewhere along the continuum by circling the appropriate level. This number can be a continuous number (e.g., between 3 and 4) or a whole number (e.g., 1, 3, or 5). This means that your answer can fall at one extreme or the other or anywhere in between. Number 1 signifies no involvement and 5, full. To avoid bias, the rating scales for indicators and sub indicators have been arranged in either forward (least to most participatory/1-5) or reverse (most to least participatory/5-1) orders. Please read each carefully before making your rating.

For each indicator, please explain your response (why you placed your circle where you did). If you used other information to make this rating besides the sub indicators provided, please include this in your comments.

Examples of Rating Scales and Marking

Highest		Lowest
---------	--	--------

*****	*****	*****	*****	*****
5	4	3	2	1

or

Lowest		Highest
--------	--	---------

*****	*****	*****	*****	*****
1	2	3	4	5

Needs Assessment

To what degree did the V/RHB include your group in assessing the needs of your group and its members?

Examples/Sub Indicators

Remember, 1 refers to no involvement, 5 to full.

How well have the V/RHB:

1. Included your group in full and active discussion regarding its health needs?

Highest		Lowest
---------	--	--------

++++++	*++++++*	*++++++*	*++++++*
5	4	3	2

2. Involved your group in various stages of the needs assessment from its design to implementation, analysis, and evaluation?

Highest		Lowest
---------	--	--------

++++++	*++++++*	*++++++*	*++++++*
5	4	3	2

3. Elicited information from your group that is important and relevant to its members?

Lowest		Highest
--------	--	---------

++++++	*++++++*	*++++++*	*++++++*
1	2	3	4

4. Used needs assessments as a first step towards involving your group more deeply in community health planning (i.e., in processes which respond to and meet your needs, for example, decision making and implementation)?

Highest		Lowest
---------	--	--------

++++++	*++++++*	*++++++*	*++++++*
5	4	3	2

Overall Rating

Lowest

Highest

*++++++
1 2 3 4 5

Discussion: Briefly describe the key experiences you used to make your rating/ratings.

Resource Mobilization

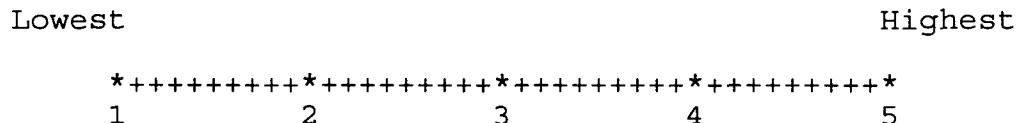
To what level were V/RHB resources (e.g., funding, educational material, advertising material, staff assistance) used to involve your group in community health planning?

Examples/Sub Indicators

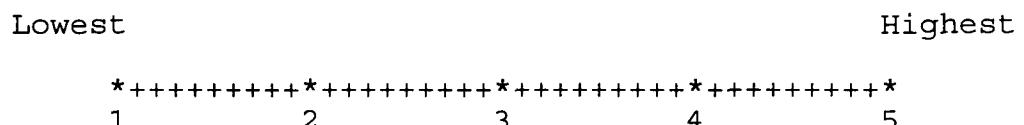
Remember, 1 refers to no involvement, 5 to full.

To what degree did the V/RHB use their resources:

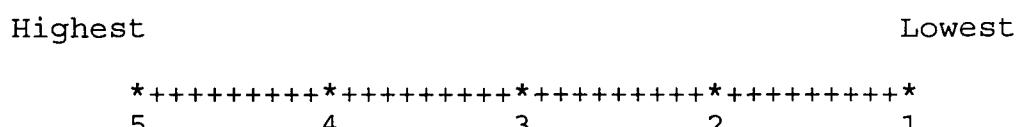
1. To inform your group about their Community Participation Process and involve your group?



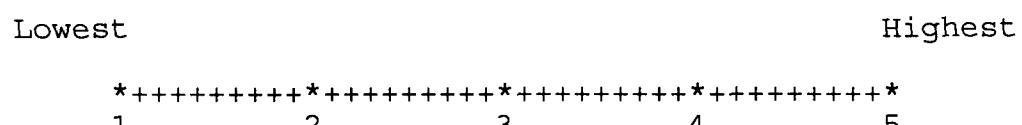
2. To acquire full participation in decision making and planning for change?



3. To benefit the members of your group?



4. To enable your group to participate and to compensate them for doing so?



5. In a flexible, open manner to reflect the needs/desires of your group members?

Highest

Lowest

* ++++++ * ++++++ * ++++++ * ++++++ *
5 4 3 2 1

6. To foster a permanent participatory process?

Highest

Highest

* + + + + + + + + * + + + + + + + + * + + + + + + + + + * + + + + + + + + + *
1 2 3 4 5

Discussion: Briefly describe the key experiences you used to make your rating/ratings.

Participation Approach

How fully did the V/RHB involve your group in planning to meet the needs of your groups and its members?

Examples/Sub Indicators

Remember, 1 refers to no involvement, 5 to full.

How successful were the V/RHB in:

1. Maintaining a balance between nurturing new avenues of participation they developed (i.e., Community Health Committees and Population Health Advisory Committees) and your group (as a more bottom-up, pre-existing avenue)?

| | | |
|--------|--|---------|
| Lowest | | Highest |
|--------|--|---------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 1 | 2 | 3 | 4 | 5 |

2. Actively seeking out your group for involvement (e.g., through recruitment material, forums, information sessions, focus groups, workshops)?

| | | |
|---------|--|--------|
| Highest | | Lowest |
|---------|--|--------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 5 | 4 | 3 | 2 | 1 |

3. Demonstrating responsiveness and accountability to the members of your group?

| | | |
|---------|--|--------|
| Highest | | Lowest |
|---------|--|--------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 5 | 4 | 3 | 2 | 1 |

4. Working towards developing effective collaborative relationships with your group for the purpose of health planning?

| | | |
|--------|--|---------|
| Lowest | | Highest |
|--------|--|---------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 1 | 2 | 3 | 4 | 5 |

5. Applying new, more flexible, bottom-up approaches to involve your group?

Lowest

Highest

6. Fostering full and active participation in all stages of planning and promoting shared learning, consciousness raising, empowerment, and social action in this process?

Highest

Lowest

* + + + + + + + + * + + + + + + + + * + + + + + + + + + * + + + + + + + + + *
5 4 3 2 1

Overall Rating

Lowest

Highest

* + + + + + + + + * + + + + + + + + * + + + + + + + + * + + + + + + + + * + + + + + + + + *
1 2 3 4 5

Discussion: Briefly describe the key experiences you used to make your rating/ratings.

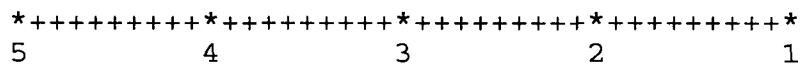
Leadership Styles

How interactively did the V/RHB involve your group members in these meetings?

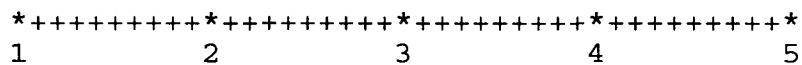
Remember, 1 refers to no involvement, 5 to full.

At what level did the V/RHB:

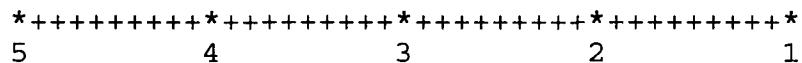
- 1 Use a facilitative leadership, i.e., one generating democratic and open discussion and valuing each participant's contribution?



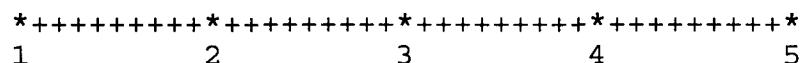
2. Share leadership with members of your group?



3. Work with your group to find a style or styles of communication that reflect(s) your group's ways of doing things and thinking?



4. Actively listen and respond to all group members, especially those least heard, most dissenting, or most marginalized?



Overall Rating

* ++++++ * ++++++ * ++++++ * ++++++ *
5 4 3 2 1

Discussion: Briefly describe the key experiences you used to make your rating/ratings.

C. INDICATORS OF SUPPORT

To follow are rating scales for indicators and sub indicators measuring the degree of support you perceive the V/RHB have given your self-help group as a community health service. It is important to note that we are not looking at whether the Health Board have given funding or other resources to your group merely to support a project or projects. Rather, we are interested in measuring the extent to which they have supported your group because it is a self-help group.

The overall rating scale provided at the end of each set of sub indicators is for you to rate the Health Board in regards to the entire indicator (e.g., Horizontal Linkages in general). The sub indicators are important sources of information in themselves but can also serve as aids to help you make your overall evaluation. Mark the rating for each indicator and sub indicator somewhere along the continuum by circling the appropriate level. Please give an individual rating of anywhere from 1-5 (or 5-1) for each. This number can be a continuous number (e.g., between 1 and 2) or a whole number (e.g., 2, 3, or 5). This means that your answer can fall at one extreme or the other or anywhere in between. Number 1 signifies no involvement and 5, full. To avoid bias, the rating scales for indicators and sub indicators have been arranged in either forward (least to most participatory/1-5) or reverse (most to least participatory/5-1) orders. Please read each carefully before making your rating.

For each indicator, please explain your response (why you placed your circle where you did). If you used other information to make this rating besides the sub indicators provided, please include this in your comments.

Horizontal Linkages

To what extent have the V/RHB served to nurture respect and collaboration between your group and other self-help groups, professionals, and community members/organizations?

Examples/Sub Indicators

Remember, 1 refers to no support, 5 to full.

How well have the V/RHB:

1. Assisted your group in working together to share resources and organize to address common concerns?

| | | |
|---------|--|--------|
| Highest | | Lowest |
|---------|--|--------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 5 | 4 | 3 | 2 | 1 |

2. Helped your group work with professionals and community organizations to share resources and organize to address common concerns?

| | | |
|--------|--|---------|
| Lowest | | Highest |
|--------|--|---------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 1 | 2 | 3 | 4 | 5 |

3. Promoted networking and referrals between your group and other self-help groups, professionals, and community organizations?

| | | |
|---------|--|--------|
| Highest | | Lowest |
|---------|--|--------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 5 | 4 | 3 | 2 | 1 |

4. Allocated resources to your group to help them develop these horizontal linkages?

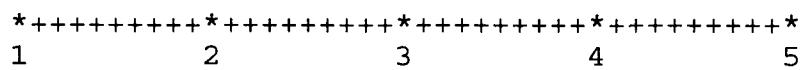
| | | |
|--------|--|---------|
| Lowest | | Highest |
|--------|--|---------|

| | | | | |
|----------|----------|----------|----------|----------|
| *++++++* | *++++++* | *++++++* | *++++++* | *++++++* |
| 1 | 2 | 3 | 4 | 5 |

Overall Rating

Lowest

Highest



Discussion: Briefly describe the key experiences you used to make your rating/ratings.

Vertical Linkages

How well have the V/RHB tried to work directly with your group to improve its potential and position as a health service?

Examples/Sub Indicators

Remember, 1 refers to no support, 5 to full.

To what extent have the V/RHB:

1. Provided support to your group through public relations and marketing to help it become established, expand membership, and thrive?

* ++++++ * ++++++ * ++++++ * ++++++ *
1 2 3 4 5

2. Contributed resources towards advancing collaborative efforts between your group and the V/RHB (including staff, Population Health Advisory Committees and Community Health Committees) to meet the health needs of residents?

* ++++++ * ++++++ * ++++++ * ++++++ * ++++++ * ++++++ * ++++++ *
5 4 3 2 1

3. Allotted resources (e.g., resource material, facilitation training, funding) to help your group organize and evolve as effectively as possible?

* ++++++ * ++++++ * ++++++ * ++++++ * ++++++ * ++++++ * ++++++ *
1 2 3 4 5

4. Given your group support through recommending it to residents as an effective complementary health service?

* + + + + + + + + * + + + + + + + + * + + + + + + + + + * + + + + + + + + + * + + + + + + + + + + *
1 2 3 4 5

5. Supported your group in a manner which honours and maintains your integrity as a grass-roots, bottom-up health service?

Highest

Lowest

* ++++++ * ++++++ * ++++++ * ++++++ *
5 4 3 2 1

Overall Rating

Highest

Lowest

* + + + + + + + + * + + + + + + + + * + + + + + + + + + * + + + + + + + + + *
5 4 3 2 1

Discussion: Briefly describe the key experiences you used to make your rating/ratings.

D. RECOMMENDATIONS: WORKING TOGETHER FOR THE FUTURE

Please briefly discuss some of the ways you feel the V/RHB can involve and support self-help groups more effectively.

E. RECENT HEALTH BOARD INVOLVEMENT AND SUPPORT OF YOUR GROUP

Have the V/RHB involved/supported your self-help group since the study deadline (i.e., since January 1, 1998)? If so, how?

F. BOTTOM-UP EFFORTS TO WORK WITH THE V/RHB

Over the last few years has your self-help group/organization tried to initiate and maintain relationships with the V/RHB? If so, please explain how and also whether your efforts to do so were initiated before or after the end of 1997 or during both time periods.

G. EVALUATING THE EVALUATION

Feel free to evaluate this evaluation. For example: What impact has it had on you; do you think it is effective; what would you keep the same and change; and so on?

Please don't forget to put an asterisk beside any information you want quoted. Thank you again.

APPENDIX 3: A GENERAL AIDE MEMOIRE

STAGES OF PARTICIPATORY EVALUATIONMajor Stages

These stages may follow a variety of orders and may overlap and occur together. They are cyclical in nature.

Identifying need for study

- conducting needs assessment
- incorporating general experience/knowledge

Recruiting participants

- casting as wide a net as possible
- being open and flexible about who qualifies
- being open and flexible about who leaves and enters and when

Designing study (evaluation)

- Determining:
 - needs
 - purpose, goals, and objectives
 - audience
 - framework/format
 - process
 - specific questions
 - kinds of data to be collected
 - target audiences
 - potential use/distribution of results

Gathering/recording information

- ongoing information collecting and recording
- implementing surveys and recording results

Analyzing information

- ongoing information analyzing
- analyzing surveys
- doing final evaluation

Distributing

- getting evaluation results out to the public
- getting other information out to the public

Making recommendations

- offering advice on how we can use evaluation results
- offering advice on how we can use other information

Evaluating study

- ongoing evaluating
- doing final evaluation
- conducting follow-up evaluation

Ongoing/Recurring Components

- Educating/taking action
- Consciousness raising/empowering
- Validating information gained
- Validating process
- Negotiating when conflict exists
- Meeting other needs and developing capacities

APPENDIX 4: REVISED LETTER OF PARTICIPANT RECRUITMENT

in women's self-help groups in Vancouver. Both stakeholder groups will be involved, through interviews and focus groups, in first working on the evaluation design and then actually doing the evaluation. Interviews will be unstructured even though an aide memoire will guide the process. Focus groups will be largely participant controlled even though they will be well facilitated. Questionnaires will also be used to gather data from stakeholders who would like to be included in the study but do not have sufficient time for interviews and focus groups.

Questionnaires will take roughly 60 minutes to fill out, interviews will take 60 to 90 minutes, and focus groups will take roughly 90 to 120 minutes. Interviewees and focus group participants will be asked to both design and do the evaluation and, therefore, will be included in at least two interviews or focus groups. Participants will be asked to do no more than four interviews or questionnaires but may choose to do more and to be involved in both interviews and focus groups. Those who do the questionnaire will bypass the evaluation design stage.

Subjects will be recruited by the "snowball" sampling technique. Key informants will be sought through existing women's self-help groups linked to Vancouver's community health promotion process and through the VHB. It is through letters such as this that I intend to make initial contact with potential participants in both major groups.

Participation in this study is entirely voluntary and you may refuse to participate or may withdraw from the study at any time without jeopardy to your well being or continued membership in your group(s) or organization(s).

This study will follow strict rules of confidentiality. To maintain confidentiality, each participant will be given a code number or name for data gathering/handling purposes and all organizations or groups will be given the option of keeping their identities confidential. The only time information will be made available to the public is when participants have given their full and informed consent. All identifying/confidential information (names, etc.) will be kept confidential and will be stored in a locked filing cabinet at the researcher's private address until it is destroyed. Further, all anecdotal material made available to the public will be altered to protect the participants' identities.

Information gathered will be used for developing the dissertation and a final report/guide book for use by both stakeholder groups and other concerned parties.

Consent forms will be obtained from both interviewees and focus

APPENDIX 5: REVISED LETTER OF INFORMATION AND INFORMED
CONSENT FORM

been working with women in the community health promotion process; and (2) women in women's self-help groups in Vancouver. Both stakeholder groups will be involved, through interviews and focus groups, in first working on the evaluation design and then actually doing the evaluation. Interviews will be unstructured even though an aide memoire will guide the process. Focus groups will be largely participant controlled even though they will be well facilitated. Questionnaires will also be used to gather data from stakeholders who would like to be included in the study but do not have sufficient time for interviews and focus groups.

Questionnaires will take roughly 60 minutes to fill out, interviews will take 60 to 90 minutes, and focus groups will take roughly 90 to 120 minutes. Participants will be asked to both design and do the evaluation and, therefore, will be included in at least two interviews or focus groups. Participants will be asked to do no more than four interviews or questionnaires but may choose to do more and to be involved in both interviews and focus groups.

Subjects are being recruited by the "snowball" sampling technique. Key informants will be sought through existing self-help groups linked to Vancouver's community health promotion process and through the VHB. Initial contact will be done through letters informing members of the Health Board and relevant self-help groups about my project and asking them to contact me if they would like to participate, i.e., letters of initial contact.

STATEMENT OF CONSENT

Confidentiality:

I have been informed that, to maintain confidentiality, each participant will be given a code number or name for data gathering/handling purposes and all organizations or groups will be given the option of keeping their identities confidential.

I understand that the only time information will be made available to the public is when I have given my full and informed consent. I have been ensured that all identifying/confidential information (names etc.) will be kept confidential and will be stored in a locked filing cabinet at the researcher's private address until it is destroyed. Further, all anecdotal material that I allow to be made public will be altered to protect my identity.

I have been informed that information gathered will be used for developing the dissertation and a final report/guide book for use by both stakeholder groups and other concerned parties.

APPENDIX 6: EXERCISE OBJECTIVES AND TASKS

ADVISORY COMMITTEE OUTLINE # 1

1. Objectives of Dissertation:

To conduct a participatory evaluation whereby women's self-help groups, alone or with Vancouver/Richmond Health Board staff, will evaluate how successfully the latter stakeholders have included their groups in health planning and supported them as health services.

To document the results and processes of our participatory evaluation to help health planners include and support self-help groups more effectively.

2. Objectives of Participatory Evaluation (PE) :

- To have a voice
- To collectively learn
- To collectively empower
- To evaluate/teach/inform
- To stimulate action/change
- To organize
- To act/change

3. Our General Objectives:

- To meet PE objectives
- To help meet the need of participants and their self-help groups
- To help me acquire information to meet my dissertation objectives

4. Our Specific Objectives:

- To identify, and find way to satisfy, needs of participants and their groups
- To establish who participates
- To design evaluation form(s)
- To gather, record, and analyze data
- To establish who we disseminate information to and how.
- To present finding to Health Regions/Boards
- To evaluate the evaluation process

5. Clarifying what we want to do as a committee:

- Our needs
- Our deadlines and time commitments
- Feedback on/input into evaluation form
- Components of evaluation process
- Funding efforts

PROCESS STEPS

Next meeting: Clarifying needs and organizing
Discussing dissemination of results (e.g.,
presentations)
Looking at funding options
Handing out evaluation forms for later feedback

Second Meeting: Developing final evaluation draft
Checking progress re: funding, organizing
presentations

Third Meeting: Organizing presentations
Handing out information collected for validation
and determining which quotes or paraphrased I
can make public and how

APPENDIX 7: DRAFT EXERCISE ASSESSMENT FORM FOR CORE
PARTICIPANTS

EVALUATING THE EVALUATIONA. INTRODUCTION

At this stage of this study, I would like you to help assess how successful it has been as a participatory evaluation. The first section of this evaluation asks you to answer questions corresponding to criteria of authenticity (issues regarding imbalances of power and representation) to make your assessment. The second section is much more open.

You can contact me (Deborah Campbell) at (604) 936-0501 if you need any assistance with this form. Thank you for your assistance.

B. CRITERIA OF AUTHENTICITY

On a scale of one to five, or five to one, please evaluate the following and give a brief explanation for your answer. How well has this study:

1. Sought and respected your values and constructions (the ideas and understandings you have regarding these issues) and those of other participants and stakeholders?

| Highest | | | | Lowest |
|---------|---|---|---|--------|
| * | * | * | * | * |
| 5 | 4 | 3 | 2 | 1 |

Discussion (e.g., how/why did you decide to give this rating)?

2. Cultivated your and your groups' own constructions and their use?

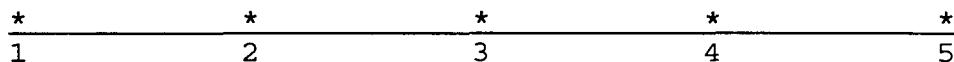
| Lowest | | | | Highest |
|--------|---|---|---|---------|
| * | * | * | * | * |
| 1 | 2 | 3 | 4 | 5 |

Discussion (e.g., how/why did you decide to give this rating)?

3. Enhanced your understanding of and respect for the construction of stakeholders/participants not within your group?

Lowest

Highest

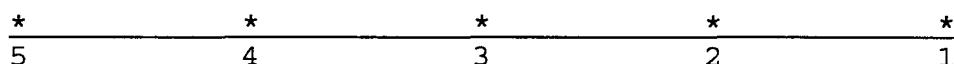


Discussion (e.g., how/why did you decide to give this rating)?

- #### 4. Generated and facilitated action?

Highest

Lowest

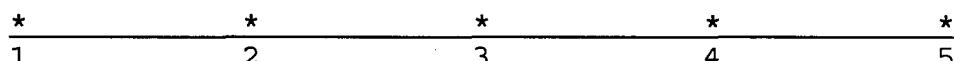


Discussion (e.g., how/why did you decide to give this rating)?

5. Empowered you and other participants to act?

Lowest

Highest



Discussion (e.g., how/why did you decide to give this rating)?

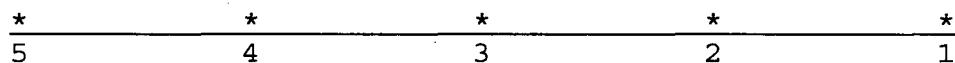
C. COMPONENTS OF PARTICIPATORY EVALUATIONS

To what extent are you pleased about:

1. the means of recruitment and inclusiveness of stakeholders?

Highest

Lowest

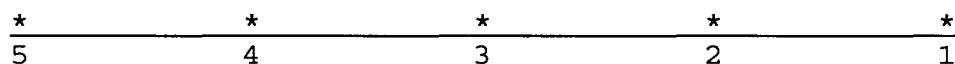


Discussion (e.g., how/why did you decide to give this rating)?

2. how well we have identified and met your needs?

Highest

Lowest

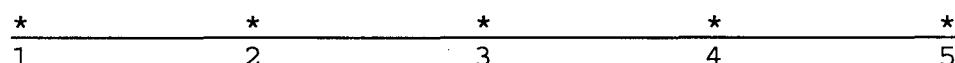


Discussion (e.g., how/why did you decide to give this rating)?

- ### 3. the goals and objectives set?

Lowest

Highest



Discussion (e.g., how/why did you decide to give this rating)?

4. our success in meeting these goals and objectives?

Lowest

Highest

* * * * *

Discussion (e.g., how/why did you decide to give this rating)?

5. the process of the study?

Lowest

Highest

* * * * *

Discussion (e.g., how/why did you decide to give this rating)?

6. the results of the study?

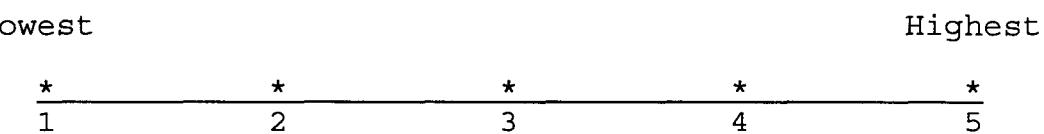
Highest

Lowest

* * * * *

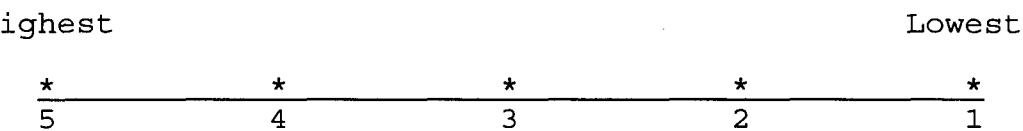
Discussion (e.g., how/why did you decide to give this rating)?

7. the analysis of the study?



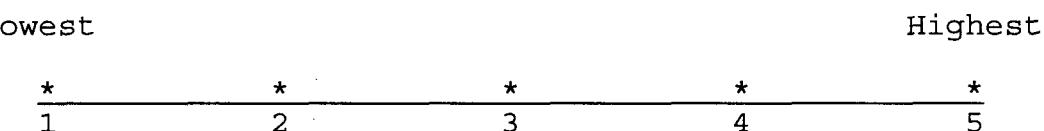
Discussion (e.g., how/why did you decide to give this rating)?

8. our target audiences?



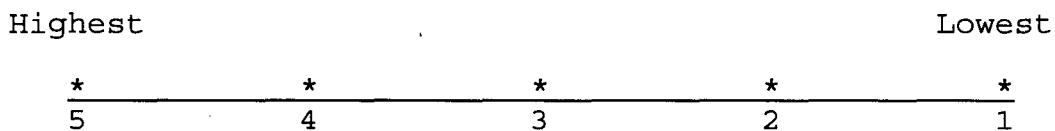
Discussion (e.g., how/why did you decide to give this rating)?

9. our means of dissemination?



Discussion (e.g., how/why did you decide to give this rating)?

10. the evaluation of this study?



Discussion (e.g., how/why did you decide to give this rating)?

D. GENERAL ASSESSMENTS

1. What general impact has this study had on you?

2. Please feel free to make additional comments here. For example, what things would you change/keep?

BIBLIOGRAPHY

-
- Alinsky, Saul. (1972). Rules for Radicals. New York: Vintage Books.
- Anyanwu, Clement Nuorom. (1981). Principles and Practice of Adult Education and Community Development. Ibadan: Abiprint Publishers.
- Anyanwu, Clement Nuorom. (1888). "The Technique of Participatory Research in Community Development." Community Development Journal. January, 23, 1, 11-15.
- Armstrong, Pat. (1996). "Unravelling the Safety Net: Transformations in Health Care and Their Impact on Women." Ed. Janine Brodie. Women and Canadian Public Policy. (pp. 129-149). Toronto, Ontario: Harcourt Brace and Company, Canada.
- Arnstein, Sherry R. (1969). "A Ladder of Participation." Journal of American Institute of Planning. July, 35, 216-224.
- Barnsley, Jan; and Diana Ellis. (1987). The Women's Research Centre and Our Assumptions About Action Research. Vancouver, British Columbia: Women's Research Centre.
- Barnsley, Jan; and Diana Ellis. (1992). Research for Change: Participatory Action Research for Community Groups. Vancouver, British Columbia: Women's Research Centre.
- Belenky, Mary Field; Blythe McVicker Clinchy; Nancy Rule Goldberger; and Jill Mattuck Tarule. (1986). Women's Ways of Knowing: The Development of Self, Voice, and Mind. New York: Basic Books Incorporated.
- Berger, Peter L.; and Richard John Neuhaus. (1977). To Empower People - The Role of Mediating Structures in Public Policy. Washington, District of Columbia: American Enterprise for Public Policy Research.
- Berger, Peter L.; and Richard John Neuhaus. (1984). "To Empower People." Eds. David C. Korten and Rudi Klauss. People-Centred Development: Contributions Toward Theory and Planning Frameworks. (pp. 250-261). West Hartford, Connecticut: Kumarian Press.
- Berkman, Lisa F.; and S. Leonard Syme. (1979). "Social Networks, Host Resistance and Mortality: A Nine-Year Follow-Up Study of Almeda County Residents." American Journal of Public Health. 109, 2, 186-204.

- Borkman, Thomasina, J. (1990). "Experimental, Professional, and Lay Frames of Reference." Ed. Thomas J. Powell. Working With Self-Help. (pp. 3-30). Silver Spring Maryland: National Association of Social Workers Incorporated.
- Borkman, Thomasina, J. (1991). "Introduction to the Special Issues." American Journal of Community Psychology. 19, 5, 643-650.
- Bottorff, Joan. L. (1997). "Linking Qualitative and Quantitative Research: New Avenues for Programmatic Research." Ed. Janice Swanson. Completing a Qualitative Project: Details and Dialogue. (pp. 227-249). Thousand Oaks, California: Sage Publications Incorporated.
- Boyce, William. (1993). "Evaluating Participation in Community Programs: An Empowerment Paradigm." The Canadian Journal of Program Evaluation. April/May, 8, 1, 89-102.
- British Columbia Ministry of Health and Ministry Responsible for Seniors. (1995). Women's Health Writes. Victoria, British Columbia: British Columbia Ministry of Health and Ministry Responsible for Seniors. January 1, 1.
- British Columbia's Women's Hospital and Health Centre Society, Consultation Working Group. (1995). The Challenges Ahead for Women's Health. BC Women's Community Consultation Report. Vancouver, British Columbia: British Columbia's Women's Hospital and Health Centre Society.
- Brown, David L. (1985). "People-Centred Development and Participatory Research." Harvard Educational Review. 55, 9, 69-71.
- Brown, David L. (1986). "Participatory Research and Community Planning." Ed. Barry Checkoway. Strategic Perspectives on Planning Practice. (pp. 123-137). Lexington: Health and Company.
- Brown, David L. (1991). "Methodological Considerations in the Evaluation of Social Development Programmes - An Alternative Approach." Community Development Journal. October, 20, 4, 259-265.
- Brown, David L.; and Rajesh Tandon. (1983). "Ideology and Political Economy in Inquiry: Action Research and Participatory Research." Journal of Applied Behavioural Science. 19, 3, 277-294.
- Bruce Christman, Jolley. (1988). "Working in the Field as the Female Friend." Anthropology and Education Quarterly. June, 19, 2, 70-85.

- Brunner, Ilse; and Alba Guzman. (Summer 1989). "Participatory Evaluation: A Tool to Assess Projects and Empower People." Eds. R.E. Conner and M. Hendricks. International Innovations in Evaluation Methodology. New Directions for Program Evaluation, No. 42. (pp. 9-17). San Francisco, California: Jossey-Bass.
- Bryk, A.S. Ed. (1983). Stakeholder-Based evaluation. New Directions in Program Evaluation (No. 17). San Francisco, California: Jossey-Bass.
- Buber, Martin. (1958). Paths in Utopia. Boston: Beacon Press.
- Carey, Martha Anne. (1997). "Quantitative Research in Policy Development." Ed. Janice Swanson. Completing a Qualitative Project: Details and Dialogue. (pp. 345-354). Thousand Oaks, California: Sage Publications Incorporated.
- Checkoway, Barry; Mark A. Chesler; and Stephen Blum. (1990). "Self-Care, Self-Help, and Community Care for Health." Ed. Thomas J. Powell. Working With Self-Help. (pp. 277-300). Silver Spring, Maryland: National Association of Social Workers Press.
- Chesler, Mark A. (1991). "Participatory Action Research With Self-Help Groups: An Alternative Paradigm for Inquiry and Action." American Journal of Community Psychology. October, 19, 5, 757-768.
- Clarke, Juanne N. (1992). "Feminist Methods in Health Promotion Research." Canadian Journal of Public Health. March/April, 83, Supplement 1, 54-57.
- Comstock, Christine M.; and Joyce L. Mohamoud. (1990). "Professionally Facilitated Self-Help Groups: Benefits for Professionals and Members." Ed. Thomas J. Powell. Working With Self-Help. (pp. 177-188). Silver Spring, Maryland: National Association of Social Workers Press.
- Cook, Thomas D. (1985). "Post-Positivist Critical Multiplicity." Eds. R.L. Shotland and M.M. Mark. Social Science and Social Policy. (pp. 21-62). Beverly Hills, California: Sage Publishing.
- Cook, Thomas D. and Donald T. Campbell. (1979). Quasi Experimentation: Design and Analysis Issues for Field Settings. Chicago, Illinois: Rand McNally.
- Corcega, Thelma F. (1992). "Participatory Research: Getting the Community Involved in Health Development." International Nursing Review. September/October, 39, 6, 185-188.

- Cousins, Bradley J.; and Lorna M. Earl. (1992). "The Case for Participatory Evaluation." Educational Evaluation and Policy Analysis. Winter, 14, 4, 397-418.
- Cronbach, L.S.; (1975). "Beyond the Two Disciplines of Psychology." American Psychologist. 30, 116-127.
- Cronbach, L.; S. Ambron; S. Dornbusch, R. Hess; R. Hornik; D. Phillips; D. Walker; and S. Weiner. (1980). Towards Reform of Program Evaluation. San Francisco, California: Jossey-Bass.
- Cronbach, Lee J.; and Patrick Suppes. (1969). Research for Tomorrow's Schools: Disciplined Inquiry in Education. New York, New York: MacMillan.
- Crowley, Helen; and Susan Himmelweit. (1992). Knowing Women: Feminism and Knowledge. Cambridge, England: Polity Press.
- Dahl, Robert A. (1982). Dilemmas of Pluralist Democracy: Autonomy Versus Control. New Haven, Connecticut: Yale University Press.
- Dalton, Linda. (1986). "Why the Rational Paradigm Persists: The Resistance of Professional Education and Practice to Alternative Forms of Planning." Journal of Planning Education and Research. Spring, 5, 147-153.
- Davey, Judith; and Maire Dwyer. (1984). Meeting Needs in the Community: A Discussion Paper on Social Sciences. Wellington, New Zealand: New Zealand Planning Council.
- de Koning, Korrie; and Marion Martin. (1996). "Participatory Research in Health: Setting the Context." Eds. Korrie de Koning and Marion Martin. Participatory Research in Health: Issues and Experience. (pp. 1-18). London, England: Zed Books Limited.
- Dhillon, H.S.; and Lois Philip. (1994). Health Promotion and Community Action for Health in Developing Countries. Geneva, Switzerland: World Health Organization.
- Driscoll, Kathleen; and Joan McFarland. (1989). "The Impact of a Feminist Perspective on Research Methodologies: Social Sciences." Ed. Winnie Tomm. The Effects of Feminist Approaches on Research Methodologies. (pp. 185-203). Waterloo, Ontario: Wilfrid Laurier University Press.
- Du Bois, Barbara. (1983). "Passionate Scholarship: Notes on Values, Knowing and Method in Feminist Social Science." Eds. Gloria Bowles and Renate Duelli Klein. Theories of Women's Studies. London, England: Routledge and Kegan Paul.

- DuBois, Lindsay. (1988). Action on Issues: Women and Health. Toronto, Ontario: The Ontario Advisory Council on Women's Issues.
- Dumont, M.P. (1974). "Self-Help Treatment Programs." American Journal of Psychiatry. 131, 6, 631-635.
- Dumont, Micheline. (1989). "The Influence of Feminist Perspective on Historical Research Methodology." Ed. Winnie Tomm. The Effects of Feminist Approach on Research Methodologies. Waterloo, Ontario: Wilford Laurier University Press.
- Epp, Jake; and Health and Welfare Canada. (1986). Achieving Health for All: A Framework for Health Promotion. Ottawa, Ontario: Ministry of Supply and Services Canada.
- Fals-Borda, Orlando. (1980). "Science and the Common People." Eds. F. Dubell, T. Erasmie, and J. de Vries. Research For the People - Research By the People. (pp. 13-40). Ljubljana, Yugoslavia: Linkoping University, Department of Education.
- Fals-Borda, Orlando. (1984). "Participatory Action Research." Development: Seeds of Change. 2, 18-20.
- Fawcett, Stephen B.; Adrienne Paine-Andrews; Vincent T. Francisco; Jerry A. Schultz; Kimber P. Richter; Rhonda K. Lewis; Kari Jo Harris; Ella J. Williams; Jannette Y. Berkley; Christian M. Lopez; and Jacqueline L. Fisher. (1996). "Empowering Community Health Initiatives Through Evaluation." Eds. David M. Fetterman, Shakeh J. Kaftarian, and Abraham Wandersman. Empowerment Evaluation: Knowledge and Tools for Self-Assessment and Accountability. (pp. 161-187). Thousand Oaks, California: SAGE Publications Incorporated.
- Fee, Elizabeth. (1983). "Women and Health Care: A Comparison of Theories." Ed. Elizabeth Fee. Women and Health: The Politics of Sex in Medicine. (pp. 17-34). Policy, Politics, Health, and Medicine Series. Baywood Publishing Company, Incorporated.
- Feuerstein, Marie-Therese. (1988). "Finding the Methods to Fit the People: Training for Participatory Evaluation." Community Development Journal. January, 23, 1, 16-25.
- Firestone, William A. (1993). "Alternative Arguments for Generalizing From Data as Applied to Qualitative Research." Educational Researcher. May, 22, 16-23.

Fonow, Mary Margaret; and Judith A. Cook. (1991a). "Back to the Future: A Look at the Second Wave of Feminist Epistemology and Methodology." Eds. Mary Margaret Fonow and Judith A. Cook. Beyond Methodology: Feminist Scholarship as Lived Research. (pp. 1-15). Bloomington, Indiana: Indiana University Press.

Fonow, Mary Margaret; and Judith A. Cook. Eds. (1991b). Beyond Methodology: Feminist Scholarship as Lived Research. Bloomington, Indiana: Indiana University Press.

Forester, John. (1989). Planning in the Face of Power. Berkeley, California: University of California Press.

Freire, Paulo. (1972). Pedagogy of the Oppressed. New York: Herder and Herder.

Friedman, Marilyn. (1992). "Feminism and Modern Friendship: Dislocating the Community." Eds. Eve Browning Cole and Susan Coultrap-Maquin. Explorations in Feminist Ethics: Theory and Practice. Bloomington: Indiana University Press.

Friedmann, John. (1973). Retracking America. New York: Anchor.

Friedmann, John. (1987). Planning in the Public Domain: From Knowledge to Action. Princeton, New Jersey: Princeton University Press.

Friedmann, John. (1988). The Dialectics of Reason. Los Angeles: University of California, Graduate School of Architecture and Urban Planning.

Gartner, Audrey. (1985). "A Typology of Women's Self-Help Groups." Social Policy. Winter, 15, 3, 25-30.

Gaventa, John. (1993). "The Powerful, the Powerless, and the Experts: Knowledge Struggles in an Information Age." Eds. Peter Park, Mary Brydon Miller, Budd Hall, and Ted Jackson. Participatory Research in the United States and Canada. (pp. 21-40). Westport, Connecticut: Bergin and Garvey.

Gould, Kathrine. (1994). Ideas About Health Care From Very Marginalized Women From All Over Vancouver. Vancouver, British Columbia: Vancouver Women's Health Collective.

Gould, Kathrine. (1994). Perspectives of Houseless Women. Vancouver, British Columbia: Vancouver Women's Health Collective.

Government of Canada. (1988). Mental Health For Canadians: Striking a Balance. Ottawa, Ontario: Health and Welfare Canada.

Grant, Linda; Kathryn B. Ward; and Xue Lan Rong. (1987). "Is There an Association Between Gender and Methods in Sociological Research." American Sociological Review. December, 52, 856-862.

Green, Lawrence W.; and Marshall W. Kreuter. (1991). Health Promotion Planning: An Educational and Environmental Approach. Second Edition. Mountain View, California: Mayfield Publishing Company.

Green, L.W; M.A. George; M. Daniel; C.J. Frankish; C. Herbert; W.R. Bowie; and M. O'Neill. (1995). Study of Participatory Research in Health Promotion: Review and Recommendations for the Development of Participatory Research in Health Promotion in Canada. Ottawa, Ontario: Royal Society of Canada.

Greene, Jennifer C. (1987). "Stakeholder Participation in Evaluation Design: Is it Worth the Effort?" Education and Program Planning. 10, 379-394.

Greene, J.C. (1988a). "Communication of Results and Utilization in Participatory Program Evaluation." Evaluation and Program Planning. 11, 341-351.

Greene, J.C. (1988b). "Stakeholder Participation and Utilization in Program Evaluation." Evaluation Review. 12, 91-116.

Greenwood, Davydd J.; William Foote Whyte; and Ira Harkavy. (1993). "Participatory Action Research as a Process and as a Goal." Human Relations. 46, 2, 175-192.

Guay, J. (1984). L'intervenant Professionnel Face a L'aide Naturelle. Chicoutimi, Quebec: Gaetan Morin.

Guba Egon G.; and Yvonna S. Lincoln (1981). Effective Evaluation. San Francisco, California: Jossey-Bass.

Guba, Egon G.; and Yvonna S. Lincoln. (1989). Fourth Generation Evaluation. London, England: Sage Publications Limited.

Gunew, Sneja. (1991). "Introduction." Feminist Knowledge: Critique and Construct. London, England: Routledge.

Hanen, Marsha. (1989). "Feminism, Reason, and Philosophical Method." Ed. Winnie Tomm. The Effects of Feminist Approaches on Research Methodologies. (pp. 31-50). Calgary, Alberta: Wilfred Laurier University Press.

- Harris, Elayne M. (1992). "Accessing Community Development Research Methodologies." Canadian Journal of Public Health. March/April, 83, Supplement 1, 62-66.
- Hirschman, A.O. (1970). Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations, and States. Cambridge, Massachusetts: Harvard University Press.
- House, Ernest T. (1990). "Methodology and Justice." Ed. Kenneth A. Sirotnik. Evaluation and Social Justice: Issues in Public Education. 45, Spring. (pp. 23-36). San Francisco, California: Jossey-Bass Incorporated Publishers.
- House, Ernest T. (1993). Professional Evaluation: Social Impact and Political Consequences. Newbury Park, California: Sage Publications, Incorporated.
- Huberman M. (1987). "Steps Toward an Integrated Model of Research Utilization." Knowledge: Creation, Diffusion, Utilization. 8, 586-611.
- Huberman M. (1990). "Linkage Between Researchers and Practitioners: A Qualitative Study." American Educational Research Journal. 27, 363-391.
- Huizer, Gerrit. (1986). "Women in Resistance and Research: Potential Against Power." Eds. Leela Dube, Eleanor Leacock, and Shirley Ardener. Visibility and Power: Essays on Women in Society and Development. (pp. 235-251). Oxford, England: Oxford University Press.
- Israel, Barbara A. (1985). "Social Networks and Social Support: Implications for Natural Helper and Community Levels Interventions." Health Education Quarterly. 12, 65-80.
- Johnson, Joy. L. (1997). "Generalizability in Qualitative Research: Excavating the Discourse." Ed. Janice Swanson. Completing a Qualitative Project: Details and Dialogue. (pp. 191-208). Thousand Oaks, California: Sage Publications Incorporated.
- Katz, Alfred. (1981). "Self-Help and Mutual Aid: An Emerging Social Movement." Annual Review of Sociology. 7, 129-155.
- Kennedy, M.M. (1983). "Working Knowledge." Knowledge: Creation, Diffusion, Utilization. 5, 193-211.
- Killilea, Marie. (1976). "Mutual Help Organizations: Interpretations in the Literature." Eds. Gerald Caplan and Marie Killilea. Support Systems and Mutual Help: Multidisciplinary Explorations. New York, New York: Grune and Stratton Incorporated.

- King, J.A.; and E.M. Pechman. (1982). The Process of Evaluation Use in Local School Settings (Final Report of NIE Grant No. NIE-G-81-0900). Washington, District of Columbia: National Institute of Education.
- King, J.A.; and E.M. Pechman. (1984). "Pinning the wave to the Shore: Conceptualizing Evaluation Use in School Systems." Educational Evaluation and Policy Analysis. 6, 241-253.
- Kirby, Sandra L.; and Kate McKenna. (1989). Experience, Research, Social Change: Methods from the Margins. Toronto, Ontario: Garamond Press.
- Kraemer Tebes, Jacob; and Deborah Tebes Kraemer. (1991). "Quantitative and Qualitative Knowing in Mutual Support Research: Some Lessons From the Recent History of Scientific Psychology" American Journal of Psychology. 19, 5, 739-756.
- Lee, Bill; and Wendy Weeks. (1991). "Social Action Theory and the Women's Movement: An Analysis of Assumptions." Community Development Journal. July, 26, 3, 220-226.
- Levin, L. (1990). "Self-Care: The Hidden Health Care System." Eds. Alfred Katz and Eugene I. Bender. Helping One Another: Self-Help in a Changing World. (pp. 125-129). Oakland, California: Third World Publishing Company.
- Lincoln, Yvonna S. (1992). "Fourth Generation Evaluation, the Paradigm Revolution and Health Promotion." Canadian Journal of Public Health. March/April, 83, Supplement 1, 6-10.
- Lincoln, Yvonna S.; and Egon G. Guba. (1985). Naturalistic Inquiry. Beverly Hills, California: Sage.
- Lindsey, Elizabeth; and Liza McGuiness. (1996). Significant Elements of Community Involvement in Participatory Action Research: Evidence From a Community Project. Victoria, British Columbia: School of Nursing, University of Victoria, BC.
- Lips, Hilary M. (1987). "Towards a New Science of Human Being and Behavior." Ed. Winnie Tomm. The Effects of Feminist Approaches on Research Methodologies. (pp. 51-69). Waterloo, Ontario: Wilfred Laurier University Press.
- Lipson, Julieñ. G. (1997). "The Politics of Publishing: Protecting Participants' Confidentiality." Ed. Janice Swanson. Completing a Qualitative Project: Details and Dialogue. (pp. 39-58). Thousand Oaks, California: Sage Publications Incorporated.

- Macfarlane, Diane. (1996). "Citizen Participation in the Reform of Health Care Policy: A Case Example." Healthcare Management Forum. Summer, 9, 2, 31-35.
- Maguire, Patricia. (1987). Doing Participatory Research: A Feminist Approach. Amhurst, Massachusetts: The Centre for International Education, School of Education, University of Massachusetts.
- Maguire, Patricia. (1993). "Challenges, Contradictions, and Celebrations: Attempting Participatory Research as a Doctoral Student." Eds. Mary Brydon-Miller, Budd Hall, and Ted Jackson. Voices of Change: Participatory Research in the United States and Canada. Westport, Connecticut: Begin and Garvey.
- Maguire, Patricia. (1996). "Proposing a More Feminist Participatory Research: Knowing and Being Embraced Openly." Eds. Lorrie de Koning and Marion Martin. Participatory Research in Health: Issues and Experiences. (pp. 27-39). London, England: Zed Books Limited.
- Manzo, Kate. (1991). "Modernist Discourse and the Crisis of Development Theory." Studies in Comparative International Development. Summer, 26, 2. 3-36.
- Mark, Melvin M.; and R. Lance Shotland. (1985). "Stakeholder-Based Evaluation and Value Judgments." Evaluation Review. October, 9, 5, 605-626.
- Marshall, Barbara. (1988). "Feminist Theory and Critical Theory." Review of Canadian Sociology and Anthropology. 25, 2, 208-230.
- McGrath, Joseph E.; Janice R. Kelly; and Jean E. Rhodes. (1993). "A Feminist Perspective on Research Methodology: Some Metatheoretical Issues, Contrasts, and Choices." Eds. Stuart Oskamp and Mark Costanzo. Gender Issues in Contemporary Society. Newbury Park, California: Sage Publications Incorporated.
- Mies, Maria. (1983). "Towards a Methodology for Feminist Research." Eds. Gloria Bowles and Renate Duelli Klein. Theories of Women's Studies. London, England: Routledge and Kegan Paul.
- Mies, Maria. (1991). "Women's Research or Feminist Research: The Debate Surrounding Feminist Science and Methodology." Eds. Mary Margaret Fonow and Judith A. Cook. Beyond Methodology: Feminist Scholarship as Lived Research. (pp. 60-84). Bloomington, Indiana: Indiana University Press.

Ministry of Health, Republic of Indonesia. (1988). National Policy for Community Participation in Health. Jakarta: Ministry of Health, Indonesia.

Moore, Henrietta, L. (1988). Feminism and Anthropology. Cambridge, England: Polity Press.

Morse, Janice M. (1997). "Considering Theory Derived From Qualitative Research." Ed. Janice Swanson. Completing a Qualitative Project: Details and Dialogue. (pp. 163-188). Thousand Oaks, California: Sage Publications Incorporated.

Moser, Caroline O.N. (1987). "Women, Human Settlements, and Housing: A Conceptual Framework for Analysis and Policy-Making." Eds. Caroline O.N. Moser and Linda Peake. Women, Human Settlement, and Housing. London, England: Tavistock Publishers.

Moser, Caroline. (1989). "Gender Planning in the Third World: Meeting Practical and Strategic Gender Needs." World Development. 17, 11, 1799-1825.

Muller, F. (1980). Participation in Primary Health Care Programs in Latin America. Medellin, Columbia: University of Antioquia, National School of Public Health.

New Direction Development Division, British Columbia Ministry of Health and Ministry Responsible for Seniors. (1995). Policy Frameworks on Designated Populations. Victoria, British Columbia: New Direction Development Division, Ministry of Health and Ministry Responsible for Seniors.

New Direction in Health, British Columbia Ministry of Health and Ministry Responsible for Seniors. (1993). Community Health Centres. Vancouver, British Columbia: New Direction in Health, Ministry of Health and Ministry Responsible for Seniors.

Norris, Judy R. (1997). "Meaning Through Form: Alternative Models of Knowledge Representation." Ed. Janice Swanson. Completing a Qualitative Project: Details and Dialogue. (pp. 87-115). Thousand Oaks, California: Sage Publications Incorporated.

Osteria, Trinidad, S. (1991). Women in Health Development: Case Studies of Selected Ethnic Groups in Rural Asia-Pacific. Pasir Panjang, Singapore: Institute of Southeast Asian Studies.

Palmer, C.T.; and M.J. Anderson. (1986). "Assessing the Development of Community Involvement." World Health Statistics Quarterly. 39, 4, 345-352.

- Patton, M.Q. Ed. (1978). Utilization-Focused Evaluation. Newbury Park, California: Sage Publications.
- Patton, M.Q. (1980). Qualitative Evaluation Methods. Newbury Park, California: Sage Publications.
- Patton, M.Q. (1990). Qualitative Evaluation and Research Methods. Second Edition. Newbury Park, California: Sage.
- Paulston, Rolland G. (1979). Paradigm Conflict in the Assessment of Educational Reform: Evaluation as Social Critique. (ERIC Document ED 182317.) Pittsburg, Pennsylvania: University of Pittsburg.
- Paulston, Rolland G. (1983). Paradigm Conflict in the Assessment of Educational Reform: Evaluation as Social Critique. (ERIC Document ED 182317.) Pittsburg, Pennsylvania: University of Pittsburg.
- Piven, Frances Fox; and Richard A. Cloward. (1977). Poor People's Movements, Why They Succeed and How They Fail. New York: Vintage Books.
- Reinharz, Shulamit. (1981). Dimensions of the Feminist Research Methodology Debate: Impetus, Definitions, Dilemmas, and Stances. Los Angeles, California: Paper presented at the Annual Meeting of the American Psychological Association.
- Reinharz, Shulamit. (1983). "Experiential Analysis: A Contribution to Feminist Research." Eds. Gloria Bowles and Renate Duelli Klein. Theories of Women's Studies. (pp. 162-191). London, England: Routledge and Kegan Paul.
- Reinharz, Shulamit. (1984). "Women as Competent Community Builders: The Other Side of the Coin." Eds. Annette U. Rickel, Meg Gerrard, and Ira Iscoe. Social and Psychological Problems of Women: Prevention and Crisis Intervention. (pp. 19-43). New York, New York: Hemisphere Publishing Corporation.
- Reinharz, Shulamit. (1992). Feminist Methods in Social Research. Oxford, England: Oxford University Press Incorporated.
- Remine, Daniel; Robert M. Rice; and Jenny Ross. (1984). Self-Help Groups and Human Service Agencies: How They Work Together. New York, New York: Family Services America.
- Riessman, Frank. (1985). "New Dimensions in Self-Help." Social Policy. Winter, 15, 3, 2-4.

- Rifkin, Susan B.; and G. Walt. (1986). "Why Health Improves: Defining the Issues Concerning 'Comprehensive Primary Health Care' and 'Selective Primary Health Care'." Social Science and Medicine. 23, 559-566.
- Rifkin, Susan B.; Frits Muller; and Wolfgang Bichmann. (1988). "Primary Health Care: On Measuring Participation." Social Science and Medicine. 26, 9, 931-940.
- Romeder, Jean-Marie. (1982). Self-Help Groups In Canada. Ottawa, Canada: Health and Welfare Canada.
- Romeder, Jean-Marie. (1990). The Self-Help Way: Mutual Aid and Health. Ottawa, Canada: Canadian Council on Social Development.
- Sandelowski, Margarete. (1986). "The Problems of Rigor in Qualitative Research." Advances in Nursing Science. April, 8, 3, 27-37.
- Sandelowski, Margarete. (1997). "Programmatic Qualitative Research: Or, Appreciating the Importance of Gas Station Pumps." Ed. Janice M. Completing a Qualitative Project: Detail and Dialogue. Thousand Oaks, California: Sage Publications Incorporation.
- Sandercock, Leonie; and Ann Forsyth. (1990). Gender: A New Agenda for Planning Theory. Berkeley, California: University of California at Berkeley.
- Self-Help Resource Association of British Columbia. (1995). Directory of Self-Help Groups in Greater Vancouver. Vancouver, British Columbia: Self-Help Resource Association.
- Shields, J.J. Jr. (1967). Education in Community Development. New York: Frederick Praeger Publishers.
- Sirotnik, Kenneth A.; and Jeannie Oakes. (1990). "Evaluation as Critical Inquiry: School Improvement as a Case in Point." Ed. Kenneth A. Sirotnik. Evaluation and Social Justice: Issues in Public Education. New Directions for Program Evaluation. 45, Spring. (pp. 37-59). San Francisco, California: Jossey-Bass Incorporated Publishers.
- Silverman, Phyllis R. (1980). Mutual Help Groups: Organization and Development. London, England: Sage Publications Limited.
- Smith, Dorothy. (n.d.). An Analysis of Ideological Structures and How Women are Excluded: Considerations for Women's Studies. Vancouver, Canada: Vancouver women's Health Collective.

- Smith, Dorothy. (1988). "Institutional Ethnography: A Feminist Method". Ed. Arlene Tigar McLaren. Gender and Society: Creating a Canadian Women's Sociology. (pp. 62-79). Toronto, Ontario: Copp Clark Pitman Limited.
- Smith, M.L.; and G.V. Glass. (1987). Research and Evaluation in Education and the Social Sciences. Englewood Cliffs, New Jersey: Prentice-Hall Incorporated.
- Spacks, Patricia Meyer. (1985). Gossip. Chicago, Illinois: University of Chicago Press.
- Stanley, Liz; and Sue Wise. (1983a). "Back Into the Personal' or: Our Attempt to Construct 'Feminist Research'." Eds. Gloria Bowles and Renate Duelli Klein. Theories of Women's Studies. (pp. 192-209). London, England: Routledge and Kegan Paul.
- Stanley, Liz; and Sue Wise. (1983b). Breaking Out Again: Feminist Ontology and Epistemology. London, England: Routledge.
- Stanley, Liz. (1990a). "Feminist Praxis and the Academic Mode of Production: An Editorial Introduction." Ed. Liz Stanley. Feminist Praxis: Research Theory and Epistemology in Feminist Sociology. London, England: Routledge.
- Stanley, Liz; and Sue Wise. (1990b). "Method, Methodology and Epistemology in Feminist Research Processes." Liz Stanley. Feminist Praxis: Research Theory and Epistemology in Feminist Sociology. (pp. 20-60). London, England: Routledge.
- Staudt, Kathleen. (1997). "Gender Politics in Bureaucracy: Theoretical Issues in Comparative Perspectives." Ed. Kathleen Staudt. Women, International Development, and Politics: The Bureaucratic Mire. (pp. 3-34). Philadelphia, Pennsylvania.
- Surarith, Somporn. (1987). "Women's Struggle for Housing Rights in Thailand." Canadian Women's Studies. 11, 2, 15-16.
- Swanson, Janice M.; Roberta F. Durham; and Judith Albright. (1997). "Clinical Utilization/Application of Qualitative Research." Ed. Janice Swanson. Completing a Qualitative Project: Details and Dialogue. (pp. 253-281). Thousand Oaks, California: Sage Publications Incorporated.
- Tandon, Rajesh. (1981). "Participatory Research in the Empowerment of People." Convergence. 14, 3, 20-27.
- Taylor, Michael. (1982). Community, Liberty, and Anarchy. Cambridge: Cambridge University Press.

- Thompson, Joy C. (1992). "Program Evaluation Within a Health Promotion Framework." Canadian Journal of Public Health. March/April, 83, Supplement 1, 67-71.
- Thompson, M.S. (1980). Benefit-Cost Analysis for Program Evaluation. Newbury Park, California: Sage Publications.
- Thorbek, Susanne. (1987). Voices From the City: Women and Bangkok. London: Zed Books Limited.
- Thorbek, Susanne. (1988). "Women and Urbanization." Acta Sociologica. 31, 4, 283-301.
- Thorne, Sally. (1997). "The Art (and Science) of Critiquing Qualitative Research." Ed. Janice M. Morse. Completing a Qualitative Project: Details and Dialogue. (pp. 117-132). Thousand Oaks, California: Sage Publications Incorporated.
- Tomm, Winnie. Ed. (1989). The Effects of Feminist Approaches on Research Methodologies. Calgary, Alberta: Wilfred Laurier University Press.
- Uphoff, Norman. (1991). "A Field Methodology for Participatory Self-Evaluation." Community Development Journal. October, 26, 4, 271-285.
- Vancouver Health Board. (n.d.). New Directions in Health: What's It All About. Vancouver, British Columbia: Vancouver Health Board.
- Vancouver/Richmond Health Board. (1997). Inaugural Health Plan Summary. Vancouver, British Columbia: Vancouver/Richmond Health Board.
- Vancouver/Richmond Health Board. (1998). Vancouver/Richmond Health Board: Working Together for a Better Future. Annual Report, 1997-1998. The Vancouver Courier. Sunday, December 6, 25-32.
- Vargas Vargas, Laura. (1991). "Reflections on Methodology of Evaluation." Community Development Journal. October, 26, 4, 266-270.
- Vittano, A.J. (1972). "Power to the People: Self-Help Groups." Social Work. 17, 4, 7-15.
- Weiss, Carol H. (1983). "Towards the Future of Stakeholder Approaches in Evaluation." Ed. A. Bryk. Stakeholder-Based Evaluation. (pp. 83-96). San Francisco, California: Jossey-Bass.

- Weiss, Carol H. (1986a). "The Stakeholder Approach to Evaluation: Origins and Promise." Ed. Ernest R. House. New Directions in Educational Evaluation. (pp. 145-157). London, England: The Falmer Press.
- Weiss, Carol H. (1986b). "Towards the Future of Stakeholder Approaches in Evaluation." Ed. Ernest R. House. New Directions in Educational Evaluation. (pp. 186-198). London, England: The Falmer Press.
- Weiss, Carol H. (1998). "Have We Learned Anything New About the Use of Evaluation?" American Journal of Evaluation. 19, 1, 21-33.
- Weiss, C.H.; and M.J. Bucuvalas. (1980). Social Science Research and Decision Making. New York, New York: Columbia University Press.
- White Stewart, Mary. (1988). "Feminism and Sociology: An Unfortunate Case of Nonreciprocity." A Feminist Ethic for Social Science Research: Nebraska Sociological Feminist Collection. Women Studies, Volume 1. (pp. 187-200). Lewiston, New York: The Edwin Mellen Press.
- Williams, D.D. Ed. (1986). Naturalistic Evaluation. New Directions for Program Evaluation. 30. San Francisco, California: Jossey-Bass.
- Wilson, Holly Skodol; and Susan Ambler Hutchinson. (1997). "Presenting Qualitative Research Up Close: Visual Literacy in Poster Presentations." Ed. Janice M. Morse. Completing a Qualitative Project: Details and Dialogue. (pp. 63-85). Thousand Oaks, California: Sage Publications Incorporated.
- Wollert, Richard; Bob Knight; and Leon H. Levy. (1984). "Make Today Count: A Collaborative Model for Professionals and Self-Help Groups." Eds. Alan Gartner and Frank Riessman. The Self-Help Revolution. (pp. 129-137). New York, New York: Human Sciences Press Incorporated.
- World Health Organization. (1981). Development of Indicators for Monitoring Progress Towards Health for All by the Year 2000. Geneva, Switzerland: World Health Organization.
- World Health Organization. (1986). Ottawa Charter for Health Promotion. Ottawa, Ontario: Canadian Public Health Association.
- Wuest, Judith; and Marilyn Merrit-Gray. (1997). "Participatory Action Research: Practical Dilemmas and Emancipatory Possibilities." Ed. Janice M. Morse. Completing a Qualitative Project: Details and Dialogue. (pp. 283-306). Thousand Oaks, California: Sage Publications Incorporated.